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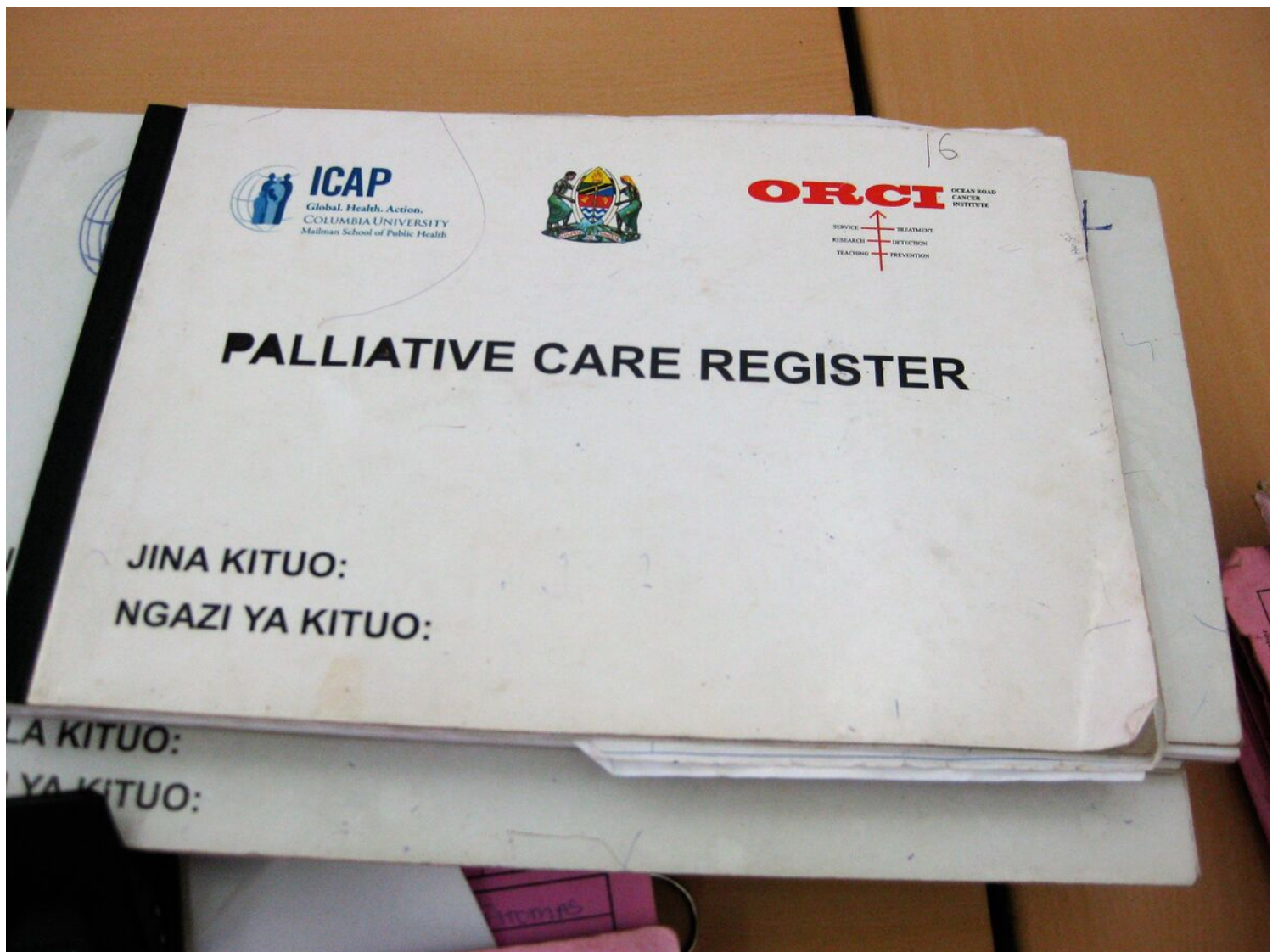
Palliative Care - not a Luxury, but a Human Right and an Essential Element of Universal Health Coverage (UHC)

Remarkable developments in recent years

Palliative Care Tanzania: A growing need for cancer patients

By Andrea Buhl

The World Health Organization defines palliative care as a holistic approach for patients and their families who are living with life-threatening diseases, particularly emphasising the treatment of pain. Universal access to palliative care is today considered as basic human right. On the African continent, palliative care is a relatively new discipline and its development was hampered for many years, amongst others by the fact that pain management was no integral part of healthcare. Within the last ten to fifteen years palliative care has developed substantially in several African countries, but many are still lacking basic provision. The United Republic of Tanzania, in East-Africa, is one of those countries with remarkable developments in palliative care provision. The following article describes these developments looking at the example of a Tanzanian cancer hospital, which was one of the first institutions to provide palliative care in the country.



In 2012 almost 1.000 new patients were registered for the ORCI palliative care service. Photo by Andrea Buhl

The growing burden of cancer in Africa

For many decades, the focus of global health and health systems in sub-Saharan Africa (SSA) was predominantly on infectious diseases, in particular HIV/AIDS, which has led to the misconception that non-communicable diseases (NCDs) are not a major problem for this region. But the continent is currently facing a new double burden with an increase of NCDs, such as cardiovascular diseases, respiratory diseases, diabetes and cancer. Overburdened and underfinanced health systems in many countries together with changing demographics, improved economic conditions and increasing urbanization increase NCDs risk factors, like unhealthy lifestyle. Although infectious diseases are still the leading causes of death in SSA, the emergence of NCDs, notably cancer has become a significant challenge for health systems on the continent as it stands out with the highest mortality and fastest deterioration of patients. SSA has seen an enormous increase of cancers cases in the last few years with approximately 1 Mio. new cases annually, and about 700.000 related deaths (Cancer Today 2018a), which accounts for estimated 70% of all cancer deaths globally. (Lyimo et al. 2020) Because screening examinations are scarce and the diagnosis is often only made in advanced stages, the mortality and morbidity rates are steadily rising.

Tanzania, a country with a population of 56,3 Mio. people, is one of those countries. Estimated 42.000 new cancer cases and anticipated 28.000 deaths annually. (Cancer Today 2018b) Precise numbers are not available because Tanzania, as many other African countries, has neither a population-based cancer registry, nor hospital-based ones. Cancer of cervix, prostate, breast, colorectum, oesophagus, and liver as well as Kaposi sarcoma are the most prevalent ones in the country. (Cancer Today 2018b) Cases of cervical cancer have extremely increased within recent years, being the leading cause of cancer mortality. Many cancer cases of all kinds are diagnosed and treated at a very late stage, due to insufficient opportunities for screening, lack of knowledge in rural health facilities, and individual and economic reasons of those affected. By the time the diagnosis is made, many diseases are so advanced that cure is no longer possible, and pain and symptom management become the main needs. That is when palliative care is supposed to step in at the latest.

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Palliative Care Developments in sub-Sahara Africa

The holistic approach of palliative care is intended to support patients, their relatives and caregivers while facing a life-limiting disease, focusing on the patient as 'a whole' and on her or his individual care and suffering, whether of bodily or mental nature. Although the reach of palliative care provision is steadily growing across the globe, these developments vary greatly by region, and palliative care is still in its infancy in many parts of the world. The fastest developments are currently made in several SSA countries with the support of the head organization African Palliative Care Association (APCA) in many international funders.

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APCA's mission is to help with adapting "modern palliative care from the UK [...] to African traditions, beliefs, cultures and settings." This should be achieved through **four main pillars**:

- increase knowledge and awareness about palliative care
- strengthening health systems by integration of palliative care (service delivery, workforce, health information, access to essential medicines and financing)
- creation of research evidence for palliative care in Africa and
- ensuring its sustainability

Although, hospices and palliative care movement in SSA has started already in the 1970s in isolated centres, however, further developments were tied to the emergence of HIV/AIDS at the turn of the millennium when people were rapidly dying due to the non-availability of ART at the time. The recent APCA Atlas 2017 describes the fast developments of palliative care provision on the continent in recent years, showing that meanwhile only 9 countries are not having any services dedicated to hospice and palliative care. Twelve countries are even having stand-alone palliative care policies meanwhile, which is important for recognition and access as well as for budget allocation.

The Worldwide Palliative Care Alliance categorizes countries based on their palliative care developments in **four levels**, with the lowest having no known hospice-palliative care activities at all, and the highest for countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision.

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The latter category includes Uganda, which is the showpiece of the continent in this regard and where APCA is based. There are a few SSA countries in the second highest level, where hospice-palliative care services are even at a stage of preliminary integration into mainstream service provision: South Africa, Kenya, Tanzania and Zimbabwe. This level refers to national activism, variety of services, professional and community awareness, availability of strong pain killers (such as morphine), basic impact of palliative care on policy, different training and education initiatives, and concept of a national palliative care association. These countries have made considerable progress in palliative care provision, activism and training in recent years. For example, in Kenya the number of palliative care services has increased from 8 to 44 and in Tanzania from 10 to 20 between 2005 and 2016. In the world map of palliative care services, Tanzania, in particular, has changed from the level of isolated or regional provision to preliminary integration.



For most cancer patients, oral morphine and concomitant drugs are the preferred option to relieve pain – if available. Photo by Andrea Buhl

Palliative Care in Tanzania

Also, Tanzania was one of the first countries in Africa to establish palliative care services, for many years, even decades, this was only very limited to certain regions and institutions. One of those first institutions was the Ocean Road Cancer Institute (ORCI) in Dar es Salaam, which

has been providing palliative care since 1994. As a result, the institute was long considered an innovative pioneer, but, in the meantime, other organizations have caught up and provide even more comprehensive palliative care services today. One example is the Selian Lutheran Hospital in Arusha, Northern Tanzania, which has extended its palliative care program to hospitals of the Evangelical Lutheran Church Tanzania (ELCT) and established a comprehensive and impressive network of palliative care providers supported by home-care volunteers across many districts to provide palliative care to thousands of people, mainly those living with HIV/AIDS.

The ORCI registers up to 5.000 new cancer patients every year. Of those present around 80% with late stage cancer, and palliative treatment and pain management become the main concerns. The ORCI has its own palliative care support team consisting of two fulltime nurses, supported by a varying number of trained colleagues from other departments, such as physicians, nurses, pharmacists and social workers. But for the high numbers of patients in need, this is not sufficient at all. In 2012, 1.000 patients were registered at the palliative care office - around 20% of all ORCI patients – which not even covers the actual need to a certain extent.



Palliative care counselling room at ORCI. Photo by Andrea Buhl

The majority of patients come from faraway places across the country and travel far to reach the hospital, often without accompanying relatives providing the necessary care. Thus, most of them are dependent on in-hospital support. The hospital palliative care team's duties are taking care of in-patients with palliative care needs, especially pain management, counselling out-patients and their relatives, organizing home-visits, and supporting and training hospital staff

and community health workers. Additionally, the palliative care team together with the hospital's own pharmacy administer the supply of oral morphine for the whole country and provide trainings in handling the controlled pharmaceutical.

Oral morphine is nowadays widely accepted as being the first-line drug for treatment of moderate- to severe cancer pain, but in many parts of the world it is only limited available and many myths and fears about its use still exist. Therefore, many cancer patients are dying with no effective way to relieve their physical suffering.

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Anne Merriman, founder of Hospice Africa Uganda, mentioned that 'palliative care without morphine is only supportive care... and lack of access to morphine is torture.' In Tanzania, administering and prescribing morphine is strongly regulated, and even if available, often fears around it, designated as 'opiophobia', hinder its generous prescription for those in pain. Many of ORCI's cancer patients are receiving oral morphine to ease their pain, but problems arise from frequent national stock-outs, incorrect use (not overdose but rather underdose), fear of side effects, and missing options for re-fill in home regions.

Therefore, continued palliative care at home after discharge is desperately needed for all patients, but especially for those with incurable cancers and associated pain.

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Unfortunately, the offer for home-based palliative care is very limited and restricted to certain regions and often disease-specific, such as programs only targeting HIV positive people. These programs would also include cancer patients, but the real problem often results from the lack of referral from ORCI to these regional organisations, and/or ignorance of this by patients, families and local health workers. That is why in-hospital palliative care teams, as the one at ORCI, are an importance starting point for continued care at home.

The story of Neema and Lucy

Neema temporarily lived with her daughter Lucy and grandchildren in a tiny house at the outskirts of Dar es Salaam, a one-hour bus ride away from ORCI. The almost eighty years old woman used to live with her other children and their families in a rural region of North-West Tanzania, a one-day trip away from Dar es Salaam, since her husband has died. When Neema discovered a nodule in her breast, Lucy took her to Dar es Salaam to the hospital and she was quickly referred to the ORCI and started chemotherapy and radiation. After she had finished the first round, she was sent back home to have a rest and return after half a year. But family responsibilities and fear of treatment kept her home longer. She returned to ORCI after one year, when her disease was very advanced, and they had to remove her breast and treat with intensive radiation. When I visited the family at home, Neema was very tired and almost unable to walk or even sit, she had to be supported by her oldest grandson. Her left arm was extremely swollen and large, as it would burst every moment and the mere sight was painful. The lymphedema had occurred after the amputation and worsened with radiotherapy. Lucy gave her a dose of oral morphine, and soon after she dozed off. Lucy and her oldest son, who was almost twenty, seemed exhausted. They were caring for Neema day and night for weeks now. Her conditions had worsened over the last weeks and she had to be admitted again to ORCI when she was not able to return home from the last check-up and morphine refill. Beside pain medication they had no support from the hospital or elsewhere. They had no money to pay additional treatment or help. They were fearing Neema's death and wanted her to die back home, but they realized that she was not able to travel there anymore. One week after my visit, Neema had died and the family collected enough money to send the coffin with her death body back home for the funeral.

Like Neema Charles and her caring daughter and grandson, countless other cancer patients and their relatives would benefit from home-based palliative care. But ambulatory palliative care services are scarce. The palliative care team at the ORCI has started a home-based care program in 2010 to support out-patients and their caring relatives in the area of Dar es Salaam. But as human capacities and financial resource are lacking, the program was provided very limited or even interrupted at all. Since ORCI's patients are coming from all over the country to seek treatment, continued palliative care support at home is needed throughout the whole country. Even the ELCT's program is not enough to provide care for all those in need. What the country really lacks is a comprehensive national network of local palliative care providers, a good referral system, regular exchange between providers and, in principle, knowledge among medical staff throughout the country and the population as a whole about the availability and advantages of palliative care provision. In the coming years, the demand for palliative care will continue to grow strongly, as many chronic diseases are on the rise and hospital capacities are growing only slowly in comparison.

Additional information/Acknowledgement

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