Five ways palliative care in rural Malawi shows that every life matters

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Introduction

In 2017, the Royal College of Physicians of Edinburgh gave its support to EMMS International's 'Every Life Matters' campaign to help improve access to pain relief and palliative care in rural Malawi. The campaign raised £1.73 million, including £846,248 of matched funding from the UK government. As a result, the Chifundo (Compassion) project was launched to address the huge gap in service provision in Malawi and meet the need for more specialist facilities and healthcare workers, better access to essential medication and improved nutrition for patients.

The Chifundo project[1] aims, by mid-2021, to see 9,965 families (59,790 people) in catchments of 26 rural or hard-to-reach health facilities and all four central hospitals of Malawi, receive holistic palliative care and be referred to relevant help with food provision. These health facilities in all 27 mainland districts give patients with life-limiting illness and their families free care as in the National Palliative Care Policy, including pain relief, food supplements, disease information, legal aid and spiritual support, plus farm training and practical social help. The project is led by Edinburgh-based healthcare charity EMMS International and implemented with its partners in Malawi: Palliative Care Support Trust (PCST), Palliative Care Association of Malawi, David Gordon Memorial Hospital, Nkhoma Mission Hospital and Mulanje Mission Hospital. The project was funded through the 'Every Life Matters' campaign in 2017 with donations from the public being matched pound-for-pound by the UK government.

Malawi is listed 172 out of 189 (2018[2]) on the Human Development Index. It is a low-income country with a growing population of 18 million people and has a life expectancy of 63 years (World Bank, 2017[3]). A total of 9.2% of adults are living with HIV (UNAIDS, 2018[4]), and there are high rates of oesophageal and cervical cancer, with general cancer prevalence on the rise. Specialist cancer care is provided only at two of the country's four tertiary-level public hospitals and radiotherapy is not available inside Malawi.[5]

The five ways

In December 2019, the Chifundo project reached its halfway milestone and from activities to date we can make observations of how it is addressing critical healthcare needs in Malawi, implementing and developing best practice in the provision of palliative care in low-/middle-income countries, and how it shows that every life matters.

1. Coping with the rise of noncommunicable diseases (NCDs)

In Malawi, NCDs are estimated to account for 32% of all deaths.[6] Changing demographic and lifestyle factors, alongside environmental, economic, cultural and occupational pressures, contribute to the increasing prevalence and impact of NCDs.[7]

Palliative care is a 'best buy' in addressing the impact of noncommunicable diseases. The WHO highlights[8] basic palliative care as an overarching and enabling action to reach the objective of strengthening health systems to deal with noncommunicable diseases. It calls for action to 'Develop and implement a palliative care policy, including access to opioid analgesics for pain relief, together with training for health workers'. For care for cancer in particular it describes palliative care as an effective intervention, including home-based and hospital care with access to opiates and essential supportive medicine.

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Figure 1 Supplementary foods for patients suffering from malnutrition

Figure 2 Photograph of Jeremiah with his mother outside their home

EMMS International and its partners in the Chifundo project are putting this recommendation into action through bringing 30 healthcare facilities up to African Palliative Care Association certified standards (four Level 3, eight Level 2 and 18 Level 1) and ensuring 120 healthcare workers in palliative care are trained through a combination of intensive instruction and clinical attachments.

2. Leaving no-one behind

While great strides have been made in tackling the HIV/AIDS epidemic it is important that services for people living with HIV/AIDS (PLWHA) continue to grow and develop to meet their long-term needs and this includes palliative care. To date, PLWHA make up 50% of beneficiaries of the project (3,310 out of 6,618). In a country with a 10% prevalence of HIV this demonstrates how the long-term effects of HIV/AIDS requires expansion of palliative care services. The highest prevalence (20%) is in the more rural Mulanje district, where one of the implementing partners, Mulanje Mission Hospital, is based, highlighting the need for particular effort in rural areas.

The Chifundo project is addressing the significant gaps in rural care: 94% of beneficiaries to date are in rural areas (6,221 out of 6,618).

3. Taking a holistic approach

The project approach strengthens healthcare services by ensuring health facilities are accredited for their palliative care services, training more healthcare staff in palliative care, establishing service level agreements between health facilities and district health offices to ensure resources for palliative care, and advocating for strengthening of service level agreements to cover payment of cancer patients' anaemia treatment and hospital/home visits.

However, the project is going beyond this with the addition of nutrition, legal, spiritual, social and agricultural training support for patients and their families. This is in line with the WHO definition of palliative care, which 'integrates the psychological and spiritual aspects of patient care'.[9]

4. Care for the family

Again, in line with the WHO definition of palliative care the holistic approach extends to the family also and 'offers a support system to help the family cope during the patient's illness and in their own bereavement'.[9]

Legal support helps patients and their families to settle their affairs in accordance with their own wishes, tackling the poverty that stems from the widespread problem of widows being disinherited in spite of their legal right to inherit. Agricultural training addresses the problem of food poverty at community and family level, as well as for patients, and complements provision of supplementary foods donated to patients suffering from malnutrition (Figure 1). Spiritual care, including bereavement support, helps patients and families alike.

5. Reducing the rate of decline into poverty of affected families

A lack of palliative care services or awareness compounds the problem of poverty. EMMS International's projects and research[10] in India concluded, 'Holistic palliative care can reduce the desperate poverty driven by life-limiting illness, and can do so systematically, on a large scale, in-depth, especially if started early in the illness. Home-based care also frees up hospitals to serve more patients with treatable conditions'. This is achieved through patients spending less money on healthcare, medicine and travel owing to symptom management, cheaper medicine and home-based care. Improved health and symptom management of patients can allow them to return to work and other income-generating activities. Similarly, family members are freed from burdensome hospital transport and bedside care at home and in the hospital, allowing them to stay in education and employment. Work is ongoing in Malawi, through a PhD largely funded by EMMS, to quantify the financial impact of improved access to palliative care.[5]

Case study

The concepts noted are perhaps best demonstrated in the life and care of Jeremiah (Figure 2). When we first met Jeremiah almost 2 years ago, aged 14 years, he was hungry and in pain. His mother struggled to find enough food for the family, even though food was essential for Jeremiah's medicine. He lay on a grass mat in pain from cancer in his leg and pressure sores on his body.

Thanks to the generous support of the 'Every Life Matters' appeal, and matched funding from the UK government, Jeremiah and others like him are getting the care they deserve. Even though a cure is not available, there is still much that can be done to improve the quality of life of Jeremiah and his family.

EMMS International's partner, PCST, has been able to help renovate the family home so that they have safe and dry accommodation, especially in the rainy season. When needed, Jeremiah gets additional food support to help him stay strong and continue with his medication. Families like his are benefitting from support to set up kitchen gardens to help fight off hunger.

Jeremiah receives regular visits from specialist healthcare workers to help him manage his pain and other symptoms. This eases the burden of care on his mother too.

Two years ago, Jeremiah missed going to school and playing football with his friends. Thanks to a wheelchair provided by PCST he is able to sit up and be more mobile. He can spend time with his friends and enjoys the visits of a teacher who comes to his home for weekly lessons.

Conclusions

The Chifundo project is building on 20 years of development of palliative care in Malawi, in which EMMS International has played a significant role. Public and UK government support are facilitating the development of much-needed healthcare services in Malawi. The rise of NCDs, growth of population and long-term impact of HIV/AIDS are contributing to a growing need for such services. Effective palliative care addresses not just the needs of patients, but also of their families. This requires holistic care that recognises the variety of factors beyond the illness alone and addresses them in an appropriate way for the rural Malawian context.

Footnote

EMMS International was founded in Edinburgh in 1841 by John Abercrombie and a group of like-minded people who were concerned for the wellbeing of the sick and poor in remote parts of the world. Today, as a Scottish registered Charity, it works to improve health and healthcare for those living in poverty in Malawi, India, Nepal and Edinburgh.

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References

1 EMMS International. Chifundo Project Description. 2019. devtracker.dfid.gov.uk (accessed 01/07/18).
2 United Nations Development Programme. Human Development Report. 2018. http://hdr.undp.org/en/data (accessed 30/01/20).
3 World Bank. Data – Life expectancy at birth – Malawi. 2017. https://data.worldbank.org/indicator/SP.DYN.LE00.IN?locations=MW (accessed 30/01/20).
4 UNAIDS. Country Profile: Malawi. 2018. https://www.unaids.org/en/regionscountries/countries/malawi (accessed 30/01/20).
5 Bates MJ, Namisango E, Tomeny E et al. Palliative care within universal health coverage: the Malawi Patient-and-Carer Cancer Cost Survey. *BMJ Support Palliat Care* 2019; bmjspcare-2019-001945.
6 World Health Organisation. Noncommunicable Disease Country Profiles (Malawi). 2018. https://www.who.int/nmh/countries/mwi_en.pdf?ua=1 (accessed 30/01/20).
7 Gowshall M, Taylor-Robinson SD. The increasing prevalence of non-communicable diseases in low-middle income countries: the view from Malawi. *Int J Gen Med* 2018; 11: 255–64.
8 World Health Organisation. Tackling NCDs: best buys and other recommended interventions for the prevention and control of non-communicable diseases, 2017. https://apps.who.int/iris/bitstream/handle/10665/259232/WHO-NMH-NVI-17.9-eng.pdf?sequence=1&isAllowed=y (accessed 30/01/20).
9 World Health Organisation. Cancer: WHO Definition of Palliative Care https://www.who.int/cancer/palliative/definition/en/ (accessed 30/01/20).
10 Ratcliff C, Thyle A, Duomai S et al Poverty reduction in India through palliative care: a pilot project. *Indian J Palliative Care* 2017; 23: 41–5.