Institution: University of Edinburgh		
Unit of Assessment: 1		
Title of case study: G: Integration of palliative care into health systems in Sub-Saharan Africa leads to widespread availability of care and pain relief		
Period when the underpinning research was undertaken: 2002 – 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	**Role(s) (e.g. job title):**	**Period(s) employed by submitting HEI:**
Liz Grant	Chair of Global Health & Development	1998 – present
Scott Murray	St Columba's Chair of Primary Palliative Care	1990 – present (Emeritus since 2018)
Mhoira Leng	Senior Fellow	2014 – present
Period when the claimed impact occurred: August 2013 – December 2020		
Is this case study continued from a case study submitted in 2014? N		

1. Summary of the impact

Underpinning Research: Integrated palliative care, including the availability and appropriate use of opioids, is an important health service intervention, but one that is absent in many low-and-middle income countries (LMICs) due to lack of training, limited evidence of need and fear of morphine use as an effective analgesic for severe end-of-life care. University of Edinburgh (UoE)-led research has shown that palliative care can be delivered effectively in LMICs to alleviate patients' and family suffering while simultaneously strengthening weak health systems.

Significance and Reach of Impact: The World Health Organization recommends integrating palliative care into health systems specifically using the UoE group's approach. This has led to direct palliative care training of more than 7,300 healthcare professionals in 8 LMICs, educating more than 20,000 community health workers and caring for more than 60,000 patients and family members.

Integrated palliative care is now available within regional and national public health services in many resource-poor settings. For example, Rwanda and Uganda have included palliative care in their national health plans and committed to palliative care access for everyone nearing the end of life, including in their large refugee communities. Morphine availability and consumption for palliative care in Rwanda has steadily increased from zero in 2012 to a supply for 5,000 patients in 2019. In Uganda, morphine availability for palliative care increased 5-fold since 2012.

2. Underpinning research

The Challenge: Inadequate availability of palliative care and pain relief in LMICs
In 2015, more than 80% of the 61 million individuals worldwide experiencing serious health-related suffering lived in LMICs, yet global inequity of access to pain control and end-of-life (palliative) care was poorly understood [3.1]. Palliative care services, when funded, were delivered outside of public health systems because the evidence for why or how to incorporate palliative care into routine services did not exist.

The global palliative care group at UoE, led by Grant and Murray, was one of the first to highlight the impacts of inequitable access to palliative care between the United Kingdom and LMICs, showing that while patients in Kenya were less isolated and distressed than patients in Scotland, and had stronger community and faith support networks, they died in severe unalleviated physical pain, with little or no access to morphine [3.1].

Developing palliative care availability and training in government hospitals in Uganda
UoE researchers quantified, for the first time, the need for palliative care in hospitals and showed that almost half of the patients in the Ugandan national referral hospital required palliative care [3.2]. To address this, UoE researchers developed a new programme, which involved specific workforce training in holistic palliative care, practical care demonstrations for all levels of staff, and

clinical research, alongside a human resource plan — which became known as the Linked Nurse Scheme — to deliver appropriate palliative care. This programme was known as the integrated training-research-practice model. The UoE group's analysis indicated that implementation of this scheme led to a trebling of patients receiving palliative care [3.2]. In collaboration with the Ugandan Ministry of Health, Makerere University, the International Palliative Care Children's Network, Palliative Care Association of Uganda and National Nursing Council, 2 action research programmes trained 40 senior palliative care clinicians including 35 nurse specialists (see [3.7] as a representative example). This research also provided the first evidence that nurses can safely prescribe oral morphine when effectively trained [3.2].

Integrating palliative care into national health systems
To explore whether UoE's above-described model of palliative care could be successfully integrated into national health systems, Grant led an intervention study [3.8] examining 12 hospital settings (national, provincial, district, urban, rural, semi urban) in 4 African countries [3.3]. This study found that as a result of the integration of the model, the number of patients identified for palliative care increased by a factor of 2.7 and oral morphine consumption increased by a factor of 2.4 over 2 years [3.3]. The group subsequently developed an integration framework called "The 11 Ps of successful palliative care integration" (published in [5.2]) and tested it in collaboration with the Ministry of Health in Rwanda [3.9] to identify strategies for scale-up, including the first national plan for the distribution of oral morphine.

Raised awareness of the costs and needs of palliative care in LMICs
In addition to identifying medical challenges, UoE's cumulative studies with African partners have highlighted challenges with health literacy, cultural and socio-economic factors and increased awareness of the experiences of living with diseases such as heart failure [3.4]. The research has provided evidence that the absence of palliative care services in LMICs results in significant costs to the individual, family and local community. Patients continue to seek (and pay for) futile curative treatment in hospitals and through traditional healers, and lack of effective analgesic medication leaves patients in severe pain, unable to carry out any roles, and needing other family members to stay at home rather than working or attending school [3.4]. Additionally, the mounting costs of futile treatments can perpetuate financial losses that entrap families in poverty cycles while stunting local economic growth, for example children leaving school early to pay for household and hospital bills [3.3; 3.5].

3. References to the research

[3.1] Murray SA, Grant E, Grant A, Kendall M Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their carers BMJ 2003; 326 :368 doi: 10.1136/bmj.326.7385.368

[3.2] Downing J, Batuli M, Kivumbi G, Kabahweza J, Grant L, Murray SA, Namukwaya E, Leng M. A palliative care link nurse programme in Mulago Hospital, Uganda: an evaluation using mixed methods. BMC Palliat Care 2016; 15: 1-13. doi: 10.1186/s12904-016-0115-6

[3.3] Grant L, Downing J, Luyirika E, Murphy M, Namukwaya L, Kiyange F, Atieno M, Kemigisha–Ssali E, Hunt J, Snell K, Murray SA, Leng M Integrating palliative care into national health systems in Africa: a multi-country intervention study. J Glob Health 2017; 7:010419. doi: 10.7189/jogh.07.010419

[3.4] Namukwaya E, Grant L, Downing J, Leng M, Murray S. Improving care for people with heart failure in Uganda: Serial in-depth interviews with patients' and their health care professionals. BMC Res Notes. 2017;10:184 doi: 10.1186/s13104-017-2505-0.

[3.5] Downing J, Grant L, Leng M, Namukwaya E. Understanding models of palliative care delivery in sub-Saharan Africa: Learning from programs in Kenya and Malawi. J Pain Symptom Manage. 2015; 50: 362-370. doi: 10.1016/j.jpainsymman.2015.03.017

Selected Grants:

[3.7] Grant L, Leng M, Kiwanuka R, Downing J. Uganda Nurse leadership professional programme for palliative care. Department for International Development (DFID) Health Partnership Scheme 2015-2017 GBP248,428

[3.8] Grant L, Leng M, Downing J, Mwangi-Powell F, Murray S, Logie D. Strengthening and integrating palliative care into national health systems through a public health primary care approach DFID / Tropical Health and Education Trust (THET) Health Partnership Scheme 2012-2015 GBP1,536,189

[3.9] Grant L, Leng M, Downing L, Muhimpundu M-A Strengthening and Integrating Palliative Care into the Rwanda Health System: Rolling out the model DFID Health Partnership Scheme A2.22 2015-2017 GBP248,616

4. Details of the impact

Impact on policy and guidelines

The UoE model of integrating palliative care in resource-poor settings has influenced health sector decision-making: The Rwandese Ministry of Health adopted the model, naming palliative care as a service for the first time in its official health documentation. In addition, and as a direct result of the UoE group's evidence of the clinical and cost-effective value of sustained consistent palliative care, the Director General included palliative care into the national health insurance scheme. The Executive Director of the Rwanda Palliative Care & Hospice Organization stated: *"This research on the methods of integration was instrumental in encouraging the then Health Minister […] to commit that everyone in Rwanda would receive palliative care. […] Through the support of the University of Edinburgh […] there was a direct line between the research innovations emerging and them being turned into policies for enhanced palliative care delivery."* [5.1].

The UoE group's palliative care research has informed the World Health Organization (WHO) palliative care guides. For example, "Planning and implementing palliative care services" (2016), cites UoE's THET/DFID-funded Integrated Palliative Care Project [3.8] as an exemplar for successfully integrating palliative care, and reproduces Grant's "11 Ps" framework in the form of a checklist [p.38–42; 5.2]. This guideline links to the World Health Assembly's resolution WHA69.19 (2014), which committed to making palliative care accessible for everyone. UoE research is contributing to delivering on this commitment: the Executive Director of the Worldwide Hospice Palliative Care Alliance (WHPCA) declared: *"The outcomes of the research that her* [Grant's] *team are carrying out in Gaza, Sudan and in the refugee camps in N. Uganda is supporting the commitment that the WHO and WHPCA have made for ensuring palliative care is accessible for all people in all circumstances so that no-one is left behind."* [5.3a].

In 2018, the American Society of Clinical Oncology published a new guideline to provide expert guidance to clinicians and policymakers on implementing palliative care of patients with cancer and their caregivers in resource-constrained settings. The 5 listed recommendations on the most appropriate palliative care models (resources, training needs, standards of care, staffing requirements, and spiritual psychosocial care at different service levels) were primarily based on UoE's literature review and models presented in publication [3.5] [p. 9–10; 5.4].

Impact on training

The training programme developed in part through UoE's project [3.8] has delivered training to more than 7,300 healthcare workers in Uganda, Rwanda, Zambia, Kenya, Sudan, Mauritania, Gaza and India. More importantly still, the programme has equipped palliative care trainers to teach community health workers. This has increased the number of health professionals and community health workers able to deliver palliative care in each of these countries from fewer than 1,000 in 2013 to over 20,000 in 2019 [5.5]. As a result of the training, staff representing palliative care specialities are represented at district and provincial senior workforce level for the first time. This upscaling of knowledge, skills, research capacity and leadership potential at the national and provincial management level was endorsed by the European Association for Palliative Care through an Academy Award for Palliative Care in 2017, and was cited by DFID as a scalable exemplary programme [5.6].

The Makerere Nurse Link programme has been expanded to 13 Ugandan hospitals and has succeeded in widening access to palliative care in all wards in the national and district referral hospitals in Uganda [3.2]. Nurse training in palliative care, based on the programmes jointly developed by UoE and Makerere University, has been rolled out by National Palliative Care Associations in conjunction with governments, universities and non-governmental organisations in northern Uganda [5.7], as well as in 10 countries both within and outside of Africa, including Kenya, Rwanda, Zambia, India and Gaza [3.3; 5.8a–d].

A further major impact from the research was the development of a Palliative Care Curriculum Toolkit [5.9]. This has enabled the University of Rwanda (2016), Makerere University (2016), Gulu University (2018), University of Zambia (2016), Islamic University of Gaza (2019) and University of Malawi (2017) to incorporate palliative care teaching into their medical, nursing and theological undergraduate and Master of Medicine curricula for the first time, ensuring that the next generation of health practitioners understands palliative care principles and has the skills and knowledge to implement them [5.5].

Impact on health services
UoE's evidence base contributed to the recognition of the global health importance of palliative care by the Lancet Commission on Global Access to Palliative Care, as well as the WHPCA. The Executive Director of the latter described Grant's contribution as follows: *"The impact of her ongoing work to relieve serious health related suffering has already affected tens of thousands of lives in multiple countries. Findings from the research programmes which Dr Grant and her team led in Kenya, Rwanda, Uganda and Zambia have provided important evidence for strategies to implement palliative care approaches, and services into the health systems of these countries."* [5.3a]. As an example of this, the Executive Director of the International Association for Hospice and Palliative Care stated that UoE research *"has led to changes in palliative care policy and is being used by the Counties in Kenya who are progressing to Universal Health Coverage."* [5.3b].

The research demonstrated that not only is integrating palliative care into health systems in LMICs possible, but that it simultaneously strengthens health systems by motivating staff and establishing stronger chronic disease management services. The Chief Executive of Africa Palliative Care Association (APCA) confirms: *"this partnership between the University of Edinburgh and APCA […] has had significant impact across Africa by providing evidence-based models on how to integrate palliative care into health systems in a number of countries."* [5.10].

For example, palliative and chronic disease services in the Ugandan Adjumani Camp for South Sudanese refugees directly resulted from the work, as testified by the Minister of Health from Uganda [5.7]. In addition, 12 of the UoE group's clinical protocols have been approved and adopted or adapted by Ministries of Health in Uganda, Kenya, Sudan, Burundi, Cameroon and Gaza, where integration is being replicated in more than 30 hospitals [5.8].

A major consequence of this widespread adoption of the UoE model has been an increase in availability of pain relief and alleviation of palliative symptoms for all diseases for individuals in provincial and national hospitals as a direct result of training workers and increasing availability of oral morphine, where before there was none (see below).

Impact on clinical practice
Integration of UoE's model of palliative care to routine care has led to developing and delivering training packages for all cadres of health worker, and establishing systems of referral and documentation of clinical morphine use. This, in turn, has resulted in increased use of morphine as analgesia through public systems.

In Uganda, officials at Makerere University have documented that *"through this research partnership our overall hospital oral morphine consumption has increased by more than 500%*

with referral pathways to and from district and community level palliative care programmes improving as Ugandan palliative care capacity increases." [5.8a].

Through the first *Integrate Rwanda* project [3.9], oral morphine dispensing rose from 0.2kg per year to almost 5kg per year and became available in 8 hospitals, from not being available in any hospitals before. By 2019 (after the second UoE-led project), oral morphine liquid was available in 191 government hospitals free to patients needing palliative care, with additional availability from morphine tablets. Total oral morphine liquid dispensed increased from 9.9kg in 2017 to 24.2kg in 2018 and 37.4kg by the end of 2019 [5.11]. This represents an increase from an average of 27 patients receiving pain relief to over 5,000. Notably, this is being implemented in a safe, monitored way, is included within national insurance schemes, and represents one of the most effective increases in access to pain control for palliative patients seen globally.

5. Sources to corroborate the impact

[5.1] Testimonial from Rwanda Palliative Care & Hospice Organisation (Jun 2019)

[5.2] WHO (2016): Planning and implementing palliative care services: a guide for programme managers (referencing [3.3 and 3.8] & final evaluation report; p. 38-42)

[5.3] Testimonials from directors of international palliative care organisations supporting the impact of UoE work on palliative care provision in LMICs:
a. Testimonial from the Executive Director of the Worldwide Hospice Palliative Care Alliance, February 2020
b. Testimonial from the Executive Director of the International Association for Hospice and Palliative Care, February 2020

[5.4] Osman *et al* Palliative Care in the Global Setting: ASCO Resource-Stratified Practice Guideline. J Glob Oncol 2018 :4, 1-24; doi: 10.1200/JGO.18.00026

[5.5] Testimonial from THET Chief Executive (Jan 2021)

[5.6] Case study on THET website describing Palliative Care Leadership Programme 2015–2017, August 2018

[5.7] Testimonial from Ministry of Health Uganda (May 2019)

[5.8] International implementation of nurse training based on Makerere Link Nurse programme
a. Testimonial from Deputy Dean of School of Medicine at Makerere University (Dec 2020)
b. Incorporation of palliative care into nurse training in Kenya, Rwanda and Zambia: Grant L, et al. Integrating palliative care into national health systems in Africa: a multi-country intervention study. Journal of Global Health 2017 7(1). doi: 10.7189/jogh.07.010419 (i.e. paper [3.3])
c. Jeba, Jenifer et al. Joint position statement Indian Association of Palliative Care and Academy of Family Physicians of India - The way forward for developing community-based palliative care program throughout India: Policy, education, and service delivery considerations. Journal of Family Medicine and Primary Care 2018 7(2): 291-302. doi:10.4103/jfmpc.jfmpc_99_18
d. Scottish-Palestinian Health Faculty newsletter, December 2020, p. 13-16

[5.9] Palliative Care Curriculum Toolkit, developed by University of Edinburgh (Oct 2016)

[5.10] Testimonial from Executive Director, Africa Palliative Care Association (Feb 2020)

[5.11] Ministry of Health Rwanda Pharmacy oral morphine procurement systems report prepared by the Head of Palliative care in the Rwanda Ministry: Palliative Care Coordinator; Rwanda Biomedical Center (July 2019)