Institution: The University of Edinburgh

Unit of Assessment: 1

Title of case study: M: Defining patient needs and delivering evidence-based palliative and end-of-life care for non-malignant disease, through services that can be delivered in developed and low-income countries

1. Summary of the impact (indicative maximum 100 words)

Impact: Health and welfare; evidence-based palliative care for patients with non-malignant disease beyond cancer patients and in low-income countries; influencing policy; public engagement.

Significance: Care quality-standard changes and targeted interventions: for example, up to 50% fewer unplanned hospital admissions from nursing homes. Palliative care service development/redesign internationally; clinical tools deployed internationally.

Beneficiaries: Patients and their families/carers; NHS and healthcare providers; policymakers including UK and international governments; medical charities.

Attribution: The work was performed by an international team led by S. Murray at UoE.

Reach: International; policy changes and new guidelines/service structures in 11 countries (UK, Europe, N. America, Asia, sub-Saharan Africa); applicable to all those at end of life.

2. Underpinning research (indicative maximum 500 words)

Using a qualitative, rigorous serial interview technique, Professor Scott Murray (St Columba's Hospice Professor of Primary Palliative Care, UoE, 1990–present), with Dr Kirsty Boyd (Honorary Clinical Senior Lecturer, UoE, 2000–present) and Dr Marilyn Kendall (Senior Research Fellow, UoE, 1999–present), were the first to establish the needs of patients terminally ill with non-malignant disease, highlighting the health inequalities affecting this group [3.1].

Prior to 2000, palliative care was largely limited to cancer patients in the last month of life in hospices in developed countries. Since 2001, Murray has created an internationally leading team to establish the evidence base to inform palliative care interventions and pathways for non-malignant disease. The breadth of this multi-disciplinary research group has enabled construction of a wide paradigm of palliative care. International collaborative research evolving from this activity has led to developments in Europe, America, Africa and Australasia.

Supported by major awards (e.g., £467K from the National Institute for Health Research), Murray generated a compelling dataset on which innovations to redesign palliative care services could be based. Murray, Boyd and Kendall designed multi-perspective, serial, in-depth interviews and deployed them with patients with various progressive illnesses (lung cancer, bowel cancer, glioma, heart failure, chronic obstructive pulmonary disease (COPD), liver failure, frailty) and their carers. This enabled the team to describe and explore dying experiences, and identify and map typical patterns of physical, social, psychological and spiritual distress at the end of life [3.1, 3.2].

The work established compelling evidence that palliative care should be implemented:

1. ***To all patients with progressive life-threatening illness***, not just cancer patients as currently predominates [3.3]. Indeed, there has been a 200% increase in non-cancer palliative care patients in the UK since 2008. Murray established that patients with heart failure and COPD have a similar symptom burden and indeed have this for longer than do patients with cancer [3.4].
2. ***At diagnosis, not just in the terminal stages.*** By clearly demonstrating that patients may have greater distress at, or even before, formal diagnosis of cancer than in the terminal stage, and by mapping all dimensions of health (physical, social, psychological and spiritual) in individuals with life-threatening illness and their carers; the work established the importance and

interconnectedness of these factors [3.5].

3. ***In low-income and transitional economies***. The team showed that palliative care can function in healthcare resource-poor environments [3.6].

3. References to the research (indicative maximum of six references)

3.1 Kendall M, Murray S, Carduff A, et al. Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs. BMJ. 2009;339:b4122. DOI: 10.1136/bmj.b4122.

3.2 Murray S, Sheikh A. Serial interviews for patients with progressive diseases. Lancet. 2006;368:901–2. DOI: 10.1016/S0140-6736(06)69350-1.

3.3 Murray S, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. BMJ. 2005;330:1007–11. DOI: 10.1136/bmj.330.7498.1007.

3.4 Murray S, Boyd K, Kendall M, Worth A, Benton T, Clausen H. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. BMJ. 2002;325:929. DOI: 10.1136/bmj.325.7370.929.

3.5 Murray S, Kendall M, Boyd K, Grant L, Highet G, Sheikh A. Archetypal trajectories of social, psychological, and spiritual wellbeing and distress in family care givers of patients with lung cancer: secondary analysis of serial qualitative interviews. BMJ. 2010;340:c2581. DOI: 10.1136/bmj.c2581.

3.6 Murray S, 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.

4. Details of the impact (indicative maximum 750 words)

Pathways to impact

Because of the "orphan" nature of non-cancer palliative care at the outset of the work, the team engaged in an important drive to establish the importance of this service and its development with professional groups and healthcare students. To assist in this, Murray and colleagues founded the International Primary Palliative Care Network in 2007. This global network (committee members from UK, Australia, Canada, South Africa, Belgium) leads its field in research, advocacy and service innovation. It helps researchers from all continents collaborate and advocate for palliative care in the community.

Impact on clinical practice and education

Murray's team developed the Supportive & Palliative Care Indicators Tool (SPICT) to identify for palliative care more people dying with conditions such as COPD and dementia [5.1]. In 2009, they introduced routine advance care planning in all nursing homes in Midlothian, Scotland, decreasing hospital admissions by 50%, and greatly improving the overall quality of care as evaluated by relatives. Both of these interventions are now being rolled out throughout the UK; the latter won a Scottish Award for Excellence in Dementia Care and has prevented thousands of hospital admissions and deaths, with considerable economic benefits [5.2]. Internationally, the SPICT has been adopted in the UK, Spain, Holland, Ireland and Uganda.

All UK hospices now have community care teams supporting patients with non-malignant diseases. Non-cancer palliative care rose from 6% of UK services in 2000 to 18% in 2012 (National Council for Palliative Care [5.3]). The research has also informed quality improvement standards for heart failure in UK and Europe [5.4].

Regarding educational practice, in 2008, the team won the BMJ's "Making a Difference Campaign", so that until 2011, the BMJ prioritised publications about non-cancer palliative care. Moreover, this opportunity was used to advocate successfully for a new journal, BMJ Supportive & Palliative Care, launched in 2011. Illustrations of the conceptual framework for service are now incorporated in major undergraduate and postgraduate medical texts [e.g., 5.5].

Impact on public policy

Through the Palliative Care Network and other channels, such as the independent think-tank Demos, which cited the work in 2010 [5.6], Murray and colleagues have stimulated governmental and public debate about demographic and end-of-life challenges. The work has directly influenced both UK Government policy and previously cancer-only-funding charities, such as Marie Curie Cancer Care, so that they are both now investing twice as much in palliative care for non-cancer patients than they were a decade ago.

UK, Irish and Singaporean government policies reference the work [5.7–5.9, respectively], calling for a re-design of services to better meet diverse needs. In 2013, Murray, as an executive member of the International Association of Hospice and Palliative Care, co-authored a successful submission to the World Health Organization to list palliative care medications in a separate section from oncology, and for morphine to be listed as an essential medicine for palliative care for the first time.

Impact on society

Murray became a founder member of a national group to encourage a public discourse about death and dying, and mobilise communities and individuals to be involved in preventing and minimising distress at the end of life. The website of this group had 1908 unique hits during a recent "death awareness" week [5.10]. Similar public involvement strategies are increasingly being integrated in other national end-of-life strategies [e.g., 5.9].

Impact on international development

In 2011, the team was instrumental in founding an African Palliative Care Research Network, which currently supports the first African-based BSc and MSc in palliative care. Furthermore, the group, with Edinburgh University Global Health Academy, was awarded a £1.5M Department for International Development grant to integrate palliative care into the health systems of Rwanda, Kenya, Uganda and Zambia. The team has helped develop the first patient pathway for palliative care from a tertiary hospital down to district and health centre levels in Africa. The Palliative Care Unit at Makerere University, Uganda, led by Leng (Honorary Research Fellow, UoE), trials many innovations. African Ministry of Health personnel have attended training in Edinburgh, and the team has advised the Zambian Ministry of Health on cervical cancer care.

5. Sources to corroborate the impact (indicative maximum of 10 references)

5.1 Boyd K, Murray S. Recognising and managing key transitions in end of life care. BMJ 2010;341:c4863. DOI: 10.1136/bmj.c4863.

5.2 Badger F,Clifford C, Hewison A, Thomas K. An evaluation of the implementation of a programme to improve end-of-life care in nursing homes. Palliat Med. 2009;23:502–11. DOI: 10.1177/0269216309105893.

5.3 National Council for Palliative Care (2013). National Survey of patient activity data for specialist palliative care services. http://www.ncpc.org.uk/sites/default/files/MDS%20Full%20Report%202012_1.pdf *[page 44.]*

5.4 Jaarsma T, Beattie J, Ryder M, et al; Advanced Heart Failure Study Group of the HFA of the ESC Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. Eur J Heart Fail. 2009;11:433–43. DOI: 10.1093/eurjhf/hfp041.

5.5 Davidson's Principles & Practice of Medicine. 21st Edition, London; Churchill Livingston *[Available on request. See page 284]*.

5.6 Garber J, Leadbeater C. Dying for Change. London; DEMOS (2010). http://www.demos.co.uk/publications/dyingforchange. *[Murray's work cited on p. 27 and 28.]*

5.7 UK Department of Health (2008). End of life Care Strategy: promoting high quality care for all adults at the end of life http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277.

5.8 The Irish Hospice Foundation (2011). Primary Palliative Care in Ireland: Identifying improvements in primary care to support the care of those in their last year of life http://www.lenus.ie/hse/bitstream/10147/192381/1/Primary%20Palliative%20Care%20in%20Ireland.pdf.

5.9 Singaporean guidelines. Duke Nus Graduate Medical School. Report on the National Strategy for Palliative Care. Singapore (2011). http://www.duke-nus.edu.sg/sites/default/files/Report_on_National_Strategy_for_Palliative_Care%2031Jan2012_0.pdf. *[Murray and team's work referenced on pages 14, 15 & 61.]*

5.10 Scottish Partnership for Palliative Care. Good Life, Good Death, Good Grief website. http://www.goodlifedeathgrief.org.uk/content/about/.