

Institution: University College London
Unit of Assessment: 04 - Psychology, Psychiatry and Neuroscience
Title of case study: Improving end-of-life care
<p>1. Summary of the impact</p> <p>UCL research into end-of-life care has informed policy on palliative care for dementia patients and influenced NICE quality standards for end-of-life care in three areas: spirituality, psychological assessment, and advance care planning. The research has also been used by the charity St Mungo's to develop educational resources for services working with homeless people with advanced liver disease. Evidence collated by UCL on the importance of palliative care in heart failure has formed the basis of Caring Together, a £5m investment by Marie Curie Cancer Care and the British Heart Foundation to improve end-of-life care in heart failure. A review of the effectiveness of hospice care is being used to support commissioning bids for end-of-life care services.</p>
<p>2. Underpinning research (indicative maximum 500 words)</p> <p>The Marie Curie Palliative Care Research Unit (MCPCRU) is a multi-disciplinary research group that collaborates widely within and outside UCL. Since 2004, the group has developed and tested complex interventions to improve palliative and end-of-life care, using rigorous mixed methods, and collected data directly from patients and carers to inform intervention content and assess effectiveness in randomised controlled trials.</p> <p>An early systematic review in palliative care, published in 2005, found that further systematic research was urgently needed to inform an important and developing area of clinical practice, as the only papers meeting the full criteria for inclusion in the review found equivocal evidence of the efficacy for a palliative model of care in dementia [1]. This paper has been highlighted by the Cochrane Collaboration as of particular importance.</p> <p>In 2006, we demonstrated through retrospective case note analysis the poor quality of end-of-life care provided to people with dementia in UK acute general hospitals [2] and then through a large MRC funded cohort study how 25% of people with moderate/severe dementia will die during their unplanned medical admission [3]. This was extended in 2011 with a study into the consequences of behavioural and psychological disorders (BPSD) and pain, during an acute hospital admission, in people with dementia. This explored two specific areas: how BPSD affect outcomes for the person with dementia, informal carers and the hospital, and the detection and management of pain in people with dementia [4]. Results of this study have been disseminated through seminars held with the Alzheimer's Society.</p> <p>Another long-running strand of research has determined whether spiritual beliefs may affect outcome of bereavement [5]; development of a standardised measurement for spiritual belief; and spiritual and religious interventions for the wellbeing of adults in the terminal phase of disease. Recognising also the importance of measurable psychological assessment in cancer care, our team led work in 2008-09 to validate the National Comprehensive Cancer Network Distress Thermometer. This tool was originally developed in the US, but we tested it and adapted it for use in a UK population [6]. In addition, the group has conducted a number of studies to investigate the acceptability, timing and content of advanced care planning discussions with cancer patients [7].</p> <p>In 2011, further work investigated the palliative needs of heart disease patients. This identified three themes that were consistently reported by both patients and health professionals: a lack of continuity in the care provided to advanced heart failure patients, poor communication, and inconsistency in changing the emphasis of care from life prolonging to supportive [8].</p>

Impact case study (REF3b)

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

- [1] Sampson EL, Ritchie CW, Lai R, Raven PW, Blanchard MR. A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. *International Psychogeriatrics* 2005; 17(1):31-40 <http://doi.org/bcwm53>
- [2] Sampson EL, Gould V, Lee D, Blanchard MR. Differences in care received by patients with and without dementia who have died during acute hospital admission: a retrospective case note study. *Age & Ageing*. 2006 Mar;35(2):187-9. <http://doi.org/chkchj>
- [3] Sampson EL, Blanchard MR, Jones L, Tookman A, King M. Dementia in the acute hospital: prospective cohort study of prevalence and mortality. *Br J Psychiatry*. 2009 Jul;195(1):61-6. <http://doi.org/br88rw>
- [4] Scott S, Jones L, Blanchard MR, Sampson EL. Study protocol: the Behaviour and Pain in Dementia Study (BePaid). *BMC Geriatr*. 2011 Oct 17;11(1):61. <http://doi.org/c2fdqg>
- [5] Walsh K, King M, Jones L, Tookman A, Blizard R.; Spiritual beliefs may affect outcome of bereavement: prospective study. *BMJ*. 2002 Jun 29;324(7353):1551. <http://doi.org/fcwdpg>
- [6] Gessler S, Low J, Daniells E, Williams R, Brough V, Tookman A, Jones L. Screening for distress in cancer patients: is the distress thermometer a valid measure in the UK and does it change over time? A prospective validation study. *Psychooncology*. 2008 Jun;17(6):538-47. <http://doi.org/fk75tn>
- [7] Barnes K, Jones L, Tookman A, King M; Acceptability of an advance care planning interview schedule: a focus group study; *Palliat Med*. 2007 Jan;21(1):23-8. <http://doi.org/b37fmn>
- [8] Low J, Pattenden J, Candy B, Beattie JM, Jones L. Palliative care in advanced heart failure: an international review of the perspectives of recipients and health professionals on care provision. *J Card Fail*. 2011 Mar;17(3):231-52. <http://doi.org/c2ds2g>

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

End-of-life care is of increasing importance for health and social care providers as well as patients, families and society. Death is a universal outcome, but more people are living to older ages with a range of advanced progressive conditions including cancer. Providing appropriate, evidence-based, high-quality care through deterioration and in death is a major challenge. Our work has provided the first firm evidence base in this area, which has widely informed policy and guidelines, and we have begun to work on specific interventions to improve end-of-life-care. High-quality end-of-life care for all has long-term impact on the experiences of carers and families into bereavement. Improved bereavement outcomes impact on health and costs to society.

Informing policy on dementia: Our work on dementia has had a wide influence on national policy. It was heavily referenced in the Alzheimer's Society report *My life until the end: Dying well with dementia* (2012) [a]. Our interventional studies informed recommendations for the UK NICE-SCIE *Guideline on Supporting People with Dementia and their Carers* (2006) [b] and *Living Well with Dementia: A National Dementia Strategy* (2009) [c]. Epidemiological data from our acute hospital studies (including output [3]) has been used as evidence in the NHS Confederation's report *Acute awareness: Improving hospital care for people with dementia* [d] and the Alzheimer's Society's report *Counting the Cost: Caring for people with dementia on hospital wards* (2009) [e]. In 2009 we worked with Marie Curie Cancer Care on an assessment of end-of-life care for people with dementia in the London Borough of Haringey. This found that with timely support in the community, it would be possible to prevent some crises occurring, or in the event of the crisis happening, provide an intervention that would reduce the need for a hospital admission [f]. This was used as a best practice example in the 2010 NICE Guidance: *End of life care for people with dementia: Commissioning guide* [g].

Impact case study (REF3b)

Influencing NICE guidelines 2011: Evidence from our research was incorporated into NICE guidance in 2011 in 3 areas: spirituality, psychological assessment, and advance care planning.

Spirituality: Our work is referenced in the NICE quality standard on *End of life care for adults* (QS13) supporting documents under Statement 6 – Holistic support – spiritual and religious [h]. It was also used in 2009 in the Department of Health National End of Life Care Programme publication *Draft Spiritual Support and Bereavement Care Quality Markers and Measures for End of Life Care* [i].

Assessment of psychological needs: The distress thermometer is now recommended as part of holistic assessment of patients not only in palliative care but earlier in illness, in the National Holistic Common Assessment that forms part of the NICE quality standards for end-of-life care published in 2011 [j]. This simple tool is now widely used in UK clinical practice as part of holistic assessment of patients not only in palliative care but also earlier in illness [k].

Advance care planning: Advance care planning for all with advanced illness is a key recommendation of the Department of Health *End of Life Strategy 2008* and also of service initiatives such as the Gold Standards Framework; this is being extended to care for children and young people [l]. Our work provides empirical research evidence to inform policy development. Output [8], above, is cited in the Royal College of Physicians' 2009 *Advance Care Planning: National Guideline: Concise Guide to Good Practice 12* [m] and *Capacity, care planning and advance care planning in life limiting illness: A guide for health and social care staff* published by DH National End of Life Care Programme in 2011 [n]. The relevant parts of these, are in turn referenced in the 2011 NICE quality standards for end-of-life care [o].

Improving end-of-life care services

We collated evidence on the importance of palliative care in heart failure (output [9]), which has formed the basis of Caring Together, a £5 million investment by Marie Curie Cancer Care and the British Heart Foundation to improve end-of-life care in heart failure [p]. Between June 2011 and June 2013, 232 heart failure patients were referred to Caring Together across its three pilot sites. All these patients and their carers have benefited from the implementation of the core components of Caring Together, including the comprehensive assessment of needs. Very few patients required referral to specialist palliative care or hospice inpatient stays. Many of them benefited from referral to hospice day therapies at the three hospices in the pilot sites [q].

Work with St Mungo's charity led to an influential report in May 2011 (*Supporting homeless people with advanced liver disease approaching the end of life*) on end-of-life experiences of homeless people facing death from advanced liver disease. As a result of this report, St Mungo's developed and implemented a palliative care education programme for extension to other homeless services; a resource pack was published in February 2013 [r].

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

- [a] The Alzheimer Society's "My life until the end: Dying well with dementia" report from 2012 widely cites UCL's work. See particularly pages 18 and 22, http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1537
- [b] <http://www.nice.org.uk/nicemedia/pdf/cg042niceguideline.pdf>; Full guidance, including references to outputs [1] and [3] <http://guidance.nice.org.uk/CG42/Guidance/1-7/pdf/English>
- [c] National Dementia Strategy 2009: <https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy>
- [d] Acute awareness: Improving hospital care for people with dementia. NHS Confederation 2010. http://www.nhsconfed.org/Publications/Documents/Dementia_report_Acute_awareness.pdf. See page 8.

Impact case study (REF3b)

- [e] See pages 8-10, 16, 42-43 of the report <http://www.alzheimers.org.uk/countingthecost>
- [f] End-of-life care for people with dementia, October 2009, <http://www.mariecurie.org.uk/Documents/HEALTHCARE-PROFESSIONALS/Innovation/project-report-0210.pdf>
- [g] <http://www.nice.org.uk/media/0A2/66/CommissioningGuideEoLDementia.pdf> See page 14.
- [h] NICE Quality standard for end-of-life care for adults, 2011
<http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-qs13>
<http://www.nice.org.uk/media/EE7/57/EoLCFinalQS.pdf>
- [i] <http://www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/draft-spiritual-support-and-bereavement-care-quality-markers-and-measures-for-end-of-life-care.aspx> See systematic review which underpinned this document:
<https://www.gov.uk/government/publications/spiritual-care-at-the-end-of-life-a-systematic-review-of-the-literature>
- [j] Holistic common assessment:
http://www.endoflifecare.nhs.uk/assets/downloads/HCA_guide.pdf
Distress thermometer also recommended in NCAT's Holistic Needs Assessment for people with cancer: http://www.rcplondon.ac.uk/sites/default/files/hna_full_practical_guide_web.pdf
- [k] Use of Distress Thermometer:
Cumbria/Lancashire: http://www.endoflifecumbriaandlancashire.org.uk/info_patients_carers/last_weeks_life/distress_thermometer.php;
West London Cancer Network: <http://www.nwlc.nhs.uk/Downloads/Specialist-and-palliative-care/The%20Distress%20Thermometer%20leaflet%20draft.pdf>
- [l] Lewis M and National Steering Group, Department of Health (2008) *Better care, better lives. Improving outcomes for children young people and their families living with life limiting and life threatening conditions*. Project Report. Department of Health. <http://eprints.uwe.ac.uk/5178/>
- [m] Advance care planning, national guidelines: <http://www.rcplondon.ac.uk/resources/concise-guidelines-advance-care-planning> See reference 70
- [n] Holistic common assessment:
http://www.endoflifecare.nhs.uk/assets/downloads/HCA_guide.pdf
Distress thermometer also recommended in NCAT's Holistic Needs Assessment for people with cancer: http://www.rcplondon.ac.uk/sites/default/files/hna_full_practical_guide_web.pdf
- [o] NICE Quality standard for end-of-life care for adults, 2011
<http://www.nice.org.uk/media/EE7/57/EoLCFinalQS.pdf>
- [p] Caring Together: <http://www.bhf.org.uk/get-involved/in-your-area/scotland/caring-together.aspx>; £5m programme: <http://www.carers.org/news/caring-together-and-getting-it-right>; our literature review is referenced in the following presentation: http://www.palliativecareggc.org.uk/uploads/file/events_docs/Caring%20Together%20Programme%20Presentation%20Iain%20Armstrong%20HF%20Learning%20Event%20March%202010.pdf See page 13
- [q] Caring Together October 2013 newsletter, confirms how many patients benefited in the first two years of the programme: http://www.mariecurie.org.uk/Global/commissioners-and-referrers/Caring-Together-e-bulletin_October2013.pdf
- [r] Homelessness and End of Life Care, 2013, <http://www.mungos.org/endoflifecare>