

**Impact case study (REF3b)**

<b>Institution:</b> University of Hull
<b>Unit of Assessment:</b> C22: Social Work and Social Policy
<b>Title of case study:</b> Living and dying well: holistic care at the end of life
<p><b>1. Summary of the impact</b> (indicative maximum 100 words)</p> <p>The research has had significant impact in the UK on the development of social and spiritual support for people at the end of life and their families. With Professor Holloway as Social Care Lead on the National End of Life Care Programme (NEoLCP) since 2009, the research has underpinned the launch of a framework for the delivery of social care at the end of life which is now in its second phase of implementation. The framework is endorsed by the Association of Directors of Adult Social Services and has led to local and regional Action Plans and social care practice initiatives. The research on spirituality has led to scoping and training initiatives in healthcare practice and in the funerals industry within the UK and internationally.</p>
<p><b>2. Underpinning research</b> (indicative maximum 500 words)</p> <p>Although research into dying and bereavement is one of the oldest specialisms in social work, this work has been increasingly confined to the small number of social workers in hospices and palliative care settings, which accommodate only a small percentage of people dying in any given year, and older people, who form the majority of those supported by adult social care services, predominantly dying in general hospitals. Further, although the term ‘holistic care’ has been used since the 1990s to claim an approach which addresses the whole person, the concept has been poorly defined and holistic practice often indistinguishable from multi-disciplinary practice .</p> <p>The research was undertaken from 2003 to 2011 by Margaret Holloway (Professor of Social Work, University of Hull, 2004 to present) with colleagues at Hull, Sheffield, Staffordshire, Aberdeen and Hong Kong Universities (see Section 4). Since moving to Hull, Professor Holloway has developed her long-standing research on death, dying and bereavement to offer three key insights, whose impacts are interrelated. Each has had significant impact on end of life care - in the UK (i) and beyond (ii and iii).</p> <p>i. <i>A focus on the end phase of life of older people and end of life care which is not disease-specific but proceeds from a holistic approach to assessment and care planning.</i>  The research demonstrated that end of life care should belong to mainstream social work and that as people live longer but with increasing levels of frailty and ill-health, end of life planning and care is at the heart of personalised support for older people and people living with long-term conditions. The research challenges the perception that the last 2-3 days of life constitute the dying phase arguing that medical advances have led to a prolonged, liminal phase before death in which social care workers already provide high levels of support and should recognise that this person is in the final phase of life and may wish to make preparations for their death (references 3.2 and 3.3)</p> <p>ii. <i>The translation of evidence of the broad range of spiritual needs displayed by dying and bereaved people into models of spiritual care which can be utilised by secular professionals.</i>  Holistic care belongs to the hospice vision and is usually claimed as the model for end of life care. Social work has traditionally used the term ‘psycho-social’ care (now adopted by other health care professions) to describe its approach to the ‘whole person’. The research highlighted the acute neglect of existential and spiritual dimensions in supposedly ‘holistic care’, and considerable reluctance in social work in particular to engage with either religious or spiritual need (references 3.2 and 3.4).</p> <p>iii. <i>The meaning of quality end of life care in multicultural settings, including a focus on transcultural spirituality.</i>  The ‘modern death thesis’ is based to a significant degree on the assumption that the UK is a largely secular society. The research provided empirical evidence that many people draw on a range of internal and external resources in the face of death that do not fit neatly into a religious/secular dichotomy. Further, it developed models which assist those in secular professions and workplaces, irrespective of their personal beliefs, to engage with this dimension. The</p>

## Impact case study (REF3b)

theoretical insights have contributed substantially to the development of the concepts of 'humanistic spirituality' and 'transcultural spirituality' and to their applications in practice by the caring professions (references 3.1 and 3.5).

The research comprised of 7 projects exploring what makes for quality care at the end of life:

- a. 2003-2005 *Exploring and understanding the views of Chinese older people about cancer and end-of-life care*, Health Foundation, £125k, CI.
- b. 2005 *Towards Transcultural Spirituality*, £3k, British Academy (with Prof Cecilia Chan).
- c. Continuing programme of scholarship, drawing on own empirical work, culminating in the publication of Holloway, M. (2007) *Negotiating Death in Contemporary Health and Social Care*, Bristol: Policy Press.
- d. 2008 – 2010 *Spirituality in Contemporary Funerals*, Arts and Humanities Research Council, £109k, PI with CIs Vassos Argyrou (Reader, 2003 to present), Peter Draper (Senior Lecturer, 2003 to present) Sue Adamson (Research Fellow, 2003 to 2011) and Daniel Mariau (Lecturer, 2003 to present).
- e. 2010 *Spiritual Care at the End of Life*, Department of Health, £50k, PI
- f. 2010-11 *Training programmes for funeral directors, clergy and BHA celebrants in Yorkshire and Humberside: a pilot project*, Higher Education Innovation Funding, £10k, with Sue Adamson and Peter Draper.
- g. 2011 *Supporting People to Live and Die Well: an evaluation of phases 1 and 2 of the implementation of the NCoLCP Social Care Framework (Roadshows and Test-sites)*, NCoLCP, £2k, with Sue Adamson.

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

1. Holloway, M. (2006) Death the Great Leveller? Towards a transcultural spirituality of dying and bereavement, *Journal of Clinical Nursing, Special Issue Spirituality*, 15:7, 833-839. Invited contribution generating regular citation.
2. Holloway, M. (2007) *Negotiating Death in Contemporary Health and Social Care*, Bristol: Policy Press. Submitted as an output in RAE 2008; highly reviewed in academic journals *British Journal of Social Work*; *Sociology of Health and Illness*; *Health and Social Care in the Community*; *Research, Policy and Planning*, *Nursing Standard*, *Practice*; and recommended by the magazines *Professional Social Work*, as 'relevant to social workers and health care practitioners alike', and *Bereavement Care*, as 'the one book to buy'.
3. Holloway, M. (2009) 'Dying Old in the Twenty-first Century: a neglected issue for social work', *International Social Work* 53:5, 1-13. Developed from a paper given in the 2007 ESRC seminar series, *Social Work and Health Inequalities*, Seminar Reflection and Action.
4. Holloway, M. and Moss, B. (2010) *Spirituality and Social Work*, London, Palgrave. Contains 'Fellow Traveller Model' and challenge to the western paradigm of social work practice.
5. Holloway, M., Adamson, S., Argyrou, V., Draper, P., Mariau, D. (2010) *Spirituality in Contemporary Funerals: Final Report*, ISBN 1 903 704 49 9. First large qualitative study of funerals with empirical evidence developing the notion of humanistic spirituality.

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

Demographic trends and cultural pluralism have together raised new challenges for end of life care services. This research goes to the heart of these challenges. The impacts are cumulative and ongoing. They are best described under two streams: *social* and *spiritual* care at the end of life. The underpinning research has created a significant cultural shift amongst health and social care practitioners and a step change in service provision for dying and bereaved people. It has also contributed to public and policy debates about how we as a society 'manage' and respond to death. The non-academic beneficiaries of the underpinning research are people at the end of their life, their families and carers, healthcare and social care professionals, clergy and the funerals industry, policy advisors and implementers.

#### Stream 1: Social care at the end of life

Following her participation in a Westminster Forum Seminar on End of Life Care, at which the urgent need to engage social care professionals in delivering the national End of Life Care

**Impact case study (REF3b)**

Strategy 2008 was highlighted, Prof Holloway was appointed as Social Care Lead for the National End of Life Care Programme (NEoLCP). Referencing Holloway's research, the Social Care Advisory Group of the NEoLCP published its report 'Supporting People to Live and Die Well: a framework for social care at the end of life', in July 2010 (see 5.1). Also known as the Social Care Framework (SCF) this was rolled out at 9 Regional Roadshows attended by 1400 people from all sectors of social care. Also in phase 1 of the SCF implementation, 8 test-sites were commissioned and evaluated, addressing the 10 objectives of the SCF, with the aim of strengthening the paucity of evidence available to service commissioners. By March 2013, when the NEoLCP closed, designated End of Life Care Leads had been appointed in over 100 local authority adult social services and over 200 end of life care champions in social care had signed up; by July 2013, the total membership of the integrated (health and social care) end of life care facilitators and champions network had grown to 600. The SCF and End of Life Care Guidance are both endorsed by the Association of Directors of Adult Social Services (ADASS) and published on its website. By March 2013 over 40 of the 153 Adult Social Care Departments had approved local End of Life Care Action and Business Delivery Plans and over 500 requests were received by ADASS for the *Sharing Successful Strategies* progress report on its publication in July 2013.

Drawing on Holloway and Adamson's analysis of the data accumulated over Phase 1 of the roll-out of 'Supporting People to Live and Die Well' (2g) 13 regional projects were established to address specific local needs and build on earlier initiatives, with a view to embedding end of life care in ongoing mainstream social care practice. Also in phase 2, there has been a particular focus on social workers and social work education through the launch in July 2012 of a 'Route to Success for Social Work' (which references Holloway's research) and the insertion of end of life care skills in the new Professional Capabilities Framework (JUCSWEC). The newly established College of Social Work profiled Professor Holloway's work and developments in end of life care in its July 2012 newsletter and hosted an on-line debate with Professor Holloway as guest. Discussions are underway to establish an end of life care 'community of interest' in the College and the ADASS Workforce Network has invited the development of an end of life care national workforce strategy in social care.

The combined impact of this stream of activity has been to significantly raise awareness in mainstream social care of the importance of end of life care at the same time as raising the profile of social care amongst healthcare end of life specialists, and to promote tangible service and practice developments on a national scale.

**Stream 2: Spiritual care at the end of life**

Holloway's research on humanistic spirituality and spiritual care at the end of life is widely known amongst health and social care practitioners, as evidenced by numerous invitations since 2008 to present to mainly practitioner audiences, e.g. at 2 national conferences of the National Council for Palliative Care, the Making Research Count networks in York and Norwich, the Glasgow Schools of Social Work Public Lecture Series (also podcast), the Cheshire Association of Hospices Annual Lecture, conferences at St Christopher's, Princess Alice and Leicestershire and Rutland Hospices, and the Churches Regional Commission.

There has been significant uptake of her research findings on spirituality amongst healthcare professionals, hospital chaplains and parish clergy, and her 'Fellow Traveller Model' for spiritual care is gaining increasing currency. For example, she has been asked to assist hospices in developing interdisciplinary models for spiritual care and is an invited member of the European Association for Palliative Care's symposium on Spiritual Care. A Spiritual Care systematic literature review was commissioned by the Department of Health in 2010 because audits of the Liverpool Care Pathway indicated that Standard 7 – Spiritual Care – was barely addressed in clinical practice. It is being widely used as the starting point for addressing the inhibitions experienced by practitioners, both in the UK and further afield (for example, Hospices New Zealand has used it to inform the development of their spiritual care guidance for practitioners (5.6); the Interdisciplinary Centre for Palliative Care at the University of Munich Medical School requested and received permission from the DH to translate into German (5.9).

Holloway's research (3.1, 3.4, 3.5) also informed the structure and content of a 6-session module

## Impact case study (REF3b)

on spirituality developed within the e-learning platform End of Life Care for All (e-ELCA) launched in April 2011 with 1576 active users of the module up to 31 July 2013 (5.10)

A second strand derives from the research into contemporary funerals (3.5) with a specific focus on the evidence for and nature of spirituality and religion within today's personalised, reportedly secularised, ceremonies. Although a local study, the findings of this research have had national impact for funerals professionals and the wider public and was presented by a British Humanist Association (BHA) celebrant at the BHA Annual Conference in October 2010. For the funerals professionals this involved the development and piloting from December 2010 – March 2011 of a training programme for celebrants, at the request of Cooperative Funeralcare, the Anglican Diocese of York and the BHA (total 100 pilot participants). A further request has been received from the Berkshire Archdeaconry and Prof Holloway was a keynote speaker at the National Cremation and Burial Society's annual conference in 2012 (lecture subsequently published in *Pharos International: The Official Journal of the Cremation Society of Great Britain and the International Cremation Federation: Statistics issue*, 2013).

For the wider public, a number of media outputs have prompted enquiries from individuals:

- *Education Guardian* 24 March 2009 p.11: 'The Final Ringtone'
- *The Church Times* article February 2012
- *Funeral Service Times* articles September 2010 and April 2011
- Telephone interview for Five News, 16 April 2009
- *Yorkshire Post* 16 March 2009, 'Funeral duty for university study team'
- *Hull Daily Mail* 30 March 2009, 'Building up a picture of modern-day spirituality'
- BBC Radio Humberside live interviews 18 February 2011 and 29 March 2009
- BBC Radio Leeds live interview 5 April 2009

Parts of the body of underpinning research were undertaken by the University in collaboration with other HEIs as follows: *Exploring and understanding the views of Chinese older people about cancer and end-of-life care* – with Sheila Payne (PI) and Jane Seymour (CI) both at University of Sheffield at the time.

*Spiritual care at the end of life* – with Wilf McSherry (University of Staffordshire) and John Swinton (University of Aberdeen)

*Towards Transcultural Spirituality*- with Prof Cecilia Chan, Hong Kong University.

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

1. *Supporting People to Live and Die Well: a framework for social care at the end of life.* Published July 2012; also available online - over 5000 downloads by March 2013.  
<http://www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/supporting-people-to-live-and-die-well.aspx>
2. *Sharing successful strategies for implementing 'Supporting People to Live and Die Well'* jointly published NHS Improving Quality/ADASS July 2013; over 500 hard copies distributed July 2013 and available online  
<http://www.nhs.uk/resource-search/publications/sharing-successful-strategies-for-implementing-%E2%80%98supporting-people-to-live-and-die-well.aspx>
3. Anonymised focus group interview from PhD research on social work leadership, citing impact of NEoLCP initiative; available on request.
4. Testimonial from senior manager NHS Improving Quality
5. Testimonial from former end of life care lead Association of Directors of Adult Social Services.
6. E-mail from member of Hospices New Zealand Spiritual Care Strategy Group
7. Testimonial from Cooperative Funeralcare
8. Testimonial from British Humanist Association
9. Request and permissions for University of Munich Medical School.
10. Registrations for the spirituality sessions e-learning (e-ELCA)