Institution: The University of Nottingham

Unit of Assessment: 3 Nursing

Title of case study: Improving understanding, implementation and uptake of advance care planning for end of life care

1. Summary of the impact

The University of Nottingham's Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care has enhanced the understanding, implementation and uptake of advance care planning for end of life care. Its work has shaped public policy and influenced national initiatives that have improved quality of life and reduced the number of deaths in hospitals. The research has been cited as an exemplar by the World Health Organisation and has helped inform policymaking at European level. It has guided professional practice, educated care staff and contributed to a more positive public attitude towards talking about end of life issues.

2. Underpinning research

Up to a third of UK citizens suffer during a final illness because of an absence of palliative care assessment and a lack of opportunity to express their wishes for end of life care. Since its founding in 2006 the University of Nottingham's Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care has carried out research to address this issue through advance care planning (ACP). Work in this field has been of particular relevance given significant changes introduced in the Department of Health's end of life care policy (End of Life Care Strategy, 2008) and in law by the 2007 Mental Capacity Act, which gave legal status to advance decisions to refuse treatment and nominations of lasting powers of attorney.

In 2007 the Centre began a three-year, three-phase study to develop and evaluate peer education in advance end of life care planning. Professor Jane Seymour (Sue Ryder Care Professor in Palliative and End of Life Studies, 2005-present), working with Dr Kathryn Almack (Senior Research Fellow, 2006-present) and colleagues from Aberdeen, Lancaster and Manchester, led the research, which was funded by the Burdett Trust for Nursing. It identified concerns and information/education needs among different stakeholders, including health and social care staff and older people. Focus-group discussions and follow-up workshops revealed community nurses' attitudes towards ACP and their perceptions of the barriers towards its successful implementation [1], while an examination of the links between sexual orientation and concerns about end of life care highlighted the difficulties experienced by marginalised groups of older people [2]. Study participants felt initiating discussion about ACP difficult but important and wanted more information and guidance to help tackle the issue. Researchers also trained lay and staff volunteers as 'peer educators' in ACP, with a longitudinal qualitative evaluation showing two thirds reported peer education activities a year later [3].

Concurrent research by Seymour, Almack, Professor Karen Cox (Professor of Cancer and Palliative Care, 2002) and Dr Kristian Pollock (Research Fellow 2005; Principal Research Fellow, 2013) took the form of a multi-site longitudinal survey of the care of patients with palliative care needs. Funded by the Trent Cancer Network, this highlighted the factors influencing the initiation of conversations about end of life care [4]. Patient participants showed varying degrees of reticence, evasion or reluctance to initiate conversations about end of life care preferences, usually assuming that carers would take the lead – but staff were themselves often hesitant to do so. Staff-identified barriers included the perceived risks of taking away hope and issues of timing. The study was a pilot for a larger community-based study, which began in 2012 and is ongoing.

A related strand of research by Dr Ruth Parry (Research Fellow, 2003; Senior Research Fellow, 2010) into communication and decision-making in rehabilitation [5]. This work, carried out from 2003 to 2007, examined how practitioners raise sensitive issues and encourage involvement in decision-making. The findings have since been used to develop interventions to help staff talk to patients about advance end of life care plans.

3. References to the research

1. Seymour, J, Almack, K, and Kennedy, S (2010) Implementing advance care planning: a

qualitative study of community nurses' views and experiences, *BMC Palliative Care*, 9:4 [open access; highly accessed] doi: 10.1186/1472-684X-9-4. Listed in REF2

2. Almack, K, Seymour, J, and Bellamy, G (2010) Exploring the impact of sexual orientation on experiences and concerns about end of life care and on bereavement for lesbian, gay and bisexual elders, *Sociology*, 44(5), 908-924 [accepted for special issue; journal ranking in 2010: 22/132 in sociology] doi: 10.1177/0038038510375739. Listed in REF2

3. Seymour, JE, Almack, K, Kennedy, S, and Froggatt, K (2011) Peer education for advance care planning: volunteers' perspectives on training and community engagement activities, *Health Expectations*, 16, 43-55 [journal ranking in 2011: 11/62 in health policy and services] doi: 10.1111/j.1369-7625.2011.00688.x. Listed in REF2

4. Almack, K, Cox, K, Moghaddam, N, Pollock, K, and Seymour, J (2012) After you: conversations between patients and healthcare professionals in planning for end of life care, *BMC Palliative Care*, 11:15 [open access; highly accessed] doi: 10.1186/1472-684X-11-15. Listed in REF2

5. Parry, RH (2009) Practitioners' accounts for treatment actions and recommendations in physiotherapy: when do they occur, how are they structured and what do they do? *Sociology of Health and Illness*, 31, 835-853 [journal ranking in 2011: 13/137 in sociology] doi: 10.1111/j.1467-9566.2009.01187.x. Listed in REF2

Key grants

1. Seymour, J, Clarke, A, Sanders, C, Froggatt, K, Gott, M, and Welton, M (2007-2009): Extending peer education for end of life care: working and learning with older people, Burdett Trust for Nursing – £200,000

2. Cox, K, and Seymour, JE (2007-2009): Choice and decision-making in palliative care: a study of patients', carers' and health professionals' experiences, Trent Cancer Network – £44,000

3. Parry, RH (2003-2007): Patient involvement in explanatory and goal-setting communication in physiotherapy, Nursing and Allied Health Postdoctoral Fellowship Department of Health National Coordinating Centre for Research Capacity Development (now the NIHR TCC) – £192,883

4. Details of the impact

Research by the Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care has improved the understanding, implementation and uptake of ACP. It has informed public policy and professional practice, educated care staff and raised public awareness of the issue.

The research played a significant role in guiding policy by informing the development of the Department of Health's End of Life Care Strategy, launched in 2008 and led by the National End of Life Care Programme. Claire Henry, Head of Programmes for Long-Term Conditions and End of Life Care at NHS Improving Quality, has described the Centre's contribution, which involved consultation and cited research, as "extensive and innovative", remarking: "[It] was influential and provided a foundation upon which further work and research has been based." [a] Data published in 2012's Fourth Annual Report revealed the Strategy's effect on reducing the number of people dying in hospital: between 2008 and 2011 around 30,000 more were able to pass away in their usual place of residence (i.e. home or care home) [b].

The Centre's research also informed the work of Dying Matters, a national coalition established by the National Council for Palliative Care to raise public awareness of and debate about ACP. In 2009, the year it was founded, the coalition asked the Centre to help shape its campaign and priorities and to collaborate in disseminating key findings and messages [c]. Since 2009 the coalition has gained 20,000 members from across the NHS, voluntary and independent health and social care sectors, community organisations and academia. In 2012 Sir Mike Richards, then NHS

England's National Clinical Director for End of Life Care, noted the "marked contrast" brought about by Dying Matters, observing: "Dying Matters continues to make major strides towards engaging the public and tackling the taboo of discussing death and dying" [b].

The Centre was subsequently asked to apply its findings to develop an educational guide about ACP. Produced in collaboration with the Dying Matters coalition and the National End of Life Care Programme, it was first published in 2009; it was revised in 2011 and is now available in seven languages. Some 1,200 individuals requested copies of the original version, which an Institute of Healthcare Management evaluation found was used by a wide range of healthcare professionals and accessed by service users directly [d]. Users reported that it helped facilitate otherwise "difficult" conversations.

In 2010 the Dying Matters coalition and the National End of Life Care Programme commissioned the Centre to develop a volunteer training programme about ACP, building on its original research and prototype. This was published in 2011 [e], with significant uptake in London, Devon and the Midlands. For example, between March and September 2012 Gentle Dusk, a London-based consultancy specialising in preparing and supporting end of life care, trained 32 volunteers – one of whom went on to write an article for 'Heart Matters' magazine, which is sent to half a million people. In September 2012 Gentle Dusk secured new funding from NHS London to train 30 volunteers attached to GP practices. Twelve community groups benefited from courses run by Rowcroft Hospice, Devon, in March 2012.

The research findings highlighting the marginalisation of certain groups with regard to ACP – specifically, older lesbian, gay, bisexual and transsexual (LGBT) people – were widely disseminated to policymakers, practitioners and the public, resulting in a commission from the National End of Life Care Programme for a knowledge-exchange project to improve practice. This in turn led to a national conference on the subject and the provision of evidence briefings and consultation for national guidance. Almost 700 copies of the resource [f] have been distributed to individuals and organisations since its launch in 2012. Evaluative data indicate the majority of users have both changed the way they work with LGBT people and are seeking to change the way colleagues practise. In December 2012 Almack co-convened a group now working to sustain this work, involving organisations such as Marie Curie Cancer Care, Macmillan Cancer Support, Help the Hospices and the Social Care Institute for Health.

The research also informed professional practice at a high level. The Royal College of Physicians' 2009 evidence-based guidelines for ACP cited the Centre's work and were reviewed by Seymour [g]. In 2011 Seymour led a working party for the National End of Life Care Programme to revise guidance for health and social care staff [h], drawing on the Centre's analysis of staff's educational needs.

The research has been presented internationally, including at the inaugural International Advance Care Planning and End of Life Care (ACPEL) Conference, held in Melbourne in 2010, which led to the establishment of the International Society of Advance Care Planning and End of Life Care, a partnership between healthcare professionals and academics that now has more than a thousand members. The study on peer education was cited as an exemplar in the 2011 World Health Organisation guidance for palliative care and older people [i], which is aimed at health policymakers and decision-makers, health professionals and research funders and has been used by the European Union Geriatric Medicine Society and the International Association of Gerontology and Geriatrics (European Region) for lobbying the European Commission/Parliament.

In December 2010 the Centre's research also informed a European Council Symposium on the end of life decision-making process, with the event's conclusions presented to the Steering Committee on Bioethics in June 2011. The committee agreed to develop European guidelines as part of its work programme [j]. Seymour was also recently invited to participate in the development of a European Association for Palliative Care White Paper setting out key recommendations for ACP practice and policy.

In 2010 the innovative nature of the research led to Seymour being invited to sit on a steering group for Dying for Change, a project run by leading cross-party think-tank DEMOS and commissioned by Help the Hospices. The subsequent report recommended normalisation of ACP and greater focus on volunteers. In a related development, the research informed Help the Hospices' Commission into the Future of Hospice Care (2011-2013), on which Seymour also sits.

Wider outreach activities have included an appearance on BBC Radio 4's Woman's Hour in 2011 and the co-organisation of two public events in Nottinghamshire in February 2010 and August 2011. A follow-up evaluation of the 2010 event showed all respondents would recommend a similar event to someone else and that around a third felt more comfortable about discussing death and dying.

5. Sources to corroborate the impact

a. Statement from Head of Programmes for Long-Term Conditions and End of Life Care, NHS Improving Quality (August 2013)

b. Department of Health (2012): The End of Life Strategy: Fourth Annual Report, Crown Copyright: London (see pages 13 and 8)

c. Seymour, JE, French, J, and Richardson, E (2010): Dying matters: let's talk about it, *BMJ*, 341:c4860, BMJ "Spotlight" supplement, *Palliative Care Beyond Cancer*

d. Institute of Health Care Management (2010): *An Evaluation of 'Planning For Your Future Care: A Guide' – Final Report*
http://www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/an-evaluation-of-planning-for-your-future-care-a-guide.aspx

e. *A volunteer training programme about Advance Care Planning*, published by the National End of Life Care Programme/Dying Matters coalition (2011)
http://www.endoflifecare.nhs.uk/education-and-training/acp-for-volunteers

f. National End of Life Care Programme (2012): *The route to success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people*
http://www.endoflifecare.nhs.uk/search-resources/resources-search/publications/the-route-to-success-in-end-of-life-care-%E2%80%93-achieving-quality-for-lesbian,-gay,-bisexual-and-transgender-people.aspx

g. Concise Guidance to Good Practice, Number 12, Advance Care Planning: National Guidelines, published by Royal College of Physicians (2009)
http://www.rcplondon.ac.uk/sites/default/files/documents/acp_web_final_21.01.09.pdf (see page 2 and references 1, 63)

h. National End of Life Care Programme (2011): *Capacity, care planning and advance care planning in life limiting illness*
http://www.endoflifecare.nhs.uk/assets/downloads/ACP_booklet_June_2011__with_links.pdf

i. World Health Organisation (2011): *Palliative Care for Older People: Better Practices*
http://www.eapcnet.eu/LinkClick.aspx?fileticket=UsdZAJEA5FI%3D&tabid=289 (see pages 22 and 41)

j. Seymour, JE (2010): End-of-life decision-making for people who lack capacity to decide: perspectives from the UK, *Council of Europe Symposium on Medical End of Life Decisions*: Strasbourg, France http://www.coe.int/t/dg3/healthbioethic/Source/end_of_life_compilation_E.doc