

Institution: BRUNEL UNIVERSITY (H0113)
Unit of Assessment: 23 – Sociology
Title of case study: The public policy impact of research on end-of-life care
<p>1. Summary of the impact (indicative maximum 100 words)</p> <p>This research has had impact on public policy, public understanding and practitioner debates concerning end-of-life care, with particular relevance for debates about assisted dying, the significance of which can be judged by the intense media interest that accompanies stories about euthanasia or assisted suicide. The findings have prompted significant interest from media, health professional and legislative bodies, whose stance in debates has been altered as a result. Were assisted dying to be legalised in the UK, evidence from jurisdictions where it is currently practiced suggests that it would affect the deaths of about 12,000 UK people annually.</p>
<p>2. Underpinning research (indicative maximum 500 words)</p> <p>The underpinning research for these impacts was carried out at Brunel between 2004-2008 by Clive Seale, professor of sociology, continued while Clive Seale worked at Queen Mary University of London 2008-2012 as professor of medical sociology, subsequently returning to Brunel as professor of sociology in September 2012. It was funded by the Nuffield Foundation and the National Council for Palliative Care and Seale was the sole researcher. The research, involving postal surveys of nationally representative samples of doctors done in 2004 and 2008, established that:</p> <ol style="list-style-type: none"> 1. Euthanasia is rare in the UK, although it happens. Physician-assisted suicide does not occur. 2. UK doctors are particularly concerned to discuss end-of-life decisions with patients, but not as much as doctors in countries where assisted dying is permitted. 3. UK doctors frequently make other end-of-life decisions that are allowable under UK law, which they believe have an impact on length of life. 4. UK doctors are, on the whole, opposed to the legalisation of assisted dying (euthanasia and assisted suicide) unlike the British general public. 5. One in ten dying patients make requests for a hastened death and these sometimes persist in spite of the care provided. A high rate of such requests occurs in palliative care. 6. Doctors' with religious or faith beliefs are less willing to carry out (or to say they carried out) actions that were partly intended to end life, or to provide continuous deep sedation until death. 7. There is a relatively high rate of use of continuous deep sedation until death in UK medical practice. 8. 'Vulnerable' people (for example, older people in care homes or with dementia) are no more likely than other patients to be subject to decisions that doctors think will have shortened their lives, or to receive continuous deep sedation until death (so that a 'slippery slope' does not appear to exist). <p>These studies are significant in providing for the first time reliable nationwide data on doctors' attitudes and practices. They remedy a gap in knowledge about UK medical practices, a field that in other European countries – such as Belgium and The Netherlands - has been more extensively studied. Due to Seale's contacts and research collaborations with researchers in these countries, results are directly comparable with studies in these other countries, enabling international trends and comparisons to be made.</p> <p>The results are directly relevant to issues that were previously debated by UK legislators in the absence of good evidence. In this respect, the survey results play a similar role to findings produced by Seale and colleagues in studies based on survey research going back to the early 1990s. Claims and counter claims about the extent of euthanasia in the UK (finding 1), about the state of medical opinion and how it compares with general public opinion regarding the legalisation of assisted dying (finding 4), about the extent to which dying people request an assisted death (finding 5), and claims about the impact of death-hastening practices on 'vulnerable' groups have</p>

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been addressed by the research. Other matters such as the influence of religious beliefs on medical decision-making, and the high rate of sedative drug use (findings 6 and 7) have raised new issues that are of concern to professional groups, professional regulatory authorities and the general public.

3. References to the research (indicative maximum of six references)*Journal articles (peer reviewed)*

1. Seale C. (2006) National survey of end-of-life decisions made by UK medical practitioners. *Palliative Medicine* 20(1): 3-10. doi: 10.1191/0269216306pm1094oa (Cited 94 times; Google Scholar 10th Sep 2013)
2. Seale, C. (2009) Legalisation of euthanasia or physician-assisted suicide: survey of doctors' attitudes *Palliative Medicine* 23(3): 205-212. doi: 10.1177/0269216308102041 (Cited 57 times; Google Scholar 10th Sep 2013)
3. Seale C. (2009) End-of-life decisions in the UK involving medical practitioners *Palliative Medicine* 23(3): 198-204. doi: 10.1177/0269216308102042 (Cited 53 times; Google Scholar 10th Sep 2013)
4. Seale C. (2010) Continuous deep sedation in UK medical practice: descriptive study. *Journal of Pain and Symptom Management* 39(1): 44-53. <http://dx.doi.org/10.1016/j.jpainsymman.2009.06.007> (Cited 27 times; Google Scholar 10th Sep 2013)
5. Seale, C. (2010) The role of doctors' religious faith and ethnicity in taking ethically controversial decisions during end-of-life care *Journal of Medical Ethics* 36: 677-682 doi: jme.2010.036194v2 (Cited 36 times; Google Scholar 10th Sep 2013)
6. Nuffield Foundation grant 2004-5 £5,585; National Council for Palliative Care grant 2007-8 £46,56

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

As the research showed, one in ten people who die at some point make a request for an assisted death, translating to about 60,000 such requests annually. Research from countries where euthanasia is legal show that approximately 2% of deaths are by euthanasia, which would translate to about 12,000 deaths annually. In January 2012 the *Daily Telegraph* reported that up until that date 182 British people had travelled to Dignitas in Switzerland for an assisted suicide. British Social Attitudes surveys have, for some years, shown UK public support for permissive legislation on assisted dying to stand at approximately 80%. The Nexis newspaper database of all national newspapers showed that in the five years to March 2013 there were 1816 newspaper articles containing three or more mentions of terms describing assisted dying. This is therefore an issue of considerable public significance, where research relevant to debates about the topic has considerable reach.

Attempts to change the law to allow assisted dying are periodically made in the UK, the most recent of these being a Bill in the House of Lords sponsored by Lord Joffe and accompanied by a select committee report, which was defeated (or talked out) in 2006. Evidence given to the Select Committee by the National Council of Palliative Care indicated the need for better information about, for example, the extent to which assisted dying was currently being practiced in the UK, and the state of medical opinion about the desirability of legislation. The surveys reported in this impact case study have subsequently provided this information, and this has fed into debates in a variety of forums involving legislators, policy makers and lobby groups associated with renewed attempts (and opposing efforts) to get permissive legislation passed.

At the time of the Joffe Bill, the British Medical Association briefly changed its stance on the desirability of legalising assisted dying from one of opposition to one of neutrality. This has now changed back to opposition, but it prompted a great deal of debate about the true state of medical opinion. The select committee commissioned a report into the evidence about medical opinion and this revealed a collection of rather poorly conducted studies, with uncertain response rates and question wordings that did not allow trends over time, or comparisons with surveys of general public opinion, to be reliably made. The second 2008 survey, by remedying the methodological problems of earlier surveys, established this conclusively so that it is now well understood that the UK medical profession and the UK general public differ markedly in their levels of support for such

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legislation, with doctors being largely opposed. This is an important finding, as UK parliamentarians have, historically, been highly influenced by medical opinions on this matter.

Further to this, the relevance of the research for guidelines issued by the Director of Public Prosecutions following the Diane Pretty case and the ongoing experience of UK citizens travelling to Switzerland to avail themselves of the services of Dignitas, concerning the conditions under which a prosecution would and would not be pursued against a person for assisting in a suicide, have been brought out in the pages of the British Medical Journal and subsequent correspondence, and in evidence given in 2010 to the Commission on Assisted Dying, chaired by Lord Falconer at Demos, where Seale gave evidence in a session to which the Director of Public Prosecutions also contributed evidence.

In addition, some of the results, particularly those concerning the high rate at which sedative drugs are used in UK end-of-life care and the role played by doctors' personal religious beliefs, have excited the attention of journalists, professional regulatory bodies, and professional groups.

On sedation, the *Daily Telegraph* in 2010 ran a number of stories, influenced by the study results, expressing concern about the over-use of sedation said to be associated with the roll-out of the Liverpool Care Pathway (LCP), a scheme or checklist aimed at guiding the professional practice of health care providers in end-of-life care. A BBC Radio 4 report involving an interview with Seale also fuelled this concern, and Seale has been invited to discuss his findings on sedation at meetings of professional groups concerned with the Liverpool Care Pathway and the use of sedatives. Recently, the LCP has been disbanded because of public concerns about its use in health care settings. Further qualitative and observational research on the use of sedation involving Seale in collaboration with researchers in Nottingham (UK), Rotterdam (Netherlands) and Ghent (Belgium) is continuing into this subject, and this will elucidate the complex relationship between the use of continuous deep sedation until death, and euthanasia, as this applies in different legislative environments.

On religious beliefs, mass media coverage of the research has highlighted the implications of the findings for debates about the place of doctors' personal religious beliefs in their clinical practice. This has implications for General Medical Council guidance to doctors. Again, this element of the findings has received coverage in national and international mass media (for example, participation in a debate on BBC World Service).

Evidence of impact from 2008 onwards includes the following:

- *UK newspaper coverage:* Express (leader), Sunday Express (leader), Times, Guardian, Glasgow Herald, Daily Telegraph, Sunday Herald, Daily Mail.
- *UK broadcast media coverage:* Interviews on BBC4 Today programme, BBC World Service, BBC local radio; reports on BBC News website.
- *Internet coverage:* The research findings have been reported and their implications discussed on many websites. Some of the more significant include:
 1. Help the Hospices <http://www.helpthehospices.org.uk/media-centre/latest-news/doctors-against-assisted-dying/>
 2. Living and Dying Well http://www.livinganddyingwell.org.uk/index.php?option=com_content&view=article&id=67:what-do-doctors-think-about-assisted-dying&catid=45:medicine&Itemid=64
 3. Dignity in Dying <http://www.dignityindying.org.uk/research/research-from-the-uk.html>

The media impact was so extensive that it prompted Seale to carry out a study of the media coverage, reported in a 2010 journal article :

Seale C. (2010) How the mass media report social statistics: a case study concerning research on end-of-life decisions. *Social Science and Medicine* 71, 5: 861-868.

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<http://dx.doi.org/10.1016/j.socscimed.2010.05.048>

The implications of the findings for public policy and legislation regarding assisted dying were developed in the following practitioner publications:

- Seale, C. (2009) Counting end of life decisions. *British Medical Journal* 14th September 339:b3690
- Seale, C. (2009) Doctors' attitudes surveyed. *British Medical Journal* 14th September 339:b3761
- Seale C. (2009) Risk of excluding medical input for assisted suicide. *Daily Telegraph*. September 25th.
- Seale, C. (2010) Do it properly or not at all. *British Medical Journal* 1 April 340:c1719
- National Council for Palliative Care (2010) End of life treatment: decisions and attitudes of doctors. Briefing 17. London: NCPC.

The work has also been of interest to relevant professional groups, as reflected in invitations to the following meetings:

- 2009: 29th October Royal College of Obstetrics and Gynaecology: "End of life decisions in UK medical practice"
- 2009: 24th November: Help the Hospices conference on 'Making life before death matter', Harrogate, UK: "End of life decisions in UK medical practice"
- 2010: 28th January. National Council for Palliative Care conference on the use of sedation in palliative care, London: "Findings from a recent survey on the use of sedation in end-of-life care by UK doctors"
- 2010: Feb 1st, Royal Society of Medicine, conference on 'Is the principle of double effect still relevant in end of life care?'
- 2011 October 11th. Health Care Professionals for Assisted Dying annual meeting: 'Attitudes of UK doctors to assisted dying'
- 2013 10th June: 'The use of sedatives in end-of-life care: legislation and practice'. Wales medical sociology group, Swansea University

Policy-making forums related to the legislature, particularly the House of Lords, have shown considerable interest in the findings. For example:

- 2010 6th July: Contributed to assisted dying consultation, St George's House, Windsor Castle, chaired by Baroness Warnock. <http://www.stgeorghouse.org/consultations/social-and-ethical-consultations/recent-consultations/assisted-dying/>
- 2010 14th December: Evidence given to Commission on Assisted Dying, chaired by Lord Falconer at Demos: <http://www.commissiononassisteddying.co.uk/watch-evidence>

The report from the Commission on Assisted Dying is available here:

<http://www.demos.co.uk/publications/thecommissiononassisteddying>

Seale's research is discussed in five of the 12 chapters

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

Individual users / beneficiaries who could be contacted by the REF team to corroborate claims:

Related to impact on legislature and policy makers:

- Baroness Ilora Finlay, House of Lords
- Lord Joel Joffe, House of Lords

Related to the impact on professional groups:

- Mr Simon Chapman, Director of Policy, National Council for Palliative Care
- Professor Ray Tallis, Chair, Health Care Professionals for Assisted Dying
- Dr Nigel Sykes, Medical Director, St Christopher's Hospice.