Euthanasia in the UK: the real story

When Professor Clive Seale, Professor of Sociology at Brunel University, published the results of his survey on decisions taken at the end of life, including euthanasia and physician-assisted suicide, it sparked a media outcry with reports that UK doctors are illegally helping eight patients a day to die. Dawn Powell talks to Professor Seale about the truth behind the headlines.

In his survey on end of life decisions[1] made by UK doctors, Professor Clive Seale asked doctors to fill in an anonymous questionnaire about whether they or a colleague had committed euthanasia or helped with a patient's suicide. He also asked them if they either withdrew or withheld treatment (a 'non-treatment decision) or intensified the alleviation of pain/symptoms knowing that such actions could hasten the end of the patient's life (known as a 'double-effect' decision).

He had replies from 857 doctors, describing the care of the last patient they attended who died. After extrapolating the results of his enquiry to the population of deaths in the UK, Professor Seale found that 0.16 per cent of deaths involved euthanasia at a patient's request ('voluntary' euthanasia) and a further 0.33 per cent involved ending a patient's life without a concurrent request from the patient to do so. However, he found no cases where a physician helped a patient to commit suicide (*Table 1*). In terms of legal end of life decisions, Professor Seale found that 30 per cent of the respondents gave doses of drugs that they thought had a double-effect and 33 per cent had made 'non-treatment' decisions. He also discovered that UK doctors were less likely to commit euthanasia or physician assisted suicide than doctors in some other countries where the same survey had been conducted.

In this one to one, Dawn Powell talks to Professor Seale about the survey results and the truth behind the headlines.

When the results of the survey were announced, there was a furore in the media – what was your reaction to this?

I thought certain national newspapers were being ridiculous as they misrepresented the survey in various respects. A lot of the journalists who wrote those reports did however speak to me and were keen to get my angle on it and a number of them read the original report so did a better job. The problem arose because the Voluntary Euthanasia Society[2] (VES - now Dignity With Dying) tried to make a sort of headline about the 3,000 deaths and they to some extent set the agenda.

The VES issued their reaction to your survey before the results were even published – how did this happen and how did it affect your work?

They got hold of a press release that was intended to be embargoed. If you look at the original paper, it only has percentages in it. They made the calculations of the number of deaths and came up with this sensationalised number of eight deaths per day being due to illegal activity. It is really not the way one ought to report the results, but it made

Survey results overview

Right to die: According to the results, there are no incidences of physician-assisted suicide in the UK. Incidences of voluntary euthanasia and ending of life without an explicit request from a patient (both of which are illegal practices) were reported, however both of these occur significantly less frequently than in most of the other countries where the survey has been carried out.

Law in the way: A small proportion of the 857 doctors who replied to the survey felt UK law had inhibited or interfered with their preferred management of the patient on whose care they reported (4.6 per cent of doctors) or that a new law would have facilitated better management of that patient (2.6 per cent of doctors).

Support for ban: 51 doctors wrote comments on the questionnaires containing views about the desirability of legal change or of medical involvement in hastening death. The majority of these (82 per cent) supported the current legal ban on medical involvement in euthanasia or assisted suicide.

857 medical practitioners responded to the anonymous survey, providing details on the last death they attended. The doctors' replies were used to estimate the proportion of UK deaths where particular end-of-life decisions were made. The proportion of UK deaths involving an end-of-life decision were:

Percentage of instances as proportion of total UK deaths

(1) Voluntary euthanasia	0.16 per cent
(2) Physician assisted suicide	0.00 per cent
(3) Ending of life without an explicit request from patient	0.33 per cent
(4) Alleviation of symptoms with possibly life shortening effect	32.8 per cent
(5) 'Non-treatment' decisions (e.g. withholding or withdrawing treatment)	30.3 per cent

(1) and (2) were significantly less frequent in the UK than in the Netherlands and Australia
(2) was also less frequent in the UK than Switzerland
(3) was less frequent in the UK than in Belgium and Australia
Comparison of UK and New Zealand general practitioners showed lower rates of (4) and (5) in the UK
(5) was more common in the UK than in most other European countries.

the sort of headlines that the VES wanted to see, so they jumped the gun on the survey. They are a campaigning organisation and I suppose they have got a right to campaign in the way they see fit. The experience did lead to all sorts of useful professional contacts. As a result of this, I got in touch with the Belgian and the Dutch researchers [who carried out similar surveys]. However, some distinguished people who are not in favour of the legalisation of euthanasia believed I was working with the VES as a result of the coverage. That is not true – I am not working for the VES. I am not interested myself in taking positions on the legalisation debate.

If the purpose of the survey wasn't to start a debate on euthanasia – what was the reason for conducting the study?

I have done work before on the basis that the debate, particularly in the UK, is carried out by policy makers, politicians and ethicists – and various assertions tend to get made that can be tested by discovering facts. I could see it was possible to discover the extent of assisted suicide and euthanasia because an Australian study had done this. It was very cheap and I knew how to do it, so I thought why not? It struck me as an interesting little project.

Were the results what you expected to find or did they surprise you?

I didn't know what I would find. I was struck by the fact the rates of illegal activities were lower than in some other countries in which the surveys had been done – that was the striking thing.

Despite the fact the questionnaire was anonymous, the respondents may still have been reluctant to reveal if they committed euthanasia or physician-assisted suicide. How can you be sure that the results reflect the true extent of these practices in the UK?

You can't be absolutely sure but what else can you do? The issue of getting people to reply to socially disapproved of behaviour is a very common one in social research. People have done national surveys on alcohol use – they have got data on the amount of alcohol sold in the UK and have compared it to national estimates of self-reported data. Generally, what they have found is that people underestimate by about half. Euthanasia is illegal so however much people trust you, you can't be sure their answers

reflect the true state of things. What I would say is that it does give force to the argument that the value of the survey is in its comparative value because the same surveys have been done in Italy, Belgium and other countries (including Australia). In those countries, there were various kinds of punishment for illegal activities that would have influenced those respondents in the same way as they did in the UK. When you compare across these countries, you assume that the reduction in true reporting is the same because of a similarly illegal nature of those actions in those countries.

In your survey you found that despite having similar influences, UK doctors appeared to commit less euthanasia and physician-assisted suicide than doctors from other countries. However, you also found that UK doctors were more likely to make non-treatment decisions or give treatments with a double-effect. Why do you think this was the case?

The only thing I can think of is that the UK has a tradition of palliative care. UK doctors make a lot of decisions, which shows they are actively managing people and they are not short of ideas for things to do. They are doing things, but not illegal things – or at least, not very often compared with doctors in some other countries.

The UK may have a tradition of palliative care, but there are concerns that terminally ill people are not dying where they want to. According to statistics, three quarters of people want to die at home but only a quarter of people actually do so. What is your view on this?

I have studied this in the past and if you were asked 'where would you wish to die if you were to die tomorrow?', you would probably say at home. But, you know, it is like any kind of hypothetical opinion question. It is like opinion polls for euthanasia, which ask 'If you have a terminal illness and you were suffering unbearably, would you like a lethal injection?' – most people say yes these days. It is totally hypothetical. When people reach the situation of being close to death, they will often think 'I need help with this – I need to get to hospital' or their relatives will think this. Obviously if you want to help people die at home, you must provide more domiciliary services. A recent review of the literature on this topic showed, perhaps unsurprisingly, that this was the single most important factor in determining whether people die at home.

In a recent edition of the British Medical Journal (BMJ), Simon Conroy (Clinical Lecturer in Geriatrics at Norwich Medical School) argued that healthcare professionals in continuing care settings, such as care homes and community hospitals, should not have to offer resuscitation to patients because there was little chance of success and resources would be better spent elsewhere. What is your reaction to this?

It is like all these discussions on rationing such as high profile cases where healthcare funders refuse treatment that *National Institute for Health and Clinical Excellence* hasn't approved of and so on. You then have this conflict of the needs between the wishes of the individual and the requirements of some universal healthcare system that has to be funded and where money needs to be put where it creates the greatest benefit. The additional argument with the care homes is the harm that is done with resuscitation; it is not just about resources being withdrawn from other sources, it is also about problems with harm created. However, the issue of whether it is right not to train care home staff in resuscitation seems a bit harsh, doesn't it? When you look at the BMJ report, it has a cold rationality – inevitably one thinks: 'what about those two per cent of people that would have an extra year or so of life – why shouldn't they be given a chance?' It is a pretty horrible dilemma really ■ GM

1. Seale C. National Survey of end-of-life decisions made UK medical practitioners. *Palliative Medicine* 2006; **20**: 1-8
2. Dignity With Dying http://www.dignityindying.org.uk/ (date last accessed 28/03/06)

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