

End of life treatment: decisions and attitudes of doctors

This briefing reports on the initial findings from a survey of doctors carried out by Professor Clive Seale, of the Centre for Health Sciences at Queen Mary University of London, in 2007 and 2008. The survey was commissioned by a collaborative of national charities with an interest in end of life care, brought together by the National Council for Palliative Care. Details of the collaborative membership are set out at the end of this publication.

The survey asked doctors about decisions they had made about the provision, withdrawing or withholding of treatment at the end of life. It also contained questions about doctors' attitudes to the legalisation of physician-assisted suicide and euthanasia (see page 7 for details of the methodology). The initial results have now been published in two papers in *Palliative Medicine*.

The purpose of this briefing is to give an overview of the main findings from the published papers together with some commentary on some of the significant aspects. Those wishing to explore these issues in more detail should read the full reports in *Palliative Medicine*.

Summary of Key Points

- For the first time a direct comparison has been made between public and medical opinion on the law relating to euthanasia and physician-assisted suicide
- In contrast to the general public, the majority of doctors are opposed to legalisation of euthanasia and physician-assisted suicide
- In terms of end of life treatment decisions, the law is very rarely broken in the UK; instances of euthanasia or physician-assisted suicide are very low
- In the majority of cases where decisions are made at the end of life about the provision, withdrawal or withholding of medical treatments which have the potential to shorten life, life is shortened by less than 24 hours; in nine out of 10 cases, by less than a week
- UK doctors are consultative in their approach to making these end of life treatment decisions



Context

Why Was This Research Commissioned?

In its response to the 2005 report of the House of Lords Select Committee that considered Lord Joffe's Assisted Dying for the Terminally Ill Bill, NCPC said that it would seek to establish a collaborative of interested organisations to commission research that would inform the public debate about physician-assisted suicide and euthanasia.

The gaps in the evidence base included the extent to which euthanasia or physician-assisted suicide currently takes place, and the views of the medical profession on whether either of those activities should be legalised. The Select

Committee's view was that although this is a societal issue the views of doctors and other affected professionals should be considered very seriously. The collaborative members also considered it important to gain a more accurate picture about the important and sensitive decisions in end of life care involving the provision, withholding or withdrawal of treatment that may have the potential to shorten life (these decisions are called "end of life treatment decisions" in this briefing, although of course many other decisions about care and treatment also may have to be made at the end of life).

This survey is the first piece of research commissioned by the collaborative. It was decided to ask Professor Seale to develop his 2004 study of doctors asking them about end of life treatment decisions. The results from that earlier survey received ill-informed and inaccurate comment in the media and elsewhere following publication in 2006. In particular it has been suggested in some quarters that the withdrawing, withholding or provision of medical treatments that may have the potential to shorten life in end of life care could be equated to euthanasia.

Main Findings

End of life treatment decisions involving doctors

Definitions

The survey used the following definitions for different types of end of life treatment decisions:

- **"Non-treatment decision" (NTD):** Withdrawal or withholding a treatment occurs where, for example, chemotherapy is discontinued or a decision is made not to start intravenous antibiotics. For the purposes of the survey this was called a 'non-treatment decision' (NTD) where a respondent considered it probable or certain that this would hasten the end of life, or where they reported an explicit intention to hasten the end of life. Treatments withdrawn or withheld without any expectation that this would influence length of life were not counted as NTDs for the purposes of this survey.
- **"Double effect":** The principle of "double-effect" means that treatment can be provided with the intention of alleviating symptoms which may have, as an additional unintended consequence, a shortening of life. For the purposes of the survey the provision of drugs to alleviate symptoms was called a 'double effect' decision if the respondent also reported probable or certain knowledge that this would hasten the end of life, or where the respondent reported partly intending to end life by these means.

See the Commentary section on page 5 for further comment on the reality of "double effect" in palliative care practice.

An important reason for repeating the 2004 study was to find out more about end of life treatment decisions in the UK and in particular rates of 'double effect' and 'non treatment decisions' (NTDs).

The 2004 study concluded that the rate of euthanasia and physician-assisted suicide in the UK was low compared to most other European countries; and that UK doctors were particularly likely to take end of life decisions in consultation with care teams, patients, and their families, and to be particularly cautious about taking decisions that might shorten life by significant amounts of time.

However there were results in the 2004 study that caused concern. Of particular note – and widely reported in the media at the time and since – were figures about decisions involving either double effect or non-treatment. Results from 2004 indicated that 32.8% of deaths had involved a double effect decision, with reported NTDs being 30.3%.

This new study, which obtained responses from more than four times as many doctors, sought to explore this finding and asked doctors more detailed questions about their decision-making. Rather than asking in a single question (as in 2004) if a doctor

had either withheld a treatment, withdrawn a treatment, or used a drug to alleviate symptoms in a manner that could hasten end of life, the questions were broken down to seek information about action and motive separately.

This is explained in *Palliative Medicine*, but in short the new study showed a significantly lower incidence of double effect and non-treatment decisions. It also showed that in most of the cases where it was thought that life might have been shortened by a treatment decision, in fact it either was not shortened at all or was shortened by less than 24 hours.

The Key Findings

- **About 40% of the reported deaths involved end of life treatment decisions that were judged to have the potential to shorten life (either a decision involving “double effect” or an NTD). This contrasted with over 60% in 2004. The difference is probably due to the more detailed questions.**
- **Of those 40% of deaths:**
 - > **In nearly 2/3 of them the doctors believed that the decision either had not shortened life at all, or had shortened it by fewer than 24 hours**
 - > **In almost a further 1/3, the doctors believed that the decision had shortened life by less than a week**
 - > **Doctors believed that life had been shortened by more than a week in fewer than 10% of those cases**
- **The survey was anonymous and enabled doctors to indicate whether the reported deaths had involved either physician-assisted suicide or euthanasia:**
 - > **No instances of potential physician-assisted suicide were reported**
 - > **Euthanasia was reported in 0.51% of cases**

The 2004 survey had found that UK doctors normally make end of life treatment decisions in consultation with the patients concerned, with their families, and with fellow professionals.

In the new survey a number of respondents had added their own comments to explain why decisions had been taken. These indicate that end of life treatment decisions were taken

with considerable care, and in consultation with patients (where possible) and their families. Common themes included that giving a treatment – for example CPR, antibiotics, or artificial ventilation – would cause significant distress with little prospect of improving quality or duration of life; that patients and their families had discussed treatment and had decided that

it would be best to try to make someone as comfortable as possible, knowing this might hasten death; or that stopping treatment made sense because the side-effects (for example, daily blood tests, invasive delivery) were probably causing more harm than good. In some cases, patients themselves had clearly said that they did not want any more treatment.

Doctors and the general public: opinions on euthanasia and physician-assisted suicide

Definitions

- **Euthanasia:** Administering a drug with the explicit intention of ending the patient's life
- **Physician-assisted suicide:** A doctor intentionally providing a person with a drug in order for that person to end their own life. The doctor does not administer the drug; the person must be able to act to administer the drug themselves

The survey asked doctors about their opinions about legalising euthanasia and physician-assisted suicide. These questions matched exactly the questions used in the 23rd British Social Attitudes (BSA) survey (2007). This is the first time the medical and public opinion has

been surveyed using the same questionnaire, making a direct comparison possible.

The results show a clear difference between public opinion (as measured in the BSA survey) and the opinion of doctors when it comes to legalising euthanasia

or physician-assisted suicide. In contrast to the public, the majority of doctors are opposed to changing the law:

	PUBLIC (%) 2111 RESPONDENTS	DOCTORS (%) 3733 RESPONDENTS
EUTHANASIA		
Probably / definitely should be allowed	82	34
Probably / definitely should not be allowed	16	64
PHYSICIAN-ASSISTED SUICIDE		
Probably / definitely should be allowed	62	35
Probably / definitely should not be allowed	36	62

This difference is significant because the opinion of doctors has been critical in euthanasia or physician-assisted suicide being legalised elsewhere in the world. Neutrality or support among doctors has been a common feature in most countries where such legislation has been passed.

Some respondents added comments, which gave some insights into opinions among UK medical professionals. Those doctors in favour of assisted

dying often added notes to the effect that even if a change in the law occurred, assisted dying should be strictly controlled and regulated. Suggestions were made that if assisted suicide was allowed, it should not be carried out by doctors in order to avoid blurring the line between the caring duty of medical professionals and the deliberate ending of life.

Some interesting variations in responses from different types of doctors came out in the study.

Doctors working in palliative care and those specialising in the care of elderly people were more likely to oppose assisted dying; older, male or white doctors were slightly more likely to support assisted dying; and doctors with strong religious beliefs were more likely to be opposed.

“Double Effect”

There is widespread misunderstanding about the phrase “double effect”. For example, it is regularly used in relation to the prescription of morphine. We know much more about morphine than we used to. The evidence has clearly shown that the correct use of opioids by titration (adjusting drugs and doses to control the pain for each individual patient) does not shorten life expectancy. This does not involve “double effect”. It is unacceptable practice to increase morphine doses by such large increments that life is threatened or distressing toxicity develops. In contrast, the use of chemotherapy in the knowledge that whilst it may remove the tumour it may also result in the death of the patient, is a more

accurate example of “double effect”.

In view of the disparity between what some doctors thought might happen as a result of administering drugs and what they reported as in fact having happened, there is a need to understand better doctors’ beliefs about the consequences of using drugs at the end of life, and whether some would benefit from additional education about end of life care.

Doctors are under a duty to do no harm, which includes the duty to save and preserve life. However, at the end of life, when a person is dying, harm might be caused by “over-treatment”, through providing or continuing

treatments which prolong the dying person’s discomfort rather than provide benefit. This survey indicates that the great majority of doctors are aware of that distinction and are making decisions accordingly.

It is important to develop understanding amongst both professionals and the public about the reality of what is involved in making and implementing decisions about the provision, withholding or withdrawal of treatments at the end of life. There is a risk of avoidable distress being caused if people are given inaccurate or unclear information or advice about these issues and the ethical considerations that apply.

The contrast between medical and public opinion on legalisation

The difference between public and medical opinion in relation to the legalisation of physician-assisted suicide and euthanasia is striking. The majority of doctors are opposed to both, whilst a clear majority of the public is in favour of both, although interestingly the BSA survey suggests that members of the public are less enthusiastic about physician-assisted suicide than they are about euthanasia. Lord Joffe’s Bill would have introduced physician-assisted suicide only.

The reasons for this disparity are not clear and merit further investigation. Some have suggested that it means that doctors are out of touch with the views of their patients. An alternative explanation (identified by Professor Seale in media interviews) is that, given the recognised need to raise public awareness of death and dying (for example in the End of Life Care Strategy) and the view that death is a public taboo, it may be that doctors have a greater understanding and awareness of

these issues. It was noticeable that opposition was particularly high amongst specialists in palliative medicine and care of the elderly, who have the most experience of end of life care.

Sedation

The survey asked about the use of continuous deep sedation (CDS) in the UK, using a question worded in the same way as in surveys in other countries. Sedatives are often used to treat symptoms that are causing significant distress, and can range from maintaining a reduced level of consciousness, through to inducing a coma. The term 'continuous deep sedation' was designed to pick up cases where sedation was particularly deep.

CDS was reported in 16.5% of cases in the UK, higher than historical levels reported in, for example, Belgium and the Netherlands.

It was reported more commonly in deaths of people aged up

to 60, and was notably less common in people aged 80 or above. It was less common in care homes, cardiovascular deaths, and deaths reported by neurologists; it was more common in deaths in hospital and deaths at home. This finding may give some reassurance to those who are concerned that sedation may be used inappropriately in care homes. The finding about deaths at home is of interest, particularly given the emphasis on allowing people who are terminally ill to choose their place of death.

It is likely that some of the hospital cases of CDS involved sedation in intensive care units, where it is often provided so that patients can tolerate intubation for artificial ventilation. Because

some of these patients are very ill and subsequently die, the survey counted some of these as CDS cases, but this is a very different situation from CDS provided in response to distressing symptoms during palliative care.

Without further research, it is not possible to draw firm conclusions about practice in continuous deep sedation in the UK compared to practice elsewhere at this stage, but the apparent high rate in the UK is enough to suggest more research is warranted.

It is anticipated that a more detailed paper on the sedation aspects of this survey will be published in due course.

Next Steps

The results published in *Palliative Medicine* are the initial "headline" results from the survey. Further analysis will reveal additional insights into end of life decision making in the UK, and also help identify those areas where more focused research than was possible in this survey would prove of value. This will include sedation, as explained above.

The collaborative has not yet decided what areas of research it will pursue next, which will in any event be subject to obtaining further funding.

Establishing the collaborative to commission and fund research in this area has enabled NCP

to fulfil the commitment it made in its response to the House of Lords Select Committee report in 2005.

Since 2005 the national agenda in palliative and end of life care has developed significantly, particularly with the publication of the End of Life Care Strategy in 2008. NCP's estimate is that 300,000 people die each year with unmet palliative care needs. This is in contrast to the relatively lower numbers estimated as being likely to take up euthanasia or assisted suicide¹. The chief priority for policy makers and the focus of our energies as a nation should now be on ensuring that the Strategy is fully implemented so that everybody who needs it

has access to high quality end of life care.

There is a need to raise the sights of media debate beyond issues of euthanasia and assisted suicide to engage in a more informed way with end of life and palliative care. NCP has been asked to lead a coalition of organisations and individuals to raise public awareness about death, dying and bereavement. Broadening the focus of public discussion will be a key task of that coalition.

For further information about the coalition call the freephone number 08000 21 44 66, visit www.ncpc.org.uk/coalition or email r.parker@ncpc.org.uk

¹The House of Lords Select Committee suggested that if the law in Oregon (on which legislation Lord Joffe's Bill was based) was introduced in the UK, about 650 people would take-up physician assisted suicide in the UK each year. If the law in the Netherlands, which also permits euthanasia, was introduced in the UK, about 12,000 deaths would result from voluntary euthanasia. These extrapolations need to be treated with considerable caution.

Methodology

- The survey was sent by post to 8,857 UK doctors across a range of specialisms; 3,733 replied
- All respondents were asked about their attitudes towards physician-assisted suicide and euthanasia
- Only those who had treated at least one patient who had died in the previous 12 months were asked to complete the section of the questionnaire on the provision, withholding and withdrawal of treatment
- Of those who replied, 2,869 had attended one or more people who had died in the previous year
- The doctors who replied to the survey had attended more than 70,000 deaths in the previous year. The replies they made to the survey reported on the last death each doctor had attended and concerned 2,869 patients.

Collaborative Membership

The following organisations were members of the collaborative that commissioned the research:

The National Council for Palliative Care

Age Concern

Help the Hospices

Macmillan Cancer Support

The Motor Neurone Disease Association

The MS Society

Sue Ryder Care

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About the National Council for Palliative Care

The National Council for Palliative Care (NCPC) is the umbrella organisation for all those who are involved in providing, commissioning and using palliative care and hospice services in England, Wales & Northern Ireland. NCPC promotes the extension and improvement of palliative care services for all people with life-threatening and life-limiting conditions. NCPC promotes palliative care in health and social care settings across all sectors to government, national and local policy makers.

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