

Physician-assisted suicide in Oregon: a personal view

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ABSTRACT Proponents for the legalisation of PAS in the UK claim that it works well in Oregon in the US. About 30 patients have used PAS each year since it was legalised in Oregon in 1997. This paper reports the result of a visit to Portland in Oregon to listen to the views of healthcare professionals, hospice association leaders and proponents of PAS.

'Palliative care' and 'hospice' mean different things in the US and the UK. 'Hospice' in the US means end-of-life care at home, and many of those 'eligible' patients receive this only for the last two or three weeks of life. 'Palliative care' tends to be delivered by hospital support teams and is largely concerned with the last days of life in the acute hospital setting. There are no specialist palliative care inpatient units in Oregon. It is commonly assumed that those patients who carry out PAS must be suffering terrible pain or are depressed. However, the experience in Oregon suggests that the small number of patients who carry out PAS are not depressed, nor are they in pain. They all share an overpowering need for control and they simply want to be able to choose when they should die.

Although PAS is legal in Oregon, only a small number of doctors take part in the process. No hospitals permit PAS to be carried out on their premises. Hospice home care programs adopt an ambivalent moral stance, distancing themselves from the act of PAS whilst continuing to support the patient and their family. The implications of these findings for notions of autonomy and moral agency are discussed here.

KEYWORDS Advance directives, autonomy, choice, end-of-life care, euthanasia, hospice, moral agency, palliative care, physician-assisted suicide

LIST OF ABBREVIATIONS National Health Service (NHS), Physician-assisted suicide (PAS), Physicians Orders for Life-Sustaining Treatment (POLST)

DECLARATION OF INTERESTS I am grateful to the Winston Churchill Memorial Trust for funding for my travel and accommodation for my six-week Fellowship in the Northwest US. The views expressed in this paper are my own.

'We shall draw from the heart of suffering itself the means of inspiration and survival.'

Winston Churchill

INTRODUCTION

Over the past three years, there have been several attempts to legalise 'assisted dying' in the UK. In May 2006, Lord Joffe's Assisted Dying Bill, legalising PAS, was defeated in the House of Lords because of a lack of safeguards and clear opposition from the medical profession.¹ In Scotland, Jeremy Purvis's Dignity in Dying paper did not progress beyond the consultation stage.² Proponents of the legalisation of PAS are determined to bring this issue back to parliament. Physician-assisted suicide is an important issue for patients, their families, healthcare professionals and our society.³ Physician-assisted suicide has been legal

in Oregon, US, since 1997, and proponents of PAS in the UK argue that it works well.³ They also maintain that palliative and hospice care can co-exist comfortably with the option for PAS. My aim was to examine these claims by visiting some of those involved in the process of PAS and with the delivery of palliative care in Oregon.⁴

METHODS

I spent two weeks in Oregon interviewing doctors, nurses, social workers, ethicists, spiritual advisers, hospice workers and members of Compassion and Choices, a pro-PAS group. The interviewees consented to the interviews being taped and gave their honest views. I assured them that their views would not be attributed to them, and after noting themes from the tapes, I destroyed the recordings to preserve confidentiality.

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THE US HEALTHCARE SYSTEM

The US spends twice as much on healthcare as other industrialised countries in relation to gross domestic product. Despite this, there is a gap between rich and poor, and serious illness can result in poverty for those trying to meet their healthcare bills. Over 47 million Americans have no healthcare insurance cover. The problem is compounded by the fact that American culture demands continued rigorous treatment. Commonly, healthcare providers and the public avoid confronting end-of-life care until the last possible moment.

I did not meet any healthcare professional in Oregon who was enthusiastic about the American healthcare system. Doctors and nurses in the US are trying to deliver the best possible care given the restrictions of their healthcare system. I found that there are inspirational doctors, nurses, psychologists, social workers, ethicists and researchers who are pioneering ways of improving end-of-life care in Oregon.⁴ Whilst there are undoubtedly problems with the NHS, the problems in the US are so different that it is difficult to make direct comparisons of palliative care provision in the two countries.

PALLIATIVE CARE AND HOSPICE CARE

Palliative care and hospice care have evolved in different ways in the US compared to those in the UK. Hospice care in the US is community provision of care, which is mainly social and nursing care, supplementing care by the family. Hospice care in the US is defined by the Medicare reimbursement system which applies to 'eligible' patients. To be 'eligible', a patient must be over 65 years old and have a prognosis of less than six months. Furthermore, the patient must agree to waive any other active treatment options such as chemotherapy or radiotherapy. The reimbursement is paid on a daily basis and this amount (around \$150) has to cover all home nursing, social support, drugs and medical input.

Financial concerns are a major consideration of medical care in the US as high cost patients can bankrupt a small hospice provider. As hospice providers are part of a market economy, competition may arise between hospice programs in the same city. Since there is no out-of-hours night care at home, it is not possible to sustain dying patients living alone at home. There are no specialist palliative care inpatient facilities in Oregon. In contrast to the situation in the UK, there is no infrastructure of general palliative care provided by primary care teams. Continuity of care is thus difficult to achieve.

Hospice care in Oregon takes place at the extreme end of life. Fifty percent of patients who are referred to a hospice program die within 16 days.⁴ The healthcare professionals I met felt that patients were referred to hospice programs too late in the course of their disease.

This reflected a reluctance by patients, doctors and the public to stop active medical interventions. Palliative care teams in Oregon tend to be hospital-based and offer a consultation service. Palliative care in the hospital setting is viewed as end-of-life care. Many of the referrals to the palliative care team come from intensive care units, where the team becomes involved in complex ethical and communication issues around the withdrawal of active treatments. In the Oregon Health Sciences University Hospital, there is specialist medical palliative care and an ethicist in the team. Ethics consults are a feature of hospitals in the US and are uncommon in the UK. I found that even where there were resources for palliative care, there was some resistance from the attending physicians and surgeons to involve the palliative care team. The Oregon Health Sciences University Hospital team were involved in developing an advance directive known as the Physicians Orders for Life-Sustaining Treatment (POLST).⁵ Over the past few years, it has emerged that advance directives have drawbacks which hinder their effectiveness in ensuring appropriate end of life care. The POLST system is an attempt to improve end-of-life care by acting as a tool for communication about goals of care. It is best seen as informative rather than binding since people can change their minds, or the situation can change. Perhaps what is most useful is that the POLST form acts as a prompt to facilitate a discussion around planning for end of life care.

PHYSICIAN-ASSISTED SUICIDE

A hospice doctor described two case histories of patients who used PAS:

Case history one

'A young man moved specifically here because Oregon had the law. He had a strong belief in an afterlife. He decided upon the day he would die, took the medication, and died peacefully. The hospice nurse knew of the day in question, but was not involved. She came to the house after his death and supported the family.'

Case history two

'A patient with cancer had a friend who was a doctor. This friend told him that it was going to be a painful way to die and advised him to take advantage of the PAS law. The hospice staff felt he was not ready to die and were concerned that he may have bypassed some of the legal hoops. The family were not happy and everybody involved was uneasy. After taking the lethal prescription, the patient did not die quickly. The family were upset. Why had he not died? The wife said she had to leave, and that she could not cope with the situation. Two volunteers who knew nothing about

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nursing care sat with the patient until he died the next morning. His wife became profoundly depressed and later attempted to commit suicide.'

Physician-assisted suicide was sometimes referred to as 'hastened death'. The death certificate in a case of PAS certifies the underlying illness as the cause of death and does not mention PAS. Physician-assisted suicide is a misnomer because it is not just the physician who is involved, but family, pharmacists and nurses. Hospitals in Oregon do not permit PAS on their premises. However, there is no problem for a patient in finding a doctor who will carry out PAS. In one area of Oregon, there have been 28 cases of PAS since the legislation has been in force. The same doctor was involved in 23 of these cases.⁴ Hospice doctors do not sign lethal prescriptions but may refer the patient to another doctor who is willing to do so, or whom the patient may contact.

COMPASSION & CHOICES OREGON

Compassion & Choices is an organisation which has a list of doctors who are willing to carry out PAS. It strongly supports the legalisation of PAS and provides information and advice to those interested in PAS. They also have volunteers who may be with the patient when they take the lethal medication.

THE REQUEST FOR PAS

Of the 35,000 deaths per annum in Oregon, only about 30 people use PAS. Only 1 in 10 requesting PAS proceeds as far as picking up the medication, and, of those, only about half take it.⁶ Contrary to earlier assumptions, this small group are not suffering terribly, and they are not in pain, nor are they depressed. Oregon physicians described patients requesting PAS as having strong and vivid personalities characterised by determination and inflexibility.⁷ These people have always had a strong need for control throughout their lives. They simply want to be able to choose the time of their death and prefer to avoid a violent suicide. They dislike having to depend on others, so palliative care has no appeal for them.⁸

A patient may have no suffering, but once they have their six-month prognosis, they can start the process for PAS. The patient can come to the hospice as part of the process, and with the sole intention of committing suicide, wait the required 15 days, then take the lethal medication. The doctors involved are confident that these patients are not clinically depressed and so there is no formal psychiatric assessment. There is an urge to prevent violent suicide, and there were concerns expressed that by keeping PAS illegal, it would inhibit communication around death and dying. However, in the UK, palliative care specialists feel protected by the legislation which permits them to raise questions about death and dying without fear that the patient might think

they are suggesting PAS as an option. The main benefit of the PAS legislation in Oregon appears to be that it offers patients a way out if 'things get too bad.' The need for this safety net is fuelled by the fundamental lack of trust that these patients have in the medical healthcare system.

Hospice programs sit uneasily with PAS. Hospice staff want to support patients and families but do not want to be involved in PAS.

ETHICAL CONSIDERATIONS

Much has been written about the individual's choice, and the importance of autonomy, but little about the social consequences of legalising PAS. In the complex process of dying, it is questionable whether fully autonomous choice is a realistic possibility. There is a need to develop more sophisticated models of autonomy which take account of the social nature of dying, and to evaluate the moral agencies of the individual who is dying and of the many carers.⁹ Physician-assisted suicide cannot take place without a lethal prescription from the doctor. Thus the doctor's moral agency is not in question. The doctor is involved in a form of medicalised killing. The moral agencies of the family, nurses and pharmacists in assisted suicide are also relevant in the debate. Hospice programs in Oregon allow their staff to support a patient who intends assisted suicide; they do not permit their doctors to write lethal scripts. The hospice nurse will 'take a walk around the block' while the patient takes the medication, and will then return to support the family.⁴

Where autonomy has a strong force in ethical argument, the principle of justice is rarely discussed. In an argument promoting the principle of justice, an individual's autonomy is inevitably curtailed. Justice issues include the fact that for many people in the US, there is no access to palliative care or to physicians skilled in pain and symptom control. For proponents of PAS, the autonomy of family members, doctors and nurses is viewed only as a problem insofar as it threatens to impinge upon the sick individual's autonomy.¹⁰ A dying person's sense of autonomy is fundamentally linked to their relationships to their family or friends. The feelings of the family inevitably affect the dying person's sense of their own agency. For example, a wife's wish that her husband fight the disease may be the major concern or, conversely, if a spouse had recently died, the patient may not feel that they have any reason to live.¹⁰ As patients experience physical deterioration, they often feel ambivalent about their choices and will be dependent on help from others. This dependency on others is unavoidable but denied by most of Oregon society. A patient's sense of being in control at the end of their life is largely affected by their extreme dependency, and by their uncertainty in relation to the approach of death rather than with doctors denying their wishes.¹⁰ Mann warns that there is a risk if PAS is legalised in the UK that:

'there will be social expectations for individuals to choose PAS as soon as their physical capabilities decline to a point where they become dependent upon others in an expensive inconvenient way'.¹⁰

This is no idle threat. In Oregon, it is acceptable that individuals choose PAS to avoid uncertainty during the period of dying or to avoid dependency on others.

In legalising PAS, Oregon has created a whole new set of relationships between dying patients, their families and the healthcare professionals. New end-of-life rituals have emerged around the process of dying by PAS. For instance, the choosing of a day and hour of one's death, the presence of family and the absence of hospice staff.

CONCLUSIONS

The provision of end-of-life care is very different in Oregon to that experienced by patients in the UK. Both sides of the PAS debate wish to improve the care of dying patients. This common aim should be the foundation for future debate on end-of-life care. I believe that it is clear that the Oregon experience cannot be claimed to be a valid reason for any change to the existing law in the UK. There is a need to know more about the issues surrounding the PAS request in the UK, and to devise

ways of helping these patients without putting other vulnerable patients at risk. It is a sad reflection on the doctor–patient relationship that a patient feels the need for the legalisation of PAS purely as reassurance that there is a way out. These fears need to be addressed and attention paid to both psycho-social and spiritual care. Doctors need to demonstrate to patients that medical technology will not be applied indiscriminately but only with their informed consent. Communication tools such as the POLST may help healthcare professionals to achieve the skills to discuss end-of-life care with patients and their families. The NHS faces challenges in providing continuity of care. The experience in the US of a market-based healthcare system should act as a warning and encourage us to strive to preserve the principles of the NHS. In particular, we need to preserve the network of primary care which surely is the best safety net of all. A new model of autonomy is required which acknowledges the dependency which exists at the end of life. Palliative care strives to respect the autonomy of the individual, but there is a need to accept that families, friends, staff and a wider society are all affected by the death of an individual. Choice cannot be unlimited without a consideration of the effects on others. There is a need to move away from both the extremes of the medical paternalism of the past and the consumerism of the present, to develop a middle ground – an ethics of responsibility.

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