

CURRENT ETHICAL ISSUES IN ADVANCED CANCER CARE

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Abstract

Despite continuing advances in treatment, cancer continues to be a major cause of suffering and death, and so symptom management and end of life care will continue to be an important aspect of cancer care for the foreseeable future. An integral part of providing this care, for all clinicians involved, is understanding and managing the ethical dimensions of such care, and meeting the challenges of patient and public expectations - for relief of pain and other suffering, and for dignity and control at the time of death. This paper will highlight two aspects of care of patients with advanced cancer which are current, ethically contentious and need to be considered by all health professional working with these patients. These are medical use of cannabis and terminal sedation.

There have been many studies investigating the experiences, fears and desires of patients with advanced cancer.^{1,2} These studies clearly show that some patients in this situation wish not only to have relief of pain, but to hasten their own death, for reasons related to both physical and emotional/psychological suffering.³ Discussion of these issues inevitably raises the question of euthanasia, in particular active voluntary euthanasia, where a patient requests a doctor to give a lethal dose of a drug to end their life. Active voluntary euthanasia is not legally permitted in any state or territory of Australia (its legalisation in the Northern Territory some years ago was short-lived),⁴ but there is considerable evidence that some doctors perform euthanasia anyway.⁵ There is continuing pressure from patients and the public for legal access to euthanasia.⁶ Euthanasia has been legalised in a number of countries world-wide,⁷ notably the Netherlands, where it was officially tolerated, though still illegal, for many years, and became fully legalised in 2002.⁸ The question of euthanasia in the context of advanced cancer arises constantly and will only become more pressing with time. Physician-assisted suicide, which is legally permitted in a number of jurisdictions which do not permit active voluntary euthanasia, is also on the horizon. Physician-assisted suicide is often seen as an ethically preferable alternative to euthanasia, although it comes very close in ethical terms to actually constituting euthanasia.⁹

In Australian, questions of euthanasia and physician-assisted suicide, although important to be aware of and consider, are still theoretical. This paper highlights two aspects of care of patients with advanced cancer which are current, ethically contentious and need to be considered by all health professionals working with these patients. These are medical use of cannabis, and terminal sedation.

Medical use of cannabis

Patients with advanced cancer are one of the main groups to use cannabis for symptom relief in places where its use for medical purposes has been legalised, or at least decriminalised.¹⁰ The claimed benefits of cannabis include pain relief,¹¹ relief of nausea and stimulation of appetite,¹² and in some cases relief of psychological suffering.¹³ Use of cannabis for medical purposes is not currently legal in any Australian state. Even where marijuana is decriminalised for ordinary personal use, those caught with it are fined, and there is no exception for those using it for a medical condition. However, the landscape is changing quickly and Australian clinicians will soon have to deal with some significant ethical questions. Two Australian states, NSW and Victoria, will begin trials of medical cannabis in 2016-2017.¹⁴

These trials will involve doctors 'authorising' the use of cannabis for patients with specific medical diagnoses, with cancer being one of these. Although the term 'authorising' is used to avoid saying that doctors are prescribing cannabis,¹⁵ the process will be very similar to prescribing, and arguably will have all the ethically significant features of prescribing. That is, it will involve a doctor making a clinical assessment that cannabis would have benefits for this patient, outweighed by possible side-effects and risks, and recommending this to the patient. In other countries, for example in Canada, not all doctors have been willing to do this.¹⁶ There are a number of reasons why doctors might be hesitant to authorise medical cannabis, including concerns about lack of evidence about safe dosage levels, let alone robust evidence of benefit, possible short-term side-effects for those who are already unwell, and lack of knowledge about interactions with other medications which cancer patients typically take.¹⁷ The reason for lack of evidence is primarily that medical use of cannabis has not evolved through the usual pathway of regulatory approval

for clinical trials of drugs developed by pharmaceuticals, but been driven largely by patients using a (usually illicit) recreational drug for their own medicinal purposes.

Discussion of the ethics of medical use of cannabis can easily get tangled up with the broader question of the proper legal and ethical status of marijuana and other mind-altering substances, but in the medical literature, this is mostly avoided, and the debate focuses on potential benefits and risks to patient.¹⁸ In the context of advanced cancer, this debate is significantly hampered by lack of evidence about short-term use. Evidence about side-effects such as psychosis and cognitive damage comes overwhelmingly from long-term use of marijuana, mostly by young people, in circumstances where use is illegal and the chemical constitution of the drug is not controlled.¹⁹ This evidence is not necessarily relevant to the situation of patients with advanced cancer, who might be much older, and use a known and consistent type of cannabis over a period of months only, dying from the cancer before any long-term effects of cannabis use could become problematic.

In this regard, it is vital to consider the role of informed consent, or perhaps better, informed decision-making by the patient about use of cannabis for symptom relief. The ethical basis for informed consent is respect for patient autonomy,²⁰ which is closely linked to responsibility. When a patient makes an informed choice to take a drug, even when prescribed by a doctor, the patient is also taking on responsibility for that choice. It is not solely the responsibility of the doctor. This is the whole point of respect to autonomy. In a terminal situation, the ethical principle of respect for autonomy has particular significance, because life cannot be prolonged to any great extent, leaving the ethical obligations of beneficence and non-maleficence focused on prevention of the very subjective matter of suffering. Respect for the patient's autonomous decisions in relation to whether and how they are suffering, and what brings them relief of suffering, is surely central. Doctors do not need to see themselves as bearing full responsibility when a well-informed patient chooses to use cannabis for symptom relief, despite the unknowns and possible risks.

Requiring doctors to authorise medical use of cannabis by patients, as will happen in the upcoming Australian trials, is a complicating factor, making it harder for doctors to give the dignity of making choices and taking responsibility for those choices as their patient's death approaches. As noted above, authorising is very close to prescribing, and doctors would be asked to authorise something which they know has not been as rigorously tested as all other drugs that they prescribe. A possible alternative approach to legally permitting use of medical cannabis would be a system where doctors certify a patient's medical condition, and a government sets in place a system to determine whether an individual meets the criteria that have been set for medical use. In this way, a doctor does not have to make a judgement about

relative benefits and risks according to usual medical standards; rather, the patient makes their own choice to seek access to medical cannabis.

It will be interesting to see how the trials of permitting medical use of cannabis play out in Victoria and NSW, and in particular what lessons can be learned about the appropriate role for doctors and other health professionals in this.

Terminal sedation

Terminal sedation is another approach to the management of refractory symptoms in advanced cancer - one that is currently part of accepted medical practice, although it continues to be somewhat ethically contentious. Palliative sedation more generally is the use of medication to decrease or completely remove awareness, either intermittently or continuously, in order to relieve suffering due to refractory symptoms at the end of life.²¹ Palliative sedation is particularly relevant in advanced cancer, the reported prevalence of refractory symptoms is often quite high.²² The contentious form of palliative sedation is continuous deep sedation until death, or 'terminal sedation.'²³ Terminal sedation is practised in a number of countries worldwide,²⁴ including Australia.²⁵

There are a number of concerns discussed in the palliative care literature. Most guidelines on terminal sedation imply or state that it is only appropriate as a last resort, for 'intolerable suffering' due to 'refractory physical symptoms'²⁶ - indeed the European Association of Palliative Care (EAPC) framework describes terminal sedation when symptoms are not refractory as 'an abuse.'²⁷ The basis for this position would appear to be that awareness and capacity to interact have such high objective value that should not be given up when there are any other options. The EAPC framework acknowledges that 'refractoriness' and 'intolerability' are subjective, but still defines refractory symptoms as those which a clinician judges unable to be relieved.²⁸ This leaves open the ethically problematic possibility of a patient who wants continuous deep sedation being denied it, because a doctor does not believe that the patient's symptoms are bad enough. The second condition often put on terminal sedation is that it be used only for physical symptoms, but not for psychological or existential suffering.²¹ The motivation for this concern again seems to be making sure that awareness is not taken away except as a last resort. Perhaps psychological or existential suffering is seen as more amenable to intervention than physical suffering; just needing the right personal support or psychiatric treatment. However, in the end all suffering, whether it is in response to physical or emotional stimuli, is psychological because it is related to the meaning that the patient attaches to their symptoms.²⁹ Given this as well as the ethical importance of respect for patient autonomy, the claim for reserving terminal sedation only for physical suffering is on shaky ethical ground.

Another concern often discussed in the literature is whether terminal sedation might be a form of euthanasia.⁹ In an early paper, Billings and colleagues described terminal sedation as ‘slow euthanasia.’³⁰ The official medical position, as succinctly stated in the ANZSPM Position Statement (2013) on The Practice of Euthanasia and Assisted Suicide, is that “Palliative sedation for the management of refractory symptoms is not euthanasia.”³¹ It references this statement to the EAPC framework. But for a number of reasons, the discussion continues. One concern sometimes expressed is that terminal sedation may hasten death, especially when the patient is not provided with artificial nutrition and hydration. This concern, however, is misplaced, both ethically and empirically. Empirically, a number of studies have shown that terminal sedation does not in fact hasten death.³² Ethically speaking, the defining feature of euthanasia is that it involves an intention to cause death. It has long been accepted that medical treatment provided to relieve pain does not necessarily involve such an intention, even if it known that there is a risk of hastening death.³³ In this sense, terminal sedation is the same as use of opiates in end of life care, and clearly does not constitute euthanasia as that practice is standardly defined. As Materstvedt and colleagues argue, terminal sedation and euthanasia differ at least three crucial elements: intention, procedure and outcome.³⁴

Those who take the position that terminal sedation is a form of euthanasia tend to base their case on the fourth element which Materstvedt and colleagues highlight, which is the concept of ‘personhood,’ and the related question of when a person counts as having died. Lipuma, for example, argued recently in the *Journal of Medicine and Philosophy* that terminal sedation is ethically equivalent to euthanasia because the state of deep continuous sedation which it causes is ethically equivalent to death.³⁵ Terminal sedation clearly involves the intention to cause a deeply sedated state, so if that state counts as death, then terminal sedation involves the intention to cause death, and is indeed a slow form of euthanasia. The contentious step in the argument is the claim that the deeply sedated state is ethically equivalent to death. Materstvedt and colleagues base this claim on higher-brain definitions of death, in which a person is held to have died when they have lost the cognitive capacities for personhood, even if their body continues to be alive in some sense. Higher brain definitions of death have been proposed by many philosophers, ethicists and some doctors over the years, but have never been taken up by the medical profession or the law in any country. For this reason, Materstvedt’s argument that terminal sedation is a form of euthanasia is unlikely to be accepted and acted upon by clinicians. However, it is important in prompting reflection about what the state of deep continuous sedation actually is, ethically and personally, and whether all patients would find it an acceptable alternative to death by euthanasia or physician-assisted suicide.

This is an important question in the on-going debate over

legalisation of physician-assisted suicide and euthanasia in Australia. If terminal sedation is an effective alternative, it could be argued that these practices are unnecessary, and should not be legalised, when there are risks that they might expand to situations which are not fully voluntary. And if they are legalised, what will be the ethical responsibility of clinicians to patients who want euthanasia, when terminal sedation is available? These are matters worth further consideration.

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