

2016

Suffering, Euthanasia and Professional Expertise

Xavier Symons

The University of Notre Dame Australia, xavier.symons@nd.edu.au

Follow this and additional works at: <https://researchonline.nd.edu.au/solidarity>

ISSN: 1839-0366

COMMONWEALTH OF AUSTRALIA

Copyright Regulations 1969

WARNING

This material has been copied and communicated to you by or on behalf of the University of Notre Dame Australia pursuant to part VB of the Copyright Act 1969 (the Act).

The material in this communication may be subject to copyright under the Act. Any further copying or communication of this material by you may be the subject of copyright protection under the Act.

Do not remove this notice.

Recommended Citation

Symons, Xavier (2016) "Suffering, Euthanasia and Professional Expertise," *Solidarity: The Journal of Catholic Social Thought and Secular Ethics*: Vol. 6 : Iss. 1 , Article 5.

Available at: <https://researchonline.nd.edu.au/solidarity/vol6/iss1/5>

This Article is brought to you by ResearchOnline@ND. It has been accepted for inclusion in *Solidarity: The Journal of Catholic Social Thought and Secular Ethics* by an authorized administrator of ResearchOnline@ND. For more information, please contact researchonline@nd.edu.au.



Suffering, Euthanasia and Professional Expertise

Abstract

In most jurisdictions where euthanasia is legal, patients seeking euthanasia need to seek out the approval of their request from two clinicians (one of who is a psychiatrist). These doctors are required to assess whether euthanasia is 'appropriate' for the patient in question. In this paper I claim that doctors *qua* doctors are not qualified (or, at least, not typically) to evaluate suffering of an existential kind, and consequently they are not qualified to 'evaluate' the requests of patients seeking euthanasia. Importantly, this argument is only focused on patients who are seeking euthanasia on account of acute suffering.

To defend my central thesis, I discuss the limits of the professional expertise of clinicians, in addition to considering the nature of suffering experienced by patients requesting euthanasia (which is, typically, a combination of physiological, psychological and existential suffering).

Suffering, Euthanasia and Professional Expertise

Xavier Symons

In a philosophical context, voluntary euthanasia is taken to mean to the active and consensual ending of one person's life by another, based on the view that the person being killed is, for one reason or another, 'better off dead'.¹ One of the essential elements of this definition is the notion of beneficent killing – killing that is at least ostensibly in the interests of the patient. This is what distinguishes voluntary euthanasia from other acts of killing like murder or manslaughter.²

Significant attention has been paid to the important question of whether it is appropriate for a doctor as a member of the medical profession to be involved in the process of actively ending a patient's life.³ Surprisingly, few scholars have considered this question in relation to the phenomenon of suffering, which in the vast majority of cases is the motivation for a patient's request for euthanasia. In this paper I will discuss cases where euthanasia is requested on account of acute suffering. I will discuss the nature of the suffering experienced by patients requesting euthanasia, and consider the extent to which clinicians have the ability/expertise to understand and respond adequately to this suffering. In most jurisdictions where euthanasia is legal, patients need to seek out the approval of their request from two clinicians (one of who is a psychiatrist). These doctors are required to assess whether euthanasia is 'appropriate' for particular patients.

The claim I will make is that doctors *qua* doctors are not qualified (or, at least, not typically) to evaluate suffering of an existential kind, and consequently they are not qualified to assess the requests of patients seeking euthanasia. To defend this claim I will discuss the limits of the professional expertise of clinicians, in addition to considering the nature of suffering experienced by patients requesting euthanasia (which is, typically, a combination of physiological, psychological and existential suffering). There are three premises to my argument, and it is useful to begin with a brief summary of them.

The first premise is that doctors have a limited ability to make well-reasoned *value* judgements about a patient's situation/a patient's wishes. Medicine is first and foremost a technical discipline. Doctors are trained primarily to be proficient at healing physiological and psychological illness, and only receive limited training in ethics. For the purposes of this essay I will assume that doctors are not (or at least, not in their professional capacity) experts at evaluating the worth and value of things.⁴ This fact is borne out by the respect the medical community shows for patient autonomy.

¹ Robert Young, "Voluntary Euthanasia", in Edward N. Zalta (ed.), *The Stanford Encyclopedia of Philosophy*, (Fall 2016 Edition), accessed from <http://plato.stanford.edu/archives/fall2016/entries/euthanasia-voluntary/>, on the 28th September 2016.

² In legal jurisdictions around the world where euthanasia is sanctioned, the practice is often defined in relation to terminal illness. Yet terminal illness is not an essential component of euthanasia; people can argue that they are better off dead for a variety of reasons, only some of which would include reference to terminal illness.

³ See, for example, Edmund D. Pellegrino, "Doctors must not kill", *Journal of Clinical Ethics* 3(2) (1992): 95; Albert R. Jonsen, "Beyond the physician's reference: the ethics of active euthanasia", *Western Journal of Medicine* 149(2) (Aug. 1988): 195-198.

⁴ My primary motivation for adopting this definition is that it is a popular definition among bioethicists and clinicians. I myself see the definition as contentious, but it nevertheless will allow me to provide an argument that appeals to members of the broader medical community.

The second premise is that existential suffering is a phenomena that falls within the domain of axiology – which is to say, doctors need to make a value judgement to assess the intensity and severity of a patient’s existential suffering. When we talk about the seriousness of a patient’s cancer that is a technical question; when talk about the enduring worth of a patient’s life, that’s a non-empirical, axiological question.

My final premise is that the suffering experienced by patients requesting euthanasia has both physiological and an existential dimensions. The existential dimension of this suffering is, according to extant literature, just as significant if not more significant than the physiological dimension.

The conclusion that I will draw from these premises is that, if we adopt the understanding of medicine whereby it is first and foremost a technical discipline, then it follows that doctors are dangerously underqualified to make the normative judgement involved in assessing the appropriateness of euthanasia for a patient. The sort of judgement required is an axiological one, and this falls outside the domain of ordinary medical practice. In addition to developing this argument, I will also attempt to respond to potential objections, as well as discuss interesting implications the argument has for medico-ethical policy.

I. The Limits of Medical Expertise and Respect for the Wishes of a Patient

The first observation I wish to make concerns the expertise of doctors. Few scholars would disagree that medicine is primarily a *technical* discipline.⁵ As much is suggested by the way we educate our doctors: doctors are trained in dealing with physiological and psychological suffering, but receive little or no training in making normative judgements about a patient’s life, desires, aspirations and so forth. Doctors are taught primarily to assess the medical appropriate responses to a particular patient’s condition(s). Though they make routine normative judgements in their ordinary practice, these judgements are not part of the primary role of doctors. What doctors do first and foremost is restore patients to physiological and psychological health.

One of the consequences of this is that doctors by default tend to avoid making weighty normative judgements about their patient’s lives. It is taken as a given in contemporary medical practice that a doctor will ordinarily defer to the wishes of a patient once the parameters of medically appropriate responses has been identified. Doctors will try to stick to what is their area of clinical expertise – diagnosing and treating illness – while leaving important decisions affecting the patient’s life to the patient themselves. For the purposes of this essay, I will adopt the view underpinning the standard practice of medical professionals today – *viz.* that normative judgements somehow fall outside the ambit of medicine, and that these judgements should be left to patients or other professionals.

It is useful to situate this view within the context of the history and contemporary practice of bioethics; I will briefly discuss the history and praxis of medical ethics so as to provide background to this particular view of the limits of a doctor’s professional expertise.

⁵ I am not here trying to argue that medicine is *solely* a technical discipline, only that it has as its main focus a technical task, namely healing illness. I am conscious that almost any definition one tries to give to medicine is controversial, so I am attempting to remain at as general a level as possible. For more on this debate see Robert M. Veatch and Franklin G. Miller, “The internal morality of medicine: an introduction” *Journal of Medicine and Philosophy* 26(6) (2001): 555-557.

The ethical paradigm currently in the ascendancy in (Western) bioethics is the so-called ‘principlism’ of Beauchamp and Childress.⁶ In the late 1970s Beauchamp and Childress identified four overarching principles of biomedical ethics – beneficence, non-maleficence, justice and respect for persons – and these principles have since been adopted by most healthcare institutions in the Western world as normative framework for the practice of medicine (originally the principles were intended only for biomedical research, but they have since been widely used as a framework for clinical ethics). The last of these principles, respect for persons, has, according to the testimony of a number of bioethicists,⁷ come to be considered as the most important. Importantly, though, it is not respect for persons *simpliciter* that has been taken to be of paramount significance for research and clinical ethics. The principle of respect for persons has been ‘filled out’ by bioethicists with particular content, namely, a liberal conception of patient autonomy. It is this liberal concept of patient respect that has come to be seen as the most important factor to consider in bioethical deliberation. According to this idea, *that* a patient wishes the doctor to do *x* is a very strong *pro tanto* reason for a doctor to do *x*. It takes an even stronger *pro tanto* reason to overrule or defeat this reason for action.⁸ In contemporary medical ethics, a doctor will only disregard a patient’s or proxy decision maker’s wishes if there is a grave risk to the patient’s health, or, in the case where a treatment is being requested, the desired intervention is manifestly futile.

There seem to me to be two main reasons why the secular medical community has adopted this attitude toward patient autonomy. The first is based on a conception of a patient’s rights. Patients, on most conceptions of medical ethics, have a fundamental right to decide what sorts of interventions are performed on them.⁹ If a patient decides that they do not want a particular intervention to be performed, they are exercising a fairly basic right, and most conceptions of justice would dictate that a doctor must respect this. This means that a doctor cannot disregard a patient’s wishes just because that doctor has an alternative view on what should occur. There is nothing as such about the professional role of the doctor that gives him or her that right.

The second reason why patient autonomy is respected – and this is certainly related to the first – is that there is a sense in which a doctor *qua* doctor has a limited epistemic capacity to assess the validity or plausibility of a patient’s wishes. Doctors, despite their training and experience, are limited in their capacity to ‘enter into’ the life and subjective experiences of a patient.¹⁰ A patient’s decisions are typically motivated by deeply personal understanding of the

⁶ Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 2nd ed. (New York: Oxford University Press, 2001). See also James F. Childress, Eric M. Meslin and Harold T. Shapiro (eds.), *Belmont Revisited: Ethical Principles for Research with Human Subjects* (Washington DC: Georgetown University Press, 2005). It is important to observe from the outset that Beauchamp and Childress’s accounts of biomedical ethics leave significant latitude for ethical disagreement. Indeed, the principles were designed not to prescribe a specific ethical paradigm for medical ethics, but rather to narrow the domain of debate in which ethical conflict takes place. Medico-ethical disputes now take place within the context of the four principles, and competing parties usually attempt to defend their particular conceptions of the principles, which are in turn based on general ethical theory they have adopted.

⁷ See, for example, Roger Brownsword, “The cult of consent: fixation and fallacy”, *King’s Law Journal* 15(2) (2004): 223-251; Barbara A. Koenig, “Have we asked too much of consent?”, *Hastings Center Report* 44(4) (July-Aug 2014): 33-34.

⁸ Cf. Joseph Raz, *From Normativity to Responsibility* (London: Oxford University Press, 2013), ch.2.

⁹ Cf. Onora O’Neill, *Autonomy and Trust in Bioethics* (London: Cambridge University Press, 2002), ch.1.

¹⁰ There are a few scholars who would perhaps disagree with this. See for example, Edmund D. Pellegrino, ‘Philosophy of medicine and medical ethics: a phenomenological perspective’, in George Khushf (ed.), *Handbook of Bioethics: Taking Stock of the Field from a Philosophical Perspective* (New York: Springer, 2006), 183-202. To defend the view being proposed against Pellegrino’s critique would take us beyond the

world, aspirations and desires for certain things, concerns about significant people in one's life, and so forth. Doctors have a limited capacity to fully understand the motivations of a patient when they request a particular treatment. Recognition of this – which is essentially a manifestation of epistemic humility – leads practitioners, and indeed, has led the medical community, to take as default position deference to the wishes of a patient.¹¹

The argument of this essay takes as its point of departure this second justification for the principle of 'respect for persons'. I want to consider the implications of this view – *viz.* that medical practitioners are very limited in their ability to understand the motivations of patient requests – for the question of whether a clinician is 'qualified' to assess the appropriateness of a patient's request for euthanasia.

II. Existential Suffering and its Relationship to Physical or Psychological Suffering

Having briefly discussed medical professional expertise, it would seem appropriate to discuss the central concern of this essay, patient requests for euthanasia. Yet there remains one more clarificatory task, namely, that of providing a clear account of the nature of suffering. One cannot understand the suffering involved in requests for euthanasia unless one gains a clear understanding of the nature of suffering as such. Hence in this section I will attempt to define and distinguish different kinds of suffering.

A. Different Varieties of Suffering

Scholars in the contemporary Anglophone philosophical world have written extensively on the implications of suffering for ethics. Surprisingly, there has been limited consideration of the nature of suffering, and contemporary literature only contains cursory discussions of the phenomenology of human suffering.¹² Few philosophers offer a definition of human suffering capacious enough to take in the multifarious aspects of human experience that we associate

scope of this essay. I will, however, note that Pellegrino had reservations about medical euthanasia on independent grounds.

¹¹ This is, of course, after the doctor has made a clinical judgement about what sorts of treatments are at all viable.

One might even go so far as to say that there is a distinction between the sort of judgements that a clinician is qualified to make – technical judgements – and the judgements that are involved in understanding and assessing the wishes of a patient – axiological or value judgements. Doctors are not qualified, so to speak, to make axiological judgements. What I am saying here is slightly different from the notion of epistemic humility that I just discussed. One can have a conception of epistemic humility that leaves space for the many minor value judgements that a doctor makes throughout regular practice – these sorts of minor judgements seem trivial enough that a doctor is not being epistemically arrogant to make them. If one goes for the technical-axiological distinction, then one is committed to saying that a doctor *qua* doctor is never qualified to make axiological judgements, and would always be acting outside of their professional expertise when making such judgements. The latter seems counter-intuitive, and fortunately, for the sake of my argument, one need not adopt it for my argument to succeed.

¹² Utilitarians such as Peter Singer appear to take suffering to be a kind of primitive conscious experience (perhaps a kind of qualia felt by sentient animals). In which case it would not be entirely fair to fault them for their superficial discussion of the nature of suffering; the reason why they spend little time on this task is that they believe that suffering is a kind of primitive, unanalysable aspect of human consciousness. See for example Peter Singer, *Practical Ethics*, 2nd ed. (London: Cambridge University Press, 2011), ch.3. Yet if one does take the primitivist view of suffering, one must provide some sort of story for the non-sentient kinds of suffering we experience. Contra the primitivists, I argue that the best way to deal with these sorts of experiences is to provide a definition or description of suffering that makes sense of how these experiences fit together with other, more visceral forms of suffering.

with this elusive concept. It is fitting, therefore, to begin by identifying some of the different kinds of experiences we take to be constitutive of suffering.

I would surmise that the paradigm case of suffering for most people would be physiological suffering. By physiological suffering I am referring to the sort of suffering caused by and apparently localizable to a particular physical phenomena. I have in mind here experiences like that of cutting oneself on a rock, or jabbing one's toe against a wall. The experience of suffering in these cases might be taken as synonymous with the experience of pain, in which case we might reduce the experience to a physiological substrate in the brain.¹³

Yet the concept of suffering denotes more than just physiological pain. There are various kinds of psychological suffering one can experience, and though perhaps less tangible than physical pain, we take these forms of suffering to be just as real. The sort of suffering undergone by someone with a mental illness is a case in point. A patient who has severe depression experiences acute anxiety, low self-esteem, a pathological indifference to important events in daily life and a lack of joy and satisfaction in otherwise pleasurable activities. These sorts of psychological afflictions typically have physiological effects, yet they do not appear to be reducible to purely physiological phenomena. Indifference, for example, is a mental state involving a certain propositional attitude or attitudes, and though this mental state has physical effects or causes, it is (at least, one can make a very good case to say that it is) metaphysically not reducible to a physical substrate.¹⁴ Psychological suffering, then, appears to be something more than mere physiological suffering, though the two clearly overlap.

There is another type of suffering which appears to be even more remote from the paradigm case of physical pain. In academic contexts this kind of suffering is typically called existential suffering. The notion of existential suffering tends to be defined by characteristics rather than a terse, one sentence definition. In the medico-ethical literature, existential suffering is taken to be a kind of suffering associated with humans *qua* reflective, narrative-dependent beings. Varelius defines it thus: “existential suffering...relates to the stand a person takes as regards to what have been called existential questions – questions pertaining to the meaning, value and purpose of life.”¹⁵ Individuals who are suffering existentially experience a distinct lack of purpose, a sense of meaninglessness, a lack of hope, a loss of dignity and a solipsistic sense of isolation. A person suffering existentially takes an overwhelmingly negative stance on fundamental questions about human existence. This in turn has psychosomatic effects – “typically feelings such as weariness, numbness, futility, anxiety, hopelessness, helplessness and a loss of control”¹⁶ – yet crucially the provenance of these feelings is existential, not physiological.

One might perhaps be sceptical about distinguishing psychological suffering from existential suffering, but an analysis of some of the medical literature would appear to provide

¹³ I am tempted here to mention ‘c-fibre firing’, yet it would appear that pain has a far more sophisticated neurological substrate than this. See Istvan Aranyosi, *The Peripheral Mind: Philosophy of Mind and the Peripheral Nervous System* (London: Oxford University Press 2013), 40-42.

¹⁴ This claim may seem highly controversial to those with an expertise in philosophy of mind. I cannot fully defend the claim here, but I will make one observation: I don't believe that what I am suggesting here implies a rejection of all forms of physicalism about mental states. To my mind I am only committed to rejecting a material reductivist account of mental states, and materialist reductivism is, of course, not the only kind of physicalist account mental states.

¹⁵ Jukka Varelius, “Medical Expertise, Existential Suffering and Ending Life”, *Journal of Medical Ethics* 40(2) (2013): 104-107, 106.

¹⁶ *Ibid.*

support for such a distinction. Discussions of existential suffering in the literature tend to require the use of a vocabulary distinct from that of psychology or medicine. For example, Australian psychiatrist David Kissane's seminal article on the relief of existential suffering relies more heavily on philosophical and psycho-analytic literature than extant medical or psychological studies.¹⁷ This is in contrast to psychological and physical suffering, which, trivially, are describable using the vocabulary of clinical psychology and medicine. If indeed we need an alternative framework to discuss existential suffering, this would appear to indicate a fundamental difference between the nature of existential suffering and psychological suffering.

One could perhaps defend a claim that there exist forms of moral and spiritual suffering.¹⁸ I do not mean to deny the existence of these phenomena. However, I would presume that these experiences, if indeed they are real, are subcategories of the broader category of existential suffering. They are similar enough to existential suffering to be discussed in this context.

B. Existential Suffering and Axiology

I do not wish to be unduly detained with a discussion of suffering, but there is an important observation that should be made based upon the preceding analysis. It would seem to me that one can draw a distinction between physiological and psychological suffering as *empirical* phenomena, and existential suffering as *non-empirical* and *axiological* (by this I mean 'value-laden' and thus not 'evaluable' using empirical methods).¹⁹ Physiological suffering and psychological suffering can be measured using diagnostic tools of medicine. Existential suffering, however, does not seem even in principle to be 'measurable'. The sort of judgement one is making when one evaluates another's existential suffering is a *value judgement*. In existential judgements we make a judgement about the worth of things – we examine the situation of another in relation to our own personal values and make a judgement based on that. There is no way we could come up with a diagnostic rubric of what is of value without first making certain axiological assumptions. Thus, it would not seem that existential suffering is empirically verifiable; this is in contrast to physiological and psychological suffering, which clearly are.

III. Suffering and Euthanasia

Having now discussed the different kinds of suffering, we can turn to an analysis of suffering specifically in the context of patient's requesting euthanasia.²⁰ It is tempting to see patients suffering from serious and advanced illness as being solely afflicted by physiological pain. A closer inspection reveals that the mediate effects of advanced disease on quality of life are just as significant – *if not more significant* – than the pain and disturbance caused by the condition itself. In this section I briefly explore the complexity of the suffering experienced by

¹⁷ David Kissane, "The treatment of existential suffering", *Archives of Internal Medicine* 172(19) (Oct. 2012): 1501-1505.

¹⁸ For an interesting discussion of the distinction between bodily pain and mental pain in the context of grief, see book XIV, ch.16 of St Augustine, *Concerning the City of God against the Pagans*, trans. Henry Bettenson (London: Penguin, 2003), 576-577.

¹⁹ Of course, we can conduct empirical surveys based on patient reports about their existential suffering. But this is different from *evaluating* the existential suffering of patients. For the former we simply rely on the patient's own judgement, and base our study on this; for the latter we need to make our own judgement about the value, worth and meaning of something. The former is an empirical task, whereas the latter is normative and axiological.

²⁰ As noted in the introduction to this essay, I am focusing only on cases where suffering is motivating a patient to seek euthanasia. Though suffering is the most common reason for patients requesting euthanasia, I acknowledge that some patients might request it for other reasons. My argument does not apply to the latter.

patients suffering from a serious advanced illness, and how existential factors are inextricably linked to perceptions of the ‘bearability’ of suffering.

There have been a number of empirical studies published on the attitudes of severely ill patients toward euthanasia.²¹ In addition, significant empirical work has been produced on the attitudes of different segments of society toward the procedure. To discuss each of these studies individually would prevent us from discussing the central topic of this paper; I will therefore focus largely on an overview of extant studies produced by Hendry *et al.*²²

Hendry *et al* analysed sixteen qualitative studies and 94 surveys, sourced from countries around the world, and tried to identify common themes among participants’ responses. The results of the analysis were highly revealing. According to the researchers, “psycho-emotional factors such as hopelessness, feeling a burden, loss of interest or pleasure and loneliness were at least as significant as pain and other physical symptoms in motivating people to consider assisted dying.”²³ One example they provide is a study conducted in the Netherlands of patients who request assisted dying. That study found that “All patients considered hopelessness to be a main factor in the perception of unbearableness.”²⁴ Another example provided was a study of relatives of people who had pursued assisted dying in Washington, USA. The authors of the study found that “...almost two thirds of participants pursued a hastened death because they were concerned about how dying was eroding their sense of self. Patients expressed concern about losing their personality, ‘source of identity’, or ‘essence’. Without the ability to maintain aspects of their life that defined them as individuals, life lost its meaning and personal dignity was jeopardised.”²⁵

Hendry *et al* surmise that severe loss of function by patients overwhelmingly leads to “feelings of helplessness, loss of dignity, loss of meaning, loss of humanity or loss of ‘self’.”²⁶ Rarely is the case that suffering caused by illness is persistently unbearable.²⁷ Rather, it would appear that the impact on quality of life of an illness is what patients find most unbearable. At least four significant studies found that it was the inability to engage in the interests and activities of one’s ‘former life’ that led to patients feeling that life was no longer worth living.²⁸

²¹ See, for example, Alison Chapple, Sue Ziebland, Ann McPherson *et al*, What people close to death say about euthanasia and assisted suicide: a qualitative study. *Journal of Medical Ethics* 32(12) (2006): 706–710; Marianne K Dees, Myrra J Vernooij-Dassen, Wim J Dekkers *et al*, “Unbearable suffering’: a qualitative study on the perspectives of patients who request assistance in dying”, *Journal of Medical Ethics* 37(12) (2011): 727-734; Jacklin Elliott and Ian Olver, “Dying cancer patients talk about Euthanasia”, *Social Science and Medicine* 67(4) (2008): 647-656.

²² Maggie Hendry, Diana Pasterfield, Ruth Lewis *et al*, “Why do we want the right to die? A systematic review of the international literature on the views of patients, carers and the public on assisted dying”, *Palliative Medicine* 27(1) (2011), 13-26.

²³ *Ibid.*, 23.

²⁴ Marianne K Dees, Myrra J Vernooij-Dassen, Wim J Dekkers *et al*, “Unbearable suffering’: a qualitative study on the perspectives of patients who request assistance in dying”, *Journal of Medical Ethics* 37(12) (2011): 727-734.

²⁵ Robert A. Pearlman, Clarissa Hsu, Helene Starks *et al*, “Motivations for physician-assisted suicide: patient and family voices”, *Journal of General Internal Medicine* 20(3) (2005): 234–239.

²⁶ Hendry *et al*, 19.

²⁷ Dees *et al* found that “only patients with a psychiatric (co) diagnosis suffered unbearably all the time.” See Dees *et al*, 727.

²⁸ Dees *et al*; Pearlman *et al*; Merja Kuuppelomaki, “Attitudes of cancer patients, their family members and health professionals toward active euthanasia”, *European Journal of Cancer Care* 9(1) (2000): 16–21; Yvonne Yi-wood Mak and Glyn Elwyn, “Voices of the terminally ill: uncovering the meaning of desire for Euthanasia”, *Palliative Medicine* 19(4) (2005): 343–350.

Also important is the common theme of a ‘desire for control’ felt by patients with a terminal illness. As Hendry *et al* write, “Participants wanted to retain control of their own life or death and to be able to choose to avoid suffering or placing an extra burden on their families or making them vulnerable to prosecution.”²⁹ In a Dutch study of relatives of people who had been helped to die, Georges *et al* comment, “...Relatives who made some comments emphasised that euthanasia or physician-assisted suicide contributed to the quality of the end of the patient’s life because by shortening life further suffering could be avoided because the patient knew his/her wish concerning the end of life would be respected, because dignity in dying would be preserved, and because unbearable suffering would be alleviated.”³⁰

This is not to ignore the effects of physical suffering on patients with a severe and/or terminal illness. Many respondents in the extant literature remarked that, “the desire to end life could be a response to extreme, poorly controlled or intractable pain”³¹. Nevertheless, I wish to emphasise that the suffering experienced by patients who are candidates for euthanasia is overwhelmingly more complex than the caricature often advanced of a patient in constant, unbearable pain. Indeed, Hendry *et al* remark that it is more often the *fear* of unbearable suffering, rather than the suffering itself, that influences people who are in favour of assisted dying.³²

IV. The Problem Posed by Doctors Assessing a Patient’s Request for Euthanasia

We are now at the point where we can consider the premises of my argument and draw a conclusion. I have so far claimed that:

- Medical practitioners are very limited in their ability to understand and make axiological judgements about the motivations of patient requests
- Existential suffering is a phenomenon that falls within the domain of axiology (this kind of suffering concerns questions of worth, value and meaning)
- The existing empirical literature strongly suggests that existential suffering is an integral feature of the suffering of patients requesting euthanasia.

Readers will probably be able to identify where these premises lead. It would seem that doctors are not qualified, or at best, are underqualified, to make a judgement about whether it is appropriate to provide euthanasia to a patient. If indeed existential suffering is an integral feature of the suffering experienced by patients requesting euthanasia, then doctors do not have the resources to make a considered judgement about whether a patient’s existential suffering is severe or intense enough to warrant euthanasia. It would seem that we would need to find some alternative to this situation, or otherwise risk being accused of neglect of the most vulnerable members of our community.³³

²⁹ Hendry *et al*, 19.

³⁰ Jean-Jacques Georges, Bregji Onwuteaka-Philipsen, Martien T. Muller, *et al*, “Relatives’ perspective on the terminally ill patients who died after euthanasia or physician-assisted suicide: a retrospective cross-sectional interview study in the Netherlands”, *Death Studies* 31(1) (2007): 1–15.

³¹ Hendry *et al*, 19.

³² *Ibid*.

³³ Perhaps the most obvious alternative is to leave decision-making about euthanasia solely in the hands of the patient. I discuss this alternative and others in section 6.

V. Objections and Responses

A potential rejoinder to this is that I have confused the evaluation of existential problems with the assessment of existential suffering. For a clinician to *evaluate* existential problems would certainly require them to consult their own personal views, and, trivially, this would take them outside their ordinary professional domain. In contrast, asking a patient to provide an assessment of their own existential suffering is an *empirical*, not axiological, task for the clinician. In the latter case the value judgement is made by the patient; the clinician is merely a proxy when he decides on the appropriate course of action. If doctors took this approach they would be remaining well within the confines of their area of professional expertise.

This objection would be successful if the clinician were only to take a survey of the patient's subjective experience of suffering. Yet this would seem to be an inaccurate depiction of what occurs when physicians assess a request for euthanasia. Presumably the physician, in addition to gathering empirical information on quality of life, also brings to bare his own conception of what is valuable in the world. The importance placed on patient reports about quality of life is surely indexical to the doctor's own views about what constitutes a life worth living. This appears to be the only way a doctor can decide if this particular patient's sense of loneliness, lack of dignity, or 'life fatigue' satisfies the threshold of 'unbearability'. There seems to be nothing else that could provide them with the kind of objective standard they need to assess the validity of a patient's own evaluation of the worth of their own life.

If this is correct, then doctors are being asked to go beyond the domain of clinical medicine when they assess a patient's request for euthanasia. Clinical medicine ostensibly a technical discipline, but euthanasia would require the medical community to act beyond the bounds of their technical expertise.

A related objection, which fits in well with this thread of argument, is that doctors (particularly palliative care specialists) who routinely deal with dying patients, gain enough experience such that they become *de facto* well-qualified to make existential judgements. A palliative care specialist routinely dealing with dying patients would develop a certain wisdom about what matters most to people, and what is of greatest value in the life of a person with severe and intractable suffering. They are arguably well placed to make a judgement about when it is and is not appropriate to end a patient's life.

The trouble with this argument is that it relies on a kind of 'folk wisdom' that bears no semblance to the professional expertise that we are concerned with. The question we are considering is whether the judgement involved in assessing requests for euthanasia can be somehow assimilated into what we currently understand medical expertise to be. Unless we want to extend our conception of the medical profession to rely heavily on notions of 'life experience', then we should steer clear of relying on the personal experiences of end-of-life clinicians to justify judgements about the appropriateness of euthanasia.³⁴

³⁴ I am not attempting to rule out any clinician engagement with the existential plight of patients. On this topic, see SG Post, CM Puchalski, and DB Larson, "Physicians and Patient Spirituality: Professional Boundaries, Competency, and Ethics", *Annals of Internal Medicine* 132 (2000):578-583. I simply wish to point out the danger of basing clinical standards on what is a very difficult skill to measure and assess.

VI. Ways to Proceed

There are two obvious ways in which we could solve the problem identified with assessing patient requests for euthanasia. The first would be to leave decision making about euthanasia solely in the hands of the patient. This would seem to follow from the conviction that doctors should show epistemic humility when dealing with patients. And it would offer a solution to the problem of expertise: patients themselves are arguably the best experts at assessing their own quality of life and the value of their existence.

The issue with this solution is that it is highly contentious as to whether a patient has the ability to make a definitive judgement about the value of their continued existence. Patients who seek euthanasia are typically afflicted by intense physiological, psychological and existential suffering. Their individual reports about their quality of life, and their wishes and desires, are certainly very important; but it would seem rash to leave decision making *solely* in the hands of the patient. Intense suffering has the tendency to overshadow one's otherwise constant personal values and desires. It is prudent to have a professional involved who provides oversight of patient decisions. This is the motivation for current euthanasia legislation that mandates that two clinicians (one of whom is a psychiatrist) approve a patient's request for euthanasia.

The second solution would be to develop some sort of training for clinicians that could allow them to better deal with existential issues.³⁵ This would seem to be appropriate not merely from the perspective of end-of-life issues, but for clinician practice in general. Doctors routinely have to make value judgements of differing importance regardless of their area of specialisation. By education I am referring to something significantly more rigorous than the current short and sporadic ethics units in most clinical schools. It is arguable that pertinent empirical research identifies better and worse ways of answering existential questions, and such research could be a useful way to enrich an existing ethics curriculum.

Another alternative would be to involve individuals from other professions in the decision making process. Other professions, after all, deal more directly with questions of value. Two obvious candidates would be ethicists and members of the clergy. One approach might be to require these members of other professions to work with clinicians whenever a patient requests euthanasia.

VII. An Alternative Analysis and Response

Yet there does seem to me something peculiar about the second and third proposals. Both of them are taking us far afield from what we typically understand medicine to be. Medicine, as I mentioned in the initial sections of this essay, is primarily a technical discipline. Furthermore, it would seem that one of the main considerations buttressing support for euthanasia among policy makers is the fact euthanasia appears to be confinable to the medical sphere. We are not, in other words, legitimizing suicide, but rather a medical intervention. Yet if we start trying to make clinicians existential experts, or broaden the discipline to involve the expertise of ethicists and clergy, it appears that we are sullyng the sanitised picture of euthanasia *qua* a medical intervention. What we are ending up with is a deeply value-laden and potentially ideologically-slanted decision to end a person's life.

³⁵ Cf. Jukka Varelius, "Medical Expertise, Existential Suffering and Ending Life", *Journal of Medical Ethics* 40(2) (2013): 104-107.

I take the fact that euthanasia is not a mere medical process to be sufficient reason to prohibit the practice. It is not the sort of clean-cut procedure that many advocates suggest it is. One could draw upon supplementary arguments to support one's opposition – that we would be redefining the medical profession, that the practice would be open to abuse, that euthanasia would become indistinguishable from the sorts of cases of suicide that most find intuitively impermissible; and so forth. Yet I imagine for policy makers the core realisation that euthanasia is more than just a medical process would provide sufficient reason not to support the legalisation of the practice.