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INTRODUCTION

Assisted dying (AD) remains a highly controversial moral issue, with clinical, legal, political, religious and ethical considerations playing an important role. Lack of consensus and on-going debate are features of modern life, while the law generally sustains a broader, pluralist outlook. Advances in both life-prolonging treatments and palliative care in recent years are inextricably intertwined with this complex topic, resulting in the continuing demand for amendments on current legislations¹. This review presents an overview of the current status of this topical debate.

Definition and current legal framework

AD is a general term that incorporates both physician-assisted dying (PAD) and voluntary active euthanasia. Definitions for the above terms are provided below: Voluntary active euthanasia includes a physician (or third person) intentionally ending a person's life normally through the administration of drugs, at that person's voluntary and competent request^{2,3}. Facilitating a person's death without their prior consent incorporates both non-voluntary euthanasia (when the patient is not capable of providing informed consent eg. vegetative state, young child) and involuntary euthanasia (against patient's will) Physician-assisted dying is defined as follows: a physician intentionally helping a person to terminate their life by providing drugs for self-administration, at that person's voluntary and competent request^{2,3}. Consequently, in the first case a third person acts resulting in patient's death, whereas in PAD the action is undertaken by the patient who is given lethal medication by a physician.²

Discussion regarding withholding or withdrawing treatment and requesting assisted death has emerged in association with the simultaneous expansion of palliative care across the world. The World Health Organisation (WHO) define palliative care is an approach that "improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"⁴. It intends to neither hasten nor postpone death. Nonetheless, in practice, terminally-ill patients – often with full mental capacity - may develop a loss of self-determination as their condition deteriorates, and express a desire for AD to alleviate intractable physical symptoms.

AD is an emotionally and ethically challenging subject, which understandably receives varying degrees of acceptance among different global jurisdictions. Currently, there is legal provision for AD (or variants) in only four European countries (the Netherlands, Belgium, Switzerland and Luxemburg), Canada, Colombia and the United States of America (USA) states of Oregon, Washington, Montana, Vermont, California, Colorado, and Washington, DC, representing nearly 18% of the US population^{5,6}. Switzerland is the only country which permits the act of AD performed by a non-physician. Moreover, non-Swiss citizens can exploit the Swiss law by visiting Switzerland in order to access AD⁷. In these more tolerant jurisdictions, palliative care is seen as an important link in the same chain as AD in caring for terminally ill individuals, rather than an alternative. Elsewhere in the world, AD remains a criminal offence, prosecutable through various legal routes. For example, in the United Kingdom, all forms of AD remain illegal, and can be considered under criminal laws of manslaughter or murder, or under the Suicide Act (1961), depending upon the circumstances⁶. Prosecution guidelines were first issued by the Director of Public Prosecutions in 2009 following House of Lords ruling in the case of Debbie Purdy, which stated that there was ambiguous guidance regarding when people would be prosecuted for encouraging or assisting suicide. The guidelines suggest that while each case will be assessed on its relative merits, individuals acting in the capacity of a

healthcare professional are more likely to be prosecuted for assisting or encouraging suicide, although to-date no report-providing doctor or accompanying individual have been prosecuted for helping patients to travel abroad from the UK to end their life⁸. In England and Scotland, three AD bills have been proposed and debated, largely based upon the Oregon Death with Dignity Act (1997) from the USA, which permits AD; none were passed.

METHODS

We performed a systematic search of MEDLINE and EMBASE databases from conception to January 2018. The search terms used were 'euthanasia', 'assisted dying OR death', 'assisted suicide', 'medical ethics', 'autonomy', 'end of life' and 'sanctity of life'. We also combined free text searching with Medical Subject Headings (MeSH) terms and no restrictions were set in publication date, study design, and publication status.

MAIN TEXT

Principles of Bioethics

Autonomy and Right to Life

Beauchamp and Childress developed a standard approach to bioethics and advocated for four principles that lie at the heart of healthcare ethics and underpin decision making.^{9,10}. Respect for autonomy is one of the fundamental concepts , in combination with justice, beneficence and non-maleficence.

In medical practice, autonomy describes the right of competent adults to make informed decisions about their own medical care, prior to any investigation or treatment taking place. For a physician, respect for autonomy includes acknowledging and preserving a patient's right to self-determination and providing the necessary guidance, which would allow for an informed and independent choice, free of coercion.

However, autonomy is far from a straightforward consideration. Onora O'Neill, in an attempt to scrutinise the context of autonomy in her Gifford lectures makes a clear and compelling distinction between the approach of John Stuart Mill and Kant regarding the subject of autonomy¹¹. As O'Neill vividly describes, Mill stretches the bound of choice and "sees individuals not merely as choosing to implement whatever desires they happen to have at a given moment, but as taking charge of those desires, as reflecting on and selecting among them in distinctive ways."¹¹ The Kantian version of autonomy is guided by a 'practical reason'. Kant views autonomy as "a matter of acting on certain sorts of principles, and specifically on principles of obligation" rather than a form of self-expression and supports that "there can be no possibility of freedom for any one individual if that person acts without reference to all other moral agents"¹². O'Neill embraces the Kantian view and contextualises it as "principled autonomy" compared to "individualistic autonomy". O'Neill's work vigorously illustrates the fragility of the concept of autonomy and its contingency on a number of other considerations, particularly the network of human relationships within which it features.

The greatest expression of autonomous self-determination is the right of 'capacitous' adults to refuse any proposed intervention (irrespective of rationality), even if this decision could result in harm or death, provided they are capable of freely reaching a decision in the above manner. For this reason, obtaining informed consent from a patient after they have been offered all the relevant information regarding their situation, is of paramount importance. During the past decades, the development of liberal democracies has highlighted the significance of selfdetermination, with healthcare systems increasingly adopting more patient-centered approaches to care decisions. The right to bodily autonomy has also been enshrined under Article 8 (Table 1) of the European Convention on Human Rights (ECHR).

Table 1. Article 8. Right to respect for private and family life

1. Everyone has the right to respect for his private and family life, his home and his correspondence.

2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic wellbeing of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others¹³.

Taking the above into consideration, Article 8 encompasses inter alia the right to personal development. In a technical legal sense within the jurisdiction of Swiss law, it includes a patient's choice to avoid what they consider an undignified and severe end to their life¹⁴. Proponents of this highly contentious argument claim that seriously ill patients should have a choice in whether or not they wish to continue living with a condition that undermines their inherent dignity and personal identity¹⁵, without violating the principle of sanctity of life. Therefore, it can be argued that respecting autonomy inherently involves the prima facie right of a patient to control the circumstances and time of death by requesting help in dying. This could minimise the suffering of an individual or their family, and improve the quality of the end of the patient's life, as their wishes would be respected and dignity would be preserved^{16,17}.

A further dimension that can be considered is the treating clinician's ethical beliefs and values. During their training, most practicing clinicians have not experienced the concept of assisted dying as an expected duty in the context of patients' autonomy¹⁸. Nevertheless, it is important to consider the magnitude of patients' autonomy within modern society. Individual liberty ought not to be viewed as absolute and exceptions to Article 8 should be provided in favour of preservation and reverence to life^{17,18}.

The right to life is guaranteed by Article 2 (Table 2) of the ECHR. Under Article 2, the State is enjoined to abstain from the deliberate and illicit taking of life, as well as to protect vulnerable people against actions by which they could jeopardise their lives. The principle of sanctity of life emerges frequently in modern discussion, particularly in Anglo-American bioethics, surrounding public controversy about end of life and abortion issues. Yet its moral foundation is rarely unriddled and understood. The sanctity of life position asserts that life has sanctity and its value prevails all other values. No individual's life deserves priority and sanctity is attributed to life regardless of the physiological status, imminence of death, suffering or individual's wishes to live or die¹⁹.

This argument is often associated, but not fully equated, with religious and cultural traditions that generally object to assisted death, because human life viewed as God's sovereign creation. From a religious perspective, God is considered the only one who can determine the beginning and end of human life. The sanctity of life is a value also clearly mirrored under Article 9 of the ECHR, which refers to freedom of thought, conscience and religion¹³. It is notable, though, that Article 2 does not encompass assisted dying – i.e. in situations where a person's decision to end their life has been taken independently and with absolute perception of what it implied.

Table 2. Article 2. Right to Life

1. Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.

2. Deprivation of life shall not be regarded as inflicted in contravention of this Article when it results from the use of force which is no more than absolutely necessary:

(a) in defence of any person from unlawful violence;

(b) in order to effect a lawful arrest or to prevent the escape of a person lawfully detained;

(c) in action lawfully taken for the purpose of quelling a riot or insurrection.

The crucial issue is therefore one of balance. Patient autonomy has to be balanced against the principle of sanctity of life. It should be acknowledged though that the autonomy argument is secondary in its applicability on whether AD is ethically permissible and cannot solely guide decisions on what is morally impermissible, as it constitutes only a piece of the puzzle. The right to end a life that an individual finds intolerable has to be considered in association with its resulting impact on other rights, regulations, and the responsibilities of healthcare professionals in facilitating AD^{18} .

Justice

As discussed, justice constitutes one of the main four fundamental principles of medical ethics. All individuals in a society should be treated equally and impartially. One of the arguments that has monopolised the debate concerning AD is the "slippery slope". According to this, should assisted suicide be established, then it might be applied in circumstances that fall outside the scope of morally permissible cases, such as in patients who may not be fully competent¹⁷. Furthermore, if a person is motivated by means other than his own will, for example through external coercion, then patient autonomy is infringed.

In this regard, concerns are raised about vulnerable populations, such as the terminally ill, the mentally incapacitated, and the elderly. There remains the understandable fear that AD could potentially lead society toward an attitude that suffering should not be a part of life, interdependency is a burden, and the lives of disabled of terminally ill individuals are not worth living²⁰. The implications of such an attitude on vulnerable populations is clear, with individuals potentially forced or coerced into AD for reasons other than their own free will.

The slippery slope argument is inordinately complex and controversial evidence exist in the literature in favour of both sides. Cases of AD in the Netherlands grew from 1882 in 2002 to 5306 in 2014²¹. 81 cases were concerned with dementia and 41 with mental health related reasons only in 2014⁶. In the light of data from Holland the slippery slope argument is supported in a number of respects eg. concerns about legislation 'creep', lack of availability of good palliative care, fears in the vulnerable and elderly. Early data published from Oregon were also concordant. The number of physician-assisted deaths progressively rose from 16 in 1998 to 71 during 2011; loss of autonomy (88.7%) and ability to participate in enjoyable activities (90.1%) were the two most commonly reported end-of life concerns²². In increasingly financially constrained health and social care systems, fears have also been raised regarding the impact of budget-cutting trends and their potential impact on terminally ill individuals for whom the alternatives are only high-cost life-prolonging or quality enhancing (rather than curative) treatments.

However, recent data summarising the 20 years' experience in Oregon suggest the opposite. According to the authors, patients requesting an assisted death allegedly belong to a higher than average socioeconomic class and have a higher than average education level²³. Oregon, the first state in the US to allow AD, employed strict criteria that had an influential role in other jurisdictions⁵. The criteria comprised the agreement of another doctor, the assessment of the patient's mental capacity and the presence of a terminal illness with less than 6 months to live²⁴. Additional measures to ensure an informed and unforced decision involved adequate pain relief and access to end-of-life care²⁵. AD proponents support that safeguards and regulations in place are very powerful since only one in 50 terminally ill patients have a discussion about the process with their doctor and even fewer complete it²⁶.

Rhetoric from opponents has raised concerns of whether such safeguards could ever be adequate, which appears to be a key argument in the debate in some jurisdictions as well. Consequently, any future legal permissibility of AD should be developed in conjunction with clear regulatory safeguards to ensure the abuse of AD and protect vulnerable individuals from coercion3. Such safeguards must also preserve societal justice, and ensure equitability and availability of healthcare is not a deciding factor in AD decision making.

The Hippocratic Oath and the Principles of Beneficence and Non-maleficence

The principles of beneficence and non-maleficence, plainly described in the Hippocratic Oath, have been the foundation of medical ethics for many centuries. Beneficence states that a doctor should act in the best interest of the patient. Non-maleficence states "first, do no harm" – "primum non nocere"²⁷. Modern medical education in most countries follows legal and cultural opposition to AD and therefore conformation to these fundamental principles enshrined within Hippocratic Oath, which involve aiming to benefit, or perhaps most importantly, not doing any harm to a patient. Healthcare professionals are therefore currently not adequately trained to participate in AD. Professional opinion also remains divided on whether further involvement would benefit or damage public perception of the profession, given the potential conflict between these two ethical principles. The UK's medical representative body, the British Medical Association (BMA), has acknowledged this lack of consensus, but clearly concludes with their view that AD should not be made legal in the UK²⁸.

However, the evolution of decision-making processes in modern medicine, particularly regarding end-of-life decisions, and with patients increasingly at the heart of shared decision making (for example, the UK NHS' "no decision about me, without me" policy), have applied pressure on clinicians to reconsider their collective professional stance on AD. Indeed, an increasing number of legal challenges from patients and AD representative organisations are taking place worldwide to challenge local legislation against AD.

AD therefore challenges the conflict faced between the ultimate purpose of modern medical and social care and its founding ethical principles. Relief of suffering through AD can be argued as a distinct entity to palliative care, with the former – if safely and carefully considered – potentially an important way of fulfilling a clinician's duty to preserve autonomy and do good for a patient – for example, in cases where alternatives are treatments which provide no benefit, or do not prolong or improve the quality of life of a terminally-ill patient.^{27,29}. A further consideration is that of an individual doctor's ethical and moral beliefs, which are also an important factor should a patient request AD; indeed the BMA have proposed that should AD legislation be derived, then there should be a clear demarcation between those physicians that do and do not offer this option³⁰.

Freedom of Thought, Conscience and Religion

A further controversial issue is raised by Article 9 of the ECHR, which protects the rights of freedom of thought, conscience and religion. Its impact on the AD debate centres on whether requesting an assisted, dignified death constitutes a manifestation of belief, therefore falling within the remit of Article 9. Several European Court decisions have determined that individual views are entitled to protection only if they "attain a certain level of cogency, seriousness, cohesion and importance".³¹

Seriousness and importance are undoubtedly justified when considering an individual's decision to end their life. On the other hand, an informed desire to die with dignity may well constitute a coherent and cogent view. For instance, it remains debatable whether approaching death through a solely palliative care lens constitutes a less dignified way to die than AD.³¹ Article 9 may therefore provide a preferable framework for decisions relating to the right to die with dignity than Article 8, which focuses on a patients' autonomy; while the former aims to protect truly coherent and cogent decisions, it may be argued that the latter in isolation could potentially open a bigger door to a broader attitude towards AD.¹³

Furthermore, Article 3 should also be considered as a safeguard, as this prohibits torture and degrading treatment.¹⁷ Ultimately, each potential AD case is unique, and its various facets should therefore be approached carefully under the scope of relevant legislation (e.g. EHCR articles 2, 3, 8 and 9), and individual/societal ethical and moral perspectives. (Tables 1-4)

Table 3. Article 3. Prohibition of torture

No one shall be subjected to torture or to inhuman or degrading treatment or punishment.

 Table 4. Article 9. Freedom of thought, conscience and religion

1. Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief and freedom, either alone or in community with others and

in public or private, to manifest his religion or belief, in worship, teaching, practice and observance.

2. Freedom to manifest one's religion or beliefs shall be subject only to such limitations as are prescribed by law and are necessary in a democratic society in the interests of public safety, for the protection of public order, health or morals, or for the protection of the rights and freedoms of others.

Implications of AD in the Patient-Doctor Relationship

As discussed, a key concern of the medical profession remains the impact of legalisation of AD on the doctor-patient relationship. This relationship is fundamentally based upon trust. Although aspects of AD may be considered in conflict with certain underlying ethical obligations placed upon doctors, considering a patient's autonomous wishes, alongside the moral perspectives of the doctor, is also an important aspect of this relationship.^{32 33} This quandary is recognised by the Swiss Academy of Medical Sciences in their ethical guidelines, which acknowledges that "in certain special cases a doctor's personal decision to assist a dying patient to commit suicide is in accordance with his or her conscience and has to be respected."¹⁸

The delicate balance between the views of patients, doctors and society can pose an ethical dilemma, with the potential to serve a disruptive influence on the sanctity of the doctor-patient relationship and negatively distorting how society perceives the role and motives of healthcare

professionals. For example, as previously considered, particularly in healthcare systems where doctors play the role of gatekeeper to healthcare, a doctor's support for AD for a terminally ill individual might be negatively interpreted as a conflict of interest, with a desire to help relieve the social and economic burden of a patient's illness upon society overriding the patient's individual interests. Ultimately, should appropriate safeguarding measures be deployed alongside relevant legislation, AD may risk eroding doctors' professional integrity. ³⁴.

Current Position of Doctors' Professional Groups in the UK and the USA

As expected, the discussion around adopting assisted dying has caused much controversy among the doctors' professional groups and bodies. Several professional organisations in the UK have clearly expressed their opposing views to assisted dying such as the BMA, the Royal College of General Practitioners and the Royal College of Surgeons of England, whereas others maintain a neutral position including the Royal College of Nursing, the Royal College of Psychiatrists and the Royal Pharmaceutical Society⁵The Royal Society of Medicine has no policy on the issue since 'its remit is the education of doctors and health professionals and the promotion of debate, not the making of policy'³⁵.

Likewise, the American Medical Association representing nearly 250,000 members, vehemently opposes legalisation of assisted dying as does the American College of Physicians with more than 150,000 members⁶.

CONCLUSIONS

The debate surrounding AD is never far from the headlines, particularly while its legal status in most jurisdictions remains inadequate and discursive. However, alongside the evolution of palliative care, there appears to be an increasingly vocal desire for legislation to support AD in selected cases²¹. Developing a sensitive balance between established cultural norms and a progressive, well-balanced, transparent and safe attitude towards AD is key²⁴. More patient-centered attitudes towards health and social care increasingly place patients - quite rightly - at the heart of everything health professionals do. Patients' needs, attitudes and beliefs must be therefore be at the forefront of decision making. However, when considering these alongside the fundamental principles of bioethics as well as legislation and doctors' own beliefs, conflict can arise, thereby leaving the AD debate in a state of limbo. Whether AD should be legalised (albeit with stringent controls) remains controversial; as considered in this essay, even the basic moral principles can conflict when considering the arguments for and against supporting AD, making consensus building far from straightforward.

Ultimately, individual patients' autonomy should be balanced with a fundamental right to life, impacts on the individual doctor-patient relationship and wider society, and the safeguards required to prevent misuse of any AD regulations. The challenge remains for society to decide where this balance lies, guided by regional religious, cultural and legislative perspectives.

Developing the required ethical competencies among medical professionals is also key; given the current absence of legal support for AD in most jurisdictions, most clinicians remain untrained in such decision making. Indeed with understandable fears against crossing key ethical divides, physician support for AD ends to be lower than that of patients³⁶. Dying is a natural part of human life. With growing demand worldwide, the AD debate will increasingly come to the fore – something healthcare professionals, politicians and legislators cannot ignore.

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Competing interests

All authors declare they have no conflicts of interest.

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Contributorship

<u>AF and EP conceived, designed the study and performed the literature search. All authors</u> <u>analysed the data and drafted the manuscript. All authors contributed to and approved</u> <u>the final manuscript.</u>

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