l Review

2 Treatment, Palliative Care or Euthanasia? Comparing

End of Life Issues in Human and Veterinary

4 Medicine

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 - Abstract: Not a lot is known about either death or the dying process. Politicians and many in the medical profession in the UK tend to shy away from interfering with it by not allowing euthanasia as an end of life option for the patient. This is the first paper in a series of two, comparing the situation in human medicine and veterinary medicine, in which euthanasia is well practiced for relieving suffering at the end of an animal's life. This first part takes the form of a literature review including best practice around end of life care, its deficiencies and the need for assisted dying. Veterinary surgeons are well trained in the ethics of euthanasia and put it to good use in the best interest of their animal patients. In countries which have legalized physician assisted suicide for the terminally ill reporting indicates that it works well, without increases in involuntary euthanasia and most importantly without intimidation of the vulnerable. However, there is still an ever increasing tendency to overuse sedation and opioids at the end of life, which merits further investigation. With advances in medical science able to significantly prolong the dying process, patient autonomy demands a review of the law in the UK.
- Keywords: euthanasia; veterinary ethics; medical ethics; end-of-life; assisted suicide; palliative care;
 assisted dying

1. Introduction

Clinical veterinarians and animal owners have all experienced the relief that euthanasia brings for a terminal patient which has reached, or is at the point of reaching, a stage of unacceptable suffering. Conversely, many members of the public have witnessed the prolonged suffering of a human family member at the end of their life [1]. As medical technology advances, for some individuals the possibility of extended life in a debilitated condition may not be preferable [2].

Death is an emotive and final subject, therefore it is difficult to do controlled studies (without being intrusive), of people's end of life experiences as to how it could be improved.

It may be useful to compare the situation in veterinary medicine and human medicine as although both aim to prevent and relieve suffering, veterinary medicine has the added option of euthanasia. The ethics associated with euthanasia are incorporated into every veterinary student's training. Discussions about euthanasia in the veterinary literature could be helpful in resolving some of the reservations identified in human medicine as veterinarians have valuable experience of euthanasia.

Since most domestic animals have one-fifth the life span of people, veterinarians see death at a much higher rate than their physician counterparts [3,4].

Humans appear to have an emotional bond to their companion animals that is comparable to what they experience with family and friends [5]. High rates of family breakdown, rising levels of loneliness, mental ill health and emotional instability mean pets plug an important gap for many people. Emotional dependence on animals mean they can be over-loved and over-indulged and this,

according to the RSPCA's chief vet can lead to problems like hoarding, obesity or failure to make responsible decisions, including euthanasia, where appropriate [6].

Veterinarians are consistently ranked among the most trusted members of society [7]. Today's veterinarians are expected to provide ethical and moral guidance in animals' care [4]. The public trust veterinarians to reduce animal suffering.

This is both relevant and important because the British Medical Association (BMA) argues against any form of legal assisted dying as they say the majority of doctors think that it would destroy the doctor-patient relationship [8] (p.63). One only needs to read the authoritative studies which have come out of the Netherlands to understand that the doctor patient relationship there has not been compromised by the legalization of physician assisted suicide. In fact when euthanasia is performed it is the family physician who is most frequently involved [9].

The argument that legalization would lead to a 'slippery slope' of increased use of involuntary euthanasia of the vulnerable just does not hold water [10]. Some people would argue that euthanasia in veterinary medicine is totally unregulated. This is why it is necessary to look at regulation in the Netherlands, which has been in place since 1991, eleven years before euthanasia was officially legalized there. 'There is no evidence from the Netherlands that the legalization of voluntary euthanasia caused an increase in the rate of non-voluntary euthanasia' [11] (p.205). Evidence from Europe [12], shows that the incidence of involuntary euthanasia has remained the same or decreased since legalization of medically assisted suicide in Belgium. In the USA even The Oregon Hospice Association's concerns have been allayed [13] (p. 29), studies show that the 'slippery' surface has dried out and indeed there is no 'slope' to be found.

PICO Question. Would terminally ill patients in the UK benefit from the option of a medically assisted death, as in veterinary medicine and some foreign countries and states where voluntary suicide/ euthanasia has been legalized?

Definitions as used in this article:

- 1. 'Medically assisted dying' (MAD) is an all-encompassing term which includes all measures taken, or not taken, by doctors/physicians administering or withholding treatments, or prescribing medications to be administered by nurses or technicians or the patient, in hastening the dying process. Withholding treatments, ('forgoing life-sustaining treatment') can be voluntary, requested at the time or as previously directed in a valid 'advance directive', or non-voluntary, decided upon by the doctors, in consultation with the next of kin.
- 2. 'Physician/doctor/medically assisted suicide' (PAS) is the competent patient voluntarily ingesting or starting the infusion of a medication which they have requested, prescribed by a doctor/physician with the sole intention of causing death. It is illegal in the UK but available in some countries/states under strict regulations.
- 3. 'Physician/doctor assisted dying' (PAD).
 - Voluntarily, is at the patient's current or previously validated 'advance decision' request, where the medication to end life is administered by the physician/doctor. It is illegal in the UK.
 - Involuntarily, is at the doctor's decision where the medication is administered by the doctor. This is illegal so the patient and next of kin are not informed.
- 4. 'Euthanasia' is derived from a Greek word meaning a 'good death'. Francis Bacon in 1605 first coined the term in reference to alleviating suffering of human patients [14]. It is defined by the European Association of Palliative Care as a physician (or other person) intentionally killing a person by the administration of drugs, at that person's voluntary and competent request [15] (p. 5).
 - For animals:

Active euthanasia is the administration of medication to the patient by the vet, with the intention to end life.

Passive euthanasia is forgoing life-sustaining treatments. It may be the best option for wild animals if handling and killing them makes them suffer more than leaving them to die [16].

- 5. Yeates defines euthanasia as killing an animal in its interests [16]:
 - Voluntary euthanasia of an animal as being undertaken with a client's valid full and informed consent,
 - Non-voluntary euthanasia of an animal may be performed during an emergency to relieve suffering when the owner is unknown or uncontactable.
 - Involuntary euthanasia of animals is only legal for veterinarians 'treating' animals under the authority of a police officer or Court of Law, being against the expressed wishes of the owner [16].
- 6. 'Terminally ill' irreversible fatal illness [17].

2. Methods

2.1. Search strategy

A search of the literature was carried out using CAB Abstracts and PubMed in order to compare end of life issues between human and veterinary medicine. Preliminary searches revealed a dearth of comparative medicine papers about end of life issues. A broader CAB Abstracts search (Appendix A1) revealed 166 papers and a further CAB search (Appendix A2) revealed 25 papers (including only a few duplicates). The broader search approach did not work with PubMed in that hundreds of irrelevant papers were being included so it was decided to narrow the search terms to find papers most closely related to the PICO question. This PubMed search (Appendix A3) revealed 204 papers providing a total of 395 papers.

Other databases used were Google Scholar and a manual search of the bibliographies of some of the electronically identified articles also revealed additional relevant articles.

Search terms: (euthanasia OR assisted dying) AND ethics AND (end of life OR palliative care). For the full search terms used see Appendix A, 1-3.

This review is unique in that it considers end of life issues for both humans and animals from the author's veterinary point of view. Due to the lack of comparative medicine papers on the subject and the narrowed field of related search terms this review does not qualify as a systematic review.

In the end 28 published articles and one veterinary forum on Medically Assisted Dying on vetsurgeon.org [1] were chosen as being relevant to the subject matter of this paper and worthy of inclusion. They are summarised in the evidence tables. A further 69 resources are referred to in the context of this review and the subsequent ethical debate.

2.2. Exclusion/inclusion criteria

2.2.1. Exclusion: methods of euthanasia; non mammalian species; euthanasia for controlling stray animals; euthanasia for controlling notifiable diseases; euthanasia for controlling dangerous/aggressive dogs; individual cases; articles about withholding life supporting treatments in intensive care; non English language publications; advice about the management of euthanasia of dogs and cats.

A discussion about the justification for destroying healthy animals to control stray animal populations or for Notifiable Disease Control purposes or for aggressive/dangerous dog control, does not come under the remit of this study.

Ethical dilemmas about turning off life supporting treatments in Intensive Care Units is not encountered in veterinary medicine and is already adequately dealt with within the law.

2.2.2. Inclusion: published data relevant to the PICO question and review title.

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The studies included as evidence in this review were both quantitative and qualitative in view of the subject matter. They were primarily chosen because they surveyed a large or representative database. The summary tables of the evidence record the reference details, population studied, sample size, intervention details, study design, outcome studied, main findings and limitations. Examples of inclusions are:

153 One position statement from the American Association of Feline Practitioners (AAFP) sums up the 154 end of life issues succinctly for one species of pet animals in the United States [18].

- 155 One International collaborative guide, on artificial nutrition and hydration guidelines for those 156 attending to patients at the end of their lives, emphasizes that the dying process should not be 157 prolonged [19]. On the other hand, one white paper from the European association for palliative care 158 (EAPC) states that the provision of euthanasia and PAS should not be included into the practice of 159 palliative care [15]. One paper from the USA is a national survey of physicians about receiving
- 160 requests for assisted suicide or euthanasia, and their compliance with the requests [20].
- 161 There is a dearth of evidence comparing veterinary and human end of life issues so it was decided to 162 include a forum by veterinary surgeons on Medically Assisted Dying [1].
- 163 One published philosophical argument against the comparison of human and animal euthanasia was 164 included to add to the debate [21].
- 165 There is one systematic review, one narrative review and one qualitative study about palliative 166 pharmacological sedation [22,23,24].
- 167 One article summarized the legal status of euthanasia and PAS in the year 2000 in Canada, USA, 168 Australia & the Netherlands, with a proposal of practical legislation [25].
- 169 Three publications were produced by the BMA in 2016 about end of life care and MAD [26,8,27].

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3. The global situation for humans regarding MAD

Following strict guidelines to protect the vulnerable, voluntary, MAD is legal in the Netherlands (since 2002), Belgium (2002), Luxembourg (2009), and Switzerland (1942), for mentally competent individuals who are terminally ill, severely disabled or very elderly with medical problems.

In Canada (2016) and the American States: Oregon (1997), Washington State (2009), Vermont (2013), California (2015) and Colorado (2016) PAS is now legally possible for the terminally ill. In 2009, although not officially legalizing assisted suicide, the Montana Supreme Court's ruling changed the legal status of PAS under the state's living will law, 'The Rights of the Terminally Ill Act,' permitting physician 'aid in dying,' so if charged with assisting a suicide, a doctor could use the patient's request as a defence [28].

As far back as 1997, Colombia's High Court ruled that doctors could not be prosecuted for helping patients with a terminal illness make the legal decision to end their lives. Conditions which must be met include a medical determination that the patient has a terminal illness, and the patient's consent [29]. In April 2015 the Constitutional Court ordered the Health Ministry authorities to set guideline protocols for medical practitioners to reassure them that they would not be prosecuted for PAS of adults in their terminal phase of illness, but excluding patients with degenerative diseases. A committee comprised of a medical expert, a lawyer, and mental-health professional then have 10 days to reach an agreement that the patient qualifies for euthanasia [30].

Currently any practice of euthanasia is illegal in China, and some people argue that euthanasia legislation should be considered only when the medical care system, the moral standing of medical staff and the social insurance system have been greatly improved [31].

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On Friday 11th September 2015, 330 (v 118) MPs voted in Westminster against the Assisted Dying (No 2) Bill which Labour MP Rob Marris had brought before them, (originally Lord Falconer's bill). Rob Marris: 'The Bill is not about euthanasia; it is about the self-administration of lethal medication at the end of life' [32] (column 659). In 1981 Prince Philip was quoted as saying 'Once a determined government begins the process of eroding human rights and liberties – always with the very best possible intentions – it is very difficult for individuals or for individual groups to stand against it' [33]. Most of the MPs' arguments against the Bill were to 'protect the vulnerable'. Yet people of 80 years of age or older is the least common age group for euthanasia and assisted suicide in the Netherlands [34].

The picture is different in the USA according to a review of the epidemiology of suicide in later life. In Oregon from 1998-2011, after the Death with Dignity Act was passed, out of the 596 medically assisted deaths, 68.6% were people of 65 years or older with serious medical illness that compromised their quality of life. Similarly in Washington State from 2009-2011, after their Death with Dignity Act, out of 213 of the medically assisted deaths 68.6% were again of the 65 years plus age group, with serious medical conditions which compromised their quality of life. This was in marked contrast to natural suicides (thought to be pathological, nearly all were clinically depressed, the majority were from gunshots to the head or body), for the year 2000 in Los Angeles, only 23% of 713 natural suicides were people aged 65 years or older who had debilitating health [35]. It begs the question: Is it 3 times more difficult to pull the trigger on your own than have a supportive team around you, respecting your autonomy and decision to end your life when you are old and suffering from a debilitating medical condition?

Patients with advanced neurodegenerative disease also fall into the 'vulnerable' category. In this group Low & Ho [36] recommend using Jonsen's 4-Topic approach to resolving ethical dilemmas, which takes into consideration: 1 the medical indication for treatment, 2 patient preference, 3 quality of life which is complex, unique to each individual and a subjective phenomenon that may not be adequately understood even with substitute judgement by family members, 4 contextual features, such as social, cultural, religious, ethnic, legal, health economics and organizational practices. These factors would be taken into consideration by a hospital ethics committee [37].

Arguments that allowing PAS would be detrimental to society's moral values, such as 'It may be that legalizing PAS also provides positive role models who help normalize suicide more generally' [38], as cited by Jones and Paton, are not substantiated by the latter's study into the effect of legalization of PAS on rates of suicide [39]. They found no statistically significant increase in non-assisted suicides in States following the legalization of PAS.

In The UK the only way doctors can 'assist' the dying process is through the 'double effect'. Based on the doctrine of double effect a doctor may do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life [2].

An experienced district nurse interviewed on the BBC radio 4 programme 'We need to talk about death', Series 1, on 30th Nov 2016 said, "Sometimes dying takes a very long time" [40].

Dignitas near Zurich, set up in 1998, allows foreigners to use its services and according to its own figures, up until last year 310 Britons had died there [41]. It is a non-profit members' organisation whose motto is 'to live with dignity – to die with dignity'. They believe that 'when someone is suffering greatly, the healthy cannot judge what that individual's life is worth' [13] (p. 64). Lifecircle near Basle and Ex International in Bern also provide PAS for non-Swiss nationals. This has led to the emergence of the term 'death tourism' which is classified as a form of 'dark tourism' [42]. However these trips have to be at a time whilst the individuals are physically able to travel abroad and with associated costs amounting to over £10,000 [13] (p. 70).

In Canada it is claimed that although 'GPs would perhaps be best-suited to aid a patient in dying, it has been argued elsewhere that hastening death is beyond the purview of medical professionals and should not be part of any physician's practice. In August 2015 the Canadian Medical Association weighed in on this debate by polling its members and receiving 1,407 responses to an online survey. The survey asked whether the responding physicians would consider providing 'medical aid in dying' if requested by a patient, and results indicated that 63% would refuse. This survey points to a

much larger issue than can be addressed in this paper; there exists disagreement regarding whether physicians should be involved in assisting the death or euthanizing a patient. Assistance in dying although best-suited to be performed by a family physician, may be able to be pursued through a trained specialist if requirements are met' [43] (p. 1496-1497).

In 1997 in a study by the Department of Social and Preventive Medicine at the University of Queensland, critical care nurses, more than any other health professional group, supported the right of the terminally ill patient to PAS or euthanasia, their responses being very similar to those of community members [44].

In 1998 when people were dying horribly from AIDS, in a survey of 160 English-speaking Canadian nurses working with HIV patients, 73% believed that the law should be changed to allow physicians to practice euthanasia and PAS. 53% indicated that nurses would be willing to practice euthanasia and PAS. More than one in 5 nurses had received requests from patients to hasten their deaths by euthanasia. Nearly 98% believed that the nursing profession should be involved in policy development, and nearly 78% believed that nurses should be involved in the decision-making process with patients if such acts were legal. Given that nurses are the largest group of care providers for the terminally ill [45], it is not surprising that following an extensive and detailed consultation process with their members, the Royal College of Nurses moved in 2009 to a neutral stance in relation to assisted dying for people who have a terminal illness [46].

4. The evidence

4.1. The Netherlands & Belgium

In **1991** The Dutch Government requested the first of a series of comprehensive, nationwide, research articles into euthanasia and other medical decisions concerning the end of life (MDEL). The guarantee of anonymity of patients and physicians all strengthen the validity and reliability of the results. It found that in 17.5% of all deaths, the alleviation of pain and symptoms, with such high dosages of opioids that the patient's life might be shortened, was the most important MDEL. In another 17.5% a non-treatment decision was the most important MDEL. Euthanasia by administering lethal drugs at the patient's request seems to have been done in 1.8% of all deaths [47].

In **1991** a new procedure for reporting cases of euthanasia and PAS was introduced [48]. It requires doctors to report each case to the coroner, who in turn notifies the public prosecutor. Ultimately, the Assembly of Prosecutors General decides whether to prosecute [49].

In **1994** a study of the regulation of euthanasia in the Netherlands stated that 'the visibility and openness of this part of medical practice will lead to increased awareness, more safeguards, and improvement of MDEL' [50] (p.1346).

A follow up paper studied the period from 1990-1995. 'In the Netherlands, euthanasia and PAS have been practiced with increasing openness, although technically they remain illegal' [48] (p. 1699). 'In the Dutch health care system virtually all of the population is insured for health care costs so economic motives have not yet entered the realm of MDEL' [48] (p. 1705).

In **1996** a paper studied The Notification Procedure for PAD in the Netherlands, commissioned by the Ministers of Health & Justice. Of the 6,324 cases reported during the period from 1991 through 1995, only 13 involved prosecution of the physician. The number of reported cases increased over the period but there remained a high level of non-reporting, especially of cases in which there was no explicit request for euthanasia from the patient [49]. The Notification Procedure was then revised and came into effect in 1998 [9].

In April **2002** the Euthanasia Act was passed to regulate the ending of life by a physician at the request of a patient who was suffering unbearably without hope of relief [34].

2003 saw another follow up publication in the Netherlands which found that voluntary euthanasia was used 6 times more frequently than assisted suicide in 1990 and 1995 and over 10 times more frequently than assisted suicide in 2001 [9] (p. 396 Table 1). 'Euthanasia is frequently preferred over assisted suicide because of physical weakness or incapacity of patients' [9] (p.398).

In **2003** a paper compared the situation in six European countries. Euthanasia without the patient's explicit request, happened more frequently than euthanasia at the patient's request, in all countries apart from the Netherlands [51]. Written living-wills were available for fewer than 5% of patients in all countries apart from the Netherlands, (13%). Doctors consulted colleagues about their end-of-life decisions for about 40% of all patients in the Netherlands, Belgium, and Switzerland, and for fewer than 20% in the other countries. Nursing staff were asked most frequently in Belgium (57%) and Switzerland (50%).

'Despite important advances in pain and symptom management at the end of life, many dying patients still have pain and other physical and mental problems' [51] (p.349).

2007 Another follow up, to study end of life practices under the Euthanasia Act. They reported that euthanasia and PAS were to some extent replaced by continuous deep sedation. Physicians were administering sedatives when they had the explicit intention of hastening death, creating a grey area between sedation and euthanasia. Subsequently, in the Netherlands, the review committees disapproved the use of opioids for euthanasia [34].

In 2009 Smets et al. compared how the legal notification to a Review Committee, control and evaluation procedures following euthanasia worked in the Netherlands and Belgium. They found that the Dutch notification and control procedures are more elaborate and transparent than the Belgian, and that the Belgian procedures are primarily anonymous. Societal evaluation is made in both countries through the committees issuing summary reports to Parliament [52].

In **2009** Bilsen et al. surveyed end of life practices in Belgium under the Euthanasia Law. The percentage of involuntary euthanasia use did not increase [12].

Trends in end-of-life practices before and after the enactment of the Euthanasia Law in the Netherlands from 1990 to 2010 showed that the percentage of deaths as a result of voluntary euthanasia in Holland had not increased since studies before the introduction of the Euthanasia Act. The percentage of deaths as a result of involuntary euthanasia in Holland had decreased. However, continuous deep sedation until death occurred more frequently in 2010 (12·3%) than in 2005 (8·2%) [53].

In 2014 a study of international experts on end-of-life sedation suggested that problems were caused by the use of continuous deep sedation to alleviate psycho-existential suffering. Whilst withholding artificial nutrition and hydration this has the potential to shorten life. They suggested that there was a grey area between end of life sedation and euthanasia and that the intentions of end of life sedation should be clarified [54]. Whereas a previous narrative review from the USA, with a bias against PAS, suggested that 'expert pain relief and palliative care, including sedation to unconsciousness when necessary, should be widely available' [55].

'The goal of palliative terminal sedation is to provide the dying patient relief of otherwise refractory, intolerable symptoms, and it is therefore firmly within the realm of good, supportive palliative care and is not euthanasia,' [56] (p. 407).

In 2013 Vanden Berghe et al. described the current situation in Flanders where euthanasia is embedded in palliative care [57,13]. Palliative care professionals witnessed cases of euthanasia where the patient was relieved and grateful that their final days did not have to last any longer. This convinced those professionals that euthanasia could be part of genuinely good care. In Belgium there have been calls for an extension of the law on euthanasia to cover advanced dementia patients who had made a written advance directive for euthanasia when they still had full mental capacity [13] (p.278); as in Belgium an advance directive is only considered valid for an irreversibly unconscious patient.

Countries drafting euthanasia laws for the first time may want to consider allowing previously validated 'advance directives' for patients with advanced dementia, to come into force at a prerequested time of the patient's choosing. This would avoid the requirement for further legislation 'diluting' the law at a later date.

It is thought that end of life care in Holland has improved significantly, so this might account for the lack of increased uptake of the option of PAS. Here are two quotes from the Vetsurgeon.org forum [1]:

"The Dutch approach to end of life care is incomparably better than in the UK - carefully planned and co-ordinated care plans implemented by trained staff as opposed to the chaotic interventionist NHS treatment which is geared up to deal with accidents and emergencies and not with elderly/dying people.

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I've had 2 elderly relatives die in each country - everyone's experiences were far superior in the Netherlands where things were dealt with in a peaceful and caring way, dignified and under control of the patient and their regular carers, whereas the UK relative's experiences were a series of forced and pointless hospitalisations, hospital acquired infections, invasive treatment that did more harm than good, poor treatment in hospital, no communication between home care staff and hospital staff, and fear and stress for all concerned. This is without any mention of euthanasia in either of the cases" Anon MRCVS [1] (19th Dec 2016).

Table 1. Summary of the evidence from the Netherlands.

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Ref	Population	Sample size	Intervention details	Study design	Outcome studied	Main findings	Limitations
van der Maas et al., 1991 [47]	Dutch	9,250 Deaths	End of life issues & euthanasia	Physician questionnaires interviews & prospective survey	Use of opioids, non-treatment decisions, euthanasia by lethal drugs.	MDEL taken in 54% of patients.	Only access to abstract.
van der Maas et al., 1996 [48]	Dutch	6,060 deaths, 405 physician interviews	End of life issues & euthanasia	Physician questionnaires & interviews	Use of opioids, non-treatment decisions, euthanasia.	Involuntary euthanasia rates reduced. Better decision making.	Questionnaires: 77% response rate.
Onwuteaka- Philipsen et al., 2003 [9]	Dutch	6,060 deaths, 410 interviews	End of life issues & euthanasia	Physician questionnaires & interviews	Changes in end of life practices.	Demand for MAD has not risen. PAS & invol. euth. has not changed. Family physicians most frequently involved.	Views of patients, families & other care givers not studied.
van der Heide et al., 2007 [34]	Dutch	5,342 deaths,	End of life issues & euthanasia	Physician questionnaires.	Changes in end of life care. Reporting rates of euth. & MAD.	Increased use of deep sedation near the end. Reporting rates up. euth. & MAD down.	Confusion as to whether opioids hasten death.

Onwuteaka-	Dutch	8,496	End of life	Physician	%s of	%s:	Only access to
Philipsen et al.,		deaths.	issues &	questionnaires.	euthanasia,	stable	summary.
2012 [53]			euthanasia		reporting,	down3%	
					opioids use,	up	

"I am Dutch. Euthanasia has been legal, well-regulated and organised in Holland for many years now. It is an open, not hidden thing. My grandmother died in terrible pain and my mother had to watch this as a teenager. She was horrified and very scared to die the same way. In the sixties she got the same kind of cancer and died in the same way. My sister got cancer in 2006 when euthanasia was legal. As soon as she knew it was terminal she arranged with her GP. She had a peaceful last 3 months, knowing the decision was in her own hands, and she died at home with the dog on the bed and the GP administering the injection. What a difference. If you now read the obituaries of vets in the Dutch Veterinary Journal many of them mention that they went at a time of their own choosing. If I get terminal cancer or become demented, I at least can go back and have my own death decided on by me. I am sure this good practice will spread in the world" Asselbergs, M. [1] (30th Nov 2016).

Table 2. Summary of the evidence from Europe.

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Ref	Population	Sample size	Intervention details	Study design	Outcome studied	Main findings	Limitations
Van der Heide et al., 2003 [51]	6 European countries: Belgium, Denmark, Italy, the Netherlands Sweden, Switzerland	20,480 deaths	End of life decision making	Anonymous physician questionnaire.	% of end of life decisions & admin. of drugs to hasten death	Country variation in both. 23-51% & <1- 3.4%	Only 44% response rate in Italy.
Bilsen et al., 2009 [12]	Belgian deaths	6,202	End of life practices under Euth. Law	Physician 5 page questionnaire.	Changes in end of life care since Euth. Law.	% of invol. euth. did not increase.	Published as a correspondence to the editor.
Vanden Berghe et al., 2013 [57]	Dutch- speaking Belgians	Views of all professionals in Belgian palliative care	Embedding euthanasia in palliative care.	Narrative review	Effect of legalization of euthanasia on palliative care	Palliative care & euthanasia, when requested, can work hand in hand in the best interest of the patient	Only one in two non-sudden deaths in Flanders occurs with the support of specialist palliative care professionals
Radbruch et al., 2015 [15]	European association for palliative care (EAPC)	38 European palliative care experts	Ethical framework on euth. & PAS for palliative	Review of 2003 EAPC position statement, online survey, revision of	Concepts, definitions, values & philosophy of palliative care	Complete consensus seems to be unachievable.	Palliative care's fundamental view that sensitive communication can make the

l lawed.			care professionals	statement into white paper.	in relation to euth. & PAS.		patient's life worth living is flawed.
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4.2. Veterinary Training

Three papers discuss the training of veterinary students in the ethics of end of life issues and euthanasia, from both the United States and Europe [4,58,59]. Two papers study attitudes to euthanasia of practising veterinarians of varied age, gender, work experience and working circumstances [60,61].

4.2.1.

Herzog et al. [58] delve into the psychology of veterinary students. In 1989 there was a dearth of information relating to veterinary students, compared to medical students, dealing with ethical issues. One of the subjects which they examined was veterinary students' responses to euthanizing animals. This study used qualitative interview techniques to explore the attitudes and perceptions of veterinary students who were approaching graduation.

'Several students reported that they were distressed when an animal's suffering was prolonged because its owner did not want to accept that its disease was incurable and that death was inevitable, a situation that occurs frequently in private practice. As one student put it, "Sometimes we take cases too far and subject dogs to radiation or chemotherapy or surgery for tumours. At times this is to satisfy the client, but I think that we should take more time to explain the situation to the client better. Sometimes we take treatment too far just because we can" [58] (p. 184).

One respondent commented, 'Every day, the practicing veterinarian is confronted with something dealing with ethics. They have to think and wonder if what they are doing is ethical or not.' As part of each interview, they asked the students what they thought would be the most significant ethical issues that they would have to face when they began practice. By far the most commonly mentioned ethical dilemma related to being asked to euthanize a healthy animal for the convenience of the client. This issue was brought up by the majority of the students. Of these, 1/3 said that they would refuse to kill an animal in this situation. Only one in six of the students said that they would accede to the wishes of the client. The majority said they would try to talk the client out of the decision and suggest alternative ways to dispose of the animal (p.186). One student was positive about euthanasia of animals, saying, 'I really view euthanasia as one of the marvellous things we have over human medicine. We can end animal suffering. When used properly, it is a great, great thing' (p.187).

One student who had assisted in the euthanasia of about 15 animals said, 'I cried the first and fifteenth time. It hasn't gotten any easier over time but I have learned to mask my feelings in front of the client to be strong for them' (p.187).

Students repeatedly claimed that they were not bothered as much by euthanizing a suffering animal, and many mentioned that they were particularly upset at the prospect of euthanizing healthy but unwanted animals (p.187).

'I don't know what gives us the right to do euthanasia, but it is something we are going to do. I really feel that if you allow it to get to you it can drive you crazy' (p. 188).

'There is only so much about being ethical that can be taught. It has to come from the heart' (p.188).

They found that the primary coping strategy used to handle value conflicts was to rationalize the necessity of the procedures. That the students used logic and intellect to deal with ethical issues is not surprising, given that veterinary students are, on the whole, intelligent and articulate and tend to have a scientific orientation (p.188).

The merciful killing of an incurably ill animal in pain was considered to be humane [58] (p.188).

In a comparable study of medical students in 1998 it was found that only 41% thought their education regarding end-of-life issues had been adequate, only 27% had ever discussed end-of-life issues with a patient themselves, and only 35% thought they had had adequate exposure and education regarding advance directives [62].

In 2013 junior doctors reported that, although they may have had some form of exposure to palliative care at medical school, they felt their training had left them unprepared to care for dying patients [26] (p.35).

4.2.2.

In a more recent study in 2016 of practising veterinary surgeons' attitudes to euthanasia [60], coping strategy statements (which had been carefully chosen following extensive literature reviews), were presented to the vets and there was strong agreement and linkage between the following statements:

'It is easier for me to deal with euthanasia if I know that the animal would only have lived on for a short time'.

'The animal's advanced age makes it easier for me to deal with euthanasia'.

'Deliberate planning and the right moment make it easier for me to deal with euthanasia'.

'It is easier for me to deal with euthanasia if the animal has lived a rich life until its death'.

'Treating the owners in an understanding way is a central part of euthanasia'.

Younger veterinarians worked more often in a team and working in a team was associated with a higher agreement of the statement: 'Knowing that all veterinary medical, social and economic options have been considered makes it easier for me to deal with euthanasia'.

The willingness of the veterinarian to take the decision for euthanasia instead of the owner was linked to the number of other veterinarians working in the same practice, the more veterinarians in the same practice the less likely they were to make the decision for the owners.

Veterinarians' attitude towards euthanasia is potentially affected by age, gender and working experience; this corresponds to previous findings that younger female veterinarians are at a higher risk of work-related stress and suicidal thoughts. The presence of experienced colleagues at work – not only to discuss the medical point of view but also to provide mutual support for several difficult euthanasia cases highlights the role of a 'team' to provide support in stressful situations [60].

4.2.3.

In Magalhães-Sant' Ana's study of ethical teaching in 2014, he found that animal welfare related topics that were mentioned as part of the teaching of ethics include: the five freedoms (freedom from hunger and thirst, freedom from discomfort, freedom from pain injury or disease, freedom to express normal behaviour and freedom from fear and distress); quality of life; animal suffering; and animal pain [59].

The interviewed ethics' teaching staff contributed to his findings.

'One of the main ethical issues is for the vet to be aware of his/her own limits, what I will do and what I will not do: Will I accept to kill a healthy animal? Will I do a surgery without anaesthetic?' [59] (p.7).

Animal euthanasia was a recurring theme across the interviews and an example of the kind of ethical challenges faced by practicing veterinarians. Four sub-themes were included within the realm of euthanasia: the destruction of a healthy animal by the owners' request, the refusal by the owner to ending the life of a severely ill patient, the killing of an ill animal because the price of treatment is not covered by the value of the animal, and the culling of a herd for public safety concerns.

As part of the teaching, students are introduced to different ethical theories which also helps students understand the range of moral values within a pluralistic society: 'Students should gain the ability to realize that their choices and opinions are based on moral values and it is very important to clarify to them that many of the disagreements we have about animals are based on different moral values' [59] (p.8).

Decision-making abilities were considered an important aspect in ethics' teaching. The principle of autonomy was deemed as a relevant topic for both the veterinarian and the client, because students should learn how to guide people through making a decision in a particular situation while respecting their autonomy. The process of decision-making seems to be closely connected with critical thinking abilities. Educators provide students with the experiences that will make them aware of the different ethical issues and reflect upon them. This will help students 'becoming critical thinkers'. They introduce themes pertaining to the human-animal bond and handling end-of-life issues, such as humane killing and bereavement, breaking difficult news, understanding that ethics is also about tolerating other points of view.

Educators use cases involving financial limitations to illustrate ethical dilemmas in veterinary practice to their students.

The learning objectives for veterinary ethics are: ethical awareness, ethical knowledge and ethical skills.

Finally, appropriate professional behaviour, relying on moral values, animal welfare and codes of conduct, promotes the development of individual and professional qualities. Taken together, these findings may provide a starting point for the development of the essential competencies in ethics for European veterinary education.

'However, the crucial ethical challenge in euthanizing an animal has to do with the moral significance of the animal's quality of life and of animal suffering; and that is usually a welfare issue' [59] (p.12).

Table 3. Summary of the evidence of veterinary ethics training

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Ref	Population	Sample size	Intervention details	Study design	Outcome studied	Main findings	Limitations
Herzog,Vore & New,1989 [58]	Veterinary students	24	Ethics & euthanasia	Qualitative survey	Changes in attitude	Individuals resolved issues differently.	Some teaching practices possibly outdated.
Magalhães- Sant'Ana , 2014 [59]	European vet schools	3: Copenhagen, Lisbon, Nottingham.	Veterinary ethics, including animal welfare & decision making.	Qualitative case study	Vet. ethics teaching	Proposes a model for curriculum development of veterinary ethics.	Assuming similar to all European veterinary universities.
Dickinson, Roof & Roof, 2010 [4]	Veterinary students	28 US veterinary medical schools	Teaching end of life issues.	Survey & comments	Hours spent on end of life issues	End of life issues are an important part of the curriculum	No evidence to support statement that vet. med. is client rather than patient orientated

499 4.2.4.

500 In 2010 Dickinson et al studied veterinary student training [4].

Veterinary and medical 'Students need to think about their own values and beliefs and understanding of dying before they can be caring and insightful to others. They need to address how they feel about the dying process.

If veterinary medicine students can recognize dying, and ultimately death, as a natural part of the life cycle and feel comfortable with accepting care over cure with seriously ill animals, veterinary medicine schools will have made a major contribution to end-of-life issues in the 21st century' [4] (p.161).

Table 4. Summary of the evidence of attitudes to euthanasia

Ref	Population	Sample size	Intervention details	Study design	Outcome studied	Main fin <mark>d</mark> ings	Limitations
Yeates & Main, 2011 [61]	Veterinary surgeons in UK	58 Responses	Refusing euthanasia	Quantitative & qualitative	Frequency and reasons for & against unethical euthanasia	UK vet practice is more animal focused than client focused.	Too small numbers for a good quantitative study.
Hartnack et al., 2016 [60]	Veterinary surgeons	2478 Austrian veterinarians, only 486 returned fully completed questionnaires for analysis.	Attitudes towards euthanasia	Qualitative & quantitative questionnaire & multivariate analysis	If demographic variables influence attitude	Age, sex, experience & colleagues affect attitudes	This may only represent the 1/5 most concerned vets as answering the questions was time consuming
Folger et al., 2010 [18]	Cats	Position statement of AAFP	End of life issues.	Recommendati ons.	Ethics of modern medicine	Quality of life most important.	Does not include kidney transplants.
Meier et al., 1998 [20]	USA physicians	1,902 physicians	MAD or euthanasia	Anonymous questionnaire.	PAS or euthanasia requests & compliance	54% of cases of euthanasia were involuntary.	Due to illegality results may be less than actual frequency.
Bachelard, 2002 [21]	Humans & animals	Moral argument	Euthanasia (euth.) to relieve suffering	Philosophical argument	Significance of comparing human beings & animals	Differences limit the power of argument in favour of euth.	Suggests some human suffering sustains moral values of others.

4.3. Treatment or Palliative Care.

One narrative review discusses ethical issues surrounding end-of-life care in the United States for humans.

Technologically advanced treatments have a capability to prolong the life of a patient rather than allowing the natural dying process [63]. Healthcare services should not only target lengthening the life of people but also improve the quality of life' [64,63], especially when end-of-life decisions and the costs involved are concerned [63].

Healthcare rationing of end-of-life care in futile situations can be considered as greatest good for society but has to be weighed against patient autonomy [65,63].

There are no strict criteria to differentiate a futile treatment; hence it has to be relied on expert judgment and case prognosis. Rationing of care is present in the current healthcare system. The increasing expenditure on healthcare in the United States is too much in relation to population size and outcome and at the same time people are spending more on getting the care they need. Compassionate care can be less costly and sometimes a good preference when medicine is unable to restore the patient's health [63].

Working towards achieving greatest good for the patient by family members and by the physician falls into the "virtue theory" of ethics [63].

The level of palliative care available to the patient again is dependent on where in the world you live. On 6th October it was reported that Britain was the best place in the world in which to die according to an end-of-life care index [66].

The literature searches outlined in Appendix A revealed numerous articles from around the world, India (in 2013), Middle Eastern countries (2011) and Colombia (2012), calling for the need for improved palliative care of the dying and for the availability of access to opioids for pain relief. Some countries such as Jordan (2007), Mongolia (2007) and Uganda (2007) reported good progress. In Iran improved quality of care of terminal cancer patients was called for (2013).

The level of palliative care available to animals again is dependent on where in the world they live. In order to have an equivalent of hospice care you are talking about in-home hospice provision available mainly in the United States, however this is 'a more appealing option for the pet owner, unable to face the impending loss of their treasured companion'[67] (p.146), rather than the animal itself. 'The development of a care plan should not be rushed and it must be clearly ascertained how much the pet owner can contribute to the level of care required, this will dictate how much external care is required and if, in fact, a home-care programme is a viable option for this pet and owner. The treatment options included in the care plan need to match the beliefs and values of the owner while remaining in the best interest of the pet. Incontinence is an issue which should be discussed with the family members as many terminally ill patients will develop urinary and/or faecal incontinence' [67] (p.148). 'Educating clients regarding their pet's condition and teaching them how to provide certain types of care in the home' is essential. 'The veterinary practise should consider offering a district nursing service to re-assess quality of life and anticipate, prevent, locate and relieve pain in the patient' (p.149). 'A small number of mobile veterinary hospice and palliative care services do currently operate successfully within the UK', (p.150), ensuring that 'no aspect of care is being neglected' [67] (p.151).

4.4. Healthcare Policy Implementation

'The task of healthcare executives to manage ethical issues surrounding end-of-life care is challenging'. 'They can guide the patients to make informed treatment preferences by providing them honest information they can understand, an appropriate prognosis and available options'. 'They can document their preferences', and 'in cases of disagreement' they can 'appoint an ethics committee to address this ethical or legal issue and document its proceedings'.

They 'can compile policies, so as to introduce, promote, and discuss the use of advance directives as an admission procedure' [68,63] (p. 4).

They 'can work towards developing and implementing guidelines & policies for end-of-life care decision making, so as to avoid ethical dilemmas, especially policies for withholding or withdrawing treatment options'.

They 'can develop resources supporting palliative treatment care choices'.

They 'can provide effective support by appointing an employee assistance facility available so as to address any ethical crisis' [68,63] (p. 5).

They 'should take the initiative and discuss each patient's goal for end-of-life care or palliative care, as their preferences can differ from person to person'. 'It has a potentiality to change with illness hence the health scenario in each specific case has to be renewably evaluated'. Flexibility should be incorporated in advance directives [63] (p. 5).

'Community standards can work well where the patient's desire for the end-of-life treatment choices is not well demarcated' [69,63] (p. 5), 'so that proxies making decisions without guidance from the patient can at least know what the majority of people considering similar situations chose to do' [69] (p. 1).

'As age advances so thus the illness in many cases, hence there is a need to research and implement recommendations to relieve the stress faced by people during that critical time and optimize quality care to improve and ease the end-of-life journey' [69,63] (p. 5). 'Through research, medicine will identify and add to the understanding of the range of wholesome paths to death and devise a way of evaluating those paths and those on them. Through training and implementation, medicine will improve the journey. It is the core of medical care, a central part of the mandate from society and our forbearers in medicine, to relieve suffering and optimize well-being in every part of the life cycle. The last phase in a person's life cycle brings a high chance of suffering and of lost critical opportunities: it can also offer the potential for important gratification and realized opportunities. As the majority of people complete this life cycle whilst in our care, the role of medicine is critical. In order to discharge our role-mandate to optimize care near the end of life, including fostering the best decisions each individual can make, the medical profession must continue to undertake research and training to improve practices' [69] (p.7).

In 2007, 63% of Flemish hospitals had an ethics policy on euthanasia [70]. Only Dutch and Belgian Institutions dealt with policies on euthanasia, and it was found that in these, significant consideration was given to procedures that dealt with conscientious objections of physicians and nurses [71].

4.5. 'More Care, Less Pathway'

An Independent Review of the Liverpool Care Pathway (LCP) in England, by Baroness Julia Neuberger and 9 others was included because it discusses failings of the palliative care option [72]. It was requested by Norman Lamb MP, Minister of State for Care Support and was published in 2013.

It describes The LCP for the Dying Patient, as an approach to care, including a complex set of interventions, that resulted from a desire to replicate within the hospital sector the standard of care found in many hospices, for those thought to be dying within hours or days, accepting the difficulty of diagnosing when a patient is actually going to die.

In the review clinicians expressed their view that in their own last hours they would prefer to be treated under an approach such as the LCP, and found that many relatives of people dying whilst being treated under the LCP had felt that their loved ones had had good deaths. It would seem that when the LCP was operated by well trained, well-resourced and sensitive clinical teams, it worked well.

However it is clear, from written evidence received and relatives' and carers' input at events, that there have been repeated instances of patients dying on the LCP being treated with less than the respect that they deserve. It seems likely that similar poor practice may have taken place in the case of patients with no close relatives, carers or advocates to complain, or where families had not felt able or qualified to question what had taken place. This leads the reviewers to suspect this is a familiar pattern, particularly, but not exclusively, in acute hospitals where reports of poor treatment at night and weekends – uncaring, rushed, and ignorant – abound.

Many families suspected that deaths had been hastened by the premature, or over-prescription of strong pain killing drugs or sedatives, and reported that these had sometimes been administered without discussion or consultation. There was a feeling that the drugs were being used as a 'chemical cosh' which diminished the patient's desire or ability to accept food or drink. The apparently unnecessary withholding or prohibition of oral fluids seemed to cause the greatest concern.

Preventable problems of communication between clinicians and carers accounted for a substantial part of the unhappiness reported. Relatives and carers felt that they had been 'railroaded' into agreeing to put the patient on a one-way escalator.

In order that everyone dying in the acute sector, can do so with dignity, the present situation has to change. It is for this reason that the review made 44 strong recommendations for change.

Independent, prospective testing of the LCP had not yet been carried out after nearly 10 years of its dissemination. Fully independent assessments of end of life care in England are required, focusing on the outcomes and experience of care, as reported by patients, their relatives and carers, as well as the quality of dying. Further research into the biology and experience of dying is needed.

Some relatives and carers were not told that their loved one was dying. Respectful treatment of the dying patient and his/her carers requires time to be taken over the difficult tasks of providing information, delivering the news that the person is dying, understanding the person's needs and capacity to assimilate bad news and providing the opportunity to reflect on that information and to ask questions. This should be a non-negotiable aspect of best practice in end of life care.

Refusing food and drink is a decision for the patient, not clinical staff, to make.

The review heard that, if a patient became more agitated or in greater pain as they died, they often became peaceful because the right drugs were given to them at the right time and in the right dose. But there were complaints that opiate pain killers and tranquillisers were being used inappropriately as soon as the LCP was initiated. Many hospital patients appear to be put on a syringe driver with morphine as the 'next step' on the LCP, even if morphine is not the right drug, or pain relief is not what is needed.

Any attempt deliberately to shorten a person's life is illegal, but there is no obligation, moral or legal, to preserve life at all costs.

The availability of staff to care for the dying, both in terms of the number of staff and the level of competence, was found to be of serious concern. There were numerous reports of no access to the palliative care teams outside office hours and at weekends, both in acute hospitals and in the community.

The review panel strongly supported the work of organisations that promote public awareness of dying, death and bereavement. There was no specific Nursing Medical Council (NMC) guidance for nurses caring for patients at end of life or who are dying, this must be provided as a matter of urgency.

The review recommended that use of the LCP should be replaced over the next six to 12 months by an individual end of life care plan for each individual patient.

Unsurprisingly, this review uncovered issues: a lack of openness and candour among clinical staff; a lack of compassion; a need for improved skills and competencies in caring for the dying; and a need to put the patient, their relatives and carers first, treating them with dignity and respect. A need to ensure that guidance on care for the dying is properly understood and acted upon, and tick-box exercises are confined to the waste paper basket for ever.

Many of the elderly patients suffered from cognitive problems, including dementia, and were unable to express their wishes. Those who do not have close relatives and carers guarding their interests were by default unrepresented in the evidence submitted to the review panel. The review panel was very concerned about this, and recommended that each patient on an end of life care plan that has no means of expressing preferences and views on their care should be represented by an independent advocate, whether appointed under the Mental Capacity Act 2005, a chaplain, or an appropriate person provided through a voluntary organisation. This also applies to younger people who may lack capacity.

'The review panel strongly recommends a strategic approach to the problem. We need a coalition of regulatory and professional bodies, NHS England and patient groups, setting clear expectations for a high standard of care for dying patients – care that will also meet the important and sometimes neglected needs of their relatives and carers. Working together strategically, such a coalition could lead the way in creating and delivering the knowledge base, the education training and skills and the long term commitment needed to make high quality care for dying patients a reality, not just an

ambition. As a minimum, this would entail close co-operation between the GMC, NMC, the Royal Colleges, the Care Quality Commission, NHS England and the National Institute for Health and Care Excellence' [72] (p.47-48).

4.6. We all need food and water to survive.

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If medically assisted dying is not an option then many choose to deny themselves the necessary nutrition and fluids to live. The guidelines provided by The European Society for Clinical Nutrition and Metabolism (ESPEN), an international multidisciplinary working group, include at least 10 statements which are highly relevant to the terminal patient [19].

Firstly it is important to recognise that artificial nutrition and hydration are a medical intervention, requiring an indication, a therapeutic goal and the consent of the competent patient. Special consideration is given to end of life issues and palliative medicine; to dementia and to specific situations like nursing care or the intensive care unit. It is worthwhile to quote from 10 of their most relevant statements:

'<u>5</u>: If the risks and burdens of a given therapy for a specific patient outweigh the potential benefits, then the physician has the obligation of not providing /withholding the therapy.

Commentary: Prolonging of life may never be the sole goal and always has to be put in relation to the wellbeing of the patient. Prolonging of life may never turn into prolonging of the dying phase' [19] (p. 547).

'11: Every individual is entitled to obtain the best care available. Resources have to be distributed fairly without any discrimination. On the other hand treatments which are futile and do only prolong the suffering or the dying phase, have to be avoided' (p.547).

'<u>16</u>: For patients with advanced dementia priority should always be given to careful eating assistance /feeding by hand' (p. 549).

'<u>18</u>: Once the diagnosis of persistent vegetative state is established an advance directive or the presumed will of the patient have to be considered. If there is evidence which is applicable for the given case it has to be followed' (p. 549).

'<u>20</u>: There are no clear criteria to ascertain the beginning of the dying phase. Therefore, a nutritional intervention in this phase of life should be followed in an individualized manner.

Commentary: While death is clearly defined and irrevocable, the end of a person's life is a process. This process is expandable per se and defining its beginning is subject to individual views and interpretation. In general the health state of old persons or people with debilitating diseases are slowly deteriorating. At a certain point, deterioration accelerates, patients become bedridden and become dependent for most if not all functions to sustain life. Generally these patients suffer and derive no pleasure or feelings of wellbeing in this situation. This period should be prolonged by nutritional support if people are predominantly starving and when a gain or preservation of quality of life is possible. If this is not possible, the intention of this treatment in dying persons is to satisfy hunger and thirst. An individual's expressed wishes and needs may change in the final phase of his or her life. In fact, each person demonstrates a different type of behavior until the time of death. The indication for artificial nutrition should therefore be established at this time after careful and individualized consideration of the potential risks and benefits with the purpose of providing endof-life care. Administration of fluid and energy is not always needed at all times in this phase of life. Patients do frequently experience dryness of the mouth, an early sensation of saturation, nausea and an impaired sense of taste, but rarely hunger and thirst. Thirst generally results from unpleasant dryness of the oral cavity and crust formation and can be frequently relieved by oral care and small quantities of fluids, less than necessary to relieve dehydration. Parenteral administration of fluid does not necessarily alleviate the individual's thirst. Besides, dryness of the mouth and thirst may also be the effect or side effect of medication, oxygen therapy, breathing through the mouth, or anxiety and depression. Therefore, dryness of the mouth and thirst should first be counteracted by nursing measures such as lip care and mouth care, as well as repeated provision of small amounts of fluids. In the rare case that a patient is thirsty despite optimal care or when dehydration is associated with delirium, the effectiveness of artificial hydration could be reviewed but is doubtful to be of any

- benefit in the dying phase. At this time palliative sedation is another option and is increasingly applied' (pp. 549-550).
- 729 '23: The will of the adult patient who is capable of providing consent and making judgments has to be respected in all cases' (p. 550).
- 731 '27: Patients are authorized/encouraged to establish an advance directive or a living will according 732 to the specific laws in their countries. Certain requirements have to be fulfilled to ensure validity. 733 Valid advance directives must be respected according to the country's laws and by the treating 734 physicians' (p. 551).
 - '<u>29</u>: Quality of life must always be taken into account in any type of medical treatment including artificial nutrition.

Commentary: While for oncological patients well established tools to assess quality of life are available, widely accepted instruments for patients with cognitive impairment, suitable for use in clinical routine, do not exist in a satisfying way to the present day (2016). Nevertheless, even the patient whose competence is largely impaired gives clues as to his perception of quality of life by appropriate expressions or statements. Also the patient who is unable to give consent or make a judgment should be informed about the proposed measures; the communication should be aligned to his or her comprehension abilities. The patient's statements or reactions should be taken into account as appropriate' (p. 551-552).

- 745 '31: To achieve a mutually acceptable solution or a compromise, one should utilize all options. These include obtaining a second opinion, a case discussion in ethics, clinical ethics counseling, or obtaining the recommendations of a clinical ethics committee' (p. 552).
- 748 '34: Voluntary cessation of nutrition and hydration is a legally and medically acceptable decision of a competent patient, when chosen in disease conditions with frustrating prognosis and at the end of life' (p. 553).

Table 5. Summary of the evidence of end of life care

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Ref	Population	Sample size	Intervention details	Study design	Outcome studied	Main findings	Limitations
Karnik, Kanekar, 2016 [63]	Humans	Narrative review	Ethics & end of life care.	Review	Autonomous decision making, rationing care.	End of life care advice & preference should be given priority	A United States based study.
Neuberger et al. 2013 [72]	The dying in England.	723 Responses.	Care under the Liverpool Care Pathway (LCP)	Call for evidence, visits, sought advice, reviewed literature.	Whether the Liverpool Care Pathway was working to the benefit of patients.	44 Recommendation s for improvement. & replacement.	It suggests, without any justification, that assisted dying is not good care and is frightening.
Druml et al. 2016 [19]	Worldwide patients	ESPEN guidance	Artificial nutrition & hydration	International collaborative guidelines	Ethics of artificial nutrition & hydration	36 Statements	A very useful guide.

Todd et al., 2016 [1]	Veterinary surgeons	50 Relevant replies, 4,445 views	Medically assisted dying	Veterinary surgeons' forum.	Need for legalization of MAD.	Concerns about human suffering in UK.	Respondents chose themselves.
Maltoni et al., 2012 [22]	Near end of life patients.	1,807 patients from 10 articles.	Palliative pharmacologic al sedation.	Systematic review.	The effect of sedation on survival.	Sedation did not reduce length of survival.	The quality of the studies used ranged from fair to fair/poor.

4.7. Other Evidence

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One review from the Netherlands focusses on the moral problems that nurses encounter caring for the terminally ill [73]. 'Because of the unavoidable confrontation with the patients' suffering, it is generally the nurse who takes the initiative to ask for a morphine infusion for those who are terminally ill' [73] (p.164). They often carry a 'burden of guilt and responsibility'. Other nurses fear death occurring after the administration of medication so anxiety prevents them from becoming aware of the patients' situation and their need for medication (p.165). Nurses questioning the appropriateness of medical treatments can cause conflicts between themselves and physicians. Nurses are often constrained in following their own moral decision due to lack of authority and 'a lack of involvement in the decision-making process' (p.167) which can cause the highest stress scores in situations of ethical difficulty. Negative feelings and professional disillusionment arise when nurses are unable to resolve the moral problems with which they are confronted, and when they adopt an attitude of disengagement from the situation. 'Studies on the moral attitude of nurses describe that qualities such as courage, honesty, the ability to adopt an active attitude, having confidence, and going beyond rules and conventions when necessary, lead to the resolution of moral problems and to more satisfaction than an attitude based on disengagement' (p.167). 'Nurses should be encouraged to develop their moral behaviour by enhancing their sensitivity to the consequences of their actions, and by being encouraged to place moral aspects above other considerations' [73] (p.167) in order to defend their personal moral integrity.

Table 6. Summary of further evidence of end of life care

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Ref	Population	Sample size	Intervention details	Study design	Outcome studied	Main findings	Limitations
Beller et al., 2015 [23]	International, terminal patients requiring sedation.	14 Studies, 4,167 patients.	Palliative pharmacologic al sedation.	Narrative review.	Benefits	Insufficient evidence about efficacy of sedation and quality of life of sedated.	Only one study measured unintended adverse effects
Leboul et al., 2017 [24]	Health care providers in palliative care units in France.	28 medical & paramedical providers.	Palliative pharmacologic al sedation.	Qualitative study.	Opinions on the use and effectiveness of end of life sedation & effects on	Nurses who administer the sedation are subjected to moral distress due to the	Only truly representative of palliative care providers in specialist

					patient/carer relationships	uncertainty of their actions. Teamwork helps.	palliative care units in France.
Georges, Grypdonck, 2002 [73]	Nurses caring for the terminally ill	28 Articles	Study of moral problems encountered.	Literature review	Effects on the nurses of ethical dilemmas.	Skilled nurses cope better. Others try to avoid moral problems and	The researchers drew their results from very varied material not
					perceive and react to moral problems.	themselves, affecting their work and causing a feeling of insecurity.	always focused on moral problems of nurses caring for terminally ill patients.

Important differences between physicians' and nurses' approach to moral problems have been observed. Physicians use a more predominantly medical, scientific orientation while the nurses' approach is based more on the patients' and family's point of view [73]. Doctors and veterinarians are trained to dissociate their emotion from their professional skills for the benefit of the patient in most instances and their own benefit when dealing with dying and euthanasia. Nurses are also trained so as not to let their emotions interfere with their nursing skills, however they spend more time with the patient and hence become more aware of the patient's physical and existential needs.

Table 7. Summary of the evidence from a Canadian lawyer's perspective & the BMA.

Ref	Population	Sample size	Intervention details	Study design	Outcome studied	Main findings	Limitations
Cormack, 2000 [25]	Dutch, American, Australian & Canadians.	Varied	The legal status of euthanasia & assisted suicide.	A review bringing together historical facts.	The possibility of legalization in Canada	The principles of autonomy and beneficence provide the necessary foundation to justify change.	There is damning evidence from the Netherlands, but this is pre- legalization.
BMA 2016 a [26]	UK end of life citizens	Comprehensive overview of reports and situation in the UK & International evidence on assisted dying.	End of life issues & assisted dying.	Literature review	Seeks to set the scene as it stands.	Reviews - accessibility of end-of-life care in the UK & doctor dilemmas in end-of-life care. Assisted dying debate in the UK. International evidence on assisted dying.	Misleading inaccuracies e.g. Oregon's Death with dignity Act was not enacted until 27/10/97. Duplication of references e.g. 552 is the same as 569, 2 is the same as 18, etc.

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This concludes the literature review of papers relevant to end of life issues in human and veterinary medicine with particular regard to the comparison of euthanasia to relieve suffering in animals and the need for euthanasia to relieve suffering in humans. Some of the topics discussed in veterinary papers, such as the ethical dilemmas in making the decision for euthanasia, could help to resolve some of the reservations in human medicine currently blocking a move towards euthanasia.

The second paper in this series is an ethical discussion of the differences and similarities between end of life issues in veterinary and human medicine and whether human medicine can draw from the veterinary experience of euthanasia to relieve suffering.

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Table 8. Summary of the evidence from the BMA continued.

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Ref	Population	Sample size	Intervention details	Study design	Outcome studied	Main findings	Limitations
BMA 2016 b [8]	UK Public & doctors.	269 Members of the public. 237 Doctors	Dialogue events in 10 geographic locations.	Qualitative research. Not representativ e of the whole population.	Doctor patient relationship now & if PAD were legalized, concerns about dying, end-of-life care,	The public trust doctors & want a quick painless death. Quality of end-of-life care is inconsistent. Pain is not always completely eliminated. Treating doctors would not want to make decisions about eligibility & fear moral stress.	Recently bereaved (last 6 months) were excluded.
BMA 2016 c [27]	UK public & doctors	269 public & 237 doctors	Reflection & recommendati ons	Collating a report	End of life care & physician assisted dying (PAD).	End of life care is still failing. Some members of the public were surprised that people with dementia would be excluded from PAD. Oral assisted suicide has complications {most could be averted by the use of euthanasia}.	Some doctors thought relief of pain & suffering would outweigh the negative impacts of PAD. It would have been nice to know how many of the doctors shared this view.

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Conflicts of Interest: 'The author declares no conflicts of interest.'

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Appendix A

Literature search (A1)			
Search query	Should human medicine follow veterinary medicine by		
	including MAD or euthanasia as a legal end of life option		
	in the UK?		
Search submitted by	Ruth Eyre-Pugh		
Scarcii sabilittea by	radii 2yle 1 agii		
Search developer(s)	Clare Boulton		
Search strategy	1 ethics/ or law/ or legislation/ or regulations/ or		
CAB Abstracts on the OVID	"code of practice"/ or legal aspects/ or legal principles/		
interface	2 (ethic* or law* or legal* or legislat* or regulat* or		
	"code of practice" or code-of-practice or "code of conduct"		
	or code-of-conduct)		
	3 1 or 2		
	4 hospice care/ or hospices/ or "death and dying"/		
	or "end of life" or end-of-life		
	5 (euthanas* or palliativ* or hospice* or		
	pawspice*) or euthanasia/		
	6 (assist* adj5 (dying or death* or suicide))		
	7 4 or 5 or 6		
	8 exp veterinarians/ or medicine/ or physicians/ or		
	veterin* or doctor*		
	9 3 and 7 and 8		
	10 limit 9 to (english language and yr="1980 -		
	Current")		
Date of coverage	1980 to 2017 Week 05		
Inclusion & exclusion criteria	n/a		
Summary of CAB Abstracts	Date Searched 16/2/17		
research results	No of items found 166		

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811 Literature search (A2

Literature search (A2)	
Search query	Should human medicine follow veterinary medicine by
	including MAD or euthanasia as a legal end of life option
	in the UK?

Search submitted by	Ruth Eyre-Pugh		
Search developer(s)	Clare Boulton		
Search strategy	1 ethics/ or law/ or legislation/ or regulations/ or "code		
CAB Abstracts on the OVID interface	of practice"/ or legal aspects/ or legal principles/		
	2 (ethic* or law* or legal* or legislat* or regulat* or		
	"code of practice" or code-of-practice or "code of conduct"		
	or code-of-conduct)		
	3 1 or 2		
	4 hospice care/ or hospices/ or "death and dying"/ or		
	"end of life" or palliativ* or hospice* or pawspice*		
	5 euthanas*.mp. or euthanasia/ or (assist* adj5 (dying		
	or death* or suicide))		
	6 (exp veterinarians/ or veteran* and (medicine/ or		
	physicians/ or doctor*		
	7 3 and 4		
	8 5 and 7		
Date of coverage	1973 to 2017 Week 05		
Inclusion & exclusion criteria	n/a		
Summary of CAB Abstracts	Date Searched 17/2/17		
research results	No of items found 25		

Literature search (A3)			
Literature scareii (113)			
Search strategy	1. euthanasia or assisted suicide		
	2. ethics and medical		
PubMed accessed via the	3. end-of-life issues		
NCBI website	4. 1 and 2 and 3		
Date of coverage	PubMed - 1910 – February 2017		
Inclusion & exclusion criteria	English Language, 1980 -		
Summary of PubMed research	Date Searched 24/2/17		
results	No of items found 204		

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