Original Article on Hastened Death

Patients' views on end-of-life practices that hasten death: a qualitative study exploring ethical distinctions

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Background: Assisted dying (AD) is currently of wide interest due to legislative change. Its relationship to other end-of-life practices such as palliative sedation (PS) is the subject of ongoing debate. The aim of this article is to describe the perspectives of a group of New Zealanders with life-limiting illness, who want or would consider AD, on the provision of end of life services, including assisted death, withdrawal of life-prolonging treatment and symptom management with opioids or PS.

Methods: We recruited 14 people with life-limiting illness and life expectancy of less than a year. Their mean age was 61 (range, 34–82) years and half were enrolled in Hospice. An additional six family members were also interviewed and included in analysis. We asked them about why they would consider AD if it was available. Interview transcripts were inductively analyzed consistent with thematic analysis. We compared the findings to prevailing ethical frameworks.

Results: Most of the participants viewed current palliative care practices, such as pain relief with opioids and symptom management with PS, as hastening death, in contrast to some medical research which concludes that proportional therapeutic doses do not hasten death. Some participants did not agree with the 'doctrine of double effect' ('DDE') and saw such practices as 'slow euthanasia' and 'covert euthanasia'. They implied such practices were performed without patient consent, though they did not conceive of this as murder. Participants asserted that active and passive practices for ending life were morally equivalent, and preferred to choose the time of death over other legal means for death.

Conclusions: This article contributes to what is known about how patients perceive end-of-life practices that potentially hasten death. There is a divide in what medical ethics and most health professionals and what some patients consider active hastening death. Participants' perspective was consistent with a consequentialist framework whereas deontology often guides medical ethics at the end of life. Participants' challenge to the interpretation of legal end-of-life practices as AD represents an epistemic contest to the foundation of medical knowledge, authority and ethics and therefore carries implications for preferences in care, communication and palliative care practice.

Keywords: Analgesics; opioid; double effect principle; ethics, medical; euthanasia; palliative care

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Introduction

Ethical and conceptual debates continue back and forth about whether end-of-life practices (1), such as palliative sedation (PS) and use of opioids for pain relief, are equivalent to hastening dying or not (2-7). Research shows that such interventions do not hasten death when used proportionately (8-10), though one critique suggested methodological limitations exist although no randomized-control trials have been conducted to give a definitive answer (6). Even if they do shorten survival, medical ethicists stress that end-of-life practices and assisted dying (AD) are ethically distinct (11,12). Yet, the perception of the relatedness of end-of-life practices, and hastening death persists among the public and some health professionals (13,14). Our aim in this article is not to resolve this debate, but to explore the relatedness of AD and common end-of-life practices from the perspectives of patients approaching the end of life. Patients' views are important because they make decisions about and receive such treatments based on their understandings of end-of-life therapeutic practices. The central argument is that distinct moral and ethical (ethical frameworks are the formal theories and discourses and moral frameworks reflect informal theories and discourses) perspectives explain the divergence between the public and the medical ethics views of end-of-life practices as distinct from AD. In this regard, we argue that the participants' views represent an 'epistemic contest' (15) to medical ethics and practice.

We use AD as the most general descriptor to refer hastening death, including a lethal injection that is administered at the voluntary request of a competent patient by a health professional (defined broadly) and the patient's self-administration of a lethal prescription. By definition, any non-consensual deaths are murder rather than euthanasia (11). Sedation is referred to by various terms including continuous, terminal and palliative (16). PS and opioids for pain relief involve the titration of medications to reduce consciousness to relieve intractable suffering at the end of life in a manner ethically acceptable to patients, their families and healthcare providers (17). There are variations in guidelines, interpretation of this term and usage because sedation has many levels and nuances (18,19).

The key differences between AD and end-of-life practices are the intention, the type of intervention itself, and outcomes of the intervention. The distinction between them rests on the doctrine of double effect (DDE). According to Beauchamp and Childress, the criteria for the doctrine as follows:

(I) The nature of the act. The act must be at least morally neutral (independent of its consequences).
(II) The agent's intention. The agent intends only the good effect. The bad effect can be foreseen, tolerated, and permitted, but it must not be intended.
(III) The distinction between the means and effect. The bad effect must not be a means to the good effect. If the good effect were the direct causal result of the bad effect, the agent would intend the bad effect in pursuit of the good effect.
(IV) Proportionality between the good effect and the bad effect. The good effect must outweigh the bad effect. That is, the bad effect is permissible if a proportionate reason compensates for permitting the foreseen bad effect (20).

With end-of-life practices, the DDE relies on the intention of the doctor in the administration of potentially life-shortening medication. Some, such as Billings and Block (21), have labelled the slow increases in administered doses of pain medication so that death is assured, but does not occur too quickly, at the end of life as slow euthanasia.

Another distinction between end-of-life practices, although contested, is active versus passive euthanasia (22). Active euthanasia occurs when a patient is given a lethal substance in which case it is this action that causes death. Passive euthanasia is described by some as the withholding or withdrawal of life-prolonging treatment with the intention of hastening death because it is in the person's best interest for dying to occur sooner rather than later (22,23). The European Association for Palliative Care Ethics Task Force and later Board of Directors argued that passive euthanasia is an unhelpful and contradictory term because it does not specifically cause death (11,24). Medical associations and their affiliates assert that in some circumstances it is permissible to withhold treatment and allow a patient to die from their underlying disease (11,12,24-27). It is the intention to hasten death that separates the withdrawal of some medical interventions from others (22).

The above distinctions are theoretical conceptualizations of end-of-life practices reflect the disciplines of bioethics, medical ethics and medicine. However, what are the experiences of those directly involved in PS and other end-of-life practices? Challenges, barriers and the moral burden associated with end-of-life practices for health professionals are well-explored (28-31). Systematic reviews of family members' experiences of end-of-life practices found

Table 1 Participant inclusion and exclusion criteria

Inclusion criteria
Those with a terminal, incurable, degenerative or progressive illness defined as 12 or fewer months life expectancy approximately
Who want or would consider choosing an assisted death
18 years of age or older
Capable of making and communicating health care decisions for themselves
Exclusion criteria
Cognitively impaired
Severe psychiatric conditions

common themes including inadequate communication and information (and perhaps therefore informed consent), and feeling morally responsible for death (32,33). In the studies reviewed, PS contributed to positive experiences for families of seeing their relative's suffering end and also offered them relief (32). However, five studies also identified that families experienced distress as a result of confusion over PS possibly hastening death (32).

Patients' involvement in end-of-life decision-making is essential, yet few studies on end-of-life practices include them. General population studies have been conducted in Japan (34) and the Netherlands (35) regarding patients' knowledge of and preferences about PS. Factors such as life-expectancy, type of distress, dignity and perceived importance of preparation for death were factors in the acceptability of and preferences for the level of sedation. To the best of our knowledge, there are only two studies that included patients and their families. These were conducted in Korea (36) and Spain (37). Despite having a strong desire for relief of suffering, both studies found patients had inadequate knowledge about end-of-life practices. Their families reported that the patients experienced positive outcomes from end-of-life practices. While, Eun *et al.* (36) found some patients feared they would not regain consciousness from heavy or prolonged PS, they did not report on the perception of end-of-life practices as shortening life. García-Toyos *et al.* (37) found some patients and families believed that use of opioids for pain relief implies premature death. The study did not enquire whether this impacted on patients' willingness to take opioids. The authors attribute patient and families' views that opioids cause premature death to false and erroneous beliefs. While clinical data suggests opioids do not shorten life, the perception among patients is worthy of exploration to understand what underpins their views.

Methods

A qualitative research design was used because it offers the greatest utility to understand the deeply subjective and reflective nature of patients' perspectives. It also allows for an analytical appreciation of the nuance and moral conflict implicit in any discussion of end-of-life practices and AD. This qualitative project is grounded by a relativist ontology and a subjectivist epistemology that is informed by a constructionist paradigm (38). The context for the study was the New Zealand Parliament considering an AD bill.

Ethics

Ethical approval for the study protocol was granted by the Northern A Health and Disability Ethics Committee 2017/NTA/90. The protocol was in accordance with the Helsinki Declaration.

Recruitment

A media release was sent out in November 2017 through our University's Communications Office seeking volunteers who wanted to share their views on AD. This resulted in three brief radio interviews and two newspaper articles which were shared widely by AD-related groups and people on social media and in general patient support groups. Twenty-seven people expressed interest who were screened according to the criteria in *Table 1*. Fifteen people were eligible, resulting in 14 participants (due to one death before interviewing commenced). Eligible participants were sent the information sheet and had an opportunity to ask any questions before consenting to participate. Participants gave written informed consent before the interview commenced. They were contacted the day before

to confirm participation. Participants were phoned after the interview as per the safety protocol.

Participants

Participants consisted of eight females and six males with a mean age of 61 (range, 34–82) years. Twelve identified as New Zealand European and two as Māori (indigenous). They had a wide variety of educational and professional backgrounds. Participants were diagnosed variously with advanced cancers; motor neuron disease; end-stage chronic obstructive pulmonary disease; one person had a rare auto-immune disease as well as cancer. Half were enrolled in hospice or palliative care. Four had explicit religious/spiritual beliefs. Participants were located throughout New Zealand. Six participants' interviews also included a family member.

Data collection

An interview guide was created from issues identified in relevant literatures, pilot tested, and used responsively with participants. Interviews explored participants' experiences, meanings and views on a range of issues including: death; suffering; values; society; doctors; medicine; quality of life; control; dignity; experiences of others' death; planning for end-of-life; concerns or fears about dying. An emphasis was placed on dialogue, ensuring the participants were able to identify and then discuss the issues they saw as pertinent (39). Semi-structured interviews with JY took place in December 2017 and January 2018 at participants' homes and one at a hospice. Average duration was 100 (range, 58–155) minutes. No repeat interviews were conducted; however, some participants chose to stay in communication with JY. Interviews were audio-recorded, transcribed and returned to participants if they wished to review them and make further comments. Participants were assigned pseudonyms.

Analysis

JY listened to recordings and read through transcripts to gain an overall impression along with post-interview reflections. Qualitative data analysis software ATLAS.ti was used to facilitate the analysis. Data were inductively analyzed by JY using an approach consistent with thematic analysis (40). In the first pass of coding the transcripts JY identified segment of texts and created codes to capture the meaning and created memos about what each code pertained to, an evolving definition, and comprising ideas. The second passes of the data were to group the codes into categories, creating a second set of memos about the categories. Categories were then grouped into themes. The research team also independently analyzed a subset of transcripts and met to refine the interpretation and validate themes to reduce investigator bias and enhance reflexivity. The third pass of analysis consisted of reading through each transcript with an attention to the theme, identification of new codes, grouping of similar ones, and continued regrouping until an emergent thematic structure was identified. JW analyzed all data related to the theme of the paper.

Results

An unexpected finding from the interviews was that participants contested the ethical distinctions between AD and other end of life practices, in particular PS, opioids for pain relief, and withdrawal of life support. During interviews and unprompted, participants indicated that they considered these end-of-life practices to constitute covert euthanasia. With regards to perceptions of end-of-life practices, two key themes were identified comprised of subthemes. Firstly, that the participants believed that morphine causes death and secondly, that AD is morally equivalent to or better than a variety of legal end-of-life practices. Morphine was used as a shorthand for all opioid-based analgesics.

Morphine causes death

Morphine is intentionally used to hasten death

Most participants discussed how morphine was already used to hasten death intentionally. A participant and his wife saw morphine as lethal and given to hasten death but still recognized that the old age or stroke was a contributing factor to their mother's death.

Dennis: Mum passed away… and morphine was the passage out really. She had a stroke and became fairly incapacitated and yeah, they just morphine her up and 2 days later, oh look at that, it's all over.

Rebecca: But she really only died of old age though.

Dennis: Yeah, the last week or so. And you know, I've got family who are medical people and they said it's the best option. But it's legal to do that, but it's not actually called AD. It's just helping her not suffer.

(Interviewer explains DDE).

Dennis: it's how many milligrams, that's the distinction

(laughter).

Another participant described her family's action to intentionally hasten their father's death, based on their doctor's advice that it was possible to do so.

My father passing was very disturbed… the doctor instructed us to put his, to play with his pump, morphine pump. Which my brother-in-law did, in good faith. With a screwdriver and to this day, we think that we may have, you know (Dee).

In both examples, the view that morphine hastens death was reinforced by health professionals.

Morphine is commonly used to hasten death

There was a view among many participants that morphine was regularly given in doses large enough to cause death. Kate thought morphine was involved in a majority of deaths.

Kate: is it not, when you're terminal and when you're in a place like that, the majority of people die of a morphine overdose or a …

(Interviewer explains DDE).

Kate: it is, it is. You see that it is done, but it's not done, but it is. It is.

Similarly, Helen acknowledged that not all doctors were willing to hasten death but considered the regulatory framework insufficient to ensure that all patients' deaths were managed within the confines of the law.

Coz some doctors know just a bit more morphine and that'll shorten it. That happens… I know, I cared for an elderly woman with bone cancer in her home, coz she wanted to die at home. And the son wanted just a bit more morphine put in, so the doctor there was totally against that. Yeah, so sneaky shit goes on, sneaky shit will keep carrying on regardless of the laws.

Doctors decide timing of death

PS or the administration of very high levels of pain relief was perceived to reflect doctor's control over the timing of death, whereas Claudia would prefer to make the decision herself.

And my doctor suggested that there's absolutely no way that (I'll be in unmanageable pain for months), and I kind of have to trust him, yeah, he said palliative care team will simply come to your house, yeah, and they make the call, yeah, it's really got to unmanageable levels. And yeah, it's, coz in a way, that's AD, isn't it?... Yeah, it's, but it's not going to be my choice to, you know, is it.

Participants considered the use of morphine as a form of covert euthanasia, regardless of the illegality of it. Expanding on the illegality, all of the excerpts in the 'morphine causes death' theme exemplify that participants did not necessarily see hastening death without consent as murder. Instead, the relatedness of pain relief to AD was emphasized.

End-of-life practices are morally equivalent

Active euthanasia and withholding/withdrawing life-sustaining treatments are the same

Dennis and Rebecca pointed out that as with AD, the withdrawal of life support is also a choice made by doctors. As noted above, some scholars have classified the withdrawal of life-sustaining treatment as passive euthanasia. Participants highlighted that both decisions (active euthanasia and withdrawal of life sustaining treatments) bring about the same consequence, death.

Dennis: when you look at it now, with this life support and the doctors go hey if we take them off life support the chances are, in a way isn't that just bringing the end closer anyway? It is isn't it. They say to the family look, we don't think Johnny or Grandma's going to make it past this point, it's only the machine that's keeping them alive, what do you want us to do? Oh, turn the machine off.

Rebecca: yeah, you've given the choice to the family, so what's the difference?

Interviewer: the doctors would distinguish that withdrawing care is letting them die from their underlying disease. Whereas euthanasia and AD is more of an active bringing about death, rather than letting it happen.

Dennis: rather natural cause.

Rebecca: I still think it's natural, just accelerating it.

The role of an electro-mechanical component in care, i.e., life-sustaining treatment, is pivotal in clinical differentiations of hastening and allowing death. Participants challenged the assumption that extension/cessation of life through technology is acceptable and unproblematic but that AD is illegal and unacceptable, at least according to several New Zealand medical bodies and international medical bodies (12,26,41).

Questioning intention

One participant, who was versed in theology through his profession as a minister, characterized the DDE as 'bullshit'.

You know, bang people on the head and put them in a coma. No, no. I'm not convinced that's palliative. I mean, that is clearly, I mean, as is giving an overdose

Table 2 Comparison of participants' views with commonly held views of health professionals

Study participants' perspective	Health professionals' perspective
Morphine is frequently given to patients approaching end of life with the intention of hastening death. Covert euthanasia happens commonly and regularly. Legalizing assisted dying (AD) will bring a common practice "into the light" (i.e., no longer covert) and allow regulation	Morphine is given with the intention of relieving suffering. Covert euthanasia by health professionals is extremely rare (42)
Medical morphine is commonly used in doses that cause death for many patients. It does not matter if the intention of treatment is to relieve suffering or hasten death if the outcome is the same	Medically administered morphine is almost never the cause of death (patients die from their disease and morphine is used to relieve suffering). "Doctrine of Double Effect" ("DDE")—If the intention of treatment is to relieve suffering, the risk of hastening death is an acceptable side effect (42)
Hastening and allowing death are not different. Active and passive routes to death are morally equivalent. Thus, the doctor decides when the person dies	Allowing natural death (i.e., withdrawing or withholding life-saving treatment) is morally different than hastening death. Timing of death is beyond the control of health professionals (42)

of Oxycodone or anything else. I mean, that is clearly acknowledging that this is going to end life. We're not doing palliative care when we give those last doses of these drugs. We're speeding up the end of life… I think it's a, it's a, it's a weasel argument. If you know what is going to happen, saying we're intending to do something else, that is bullshit (laughing). I just don't want to be in that sort of position at the end (Daniel).

Daniel identified that although sedation relies on the distinction between intention and foresight of death, he questioned whether this separation was plausible to maintain. He linked sedation to the type of death he desired.

Legal end-of-life practices are undesirable

Participants considered the legal means for death, in particular voluntary stopping eating and drinking (VSED), high doses of pain relief and suicide, as less desirable than AD.

Yeah, well now I can refuse medications, refuse foods, stop eating and drinking. Makes it a slow, hard death (Heather).

They found the length and difficulty of a VSED death problematic. Although VSED would achieve a similar outcome of hastening death, they did not want to wait until they "starved to death" (Claudia). High doses of pain relief were less acceptable because they did not want to spend their last days unable to think.

If I have to have so many drugs that I'm just completely out of it or I can't speak or whatever, as far as I'm concerned, I would quite happily be dead (Dee).

By not having the option of AD available to them, most participants said they had given thought to the various methods of suicide available to them.

Well you're more likely to commit suicide if you haven't got euthanasia (Sylvia).

I thought, one day I'll be able to just chew (cyanide)… I'm a bit scared about it too, because I don't know how nice a death it would be… But that's why I think the medical people should be able to help you out, so it is painless. And not traumatic (Jacob).

Participants considered suicide in light of the harm to themselves and to others and positioned AD as less harmful and therefore preferable.

Discussion

This research adds to the limited knowledge about what patients with a life-limiting condition (with positive views of AD) think about end-of-life practices. We found that many of the participants considered end-of-life practices that may hasten death such as PS, opioids for pain relief and withdrawing life support were morally equivalent to AD. Participants viewed AD as preferable to suicide, VSED and to PS which, from their perspective, effectively amounts to a 'slow euthanasia' overdose of morphine. Such practices were equated to covert euthanasia but not considered murder when no explicit consent was sought. Their views differ from the commonly held views among health professionals, medical ethicists and the law (42). We have summarized and contrasted the two perspectives in *Table 2*. We acknowledge that not all participants nor all health professionals shared these views. Two analytics are useful for interpreting what underlies the divergence of views, ethical frameworks and epistemic contest, which we discuss in turn.

Ethical frameworks

An important finding from this study is that participants did not necessarily distinguish the morality of end-of-life practices from that of AD. This was because the consequence, death, was the same regardless of the means, and because they perceived that AD caused less harm than other options. The divergence between health professionals and participants reflect a privileging of distinct and somewhat incompatible ethical and moral frameworks. Health professionals, in the circumstances that participants were describing, would likely draw on deontological ethical frameworks. Kantian deontology privileges the intention of one's action as the most relevant consideration for judging the ethical rightness or wrongness of conduct; the consequences matter far less (43,44). Whereas participants' perspectives are consistent with consequentialism. According to consequentialism, the outcomes of an action are the ultimate basis for any judgment of that conduct (43). Health professionals must continue to practice knowing they have fulfilled what they consider to be their duties [which in some circumstances may differ from what the law permits (45-47)]; while patients and families witness the consequences of end-of-life practices. Participants' consequentialist orientation may feed into or be a result of their positive view of AD. However, given that the desire for hastened death is not uncommon among patients receiving hospice services (48-51), participants' position of moral equivalence could be common to other patients at the end of life.

Doctrine of double effect

The divergence between participants' consequentialist framework and health professional/medical ethics' deontological framework is most apparent in their approach to the DDE. While doctors and ethicists distinguish between intentionally bringing about death *vs.* providing pain relief or levels of sedation or withdrawing life-sustaining treatment (by drawing on the DDE), many of the participants, who may be on the receiving of such treatments, did not. While the analytical constructs that medical ethics relies upon are complex, some participants demonstrated their comprehension by expressing suspicion that the DDE constitutes intellectual and moral sophistry.

Results from empirical research identifies that there can be considerable ambiguity between intention and foresight of death during end-of-life care. Several studies demonstrate that doctors and nurses do not always have a clear distinction between intention and foresight (52-56). Trankle (56) interviewed physicians about how they drew on the DDE. All reported the inadequacy of DDE as a medico-legal guideline. In his words, "the narrow focus on the physician's intent illuminated how easily it may be manipulated, thus impairing transparency and a physician's capacity for honesty" (56). If the moral distinction between intention and foresight is dubious, then the rules of DDE are illogical. Moreover, if opioids and sedatives do not hasten death then why does the DDE need to be invoked, at least in some circumstances (6,53)? Our data suggests that participants thought that medicine has double standards to enable it to be opposed to AD, while secretly (or not so secretly) practicing it by drawing on the DDE.

Covert euthanasia

In addition to the example of a health professional suggesting tampering with the syringe driver, there are some studies to support participants' beliefs that covert euthanasia is occurring illegally in small numbers in New Zealand as well as around the Western world (56-60). Of the New Zealand general practitioners (GPs) who responded to an international standardized survey (61) between 4.5% and 5.6% (and nurses under their instruction) intentionally hastened death regardless of the illegality and at times, had done so without patient consent (62-64). A further 13.6% and 17.5% of GPs reported intensifying the alleviation of pain medication "partly" intended to hasten death. Reasons to cautiously interpret these self-reports include that doctors may not answer AD-related surveys honestly for fear of repercussions so underreporting is possible (65). On the other hand, some GPs are unclear about the DDE (that increasing pain medications might not be euthanasia) (14,66); some GPs are not aware of what dose or effects of opioid analgesia is likely lethal and thus the cause of death (mis-attribution of correlation and causation).

Consent for hastening death

A significant difference between participants, medical ethics, the law and health professionals' practice was that the lack of consent from patients regarding life ending practices was not considered murder. In emphasizing the relatedness between AD decisions and other end-of-life decisions, participants resisted the dominant medical and legal interpretation of killing. On this basis, we suggest participants utilize their own moral frameworks. In a context of person-centered care, the patient and family's perspectives and decision-making frameworks are a salient

focus of research and practice.

Epistemic contest

What appears to be at stake in the differing accounts of end-of-life practices are knowledge and truth. In other words, an epistemic contest where actors advocate for competing understandings of reality, knowledge and reasoning (15). Epistemology pertains to what knowledge is accepted as valid and how it is justified. Over the last 300 years, medicine has gained the moral authority "to define the real" or truth, and the standards of knowledge and objectivity (15). The dispute over the ethical interpretations of end-of-life practices involves a challenge to medicine's foundational knowledge and logic system. Participants cogently argued that AD was morally equivalent to other end-of-life medical practices. In doing so, they were contesting the epistemic basis and discursive privileging of medical knowledge and interpretation of what is true. They also challenged well-established law, medical ethics and practice interpretations of practices that may hasten death. While the doctrine 'killing is bad but letting die is permissible' is buttressed by the medico-legal institution, it is challenged by some dying individuals and their families who assert that there is no moral difference between the relief of symptoms, withdrawal of life support and AD.

We query who among participants/patients and health professionals/medical ethicists has the epistemic authority to speak the truth and whose truth prevails in this end-of-life context? The individuals in this study claimed moral authority to define the real on the basis of their experience of suffering and as a person approaching the end of life. Their epistemic claim is experiential and often limited to one or two deaths; doctors draw on their vast experiences of the end of life, scientific knowledge and formal qualifications to speak authoritatively. While clinicians consider PS as good practice, patients and families may experience PS as imposing 'social death' before biological death by removing the last vestiges of personhood and the ability to act on the world, in ways that AD does not (67). Some end-of-life research is also implicated in the epistemic contest. For example, García-Toyos *et al.* (37) dismiss patients and families' experiences of death being hastened as false beliefs, even though studies show that health professionals have hastened death (9,56-60).

Medicine deals with the inconsistencies that participants highlighted by drawing on doctrine, clinical evidence, denying or overlooking them (68,69). These responses open up an analytical space to examine the epistemic authority medicine possesses to define end-of-life practices. We recommend epistemic humility on the part of health professionals (70) to draw attention to prejudices on the listener's part (71). We do not purport to have the answers as to how this could be easily achieved, but suggest further research into how health professionals' intentions, ethics and clinical evidence may diverge from patients' and families' lived experiences of end-of-life practices that may hasten death could be reconciled and accommodated. A deeper understanding of the views of individual persons and families will help health professionals to better understand the views of individual persons and families and to enquire about their world view, being mindful not to impose their own. Being aware of one's own ethical frameworks, underpinned by moral ideologies, is a good start.

Strengths and limitations

This study is one of a few studies that explore patients' perspectives on end-of-life practices and the only one to accept participants' world views as their truth. In particular, the inclusion of two indigenous participants is unique within international AD research that does not represent indigenous perspectives. Understanding participants' perceptions of end-of-life practices that may hasten death and their views of AD will help health professionals to discuss treatment options and give insight into patients' decisions whether to accept or reject particular end-of-life options.

The context of the present study may be an explanatory factor. The New Zealand Parliament was considering AD legislation at the time of the interviews (passage of this legislation is contingent on a public referendum). The participants were a group who supported legalization. They had a vested interest in equating end-of-life practices. The study sample was recruited to represent a maximum variation sample in terms of age, ethnicity, illness, gender and location whereas most AD research tends to be with highly educated professionals. However, the sample represents a selective group who are literate and hold positive views of AD and therefore, their views may not apply to other groups of patients.

Conclusions

This article contributes to what is known about how some patients perceive end-of-life practices that potentially hasten death. Participants viewed end-of-life practices—

specifically PS, opioids for pain relief, and withdrawing life support—as morally equivalent to AD. AD was preferable to PS/slow euthanasia, VSED and suicide. Participants did not equate covert euthanasia without consent to murder. Participants' moral framework mapped to the ethical framework consequentialism as distinct from the medical ethics framework of deontology (44). Participants' challenge to the interpretation of legal end-of-life practices distinct from AD amounts to an epistemic contest to the foundation of medical knowledge, authority and practice.

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Footnote

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Ethical approval for the study protocol was granted by the Northern A Health and Disability Ethics Committee 2017/NTA/90. The protocol was in accordance with the Helsinki Declaration (as revised in 2013). Participants gave written informed consent before the interview commenced.

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