

This is an Accepted Manuscript of an article published in [Bioethics], available online at <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2011.01895.x/full> (paywalled).

Self-archived in the [Sydney eScholarship Repository](#) by the Centre for Values, Ethics and the Law in Medicine (VELiM), University of Sydney, Australia

**Please cite as:**

Douglas C, Kerridge I, Ankeny R. Narratives of 'Terminal Sedation', and the Importance of the Intention-Foresight Distinction in Palliative Care Practice. *Bioethics*. 2013. 27(1): 1–11.

## **Narratives of 'Terminal Sedation', and the Importance of the Intention-Foresight Distinction in Palliative Care Practice**

**Douglas C, Kerridge I, Ankeny R. (2013)**

### **ABSTRACT**

The moral importance of the 'intention–foresight' distinction has long been a matter of philosophical controversy, particularly in the context of end-of-life care. Previous empirical research in Australia has suggested that general physicians and surgeons may use analgesic or sedative infusions with ambiguous intentions, their actions sometimes approximating 'slow euthanasia'. In this paper, we report findings from a qualitative study of 18 Australian palliative care medical specialists, using in-depth interviews to address the use of sedation at the end of life. The majority of subjects were agnostic or atheistic. In contrast to their colleagues in acute medical practice, these Australian palliative care specialists were almost unanimously committed to distinguishing their actions from euthanasia. This commitment appeared to arise principally from the need to maintain a clear professional role, and not obviously from an ideological opposition to euthanasia. While some respondents acknowledged that there are difficult cases that require considered reflection upon one's intention, and where there may be some 'mental gymnastics,' the nearly unanimous view was that it is important, even in these difficult cases, to cultivate an intention that focuses exclusively on the relief of symptoms. We present four narratives of 'terminal' sedation – cases where sedation was administered in significant doses just before death, and may well have hastened death. Considerable ambiguities of intention were evident in some instances, but the discussion around these clearly exceptional cases illustrates the importance of intention to palliative care specialists in maintaining their professional roles.

**Keywords:** intention; hypnotics and sedatives; euthanasia; terminal care; double effect; qualitative research; end-of-life

### **INTRODUCTION**

Arguments about the morality of various forms of end-of-life care often focus on the moral significance of the distinction between intention and foresight. In particular, there is debate about whether there is an important moral difference between, on the one hand, giving sedative or analgesic drugs to relieve symptoms, foreseeing that death may be hastened; and on the other hand, using the same drugs with the intention of hastening death.<sup>1</sup> While this debate has largely turned on normative moral theories, it has been increasingly informed by the results of empirical research. Quantitative studies of doctors without specific palliative care training have suggested that

analgesics and/or sedatives are sometimes used with an intention or 'partial intention' to hasten death,<sup>2</sup> thus approximating 'slow euthanasia'.<sup>3</sup> In our own qualitative study of Australian general physicians, doctors demonstrated considerable ambiguity about their intentions and failed to distinguish consistently between intention and foresight.<sup>4</sup>

A largely unchallenged consensus has emerged from the palliative care literature that most patients can be kept comfortable with carefully titrated doses of drugs that have little effect on the timing of death.<sup>5</sup> Thus, in most cases, doctors in palliative care do not foresee that death is a likely consequence of their actions. Nonetheless, even within palliative care, it is widely acknowledged that some patients will require quite 'heavy' sedation to control their pain, anxiety or distress.<sup>6</sup> In at least some of these cases, a hastened death is foreseeable, and the intention-foresight distinction must be invoked if palliative care is to be distinguished from euthanasia or assisted suicide.<sup>7</sup>

There appears to be a range of views about 'appropriate' use of sedatives, different practices being viewed as more or less likely to foreseeably hasten death, and more or less morally contentious, depending on a variety of factors such as when sedation is given, why it is given, who is involved in the decision-making, how frequently doses are escalated or reviewed, and whether hydration is provided concurrently.<sup>8</sup> Explicit patient preferences on any of these points would naturally go a long way to providing justification.<sup>9</sup> There is however particular contention about sedation where the aim is to achieve and maintain unconsciousness until death, even where this has been chosen by the patient.<sup>10</sup> This practice is sometimes referred to as 'terminal sedation' although, without qualification, that term itself is highly ambiguous.<sup>11</sup>

What is lacking in the literature to date is a qualitative account of palliative care doctors' experience with sedation at the end of life, exploring the intention-foresight distinction in that context. We undertook a study to address this issue.

## METHODS

Ethics clearance was obtained from the Human Research Ethics Committees of the two participating universities. Recruitment was initiated by a presentation at a symposium on palliative care in 2006, and followed up with invitations sent via newsletters and bulletins of the ANZ Society of Palliative Medicine and by 'snowball sampling'.<sup>12</sup> Potential participants were invited to be interviewed for approximately one hour on end-of-life decision-making, particularly regarding the use of sedation. Two nurses and 18 doctors were interviewed. Given that ultimately we had only a small number of nurses, and given the fact that nurses might be seen to represent a different population due to their more limited authority, we have excluded them from the analysis (although the two nurses interviewed did not present any substantially different themes, or contradict the themes presented here). Some volunteers from some metropolitan centres were not interviewed, to ensure that those cities were not over-represented. Selective recruitment for religiosity was initially planned, but proved unnecessary as the sample was reasonably well balanced in this respect.

Analysis was conducted after the first 3 interviews and then again after 6 interviews, and the interview schedule was adjusted in an iterative fashion, the better to address the relevant issues as they emerged. Recruitment was considered complete when it appeared that there was saturation with regard to the principle themes of interest (relating to intention and foresight).<sup>13</sup>

Interviews were semi-structured. Religious background and beliefs were discussed (given the recognized association of religious tradition with views about euthanasia and assisted suicide).<sup>14</sup> Respondents were then prompted to discuss the distinctions and/or overlap between palliative care and euthanasia/assisted suicide. If the topics were not initiated by the respondent, the interviewer directed discussion to the use of sedation and particularly the use of continuous heavy sedation. Views about the morality and possible legalization of euthanasia were not explicitly sought but, given the nature of the discussion, most respondents gave some indication about their views on these issues.

Interviews were conducted and recorded by CDD, transcribed by a professional typist and checked for accuracy by CDD. Interview transcripts were read and discussed by all three authors. Theory was not developed in this study in the traditional sense of grounded theory.<sup>15</sup> Instead, we were ultimately looking for confirmation of, contradiction of, or variation on themes that have previously been identified, some of which had emerged in our previous empirical studies, and many of which have been discussed extensively in the moral philosophy and palliative care literature, relating to categories such as 'intention', 'foresight', 'desire', 'pain', 'psychological distress', 'professional role', 'unease/discomfort (of the doctor)' and so on. In particular we looked for passages of text that indicated clarity, implied ambiguity or explicit (acknowledged) ambiguity or uncertainty of intention or foresight; and passages of text that indicated 'comfort' or 'discomfort' of the doctor with a particular action, type of action or scenario. Following general discussions, codes were developed by CDD, with the help of Nvivo7 software,<sup>16</sup> to identify these passages of interest. The coding categories were reviewed independently and approved by the two other authors. Following coding by CDD, the coded transcripts were discussed again within the authorial group, appropriateness of coding was confirmed, and codes were gradually collapsed into dominant themes, particularly those relating to intention and foresight. Triangulation<sup>17</sup> with our previous empirical data was undertaken to ensure consistency. As a central theme was a belief by respondents that the intention-foresight distinction is a substantially important one, we looked for 'negative' or 'deviant' cases (in which data seem to contradict the emerging theme);<sup>18</sup> and found only one (reported below as Respondent 13).

We present four narratives largely unedited, followed by an analysis of the main themes articulated in them, with supplementary quotes from other interviews. Plain text in parentheses indicates editorial clarification of meaning, but these additions have been minimized as far as possible. These four were not the only narratives of 'terminal sedation' or requests for terminal sedation provided, but they were the longest and most clearly described examples, many other anecdotes being brief or fragmented. The four narratives chosen best illustrate the complexities of intention, without risk of editorial compromise. They also illustrate multiple themes.

Gender and a description of religiosity are provided for the respondents quoted. Further individual demographics are omitted because of the potential for identification in a relatively small professional community.

## RESULTS

### Participants

#### Demographics

There were 18 participants, 16 interviewed individually and the last two interviewed together by request. Six respondents were from regional centres and 12 from metropolitan centres throughout Australia. Ages ranged from 29 to 67, and there were 11 males and 7 females. Three participants did not have a formal specialist qualification in palliative medicine, but practised mostly or exclusively within that field (one general practitioner, one 'registrar' or specialist physician-in-training, and one 'Career Medical Officer'). The remaining 15 doctors were specialist palliative care physicians.

#### Religiosity/spirituality of participants

Almost all respondents indicated an interest in 'spirituality'. Six respondents identified themselves as having a Christian faith, and/or an ongoing association with organized Christianity. The remaining 12 respondents came from largely Judeo-Christian backgrounds and had a variety of roughly spiritual interests; however their views regarding the existence of God or an experience after death could best be described as atheistic or agnostic.

#### Views of participants on euthanasia or assisted suicide as a societal issue

Six respondents stated explicitly, or implied in different ways, that they were not fundamentally opposed to euthanasia or assisted suicide, including comments to the effect that they could conceive of doing it in extreme circumstances, could conceive of wanting it for themselves, felt comfortable with people choosing it, or felt comfortable with the possibility of it being legalized (including one respondent who felt that the law should be reformed). All of these respondents held agnostic or atheistic viewpoints. Of the remaining participants, 10 respondents volunteered expressions of some level of opposition to euthanasia and assisted suicide, and 2 did not give clear indications of their position on the issue.

#### 'Terminal sedation'

In the four narratives that follow, respondents give descriptions of cases that we have described as 'terminal sedation'. As noted in the introduction, 'terminal sedation' has no universally agreed meaning. We use the term here to indicate the close temporal association between death and the administration of sedative drugs, and the possibility that the drugs used actually hastened death to some degree in all four cases. It should be stressed that the respondents themselves flagged these as exceptional cases. Most respondents indicated that sedative use was generally carefully titrated against symptoms, was only rarely aimed at inducing complete unconsciousness, and infrequently or rarely influenced the timing of death. We have chosen these four narratives because they best illustrate the complexities of intention, which is the main focus of this paper, but a number of other respondents volunteered similar (albeit shorter and more fragmented) descriptions of terminal sedation. There was considerable variation amongst respondents in their practices, and several respondents indicated that they would be uncomfortable or unwilling to provide sedation in circumstances similar to those described in one or more of these four narratives. On the other hand, this variation cut across religious and ideological lines. The four narratives below are given by respondents with very different demographics; and there was nothing about the experience or background of these four respondents that distinguished them as a group from other participants.

#### **Narrative 1**

one of the most challenging and, I think, instructive situations I've ever been in, was a man[with a terminal illness]who . . . ended up on a BIPAP19machine . . . had a lot of interaction with his family and decided that he would take the ventilator off when he got to the point that he was 24 hours dependent, and he felt it was time and he wanted someone to be there to relieve any distressing symptoms that might arise. And the GP refused to have anything to do with it. . . . So I and a palliative care nurse went there . . . he took his ventilator off, I put in an IV, gave him a bit of sedation beforehand, but not, you know, to the

point where he was . . . asleep, he was just a little bit woozy, took the ventilator off, and over the next 3 or so hours, poured in what I would've thought was enough midazolam, phenobarb and opioid<sup>20</sup> to kill a horse. And, I kept him sedated and at any point where he looked in any way distressed, I would give him another small bolus. And he eventually died, and quite peacefully . . . and I use this as a teaching discussion with students, and I ask them whether what I did was palliative care or euthanasia, and more students than not will say . . . that was euthanasia. And, the outcome . . . were I to give him what I gave him over hours in one bolus would have been precisely the same; he would have died peacefully, and much more quickly, and certainly much less stressfully for me! I know that's a long story . . . but it's been a pivot point for me, and I've often gone back to it, and inspected it . . . and I still feel that I did absolutely the right thing. I feel entirely comfortable about that. The family has always felt the same way . . .

But the challenge is . . . well, if you're going to do that, what is the difference, really? What is the difference between doing that or giving a bolus . . . and what would I want? And I think I would want the bolus . . . if I got to that point . . . I mean this man, he was dying, he was going to die very soon, and he was pretty well helpless, but he could still communicate. And that's probably the point where I would pull the pin as well.

CDD: You said that you put it to the students whether that's euthanasia, or palliative care, and I'm interested to know what you think.

I don't think it was euthanasia.

CDD: Yep . . . [so] there is the bolus that you could've given, and which you think you might want yourself, and that would be euthanasia. So . . . between the euthanasia and the palliative care, there are three hours, but there's, is there anything else? Because, as we both know, there's also . . .

Well, I mean, there's this question of intent. . . . and you know I wonder whether that is just a salve . . . but . . . so what? Even if it is a somewhat superficial salve to conscience, it does allow us to do what we need to do . . . it allows me to go into a situation like that and come away from it feeling that I've done the right thing . . . So . . . however open to challenge that little bit of mental gymnastics is, I'm happy to use it as a crutch . . .

if I can't function comfortably in that, or 'comfortably' isn't the right word, but, if I can't function in that situation . . . or if others like me can't function in that situation, then we are deprived of palliative care at the time we most desperately need it . . . it's a personal salve, but it also allows a necessary system of care, a humane system of care, to operate. . . . and if it is a flawed or challengeable piece of logic . . . so be it.

Respondent 12 (male, atheist)

## Narrative 2

I had a patient ten days ago, where we had used large doses of medication to try and ease their distress, with infusions running, with quite high doses of benzodiazepines and haloperidol, 21 with intermittent phenobarbitone, and the patient was still very distressed, and the family were very distressed. And . . . I drew up a syringe of 15 mg of midazolam, and I injected it slowly intravenously, until that patient's anguish settled. And, in fact it only took 7.5 mg, now my intent was to ease this . . . intractable anguish which was there, but part of my intent was to ease the family's anguish too, and I own that it may be as to deal with my anguish as well, and I can't tell you which of all of those muddles predominated, except that this was a, a guy we'd had a lot to do with over a long period of time . . . horrible situation, and, you know, he died perhaps half an hour later. Now, I may have induced his death . . . but I can't tell you what intent is there . . .

I hesitate to use that approach, I've rarely done it in my practising life, but sometimes when there's an extreme situation, the junior staff have exhausted all they're able to do, the nursing staff are beside themselves, and we've used all that we are able to in our usual, informed way, then I am prepared, as the senior doctor involved, to take the responsibility of that decision, with a lot of reservations and misgivings, and aware that I could perhaps be criticized. It will go to the death audit committee . . . I may well have to explain what happened, to the death audit committee and while I know that as long as I say 'My intent was to relieve distress', that no one can criticize me, and that I'm legally exonerated and so forth, I still, part of me says, 'Yeah, but you knew that he was gonna die if you did it', and so, I think . . . we have to wrestle with these as individual cases, and I don't think you make rules about it and I don't think you can legislate for it. I think we should really be troubled, every time, and we should be . . . accountable for the decision we make, and, and be prepared to own it.

CDD: . . . you say that we should be troubled by it each time . . . it's not completely clear in your own mind? . . . what's the intention in those circumstances?

I: No. I think it is clear in my mind . . . but I think that . . . um, we need to be really sure that we've exhausted all possibilities . . . I think we need to wrestle with the difficulties of what we should do every time . . . I don't think there should be precedents . . . because it's been done once before doesn't mean it's right the next time.

CDD: When 'it's' been done once before?

Well, when you know that that medication has been given to ease distress, deliberately, to overcome terminal anguish, in a patient, and they have subsequently died within the next short while.

CDD: Yep. So the 'it', the thing that you feel that we need to be really . . . anguishing about . . . is the very close association between . . .

An action and reaction.

CDD: The action and death?

Mmm[assents].

CDD: And yet . . . the philosophy that surrounds this is that it's not the close association that is alleged to matter, it's the intention.

That's right, that is correct. But, but, sometimes, it's very hard to know[pause]whether . . . what the intent is, while the base, the prime intent, is to deal with the agonal state of the patient, there is no doubt that it also deals with our distress, and the family distress, and I don't think you can separate those things, they are an intimate part of it, so we have to make sure that we're not treating ourselves, when we're trying to do this, and we have to make sure that we're not treating the family, that we are actually addressing the patient's distress. I guess that's what I'm saying. And that's where you have to be very sure.

Respondent 11 (male, practising Anglican)

### **Narrative 3**

. . . it's certainly happened a couple of times in the last few years, where a patient has, despite our best attempts to get control of the pain, or existential suffering, whatever – has said, 'No, I can't take this anymore, I need to be out of here . . . I don't want to be aware of this anymore.' And I think that is unusual, but occasionally it happens and it's very confronting – you consult within the staff very quickly, get as much information as you can from the relatives, and then, you make them less aware. And I've got no qualms about that, I'm not – I'm not bringing – I'm not aiming to bring about their death, and I don't think I do bring about their death, the death is obviously imminent . . . but they are actually making a decision that they can't cope with that degree of distress and clearly, in the earlier situations, you would look at things like depression, and see whether you've got a remediable cause of that, but some people have such existential distress at the end of life that they do request to be less aware . . . some of them might request to die, but I mean, I basically talk about gaining better control and making them less aware of their distress and their circumstances for whatever time they have left . . . and then I would use the appropriate medication to gain control of that . . .

I think[it]depends on . . . where that person is in their illness trajectory . . . but the cases that I've been involved with . . . patients who are really getting really towards, right towards the end of their illness, and they're really, you know, are able, usually in a faint and weak voice, but able to say, well, you know, 'I just need to be', you know, 'I need to be more comfortable, I need to be out of this.' And I've said, 'Okay, well, we'll do what we need to do' . . .

I'm not, as a palliative care physician, here to determine the timing of your death, I'm here to try to determine the quality of your death . . . and nor do I believe[pause]and feel comfortable being the human agent of death – so, I don't feel comfortable, at this stage, with performing 'euthanasia' as such, in inverted commas. I feel that I can use my skills transparently, just as effectively. That doesn't mean I disagree with people's right to consider that, and to even maybe pursue that[euthanasia].

CDD: Do you ever have a sort of uncomfortable feeling that you're in any kind of a grey area?

– I don't – I think there must be grey areas, but certainly, I – I'm comfortable in my intent

Respondent 8 (male, atheist)

#### **Narrative 4**

. . . it was a terrible state. And she said 'I want to be sedated, this is the only way I can deal with what's happening.' She'd been in here for, I don't know, 6 months, a long while, and we sedated her, and we did it in a step-wise thing.[At first]she was hazy, off with the pixies a bit, but she liked that . . . and then she got to a point where she said 'No, I want, you know, I want to be out of it completely', so we just upped it until she was out of it completely, but there was a sense that . . . I don't feel I was killing her. I felt I was actually making her comfortable.

CDD: How did you manage fluids and so on, after that?

I don't think there was . . . any more of that at all. 'Cause she'd tried to starve herself, she'd tried to stop eating . . . stopped drinking, and it didn't work . . . aside from the fact that she was terribly sick, she was still a big, well-nourished woman, and it would have taken her a long, long while to starve herself to death.

CDD: And drinking?

And drinking. Um, she wouldn't stop it all, because most people feel awful.

CDD: Do you have any feel for how long she would've survived had she not had sedation, if she'd gone on drinking?

Um,[long pause]oh . . . weeks, still, probably . . . I don't think death was absolutely imminent . . . but . . . she was going to die from what it was. And she'd really, it'd gone on for long enough . . . she'd've died within a couple of weeks, I suppose.

CDD: You said, sometimes in those sort of circumstances, some of the other staff feel quite uncomfortable. Why do you think that is?

There's a fairly . . . small minority of Catholics, who see it as a form of euthanasia, I think. And, you can't persuade them otherwise. In the same way as, I don't think I can be persuaded that I'm practising euthanasia. And some people just feel it's . . . too close to euthanasia . . . they won't make that distinction

CDD: Why is [that distinction] important?

[Pause]I don't think I can kill another human being. . . . I feel very strongly that as doctors, we shouldn't be killing, 'cause I think it changes the whole dynamic of the relationship . . . and I hope that I couldn't kill another human being

Respondent 17 (female, practising Anglican)

### Analysis

The main themes of interest all pertain either to the intentional hastening of death or the ('merely') foreseen hastening of death, and will be considered under 5 headings relating to foresight, intention, personal discomfort, professional concerns, and illness trajectory.

#### Foresight and Its Uncertainties

In a dying patient, it may be very difficult to foresee whether the administration of sedation will hasten death, or merely coincide with an 'imminent' death due to the underlying cause. A number of respondents commented on this:

I think there are a few occasions where patients possibly died from sedation rather than from ah[sighs]you know,[they've]died from both[the underlying illness and the sedation].

Respondent 5 (female, atheist)

I would suggest that it's probably a photo finish in many instances

Respondent 3 (male, Roman Catholic)

In Narratives 1 and 3, for example, it is not clear that the administration of sedation did hasten death, nor that the respondents foresaw death as a likely result of administering sedation. (In Narrative 1, in contrast, the withdrawal of ventilatory support contributed foreseeably to the timing of death.)

On the other hand, in Narrative 2 the causative link is strongly implied (there being 'a very close association' between the action and death) and in Narrative 4, it is explicit (the respondent indicating that the patient would have survived for weeks if she had continued to eat and drink). In both cases, it seems highly likely that a hastened death was foreseen as a likely outcome of the sedation provided.

#### Intention and its ambiguities

In reflecting on these difficult cases, the palliative care physicians interviewed regard intention as a matter of genuine importance, something about which they must be quite clear. In Narratives 3 and 4, the respondents seem to have achieved that clarity for themselves, although there appears to be an underlying ambiguity about intention in Narrative 4 ('It'd gone on long enough'). In Narratives 1 and 2, the respondents explicitly acknowledge ambiguities of intention (note the use of words such as 'mental gymnastics' and 'muddles') but seem determined to try to resolve them as far as possible. Many respondents made comments to the same effect:

I think 90% of the time it's pretty straightforward, and 10% of the time, it's mental gymnastics. And the mental gymnastics are always the ones that eat you, and you sweat over . . .

Respondent 14 (female, Anglican upbringing, not a strong church-goer)

Only one respondent expressed a predominantly skeptical view about intention in this setting:

we've been so drilled, by the law, and by the concept of the principle of double effect, it's just easier to say 'Yeah, we don't intend to'

encouraging, ah, well, hastening the dying process can be a positive . . . but we can't very easily[say]'we're meaning to hasten this dying process'. . . that goes against the grain of the law, and it cuts across people's moral training[but]it is a bit of an escape clause to say 'My intention wasn't to do that''

Respondent 13 (male, Roman Catholic upbringing but now atheistic/agnostic)

Notwithstanding these comments, Respondent 13 was clearly mindful of the law and the need to practise in a manner consistent with that of his colleagues:

I prescribe terminal sedation[but]I think some of my colleagues would probably prescribe a lot more than I would . . . being a part of a team, and broader community . . . it does moderate what you're prepared to do.

## Personal discomfort with intentionally hastening death

In all four narratives, respondents give implied or explicit expressions of discomfort with the idea of intentionally hastening death. This discomfort seems to lend credence to respondents' descriptions of their own intentions. In this respect the narratives are representative of the entire study cohort. Discomfort with the prospect of performing euthanasia is of particular interest amongst those who do not have a religious or ideological opposition:

I just personally could never, ever, ever live with that

Respondent 5 (Female, no religious beliefs)

I think I would have a large degree of discomfort, from a personal perspective

Respondent 9 (Male, 'very anti-organizational religion')

morally . . . I don't have a problem with euthanasia . . . But at the same time, I don't actually think that I would be able, or want, to actually euthanase someone

Respondent 14 (Female, brought up Anglican, not a strong church-goer)

I used to be quite for euthanasia, I think as I've done more palliative care I've become a bit more on the fence about it, and I don't think I would want to be the one to have to perform that service

Respondent 18 (female, atheist)

## Professional concerns about intentionally hastening death

Narratives 1 and 3 illustrate the significance of the intention-foresight distinction to respondents who have no religious or ideological opposition to euthanasia. There were many other examples:

there may be situations where it's a blurry line [with regard to knowledge about whether death has been hastened] but . . . if there was an intention then that would be crossing the line, basically.

Respondent 10 (male, atheist)

I have absolutely no doubt that[her death]was as a result of the sedation. But . . . I still wouldn't see it as euthanasia, because it wasn't intentional, I didn't intend to do that.

Respondent 18 (female, atheist)

Many respondents referred specifically to their professional role when stating that they did not want to intentionally hasten death:

I'd feel uncomfortable with doing it as a professional. Um, would I do it to somebody I loved, if I thought that was the right thing to do? Dunno

Respondent 9 (Male, Very anti-organizational religion)

There were three overlapping 'sub-themes' relating to professional roles. First, many respondents noted that distress (including that of the family) is sometimes transferred to the treating team (as illustrated in Narrative 2). There were concerns that euthanasia could inappropriately become a response to the doctor's or the family's distress, undermining the doctor's professional duty to his or her patient:

If I was to start being influenced by the emotions of the situation around, about the timing of death, then . . . you lose clear parameters of what you're trying to do

Respondent 1 (Male, 'I've got a Catholic faith')

I've seen with doctors in the acute system . . . that[they]perhaps do have an intent to hasten death[and]my feeling is that they do it because they feel uncomfortable . . . if families are struggling with the situation, it's certainly not uncommon to get either a direct request, or implied requests, to do something to hasten death and I think perhaps[palliative care specialists]are better at addressing that, as a specific part of what we do, rather than sharing that distress, and wanting it 'all over'. . . you know, as the doctor as well.

Respondent 10 (Male, 'organized religion doesn't do a lot for me')

Second, there were concerns about doctor-patient communication. The availability of euthanasia could undermine the doctor's role in listening – and in trying to discover the cause of the patient's distress in this setting:

. . . it depends . . . what it is you hear them saying, that they want to be dead . . . or . . . 'I just don't want to go through this' . . . Teasing that sort of stuff out is part of what we do.

Respondent 17 (Female, practising Anglican)

[We]need to see that the way of dealing with a complaint is not to dispatch the complainer

Respondent 11 (male, practising Anglican)

Communication could also be impoverished if fear of the possibility of euthanasia led patients to hide their distress:

My view of euthanasia's quite open.[But]from a professional point of view, no, I want my patients to be able to put their views out there, and be able to discuss . . . in an open and supportive manner.

Respondent 9 (Male, 'very anti-organizational religion')

Third, some respondents perceived that euthanasia could become a kind of surrender response when curative measures have failed. This could potentially undermine many positive aspects of palliative medicine that separate it professionally from curative medicine:

I'm giving[what]I originally said I'd do medicine for: maximal care . . . We don't abandon[patients], we do the reverse . . .

Respondent 7 (male, 'more humanistic than spiritual')

it's really important that we're not seen as the grim reapers that just usher everyone off . . . that's not the profession that I want to be in. And we don't want people to be thinking that that's what we're doing, or they won't make the referrals for the patients who need them.

Respondent 16 (female, Jewish 'but I certainly don't get to the synagogue very often these days')

palliative care has emerged out of a review of what our responsibilities are as doctors . . . really, on our watch, that family, social experience of dying has been kind of overwhelmed[and]palliative care[is]in some ways regaining lost ground . . . I tend to regard it in those terms as, as a very positive advancement and really I don't think that euthanasia contributes to that advancement.

Respondent 3 (male, 'Roman Catholic . . . underpinning of my spiritual beliefs')

Illness trajectory and willingness to sedate to unconsciousness

In Narrative 3, the respondent notes that a decision to sedate heavily (to unconsciousness) is influenced by 'where that person is in their illness trajectory'.<sup>22</sup> Almost all respondents concurred. There was a strong sense from some respondents that 'early terminal sedation' felt too 'close' to assisted suicide because of the personal sense of 'collaboration':<sup>23</sup>

[It would make me]an accomplice almost in her death and in her decision to end her life sooner

Respondent 2 (male, Christian)

what I would be primarily ah, affronted by is the fact that I'd contributed to . . . some sort of theft of life

Respondent 3 (male, 'Roman Catholic . . . underpinning of my spiritual beliefs')

From a patient-centred perspective, 'early terminal sedation' raised some of the same concerns that arise around a request for euthanasia:

I'm not as uncomfortable[as some]around that notion[of sedating patients with existential distress]but I think you still need to go down the track of trying to unpack things, and understand[from]where that distress is coming

Respondent 20 (male, 'atheist')

I don't like the idea that there may be opportunities lost . . . contact, intimacy, sort of shared experiences lost . . .

Respondent 3 (male, 'Roman Catholic . . . underpinning of my spiritual beliefs')

In contrast, the possibility of the patient enjoying further meaningful experience is more likely to have passed when the later stages of illness are reached:

. . . where it's clearly a more terminal delirium there are no prizes for lightening off the sedation . . . you're certainly not going to be able to get them back to any sort of meaningful communication

Respondent 8 (male, atheist)

And at a late stage of illness, the sense of personal responsibility seems to be diminished:

where it seems to me we are on the final stage of the final downhill run . . . I'd have the perception that most of the things I do are probably not making much difference one way or the other[to the timing of death]

Respondent 2 (male, Christian)

## DISCUSSION

### Methodological issues and limitations

The small numbers of participants in this study together with non-random recruitment raises questions about whether the findings are 'representative' of a wider population (a common concern with regard to qualitative research). The most obvious potential concern was that the study might attract individuals with extreme religious or ideological views, particularly ideological commitments to or against euthanasia, but there was no evidence of such imbalance. In any case, the purpose of this study was not to make claims about how many doctors think a certain way, but to illustrate the variety of problems doctors face in their decision-making. The narratives above show doctors of different ages, genders, religious backgrounds and ideologies facing similar problems.

Also inherent in qualitative research is the possibility that the interviewer and authors subjectively influence the findings by the questions asked, and the passages selected for presentation. We have tried to limit this bias by independent coding by each author, and by presenting minimally edited narratives that 'speak for themselves', together with the interviewer's questions where relevant, so that readers can judge for themselves whether the respondent has been 'led'.

### The intention–foresight distinction

The main purpose of this study was to examine the distinction between intention and foresight in the practice of palliative care through a qualitative analysis of the use of sedation at the end of life. We cannot claim to know whether our respondents did or did not intend to hasten the deaths of their patients in the cases described, most obviously because we cannot assume that there is a direct relationship between 'what happened' and how informants report in retrospect what happened,<sup>24</sup> and this includes, perhaps particularly, accounts of informants' states of mind. What seems clear from this study, however, is that the intention-foresight distinction does matter to those who routinely care for dying patients. The distinction matters from both professional and personal points of view, as it allows palliative care specialists to be seen, and to see themselves, as doing one thing (providing care), and not another (hastening death). For many of the respondents, the distinction is important even though they are not morally opposed to euthanasia:

I haven't got any strong moral or religious objection to euthanasia, but it's not what I do

Respondent 8 (male, atheist)

There was evidence of significant ambiguity around intention in some of the narratives.<sup>25</sup> However, the picture we observed in this study of palliative care physicians was quite different from that

observed in our earlier study of general physicians,<sup>26</sup> and we think the differences are likely to reflect the different populations. General physicians in the first study seemed to tolerate or even encourage a sense of ambiguity of intention around analgesic or sedative use. In contrast (with the exception of respondent 13), palliative care physicians interviewed in this study seemed determined to be as clear as possible about intention, often conducting a very careful self-examination to try to ensure that they had not crossed a line. Respondents were thus quite self-conscious about intention. Indeed it could be said that most of the respondents in this study were ‘intending not to intend’ any hastening of the patient’s death. In the context of our last study, we suggested that this was ‘psychologically dubious’ but this study suggests that such self-consciousness can be a good thing. In almost every case it was apparent that respondents had made or were making efforts to check for ambiguities of intention, rather than simply saying to themselves that ‘I’m kidding myself, and that’s OK’. The doctors we interviewed appeared to have cultivated their behaviour along clear ‘intentional’ lines in much the way that Bratman seems to have imagined when he described a ‘self-governing intention’, making ‘a commitment to refrain from the patterns of thinking and acting that would be involved in an intentional killing.’<sup>27</sup> They appear to have made this commitment because they perceive it to be important, not only for personal comfort, but to preserve a professional role that allows them to best serve their patients.

Of course, these interviews do show that intention is complex; thus, while a ‘self-governing intention’ to refrain from killing might be the sine qua non of good palliative care for many specialists, there may remain a risk of self-deception or oversimplification if it is too blithely accepted. One of the respondents seemed to imply just this:

... but ... I think if you don't sometimes do the mental gymnastics, maybe it's 'cause you've fallen into such a kind of, 'Yeah, yeah, what I do is always right', and you're not, to my mind, you're not even asking yourself the question.

Respondent 14 (female, Anglican upbringing, not a strong church-goer)

#### Intention, foresight, and the Principle of Double Effect

The intention–foresight distinction is central to (but not synonymous with) the ‘Principle of Double Effect’ (PDE). The PDE asserts that one might be permitted to cause ‘harm’ or do ‘evil’, as a side effect of one’s action, if the harm or evil is foreseen but unintended (and is not disproportionate to the good one intends).<sup>28</sup> This study supports the idea that the intention–foresight distinction is morally important in end-of-life care. However, we have three concerns about incorporating that distinction into a broader ‘moral principle’ that is alleged to be the basis of clinical practice in this area, and that is taught to young doctors and medical students.

First, the narratives in this study illustrate how the PDE fails to support an absolute prohibition on killing, in so far as it fails to draw a clear line between permissible and impermissible deaths.<sup>29</sup> In hard cases, as has been argued in the philosophy literature,<sup>30</sup> there is no simple resolution of ambiguities of intention so that acts are obviously ‘Right’ or ‘Wrong’. In Narrative 1, while the palliative care specialist went through his ‘mental gymnastics’, the GP would have ‘nothing to do with it’. Most of his medical students consider his actions to be the equivalent of euthanasia. In Narrative 4, while the agent was comfortable with her own intentions, other staff at the hospital were uncomfortable and felt her actions were ‘too close to euthanasia’.

Second, the claim that the PDE applies in a palliative care setting is likely to be met with some cynicism, because the assertion implausibly suggests that the death of the terminally ill patient counts as a 'harm' or even an 'evil'. The words and actions of those involved usually suggest otherwise. Doctors, nurses and families are often hoping for death to come soon; and efforts to prolong life are withheld:

double effect worries about a bad effect versus a good effect [but] I don't see death as a bad effect.

Respondent 8 (male, atheist)

Third, even as a general guide to the 'palliatively naïve', the PDE may be a two-edged sword. On the one hand it may be a way of ensuring that doctors are sufficiently generous in the analgesia or sedation they provide:

it does [help doctors] who may be a little bit less clear about what they're doing . . . where otherwise they might've been thinking 'I can't increase the dose anymore because I might kill them'.

Respondent 8 (male, atheist)

On the other hand, promotion of the PDE may encourage precisely the sort of cultivated ambiguities that we reported in our previous study of general physicians, and this in turn may lead not to 'evil', but to very unsophisticated and uncritical end-of-life care:

I am appalled by the teaching of the double effect to the med students . . . it's an outmoded concept and a completely unnecessary concept.

I know a lot of our colleagues practise it. Outside palliative care. I'm aware that it is standard practice in some physicians just to increase doses of morphine knowing full well that the likely outcome may be death.

Respondent 5 (female, atheist)

Of course, this latter problem potentially exists whether one talks of the 'Principle of Double Effect' or of a morally important intention–foresight distinction. It may be difficult to promote the importance of the distinction without encouraging its abuses in some quarters. It is likely also that there will remain many skeptics, particularly as a result of the 'mental gymnastics' that seem to be involved in hard cases.

## Sedation and withdrawal or withholding of treatment

We have tried to limit the focus of this paper to the intention-foresight distinction. As a final comment, however, we must acknowledge the potential philosophical ‘work’ being done in palliative care by another contentious distinction, that between killing and letting die.<sup>31</sup> The legitimacy of ‘not trying to prolong life’ seems to be taken for granted in Narratives 1 and 4 and indeed seemed to be assumed by all respondents. Clearly, withholding medical hydration (as in Narrative 4) or withdrawing ventilatory support (as in Narrative 1) can have significant and sometimes obvious effects on the timing of death. When this is combined with sedation, it may contribute to the feeling that a death is ‘too close’ to being a case of euthanasia, either in terms of causation or in terms of intention or both.<sup>32</sup> A further exploration of doctors’ views on the distinction between killing and withholding and withdrawing potentially life-sustaining treatment is likely to be an important matter for future qualitative research.

## SUMMARY

This study provides empirical evidence that the intention–foresight distinction is important to Australian palliative care specialists. The significance of the distinction seems to be a matter of ‘moral psychology’ relating to personal experience and the preservation of professional roles, rather than a simple ideological commitment. ‘Intention’ may be very complex, and the intention-foresight distinction may be too difficult to draw, in exceptional cases, to distinguish euthanasia from palliative care to the satisfaction of all; but that does not in itself undermine the importance of the distinction for ‘run of the mill’ cases. Future work in this field should perhaps move on from the question of whether the ‘Principle of Double Effect’ ‘is’ or ‘is not’ a valid (‘absolute’) moral principle to further consideration of whether and why it might be important or appropriate for doctors to cultivate certain patterns of behaviour.

## Authors

Charles Douglas is a bioethicist and practising surgical oncologist who is completing his PhD on end-of-life decision-making. He is a Senior Lecturer in Clinical Ethics and Health Law at the University of Newcastle, NSW.

Ian Kerridge is a bioethicist and practising haematologist and Associate Professor and Director of the Centre for Values, Ethics and the Law in Medicine at the University of Sydney.

Rachel Ankeny is a bioethicist and philosopher and an Associate Professor in the School of History and Politics at the University of Adelaide.

## Footnotes

- 1 H. Kuhse. ‘No’ to the Intention/Foresight Distinction in Medical End-of-Life Decisions. *Med Law* 1997; 16: 643–649; R. Gillon. When Doctors Might Kill their Patients: Foreseeing is not Necessarily the Same as Intending. *BMJ* 1999; 318: 1431–1432, L. Doyal. The Moral Character of Clinicians or the Best Interests of Patients? *BMJ* 1999; 318: 1432–1433.
- 2 C.D. Douglas et al. The Intention to Hasten Death: a Survey of Attitudes and Practices of Surgeons in Australia. *Med J Aust* 2001; 175: 511–515, H. Kuhse et al. End-of-life Decisions in Australian Medical Practice. *Med J Aust* 1997; 166: 191–196.

- 3 R.W. Hunt. 1994. Palliative Care – the Rhetoric-Reality Gap. In *Willing to listen – wanting to die*. H. Kuhse, ed. Melbourne: Penguin.
- 4 C. Douglas et al. Managing Intentions: the End-of-Life Administration of Analgesics and Sedatives, and the Possibility of Slow Euthanasia. *Bioethics* 2008; 22: 388–396.
- 5 S.A. Fohr. The Double Effect of Pain Medication: Separating Myth from Reality. *J Palliat Med* 1998; 1: 315–328, N. Sykes & A. Thorns. The Use of Opioids and Sedatives at the End of Life. *Lancet Oncol* 2003; 4: 312–318.
- 6 P. Claessens et al. Palliative Sedation: A Review of the Research Literature. *J Pain Symptom Manage* 2008; 36: 310–333.
- 7 *Ibid*; N. Sykes & A. Thorns. Sedative Use in the Last Week of Life and the Implications for End-of-life Decision making. *Arch Intern Med* 2003; 163: 341–344; N.I. Cherny. Sedation for the care of the Patient with Advanced Cancer. *Nat Clin Pract Oncol* 2006; 3: 492–500.
- 8 Claessens et al., *op. cit.* note 6.
- 9 C. Pakarinnen & T. Quinn. 2010. Decision-making Process (for Palliative Sedation). In *On-line forum of European Association for Palliative Care. Sedation Consensus Group*, ed. Available at: <http://www.eapcnet.org/forum/default.asp?category=Decision-Making%20Process>[Accessed 26 Sept 2010].
- 10 Council on Ethical and Judicial Affairs. 2008. Sedation to Unconsciousness in End-of-life Care. CEJA Report 5-A-08. American Medical Association. Available at: <http://www.ama-assn.org.ezproxy1.library.usyd.edu.au/ama1/pub/upload/mm/code-medical-ethics/2201a.pdf>[Accessed June 2010]; T.E.M.D. Quill et al. Last-Resort Options for Palliative Sedation. *Ann Intern Med* 2009; 151: 421–424; L.A. Jansen & D.P. Sulmasy. Sedation, Alimentation, Hydration, and Equivocation: Careful Conversation about Care at the End of Life. *Ann Intern Med* 2002; 136: 845–849.
- 11 E.J. Cassell & B.A. Rich. Intractable End-of-Life Suffering and the Ethics of Palliative Sedation. *Pain Med* 2010; 11: 435–438 ; Quill et al., *op. cit.* note 10. Quill has recently used the term PSU (palliative sedation to unconsciousness).
- 12 P. Liamputtong. 2009. *Qualitative Research Methods*. South Melbourne: Oxford University Press: 14.
- 13 For a discussion of the principles for determining when data collection should be terminated, see J. Morse. 2007. Sampling in grounded theory. In *The SAGE Handbook of Grounded Theory*. A. Bryant & K. Charmaz, eds. SAGE Publications: 229–244: 241–243.
- 14 Douglas et al., *op. cit.* note 2; 175: 511–515; J. Sikora. Religion and Attitudes Concerning Euthanasia: Australia in the 1990s. *J Sociol* 2009; 45: 31–54.
- 15 For a very brief summary of the controversies around induction, deduction and theory-building, see Liamputtong, *op. cit.* note 12.
- 16 2006. NVivo7. QSR International.
- 17 N. Mays & C. Pope. Assessing Quality in Qualitative Research. *BMJ* 2000; 320: 50–52.
- 18 *Ibid*.
- 19 A form of breathing support apparatus.
- 20 Midazolam and phenobarbitone are sedatives. ‘Opioid’ refers to a natural derivative of opium (eg morphine) or a synthetic alternative, with analgesic and some sedative properties.

- 21 Benzodiazepines are a class of sedative drugs (eg diazepam, midazolam). Haloperidol is an ‘antipsychotic’ drug used in the treatment of delirium.
- 22 In fact, this has been a central theme in the literature on terminal sedation, even though it has not been explicitly justified: see for example V. Cellarius. Terminal Sedation and the ‘Imminence Condition’. *J Med Ethics* 2008; 34: 69–72.
- 23 For a discussion, see p 848 of Jansen & Sulmasy, *op. cit.* note 10.
- 24 D. Silverman. 2007. *A Very Short, Fairly Interesting and Reasonably Cheap Book about Qualitative Research*. Los Angeles: Sage Publications.
- 25 Lynn Jansen has recently suggested that apparent ambiguities of intention may arise from a failure to distinguish between a ‘narrow’ and a ‘broad’ sense of intention, discussed in L.A. Jansen. *Disambiguating Clinical Intentions: The Ethics of Palliative Sedation*. *J Med Philos* 2010; 35: 19–31 . We think her argument is contrived. To invite confusion, one has to use the adjective (or adverb): If Dr. Smith intentionally (i.e. deliberately) gave the drugs, and the patients died as a result, in a ‘broad’ sense it is true to say that ‘Dr. Smith ‘intentionally’ caused the patients to die’, whether or not he actually aimed at their deaths. Jansen extrapolates from this fairly limited problem of terminology to imply, without further justification, that there are two completely different and accepted uses of the noun (‘intention’) and the verb (‘intend’) such that people ‘might be unsure which sense of intention is the one we are asking about’. We think the noun and verb have fairly straightforward commonsense meanings, at least when linked to a specific outcome, eg ‘Did you give drugs with the intention of hastening death?’ Furthermore, one of the advantages of conducting in-depth interviews is that we can observe and clarify any potential misunderstandings. We observed no confusion along the lines suggested by Jansen, in this or our previous study.
- 26 Douglas et al., *op. cit.* note 4.
- 27 M.E. Bratman. 1987. *Intention, Plans, and Practical Reason*. Harvard University Press: 163.
- 28 A. McIntyre. 2004, rev. June 2009. *Doctrine of Double Effect*. In *The Stanford Encyclopedia of Philosophy*. E.N. Zalta, ed.
- 29 Warren Quinn attempted to defend a version of the PDE that was not ‘absolutist’; and he seems to have been led to the view that the PDE does not distinguish morally in the classic palliative care dilemma, in large part because death is not a bad outcome (as further discussed here in the main text): W.S. Quinn. *Actions, Intentions, and Consequences: The Doctrine of Double Effect*. *Philos Public Affa* 1989; 18: 334–351.
- 30 For a brief summary of the problems with hard cases and the idea of ‘closeness’, see pp. 339–340 of C. Douglas. *End-of-life Decisions and Moral Psychology: Killing, Letting Die, Intention and Foresight*. *J Bioeth Inq* 2009; 6: 337–347.
- 31 G. Gillett. *Killing, Letting Die and Moral Perception*. *Bioethics* 1994; 8: 312–328; J. Thornton. *Killing, Letting Die and Moral Perception: a Reply to Grant Gillett*. *Bioethics* 1999; 13: 414–425.
- 32 T.E. Quill et al. *Palliative Options of Last Resort: A Comparison of Voluntarily Stopping Eating and Drinking, Terminal Sedation, Physician-assisted Suicide, and Voluntary Active Euthanasia*. *JAMA* 1997; 278: 2099–2104.