



End of life decision-making by New Zealand general practitioners: a national survey

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Abstract

Aim To explore type and incidence of medical decisions at the end of life that hasten death made by general practitioners in New Zealand, within the context of access to palliative care.

Method An anonymous questionnaire investigating the last death attended in the previous 12 months was sent to 2602 general practitioners (GPs) in New Zealand.

Results From a 48% (1255) response, 88.9% (1116) GPs indicated access to an interdisciplinary pain management or palliative care team. Of those attending a death in the previous 12 months, 63% (693) had made a prior medical decision. These decisions included withdrawing/withholding treatment or increasing pain relief with (a) probability death would be hastened 61.8% (428) or (b) partly or explicitly to hasten death 32.6% (226). Moreover, death was caused by a drug supplied or administered by the GP in 5.6% cases (39), actions consistent with physician-assisted death.

Conclusion Physician-assisted death provided by some general practitioners in New Zealand is occurring within the context of available palliative care.

Early in 2002, Belgium became the fourth country/state/territory in the world to legalise physician-assisted death¹—after the Netherlands,² Oregon (in the United States),³ and the Northern Territory (in Australia)⁴—although the Northern Territory legislation was subsequently overturned.

The laws controlling assisted death in Oregon and the Northern Territory were predicated on the patient being terminally ill, and this was also proposed in the failed Death with Dignity Bill in New Zealand in 1995.⁵ Belgium has adopted similar policies to the Netherlands,⁶ in that the patient does not have to be terminally ill but must be experiencing unbearable, intractable suffering. A failed Private Member's Bill recently debated in New Zealand proposed physician-assisted death for terminally or incurably ill persons, on request.⁷

Research indicates that patients with cancer,⁸ HIV/AIDS,⁹ and amyotrophic lateral sclerosis¹⁰ would like the option of physician-assisted death. Similarly, physicians have also indicated that this option may be justified for some patients.^{8,11} (The official stance of the New Zealand Medical Association is that it is opposed to physician-assisted death.)¹²

Prior to legalisation, research in Australia, the Netherlands, and Belgium indicated that physicians were nevertheless providing physician-assisted death to their patients.^{13–15} In each of the studies, a similar questionnaire was used, developed for the Rummelink investigation into physician-assisted death in the Netherlands in 1990.

Interpretation of previous studies has in part been problematic due to lack of information regarding the range of physician options, particularly the extent of access to specialist palliative care. The present study was thus designed to obtain information on end of life decision-making in New Zealand within the context of palliative care availability.

The aim of this study was to explore type and incidence of medical decisions at the end of life (MDELs) that hasten death made by general practitioners (GPs) in New Zealand, within the context of access to palliative care.

Method

A survey methodology was adopted using the questionnaire from the Rummelink Death Certificate study of the Dutch investigation.¹⁶ The questionnaire was administered to GPs in New Zealand (in August and September, 2000). It asked for details on the last death in the previous 12 months for which the physician was the attendant doctor, and whether that physician had access to a multidisciplinary palliative care team.

Whilst confining responses to the last death means the incidence can only be assessed indirectly, the format was used both to anchor responses to minimise bias and to retain consistency with prior studies. There are approximately 3000 practising GPs in New Zealand and a questionnaire was sent to 2602 on a commercial mailing list.

The English version of the questionnaire was obtained from the authors of the Australian study.¹⁵ Demographics were changed to suit the New Zealand environment—ie, ethnicity and place of practice. An additional section was added related to access to palliative care services. Analysis was done using SPSS (version 9) software.

Throughout this article, 'physician-assisted death' and 'euthanasia' refer to the intentional ending of the patient's life by the physician and 'physician-assisted suicide' refers to drugs supplied by the physician to end life, but administered by the patient.

Ethics approval was given by the University of Auckland Human Subjects Ethics Committee on 10 February 2000, reference 1999/Q032.

Results

There was a 48% response rate from two mail-outs. Thirty-two questionnaires could not be delivered (unknown at address). Returned questionnaires numbered 1302 of which 47 were returned blank, some with comments for non-response, which left 1255 useable questionnaires.

Of these, 1100 respondents had access to the patient prior to death and therefore there was the potential to make an end of life decision. Non-response was attributed to the sensitive nature of the research and the workload of general practitioners.¹⁴ Demographic breakdown of responders is in Table 1.

Of the 1100 physicians who had contact with the patient prior to death, 693 (63%) reported making MDELs. The last action before death ranged from decisions to withdraw or withhold treatment or increase the alleviation of symptoms with the probability that death would be hastened 61.8% (428), through to actions partly or explicitly taken to hasten death 32.6% (226).

Moreover, of the 693 physicians who reported a MDEL, 5.6% (39) attributed death to a drug that had been prescribed, supplied or administered for that purpose—ie, euthanasia or physician-assisted suicide (see Table 2).

Table 1. Demographic breakdown of general practitioners participating in study (n=1255)

Gender	%*	Age (years)	%*	Religious	%*	Ethnicity	%*	Location	%*
Male	64	<35	11	Extremely	4	NZ European	78	City	45
Female	35	36–45	45	Very	12	Maori	1	Small city	22
DM	1	46–55	32	Moderately	22	Pacific Is	0.5	Town	15
		56–65	9	Slightly	30	Asian	5	Rural	17
		>65	4	Not	30	Indian	2	DM	1
		DM	0.2	DM	3	Other	12		
						DM	1		

*Percentages may not total 100 due to rounding; DM=data missing; City (>100,000 people); Small city (30,000–100,000 people); Town (<30,000 people).

Table 2. Medical decisions at the end of life (MDELs) by general practitioners for the last death attended in the previous 12 months (n=1100)

	Number (%) deaths attended in last year (n=1100)	Number (%) actions before death* (n=693)	Number (%) last actions before death (n=693)
No MDEL actioned	407 (37.0)		
First contact after the death	35 (3.2)		
Sudden and totally unexpected death	75 (6.8)		
No MDEL was performed (No 'yes' to Q 3-6)	279 (25.4)		
Missing data (no response)	18 (1.6)		
MDEL actioned	693 (63.0)		
Taking into account the probability that end of life hastened by:			
- Q3a withholding a treatment		258 (37.2)	28 (4.0)
- Q3b withdrawing a treatment		200 (28.9)	27 (3.9)
- Q3c intensifying alleviation of pain and/or symptoms		588 (84.8)	373 (53.8)
Q4 In part with intention of hastening the end of life by:			
- intensifying the alleviation of pain and/or symptoms		172 (24.8)	94 (13.6)
With the explicit purpose of not prolonging life or hastening the end of life and death caused by:			
- Q5a withholding a treatment		130 (18.8)	75 (10.8)
- Q5b withdrawing a treatment		71 (10.2)	57 (8.2)
Q6 Death caused by drug prescribed, supplied or administered with the explicit purpose of hastening the end of life (or patient ending own life)		39 (5.6)	39 (5.6)
			Drug given by (n=39)*
			Patients: 5 (12.8)
			Doctors: 21 (53.8)
			Nurses: 21 (53.8)
			Other: 2 (5.1)

Q=Question; *More than one question could be answered.

There was no discussion with the patient before the last MDEL in 380 (54.8%) cases (see Table 3). The patient not being competent (or not being fully competent) to make the decision was the main reason given for no discussion. However in 23.1% (88) cases where the patient was judged competent by the doctor, there was no discussion. In 17% (65) cases, the patient had expressed a wish to have death hastened at a previous time (see Table 4).

Table 3. Discussion with patient about possible hastening of death by proposed action

	Last-mentioned MDEL							
	Q3a* n=28 %†	Q3b* n=27 %†	Q3c* n=373 %†	Q4* n=94 %†	Q5a* n=75 %†	Q5b* n=57 %†	Q6* n=39 %†	Total N=693 %†
Discussed at the same time	25.0	14.8	8.6	12.8	18.7	26.3	23.1	13.4
Discussed beforehand	10.7	11.1	12.6	31.9	29.3	29.8	33.3	19.5
No discussion took place	53.6	59.3	58.7	53.2	50.7	43.9	43.6	54.8
Missing data (no response)	10.7	14.5	20.1	2.2	1.3	-	-	12.2

*See Table 2 for details of action; †May not total 100% due to rounding; Q=Question, MDEL=Medical decisions at the end of life.

Table 4. Informant in decision-making when no discussion with patient about possible hastening of death.

	Last-mentioned MDEL							
	Q3a* n=15 %	Q3b* n=16 %	Q3c* n=219 %	Q4* n=50 %	Q5a* n=38 %	Q5b* n=25 %	Q6* n=17 %	Total N=380 %
Patient not capable/not fully capable of discussion	86.7	81.3	60.7	84.0	84.2	88.0	94.1	71.3
Patient competent to discuss	13.3	6.3	32.4	14.0	15.8	4.0	-	23.1
(Missing)	-	12.5	6.8	2.0	-	8.0	5.9	5.5
Patient had expressed a wish to have death hastened	13.4	18.8	11.9	30.0	21.0	16.0	35.3	16.9
Doctor informed of wish by:†								
- Verbally by patient	-	6.3	10.0	22.0	13.2	12.0	23.5	12.1
- Written Directive	-	-	-	-	-	-	5.9	0.3
- Partner/Relative of patient	13.3	6.3	2.7	6.0	10.5	12.0	23.5	6.1
- Nursing staff	6.7	-	0.9	-	2.6	-	-	1.1
- Colleague	-	-	-	-	-	-	-	-
- Otherwise	-	-	-	-	-	-	-	-
Explicit request to hasten death made by:†								
- Partner/relative	6.7	6.3	2.7	16.0	21.1	24.0	23.5	8.9
- Colleague	-	-	-	2.0	-	4.0	-	0.5
- Nursing staff	6.7	-	0.5	-	2.6	8.0	23.5	2.4
- Others	-	-	0.5	-	-	-	-	0.3
- No explicit request	86.7	81.3	85.4	70.0	73.7	60.0	52.9	78.9

*See Table 2 for details of action; †More than one answer could be indicated; Q=Question; MDEL=Medical decisions at the end of life.

In half of the cases where a MDEL was actioned, the doctor estimated that life was either not shortened or was shortened by less than 24 hours. A further 26.8%

estimated that was life shortened by less than 7 days. In the three cases where life was estimated to be shortened by more than 6 months, death was caused by actions taken explicitly for that purpose; in two cases, withholding treatment; and in one case; administering a drug. There was a high (13.5%) non-response to this question (see Table 5).

Table 5. Estimate of life shortened by last action taken.

	Last-mentioned MDEL							Total N=693 %
	Q3a* n=28 %	Q3b* n=27 %	Q3c* n=373 %	Q4* n=94 %	Q5a* n=75 %	Q5b* n=57 %	Q6* n=39 %	
Missing (not answered)	10.7	14.8	22.5	2.1	1.3	-	-	13.5
Probably not shortened	32.1	55.6	44.2	14.9	12.0	8.8	7.7	31.7
<24 hours	3.6	3.7	15.5	37.2	17.3	17.5	35.9	19.0
1 to 7 days	50.0	18.5	15.0	31.9	49.3	43.9	48.7	26.8
1 to 4 weeks	3.6	-	2.4	13.8	13.3	22.8	5.1	7.2
1 to 6 months	-	-	0.3	-	4.0	7.0	-	1.2
>6 months	-	-	-	-	2.7	-	2.6	0.4

*See Table 2 for details of action; MDEL= Medical decisions at the end of life; Q=Question.

In 8 of the 39 cases where death was caused by a prescribed, supplied, or administered drug, more than one person was identified as administering the drug to the patient (introducing the drug into the body). In two cases, the patient was identified as ingesting the drugs acting alone. The doctor administered the drug alone in 13 cases, a nurse alone in 15 cases, and in one case it was not specified who administered the drug (see Table 2).

Of the 1255 respondents, 88.9% (1116) indicated access to a multidisciplinary pain management or palliative care team, and 97.8% (1090) of these indicated that they consulted with such a team. Twenty-two doctors (2%) stated that they had access to such a team but did not use them; the main reason given being the physician had sufficient palliative care knowledge (see Table 6).

Of those reporting physician-assisted death, 34 had access to an interdisciplinary pain management or palliative care team. In the remaining 5 cases, 3 said they would use a team if available. One of these cases involved the death of a child. The remaining 2 did not respond.

Of those who had the potential to make a MDEL males were significantly more likely to have done so (chi squared=6.422, *df* 1, *p*=0.011). There was no significant difference between those who had made a MDEL and those who did not for age, ethnicity, religion, place of practice or access to palliative care.

Doctors who performed euthanasia/physician-assisted suicide were significantly older (*z*=-3.198, *p*=0.001) and less religious (*z*=-2.309, *p*=0.021) than those who had not but had performed another type of MDEL action. There was no significant difference between these two groups for gender, place of practice, or access to palliative care. Ethnicity was not compared due to low numbers.

Table 6. Access and use of interdisciplinary palliative care or pain services (N=1255)

YES, ACCESS TO PALLIATIVE TEAM (88.9%, N=1116)	%	NO ACCESS TO PALLIATIVE TEAM (9.8%, N=123)	%
Consult team	97.8	Would consult if available	80.5
Don't consult team*	2.0	Would not consult*	13.8
Missing	0.2	Missing	5.7
<u>How often consult team (n=1090)</u>			
Very occasionally	8.2		
Occasionally	23.3		
Frequently	50.1		
Always	18.0		
(Missing)	0.4		
*Reasons don't consult/would not consult with team (n=40)			%
- GP has sufficient palliative care knowledge			38.5
- Advice/consultation unhelpful in past			2.6
- Services are inaccessible			12.8
- Difficulty in past with shared care			10.2
- Other			30.8
- (Missing)			5.1

Note: Totals rounded.

Discussion

Perhaps the most interesting study finding is that, despite legal constraints, 39 doctors had performed some kind of action which would conform to everyday concepts of physician-assisted suicide or euthanasia. Moreover this did not appear to be a consequence of the non-availability of palliative care. Of the 1100 general practitioners that had the opportunity to make a MDEL, 3.5% (39) provided a physician-assisted death. This compares with 3.7% of general practitioners (n=2356) in the Dutch study.^{16 p139}

Information that nurses introduced the drug into the patient, alone, in 15 cases requires some comment. The use of syringe drivers to deliver medication is widespread in end-of-life care, when oral medication is no longer possible. Invariably this regime would be established by a nurse, acting under physician orders thereby rendering the nurse the person to have 'introduced' the drug into the patient's body. If drugs charted are presumed to be dangerous for the patient, the nurse is obliged to refuse to carry out the drug order. In these cases, this has not happened, which suggests that either the nurses colluded with doctors in providing assisted death or alternatively they were unaware that the drug was charted explicitly to end the life of the patient. Either way, nurses are clearly involved in end of life actions and decision-making (see Table 4).^{17,18}

There is a commonsense issue in discussions of euthanasia concerning the extent by which life is estimated to have been shortened by the action. The present results

indicate that the more serious the action taken, the more likely respondents were to estimate that life had been shortened and by a longer period (see Table 5). A similar effect was noted in the Dutch study.^{16p129}

The majority of respondents in the New Zealand study estimated that the action taken had shortened life but in 78% of cases this was by less than 7 days (see Table 5). It is notable that this question had one of the higher rates of non-response at 13.5%. The wording of the questionnaire, which gave the mildest option of 'life probably not shortened' rather than 'life not shortened' may have been implicated, with respondents reluctant to imply any shortening of life if this, in their judgement, had not occurred. Several respondents noted difficulties with the wording of the questionnaire.

If this is the case, and it seems plausible, life was estimated "not shortened" or shortened by less than seven days in over 90% of cases (see Table 5). Arguably then, the actions could be seen as a compassionate response to distress experienced in the last few days of expected life when the dying phase had been diagnosed.¹⁹

In 54.8% (380) of cases the MDEL-action was taken without discussion with the patient, rendering the action legally dubious (see Table 3). It is plausible that the missing cases (12.2%) indicate no discussion, which leaves only one third of cases where a discussion took place with the patient at some time, indicating that life could be shortened by the action being considered. The physician not believing that death was hastened by the action seems to be implicated in some instances of no discussion with the patient given (a) that some respondents indicated this and (b) that the likelihood of a discussion having taken place increased with the seriousness of the action taken. However in 17 cases, there was no discussion when physician-assisted death occurred (see Table 3).

While in some cases the patient had previously expressed a wish to have death hastened (see Table 4), it should be noted that a persistent request expressed at the time the action is performed is one criteria necessary for the provision of physician-assisted death wherever this is, or has been, legalised.^{1,3,4,6}

So-called life-terminating acts without the request of the patient drew widespread criticism of Dutch practices (see, for example, reference number 20). However subsequent research suggests that similar practices are occurring elsewhere^{14,15} and clearly have occurred in New Zealand. However, these figures may not be as sinister as first appears. The combined factors of closeness to death and probable moribund state (see Tables 4 and 5) also evidenced by nursing involvement (see Table 2) probably indicating use of syringe driver or IV medications, suggests that the actions were a compassionate response to patient need—ie, shortening dying rather than shortening life.

Alternatively, these actions may indicate a lack of knowledge by the physician of what is palliatively achievable without ending the life of the patient as a way of meeting need (10% indicated they had no access to palliative care services, see Table 6). Another explanation is that the doctor acted in 'palliative' terms—ie, may have provided terminal sedation which is defensible under the principle of double effect, but interpreted this in "euthanasia" terms as an action knowingly taken to hasten death.²¹

The data discussed above, together with the supplementary qualitative data obtained from the questionnaires gives us some insight into issues for the physician when providing end of life care. Physicians of course have their own personal views and there is a requirement that they reconcile those with external demands - on the one hand to reduce suffering, on the other to preserve life. The following captures the potential polarity of these views:

I have no problems withholding medication to hasten death in a terminally ill patient. I would have a problem administering medication to hasten death, even on request from the patient or relatives. This of course does not apply to terminating an unwanted pregnancy - no problem here. (NZ GP 189)

The laws re euthanasia vs termination of pregnancy are, in my opinion, completely arse about face! If you will excuse the vernacular. (NZ GP 797)

In many instances such attempts at reconciliation were problematic for the physician concerned and it is perhaps unsurprising that some physicians called for greater external guidance:

Often patients don't ask about choosing the time and mode of death in a terminal illness and I do not initiate discussion as this is not yet a clearly legally available option. So in my opinion I am not yet obligated to offer this option (but I would prefer to be able to either offer and/or respond better to the occasional request for euthanasia). (NZ GP 447)

Although several physicians indicated they would like to be able to offer physician-assisted death in some instances, others emphasised that they would never consider this an option.

It seemed clear from comments that the general practitioners assumed responsibility for providing a good death for the patient. In order to do so some felt that they required access to specialist drugs they deemed necessary for palliative care:

GP should have unrestricted access to all specialist drugs for palliative care. (NZ GP 448)

My purpose is to save life and to make dying as pleasant as possible and pain free - dignified. I find this latter can be virtually always achieved with morphine and would be easier with heroin which for some reason is unobtainable in NZ. (NZ GP 373)

A team approach to care (implying open communication and shared decision-making) was deemed desirable by many:

In the area we share care with district nurses and rest homes. Together with local hospital. A team approach exists therefore. (NZ GP 203)

The current system of doctor and patient and families together making decisions at the end of life have worked well for generations. (NZ GP 246)

Many other physicians commented on the issue of communication around end of life actions, some wanting openness and transparency:

I feel much more respect must be made of the wishes of the person dying. More discussion needs to be had on the influence/wishes of caregivers. I support a more liberal attitude with the correct legal/ethical oversight being provided. Perhaps some "guidelines" (dare I use the word) are in order. (NZ GP 48)

And others insisting that only the patient and doctor should be involved in decision-making:

Very dangerous territory. Only the doctor and patient; **don't** include anyone else. (NZ GP 41)

This latter statement appears to be a reflection of the fear some physicians expressed that their actions may have legal repercussions:

It is such an emotional and value-dependent issue. I will do anything to protect myself medico-legally, some of the actions taken are futile and wasteful and not of any "benefit" to the patient. (NZ GP 307)

Constraints on open communication when hastening death is considered can provide the physician with challenges. One doctor articulated the difficulty for the physician in managing communication within the caring group when the law inhibited the patient's preferred (implied) end of life action:

I was more concerned about what the relatives (wife, adult daughter) thought rather than legislation. Indeed, when the patient pleaded with me for him not to have another night of extreme respiratory distress he cautioned me to "protect myself" (against the relatives) however they had previously introduced the idea! (NZ GP 63)

When physician-assisted death is secretly provided for the patient, the emotional coping of those persons who knew or were having euthanasia may be complicated by being unable to share their experience with loved ones and leave-take appropriately. Research indicates that the psychological effect for doctors providing physician-assisted death is profound, suggesting that doctors who do so in secret are at risk when they cannot talk through the actions they propose, or have taken.²²

Conclusion

Legal or not, physician-assisted death is an international reality, and New Zealand is no exception with such actions occurring in an apparently palliative rich environment. Moreover the results of this study indicate that physician-assisted death is at times occurring without consultation with the patient.

There exists a confusing state of affairs where doctors and family are torn between conflicting demands - on the one hand to relieve suffering, on the other to conform to professional and legal requirements. The current situation is problematic for everyone: doctors carry a heavy burden; patients are unable to have access to options to which they may feel entitled; families are kept in the dark or carry a similar burden to the physician.

Limitations

It is of course, important to exercise a degree of caution in interpreting the above findings. Trying to access empirical data on such a complicated and potentially sensitive activity such as medical decision-making at the end of life is extremely difficult. A questionnaire cannot do justice to the complexity of such decision-making. The wording of the questionnaire may have "forced" respondents to indicate an action performed that did not correctly reflect the actual action. Fifteen respondents criticised the wording in the questionnaire.

A very difficult questionnaire to complete - complex issues that I do not believe are able to be determined by yes/no answers. Hence my revisiting some of the questions. NB My response to the questions may have been quite different if Q3 had stated possibility rather than probability. (NZ GP 292)

Moreover, some rationalisation of actions may have occurred between the time of the death and completing the questionnaire, responses maybe reflective of cognitive processing invoking defence-mechanisms rather than action *per se*. However no death

occurred more than 12 months previously and it is plausible that many were within weeks of the questionnaire being filled out.

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