ORIGINAL ARTICLE

Relationship of neonatologists' end-of-life decisions to their personal fear of death

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Arch Dis Child Fetal Neonatal Ed 2007;**92**:F104–F107. doi: 10.1136/adc.2006.094151

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Accepted 17 August 2006

Objective: To study the relationship of Australian and New Zealand (ANZ) neonatologists' personal fear of death to their forgoing life-sustaining treatment and hastening death in newborns destined for severe disability and newborns for whom further treatment is considered non-beneficial or overly burdensome.

Design: A self-report questionnaire survey of ANZ neonatologists.

Setting: Neonatologists registered in the 2004 ANZ Directory of Neonatal Intensive Care Units.

Participants: 78 of 138 (56%) neonatologists who responded to the study questionnaire.

Main outcome measures: Between-group differences in the Multidimensional Fear of Death Scale.

Results: In newborns for whom further treatment was deemed futile, 73 neonatologists reported their attitude to hastening death as follows: 23 preferred to hasten death by withdrawing minimal treatment, 35 preferred to hasten death with analgesia-sedation, and 15 reported that hastening death was unacceptable. Analysis of variance showed a statistically significant difference between the three groups regarding fear of the dying process ($F=3.78$, $p=0.028$), fear of premature death ($F=3.28$, $p=0.044$) and fear of being destroyed ($F=3.20$, $p=0.047$). Post hoc comparisons showed that neonatologists who reported that hastening death was unacceptable compared with neonatologists who preferred to hasten death with analgesia-sedation had significantly less fear of the dying process and fear of premature death, and significantly more fear of being destroyed.

Conclusions: ANZ neonatologists' personal fear of death and their attitude to hastening death when further treatment is considered futile are significantly related. Neonatologists' fear of death may influence their end-of-life decisions.

Neonatologists commonly forgo (withdraw or withhold) life-sustaining treatment in newborn infants who seem destined to die or have severe mental or physical disability.¹ Although forgoing treatment usually culminates in the infant's death, the foremost purpose of the practice is to relieve or prevent unnecessary pain and suffering.^{2–4} Forgoing life-sustaining treatment in the aforementioned context is medically, ethically and legally sanctioned in Australia and New Zealand, though not actually codified in law.⁵ Consequently, Australian and New Zealand (ANZ) neonatologists can be confident in forgoing treatment in accordance with generally accepted "objective" sociocultural standards and without undue fear of legal reprisal.^{5–8}

Although the death of a newborn infant may inadvertently be hastened pursuant to the relief of pain and suffering, the law is not contravened because death is not the intended outcome.⁵ On the other hand, the purposeful hastening of a newborn infant's death for any purpose is unlawful in Australia and New Zealand,⁵ even though bioethicists have argued for its moral rightness.⁹ Despite its illegality, there are occasions when neonatologists may consider that hastening death is the most judicious way to alleviate a newborn infant's pain and suffering, and thereby feel compelled to act contrary to societal laws and customs.¹⁰ For example, if further medical treatment has been deemed therapeutically non-beneficial or overly burdensome, then neonatologists may consider it more compassionate and humane to purposefully hasten death unlawfully with analgesia-sedation than, for instance, to forgo gastric tube feeding, which may be lawful,^{5, 11} because the former forestalls unnecessary pain and suffering.⁹

The fact that intentionally hastening an infant's death is unlawful, often publicly unacceptable, personally confronting and medicolegally risky posits the possibility that self-reported

differences in neonatologists' preparedness to hasten death may be explained, at least in part, by subjective differences in personality predispositions, including personal fear of death.¹² The fear of death is ubiquitous, but because it is strongly aversive, individuals construct a variety of psychological defences to keep it away from conscious awareness.^{13–16} However, a vicarious brush with death in the newborn intensive care unit may arouse neonatologists' death anxiety,^{13, 17, 18} and thereby influence their decisions on matters such as forgoing life-sustaining treatment and hastening death.

The purpose of the present study was to explore the relationship of ANZ neonatologists' personal fear of death with their practice of forgoing life-sustaining treatment and their attitude to hastening death for the purpose of relieving pain and suffering in newborn infants who seem destined for severe mental and/or physical disability, and in infants for whom further treatment has been deemed therapeutically non-beneficial or overly burdensome—that is, futile.

METHODS

The 138 Australian ($n=106$) and New Zealand ($n=32$) neonatologists registered in the 2004 ANZ Directory of Neonatal Intensive Care Units were contacted by mail and asked to anonymously complete a series of questionnaires. Firstly, they were asked to provide demographic information, which included their sex, age, parental status and number of years in neonatal practice. Secondly, they were asked to complete an ethical practices questionnaire, which was a modification of the instrument developed by Sprung *et al.*¹⁹ Finally, they were asked to complete the Multidimensional Fear

Abbreviations: ANZ, Australian and New Zealand; MFODS, Multidimensional Fear of Death Scale

of Death Scale (MFODS).^{20–21} My institutional ethics committee approved the study protocol. A copy of the study questionnaires can be obtained on request.

Ethical practices

Two ethical practice questions were germane to the present study. Firstly, in infants who seemed destined to have severe mental and/or physical disability, the neonatologists were asked whether they sometimes (a) forgo (withhold or withdraw) life-sustaining treatment, such as mechanical ventilation, and (b) relieve pain and suffering with analgesia-sedation (1) knowing they may inadvertently hasten death, or (2) with the intention to hasten death. Secondly, the neonatologists were asked whether it was acceptable to (a) forgo (withdraw or withhold) treatment considered to be non-beneficial or overly burdensome, and (b) hasten death when further treatment was futile, and, if so, whether they would prefer to withdraw minimal treatment, such as supplemental oxygen or gastric tube feeding, because it was more like "letting die" than "killing", or give analgesia-sedation because it may forestall unnecessary pain and suffering.

The preamble to the questionnaire acknowledged that intentionally hastening an infant's death was unlawful. Consequently, the neonatologists were asked to put their medicolegal concerns to one side and respond to the questionnaire items as honestly as possible.

The Multidimensional Fear of Death Scale

The MFODS is a psychometrically validated 42-item self-report questionnaire including subscales analysing eight factors that measure different facets of the conscious fear of death^{20–22}: (1) fear of the dying process (six items, such as "I am afraid of dying very slowly"); (2) fear of the dead (six items, such as "I dread visiting a funeral home"); (3) fear of being destroyed (four items, such as "I do not like the idea of being cremated"); (4) fear for significant others (six items, such as "I have a fear of people in my family dying"); (5) fear of the unknown (five items, such as "I am afraid that death is the end of one's existence"); (6) fear of conscious death (five items, such as "I am afraid of being buried alive"); (7) fear for the body after death (six items, such as "I am afraid of my body being disfigured when I die"); and (8) fear of premature death (four items, such as "I have a fear of not accomplishing my goals in life before dying"). The scale items are presented as statements to which participants respond on a 5-point Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree). Positively valenced items are reverse scored so that lower scores equate with greater fear of death. Three of the MFODS subscales had low internal reliability coefficients (Cronbach's $\alpha < 0.70$, table 1): fear of the unknown (0.51), fear of conscious death (0.44) and fear of premature death (0.62). Deleting the item "I am afraid of meeting my creator" from fear of the unknown subscale increased its Cronbach's α value to 0.66, and consequently this item was omitted.^{20–23} Item deletion did not improve the internal reliability of fear of conscious death and fear of premature death and, therefore, these subscales were not modified.

Statistics

The relative mean substitution method was used to treat the small number of missing values in the MFODS item responses.²⁴ The relative mean substitution method involves computing an individual's relative position in a dataset by dividing the mean of the individual's valid data by the mean of the valid data for the remainder of the individuals. To estimate a value where datum relating to an item is missing, the aforementioned ratio is multiplied by the mean of all of the

valid data for that item.²⁴ The χ^2 test was used to test for differences between independent categorical variables. One-way analysis of variance was used to test for between-group differences in the MFODS subscales. The sample size and numbers in some outcomes were too small for multivariable analysis. The statistical analyses were carried out using SPSS V.13.0.

RESULTS

Participants

Of the 138 eligible neonatologists, 78 (56%) responded to the questionnaire, including 53 (51%) of 104 men and 25 (74%) of 34 women ($\chi^2 = 5.31$, $p = 0.021$). The male neonatologists were statistically significantly more likely to (1) be ≥ 50 years of age (23/52 v 2/25, Fisher exact $p = 0.002$), (2) have children of their own (47/53 v 16/25, $\chi^2 = 6.66$, $p = 0.01$) and (3) have been in neonatal practice for more than 10 years (36/53 v 10/25, $\chi^2 = 5.47$, $p = 0.019$) compared with females.

Descriptive statistics and correlations for the MFODS

Table 1 shows the descriptive statistics for the MFODS subscales. The subscale mean values were within an SD of the values reported by Neimeyer and Moore.²⁰ Female neonatologists had greater MFODS fear of the dead (mean = 22.3, SD = 4.48 v mean = 24.8, SD = 4.41, $t(76) = 2.30$, $p = 0.025$) compared with males.

Table 2 shows the Pearson correlation coefficients for the MFODS subscales. The intersubscale correlations ranged from negligible ($r = 0.00$) to moderate ($r = 0.41$), and included a moderate correlation between fear of the dying process and fear of premature death ($r = 0.41$). There were no large intersubscale correlations, thereby supporting the proposal that the MFODS subscales measure different facets of the fear of death.²⁰

Descriptive statistics and univariate analyses for ethical practices

Forgoing life-sustaining treatment and using analgesia-sedation to relieve pain and suffering in infants who seem destined for severe mental and/or physical disability

Of the 78 neonatologists, 76 (97%) reported sometimes withdrawing treatment and 73 (94%) reported sometimes withholding treatment in infants seemingly destined to have severe disability. Only one neonatologist did not withdraw or withhold treatment in infants faced with the prospect of severe disability.

Of the 78 neonatologists, 73 (94%) reported sometimes using analgesia-sedation to relieve pain and suffering, knowing they may inadvertently hasten death, whereas 25 (32%) of 77 neonatologists reported sometimes using analgesia-sedation to intentionally hasten death.

Table 1 Descriptive statistics for the Multidimensional Fear of Death Scale

	Mean (SD)	Cronbach's α
Fear of the dying process	17.1 (5.11)	0.77
Fear of the dead	24.0 (4.55)	0.73
Fear of being destroyed	13.7 (3.71)	0.71
Fear for significant others	12.5 (4.17)	0.78
Fear of the unknown	15.2 (3.57)	0.48
Fear of conscious death	21.1 (2.96)	0.44
Fear for the body after death	26.2 (4.08)	0.77
Fear of premature death	11.3 (3.55)	0.62

Deleting fear of the unknown item "I am afraid of meeting my creator" increased the scale's Cronbach α from 0.48 to 0.66.

Table 2 Correlation matrix for the sub scales of the Multidimensional Fear of Death Scale

	1	2	3	4	5	6	7	8
1 Fear of the dying process	–							
2 Fear of the dead	0.40*	–						
3 Fear of being destroyed	–0.03	0.12	–					
4 Fear for significant others	0.22	0.22	0.07	–				
5 Fear of the unknown	0.12	0.35†	0.18	0.22	–			
6 Fear of conscious death	0.31†	0.28†	0.16	–0.06	0.18	–		
7 Fear for the body after death	0.23†	0.36†	0.33†	0.10	0.41*	0.35†	–	
8 Fear of premature death	0.41*	0.22	0.00	0.28†	0.31†	0.12	0.14	–

Fear of the unknown item "I am afraid of meeting my creator" has been omitted.

* $p < 0.001$, † $p < 0.01$, ‡ $p < 0.05$ (two tailed).

None of the MFODS subscale mean values for the neonatologists who reported using analgesia-sedation to hasten death in infants destined to have severe mental and/or physical disability was statistically significantly different from the values for the neonatologists who reported that they did not intentionally hasten death in this clinical context.

Forgoing treatment and hastening death when further treatment is thought to be non-beneficial or overly burdensome

All 78 neonatologists accepted forgoing (withdrawing or withholding) treatment when it was considered non-beneficial or overly burdensome. In this clinical context, 73 neonatologists reported their attitude to hastening death as follows: 23 (32%) preferred to hasten death by withdrawing minimal treatment, such as oxygen or gastric tube feeding, 35 (48%) preferred to hasten death with analgesia-sedation and 15 (20%) reported that hastening death was unacceptable. One-way analysis of variance showed a statistically significant difference between these three groups with respect to fear of the dying process ($F_{2,70} = 3.78$, $p = 0.028$), fear of premature death ($F_{2,70} = 3.28$, $p = 0.044$) and fear of being destroyed ($F_{2,70} = 3.20$, $p = 0.047$), but not for the other MFODS subscales. Post hoc comparisons using the Tukey honestly significantly different test showed that neonatologists who reported that hastening death was unacceptable compared with neonatologists who preferred to hasten death with analgesia-sedation had significantly less fear of the dying process (mean (SD) 19.9 (4.81) v 15.6 (4.58), $p = 0.023$) and fear of premature death (13 (2.95) v 10.4 (3.07), $p = 0.039$), and significantly more fear of being destroyed (11.7 (4.37) v 14.4 (3.40), $p = 0.049$). The MFODS subscale values in neonatologists who preferred to hasten death by withdrawing minimal treatment were not significantly different from the values in the other two groups.

No statistically significant relationship was found between neonatologists' age, sex, country, parental status or number of years in neonatal practice and either of the death-related ethical practices.

Discussion

In concert with their European colleagues,¹ the overwhelming majority of ANZ neonatologists reported that they sometimes forgo (withdraw or withhold) life-sustaining treatment in newborn infants who face the prospect of severe mental and/or physical disability and use analgesia-sedation to relieve pain and suffering short of intentionally hastening death. In addition, ANZ neonatologists invariably accepted the notion of forgoing futile treatment—namely, treatment that is non-beneficial or overly burdensome. These research findings are not unexpected, as forgoing life-sustaining treatment has widespread philosophical, legal and ethical acceptance in present day neonatal practice.^{2–5, 25}

One third of ANZ neonatologists reported that they sometimes use analgesia-sedation to hasten death in infants who seem destined to have severe mental and/or physical disability, whereas one half of them accept hastening death with analgesia-sedation when further treatment is considered futile. These situational differences in neonatologists' preparedness to hasten death might be explained by perceived differences in the nature of the pain and suffering that is being alleviated. In infants facing the prospect of severe disability, hastening death obviates the pain and suffering associated with long-term disability, whereas hastening death in infants for whom further treatment has been deemed futile prevents the pain and suffering associated with near-term dying.

ANZ neonatologists who report a preparedness to hasten death when further treatment is considered futile prefer to hasten death with analgesia-sedation compared with withdrawing minimal treatment, because the former forestalls pain and suffering, even though it may seem more like killing than letting die.¹¹ Hence, ANZ neonatologists seem to support the moral notion that it is sometimes "better to kill than let die", even though the former is unlawful and may seem not to respect the "sanctity of life".^{5–9} In addition, it may be presumed that many ANZ neonatologists do not hold the view that pain and suffering can always be alleviated without having to hasten death.²⁶

ANZ neonatologists with greater fear of the dying process and greater fear of premature death are more likely to accept hastening an infant's death with analgesia-sedation when further treatment is considered futile, whereas those with a greater fear of being destroyed are less likely to condone such

What is already known on this topic

Neonatologists have used medical, philosophical and ethical arguments to justify forgoing life-sustaining treatment or hastening death in newborn infants destined for severe disability, or when further treatment lacks therapeutic benefit or is overly burdensome. There has been no empirical study of the relationship between neonatologists' personality predispositions, notably the personal fear of death, and their willingness to forgo treatment or hasten death.

What this study adds

Neonatologists with greater fear of the dying process and greater fear of premature death are more likely to accept hastening a newborn infant's death when further treatment is non-beneficial or overly burdensome, whereas those with a greater fear of being destroyed are less likely to condone such an action.

an action. Although the nature of the study does not permit a conclusion regarding the direction of causality, it may reasonably be speculated that neonatologists who are "afraid of dying slowly" or are "afraid of experiencing a great deal of pain when I die" (fear of the dying process) may be motivated, albeit preconsciously, to intentionally hasten an infant's death to appease their personal death anxiety. Neonatologists who are "afraid I will not have time to experience everything I want to" or "afraid I may never see my children grow up" (fear of premature death) may paradoxically seek to hasten an infant's death, perhaps for the same reason that individuals may seek to control their own death anxiety by ending their lives through suicide.¹³⁻¹⁵ In an understandably more direct association, neonatologists who do "not like the thought of being cremated" (fear of being destroyed) may preconsciously desist from intentionally hastening an infant's death, even though death may be the most judicious and humane way to alleviate pain and suffering.

This study presented neonatologists with hypothetical death-related ethical situations, and their self-reported responses, which included the unlawful hastening of death, might not have been in accord with their real-life practices. The relatively low response rate to the questionnaire and the design of the study suggest the need for caution in generalising the results beyond the confines of the study population. In any event, the possibility that preconconscious psychological factors may influence neonatologists' end-of-life practices deserves further quantitative and qualitative research study.

ACKNOWLEDGEMENTS

I thank: Dr Robert Halliday, who automated the relative mean substitution method for inserting MFODS subscale missing values in SPSS; Dr Bernadette Tobin, who reviewed the ethical practices questionnaire; Dr Jenny Peat, who provided statistical advice; and Dr David Isaacs, Dr Nadia Badawi and Dr Jonathan Gillis, who commented on an earlier draft of the manuscript.

Competing interests: None.

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