Attitudes towards hastened death in ALS: A prospective study of patients and family caregivers.

Stutzki R, Weber M, Reiter-Theil S, Simmen U, Borasio GD, Jox RJ.

Amyotrophic lateral sclerosis (ALS) may be associated with the wish to hasten death (WTHD). We aimed to determine the prevalence and stability of WTHD and end-of-life attitudes in ALS patients, identify predictive factors, and explore communication about WTHD.

We conducted a prospective questionnaire study among patients and their primary caregivers attending ALS clinics in Germany and Switzerland. We enrolled 66 patients and 62 caregivers. Half of the patients could imagine asking for assisted suicide or euthanasia; 14% expressed a current WTHD at the baseline survey. While 75% were in favour of non-invasive ventilation, only 55% and 27% were in favour of percutaneous endoscopic gastrostomy and invasive ventilation, respectively. These attitudes were stable over 13 months. The WTHD was predicted by depression, anxiety, loneliness, perceiving to be a burden to others, and a low quality of life (all \( p < 0.05 \)). Lower religiosity predicted whether patients could imagine assisted suicide or euthanasia. Two-thirds of patients had communicated their WTHD to relatives; no-one talked to the physician about it, yet half of them would like to do so.

In conclusion, physicians should consider proactively asking for WTHD, and be sensitive towards neglected psychosocial problems and psychiatric comorbidity.

_JOW comment:_ The primary motivation for a wish to hasten death is not provided in this abstract or in the paper. “Low quality of life” hardly covers a wish by patients not to gasp-to-death.


doi: 10.1371/journal.pone.0073379.


Tilburt JC, James KM, Jenkins SM, Antiel RM, Curlin FA, Rasinski KA.

The broad diversity in physicians’ judgments on controversial health care topics may reflect differences in religious characteristics, political ideologies, and moral intuitions. We tested an existing measure of moral intuitions in a new population (U.S. physicians) to assess its validity and to determine whether physicians’ moral intuitions correlate with their views on controversial health care topics as well as other known predictors of these intuitions such as political affiliation and religiosity.

In 2009, we mailed an 8-page questionnaire to a random sample of 2000 practicing U.S. physicians from all specialties. The survey included the Moral Foundations Questionnaire (MFQ30), along with questions on physicians’ judgments about controversial health care topics including abortion and euthanasia (no moral objection, some moral objection, strong moral objection).
A total of 1032 of 1895 (54%) physicians responded. Physicians’ overall mean moral foundations scores were 3.5 for harm, 3.3 for fairness, 2.8 for loyalty, 3.2 for authority, and 2.7 for sanctity on a 0-5 scale. Increasing levels of religious service attendance, having a more conservative political ideology, and higher sanctity scores remained the greatest positive predictors of respondents objecting to abortion ($\beta = 0.12, 0.23, 0.14$, respectively, each $p<0.001$) as well as euthanasia ($\beta = 0.08, 0.17$, and 0.17, respectively, each $p<0.001$), even after adjusting for demographics. Higher authority scores were also significantly negatively associated with objection to abortion ($\beta = -0.12$, $p<0.01$), but not euthanasia.

These data suggest that the relative importance physicians place on the different categories of moral intuitions may predict differences in physicians’ judgments about morally controversial topics and may interrelate with ideology and religiosity. Further examination of the diversity in physicians’ moral intuitions may prove illustrative in describing and addressing moral differences that arise in medical practice.

*JOW comment:* *PLOS-One is a high reputation journal, so this seemed worth reporting: religion and political conservatisim predict opposition to euthanasia. This would fit with most voluntary euthanasia activist’s experience.*

doi:10.1016/j.ijp.2013.09.003

**Premises and evidence in the rhetoric of assisted suicide and euthanasia.**  
Mishara BL, Weisstub DN.

In debates about euthanasia and assisted suicide, it is rare to find an article that begins with an expression of neutral interest and then proceeds to examine the various arguments and data before drawing conclusions based upon the results of a scholarly investigation. Although authors frequently give the impression of being impartial in their introduction, they invariably reach their prior conclusions. Positions tend to be clearly dichotomized: either one believes that the practice of euthanasia or assisted suicide is totally acceptable or completely unacceptable in a just and moral society. Where there is some admission of a gray zone of incertitude, authors attempt to persuade us that their beliefs (preferences) are the only sensible way to resolve outstanding dilemmas. The practice of vehemently promoting a “pro” or “con” position may be useful when societies must decide to either legalize certain practices or not. Although only a handful of countries have thus far accepted the legal practice of euthanasia or assisted suicide (Belgium, Luxembourg, The Netherlands, the U.S. states of Montana, Oregon, Vermont and Washington, and Switzerland), scholarly articles in recent trends mainly promote legalization, to the point of recommending expansion of the current practices. Is this a case of the philosophers being ahead of their time in promoting and rationalizing the wave of the future? Alternatively, does the small number of countries that have legalized these practices indicate a substantial gap between the beliefs and desires of common citizens and the universe of the ‘abstracted realm’? For the time being, what we do know is that more countries and states are debating legalization of euthanasia or assisted suicide, the nature of laws and legal practices vary greatly and both ethical and empirical assessments of current practices are the subject of much controversy. This article presents an examination of the premises and evidence in the rhetoric of assisted suicide and euthanasia. Inasmuch
as any analysis cannot be totally impartial, we do not contend that our analysis is without influence from our experiences and philosophical affinities. Notwithstanding this caveat, we venture to propose that our scrutiny of the arguments and empirical data may offer some guidance to individuals who are attempting to reach practical conclusions based upon the available evidence, whether empirical or rationalized.

*JOW comment:* The abstract itself provides no useful information but promises an examination of the ‘premises and evidence’ in the voluntary euthanasia debate.

**Assisted suicide and euthanasia.**
**van der Heide A.**

Several countries have adopted laws that regulate physician assistance in dying. Such assistance may consist of providing a patient with a prescription of lethal medication that is self-administered by the patient, which is usually referred to as (physician) assistance in suicide, or of administering lethal medication to a patient, which is referred to as euthanasia. The main aim of regulating physician assistance in dying is to bring these practices into the open and to provide physicians with legal certainty. A key condition in all jurisdictions that have regulated either assistance in suicide or euthanasia is that physicians are only allowed to engage in these acts upon the explicit and voluntary request of the patient. All systems that allow physician assistance in dying have also in some way included the notion that physician assistance in dying is only accepted when it is the only means to address severe suffering from an incurable medical condition. Arguments against the legal regulation of physician assistance in dying include principled arguments, such as the wrongness of hastening death, and arguments that emphasize the negative consequences of allowing physician assistance in dying, such as a devaluation of the lives of older people, or people with chronic disease or disabilities. Opinion polls show that some form of accepting and regulating euthanasia and physician assistance in suicide is increasingly supported by the general population in most western countries. Studies in countries where physician assistance in dying is regulated suggest that practices have remained rather stable in most jurisdictions and that physicians adhere to the legal criteria in the vast majority of cases.

*JOW comment:* This abstract comes from the highly reputable “Handbook of Clinical Neurology”: it summarises ‘established’ thinking and practice, as of 2013, in the few jurisdictions where voluntary euthanasia was/is legal. The final two sentences are reassuring.

**Why do older people oppose physician-assisted dying? A qualitative study.**
**Malpas PJ, Wilson MK, Rae N, Johnson M.**
Background: Physician-assisted dying at the end of life has become a significant issue of public discussion. While legally available in a number of countries and jurisdictions, it remains controversial and illegal in New Zealand.

Aim: The study aimed to explore the reasons some healthy older New Zealanders oppose physician-assisted dying in order to inform current debate.

Design: Recorded interviews were transcribed and analysed by the authors after some edits had been made by respondents. Setting/participants: In all, 11 older participants (over 65 years) who responded to advertisements placed in Grey Power magazines and a University of Auckland email list were interviewed for around 1 h and asked a number of open-ended questions.

Results: Four central themes opposing physician-assisted dying were identified from the interviews: one’s personal experience with health care and dying and death, religious reasoning and beliefs, slippery slope worries and concern about potential abuses if physician-assisted dying were legalised.

Conclusions: An important finding of the study suggests that how some older individuals think about physician-assisted dying is strongly influenced by their past experiences of dying and death. While some participants had witnessed good, well-managed dying and death experiences which confirmed for them the view that physician-assisted dying was unnecessary, those who had witnessed poor dying and death experiences opposed physician-assisted dying on the grounds that such practices could come to be abused by others.

JOW comment: The abstract focuses on opposition to voluntary euthanasia and provides four insights – three of which (religious reasoning and beliefs, slippery slope worries and concern about potential abuses) are of little weight in a secular society or have otherwise been discredited by evidence.


Assistance in dying for older people without a serious medical condition who have a wish to die: a national cross-sectional survey.
Raijmakers NJ, van der Heide A, Kouwenhoven PS, van Thiel GJ, van Delden JJ, Rietjens JA.

BACKGROUND: The Dutch euthanasia law regulates physician assistance in dying for patients who are suffering unbearably from a medical condition. We studied the attitudes of the Dutch population to assistance in dying for older persons who have a wish to die without the presence of a serious medical condition.

METHODS: A cross-sectional survey was conducted among a random sample of the Dutch public (response rate 78%, n=1960), using statements and vignettes about attitudes to assistance in dying for older persons who are tired of living.

RESULTS: A minority of 26% agreed with a vignette in which a physician warrants the request for physician-assisted suicide of an older person who is tired of living without having a serious medical condition. Furthermore, 21% agreed with the statement ‘In my opinion euthanasia should be allowed for persons who are tired of living without having a serious disease’. People supporting euthanasia for older persons who are tired of living were more likely than opponents
to be highly educated (OR 1.6; 95% CI 1.1 to 2.3), to be non-religious (OR 1.7; 95% CI 1.3 to 2.3), to have little trust in physicians (OR 1.6; 95% CI 1.2 to 2.2), and to prefer to make their own healthcare decisions (OR 1.7; 95% CI 1.3 to 2.3).

CONCLUSIONS: Although it is lower than the level of support for assistance in dying for patients whose suffering is rooted in a serious medical condition, our finding that a substantial minority of the general public supports physician assistance in dying for older people who are tired of living implies that this topic may need to be taken seriously in the debate about end-of-life decision-making.

JOW comment: This points to future directions in voluntary euthanasia in secular societies.

Euthanasia or physician-assisted suicide? A survey from the Netherlands.
Kouwenhoven PS, van Thiel GJ, Raijmakers NJ, Rietjens JA, van der Heide A, van Delden JJ.

Background: Legalizing euthanasia or physician-assisted suicide (PAS) is a current topic of debate in many countries. The Netherlands is the only country where legislation covers both.

Objectives: To study physicians' experiences and attitudes concerning the choice between euthanasia and PAS.

Methods: A questionnaire including vignettes was sent to a random sample of 1955 Dutch general practitioners, elderly care physicians and medical specialists.

Results: In total, 793 physicians (41%) participated. There was no clear preference for euthanasia (36%) or PAS (34%). Two thirds of physicians thought that PAS underlines the autonomy and responsibility of the patient and considered this a reason to choose PAS. Reasons for not choosing PAS were expected practical problems. A minority (22%) discussed the possibility of PAS with their patient in case of a request for assistance in dying. Patients receiving PAS more often experienced psychosocial suffering in comparison with patients receiving euthanasia. In vignettes of patients with a request for assistance in dying due to psychosocial suffering, physicians agreed more often with the performance of PAS than with euthanasia.

Conclusion: Dutch physicians perceive a difference between euthanasia and PAS. Although they believe PAS underlines patient autonomy and responsibility, the option of PAS is rarely discussed with the patient. The more psychosocial in nature the patient’s suffering, the more physicians choose PAS. In these cases, PAS seems to fulfill physicians’ preferences to emphasize patient autonomy and responsibility. Expected technical problems and unfamiliarity with PAS also play a role. Paradoxically, the choice for PAS is predominantly a physician’s one.

JOW comment: An interesting discussion of how psychosocial suffering influences the decision towards PAS over VE in the Netherlands, where both PAS and VE are legal.
The Acceptability of Ending a Patient’s Life: A France-Portugal-Spain Comparison.

Mullet E, Neto F, Pinto C, Raich RM, Sastre MT, Sorum PC.

Aims: The views of French, Portuguese, and Spanish people on end-of-life decisions were compared.

Methods: Two hundred seventy-seven adults from Barcelona, Oporto, and Toulouse judged the acceptability of life-ending procedures in 42 scenarios composed of all combinations of 3 factors: the patient’s age (30 or 80 years), the patient’s life expectancy (days, weeks, or months), and the type of procedure (suicide, suicide assisted by the physician, euthanasia by the physician at the request of a suffering patient, euthanasia of a comatose patient at the family’s request, euthanasia of a comatose patient as stipulated in the patient’s advance directives, euthanasia of a comatose patient without advance directions and without a request from the family, or euthanasia of a suffering patient without a request from the patient).

Results: In all 3 countries, the type of procedure had the major effect. The 4 procedures implemented by the patient or at the patient’s request were, on average, considered acceptable. The 2 procedures not implemented at the patient’s request were considered unacceptable. Euthanasia of a comatose patient at the request of the family was judged mildly acceptable.

Conclusion: The attitudes of the people in Toulouse, Oporto, and Barcelona concerning the acceptability of ending a patient’s life have now largely converged, although Spanish participants were statistically significantly more accepting than French and Portuguese participants.

JOW comment: More evidence for the widespread emergence of rational thinking about voluntary euthanasia.


Suicide assisted by right-to-die associations: a population based cohort study.


BACKGROUND: In Switzerland, assisted suicide is legal but there is concern that vulnerable or disadvantaged groups are more likely to die in this way than other people. We examined socio-economic factors associated with assisted suicide.

METHODS: We linked the suicides assisted by right-to-die associations during 2003-08 to a census-based longitudinal study of the Swiss population. We used Cox and logistic regression models to examine associations with gender, age,
marital status, education, religion, type of household, urbanization, neighbourhood socio-economic position and other variables. Separate analyses were done for younger (25 to 64 years) and older (65 to 94 years) people.

RESULTS: Analyses were based on 5,004,403 Swiss residents and 1,301 assisted suicides (439 in the younger and 862 in the older group). In 1,093 (84.0%) assisted suicides, an underlying cause was recorded; cancer was the most common cause (508, 46.5%). In both age groups, assisted suicide was more likely in women than in men, those living alone compared with those living with others and in those with no religious affiliation compared with Protestants or Catholics. The rate was also higher in more educated people, in urban compared with rural areas and in neighbourhoods of higher socio-economic position. In older people, assisted suicide was more likely in the divorced compared with the married; in younger people, having children was associated with a lower rate.

CONCLUSIONS: Assisted suicide in Switzerland was associated with female gender and situations that may indicate greater vulnerability such as living alone or being divorced, but also with higher education and higher socio-economic position.

JOW comment: That isolated/divorced individuals more often seek voluntary euthanasia than partnered individuals does not, in itself, appear to justify an intervention to alter their status, just as higher educational attainment or socio-economic position demands no intervention to diminish educational attainment or socio-economic position in people seeking voluntary euthanasia.

Exploring the experiences of bereaved families involved in assisted suicide in Southern Switzerland: a qualitative study.
Gamondi C, Pott M, Forbes K, Payne S.

BACKGROUND: In Switzerland, helping with assisted suicide under certain conditions is not prosecuted. With approximately 300 cases annually, this leaves behind a large group of bereaved people where its consequences are mostly unknown. The study aimed to explore family involvement in decision making prior to assisted suicide, and to examine their ways of coping during the bereavement period.

METHODS: A qualitative interview study used the principles of Grounded Theory analysis. Eleven relatives of eight patients, who died in Southern Switzerland after assisted suicide, participated in semi-structured interviews.

RESULTS: The large majority of family members faced moral dilemmas during the decision-making phase. Their respect for patient's autonomy was a key justification to resolve dilemmas. Two types of involvement were identified: categorised as 'passive' when the decision making was located with the patient, and 'active' when assisted suicide was proposed by the family member and/or
the relative was involved in some way. The relatives reported feelings of isolation during and after assisted suicide. Family members reported fear of social stigma and did not openly disclose assisted suicide as the cause of death. None of those interviewed received formal psychological support.

CONCLUSIONS: Bereaved families express moral dilemmas, feelings of isolation and secrecy in the management of assisted suicide in Southern Switzerland. These features seem underestimated and not sufficiently recognised by the healthcare professionals. Management of assisted suicide requests should include consideration of family members’ needs, in addition to those of the patient.

*JOW comment: It is a surprise that families have not been offered supportive engagement in the VE process.*


**Expanded faqs on advance care planning: driven by the community.**

Kelly C, Maloney MA, Smith L, Puls K, Spillane V, Sutton E, Silvester W.

BACKGROUND: In March 2011, Respecting Patient Choices at Austin Health established a Volunteers Program to provide education to community groups about Advance Care Planning (ACP). Commencing with 18 Frequently Asked Questions (FAQs), this expanded to 92.

AIM: To review the need for, the benefits and implications of expanded FAQs.

METHODS: The FAQs at programme commencement were compared with the FAQs by December 2012. Volunteers were interviewed regarding the FAQ development.

RESULTS: The expansion of the FAQs was driven by consumer demand at Information Sessions; 18 broad questions were not satisfactory. The 92 questions (not all asked at each session) could be grouped into themes. Themes included: Role of the GP; Conflict; Competency; Legal Issues; Organ Donation; ACP in Critical situations; Euthanasia; Dying with Dignity, Religion and ACP. The attendee feedback regarding the sessions and questions was very positive; 94.2% of 309 attendees agreed/strongly agreed that their questions were answered; 96.8% agreed/strongly agreed that the presentation increased their ACP knowledge.

DISCUSSION: The FAQs were expanded to meet community expectations about information provided at the sessions. The benefit of expanding this list was that new Volunteers would be aware of the type of questions that would be asked, and that consistent answers could be provided. The implication is that Volunteers providing information to community groups need to have detailed knowledge of the entire ACP process.

CONCLUSION: Expanded FAQs required very specific responses, provided greater satisfaction and meant that Volunteers needed high-level knowledge of the ACP process.
JOW comment: An Australian contribution – pointing to an important set of additional topics that consumers want included in advance care planning documents, including euthanasia!