DRAFT

8/28/2014

AMERICAN ACADEMY OF NEUROLOGY

2014 PHYSICIAN-ASSISTED SUICIDE SURVEY

Background and Methods

Background

In 1998, the AAN conducted the *End of Life Care Survey* to measure the attitudes, behavior, and knowledge of its members regarding end-of-life care. At the time of the 1998 survey, physician-assisted suicide (PAS) was illegal in all U.S. states, however, half of the survey's respondents believed that PAS should be made legal and 44% said they would participate in PAS if it were legal. Since that time, physician-assisted suicide has been legalized, under certain circumstances, in four states: Montana, Oregon, Vermont, and Washington.

Published in 1999, the AAN's most recent position statement on PAS is "vigorously opposed" to the act. Conflictingly, the AAN's Code of Professional Conduct (CPC), last updated in 2010, directs members to "strive to relieve the suffering and respect the expressed wishes of dying patients". As a result, AAN members are potentially conflicted by state laws, the CPC, and the 1999 position statement.

Objective

The goals of the *Physician-Assisted Suicide Survey* were to 1) to determine whether AAN members' attitudes on the moral and legal aspects of PAS have changed since the 1998 survey, and 2) to determine whether members are conflicted by the different messages given by state laws and by the AAN. Results may be used to revise the position statement, and may possibly inform an ethics colloquium at the 2015 AAN Annual Meeting. A paper based on results may be submitted for publication.

Sample

AAN members of Active, Associate, Corresponding, Fellow, or Corresponding Fellow member types were included in sample eligibility. Junior members, members over the age of 68, and members who had received an AAN survey in the past 6 months were excluded from consideration. The eligible population was split into two parts: members practicing in one of the 4 U.S. states that allow PAS, and members from the other 46 U.S. states (one member from Puerto Rico was included in the sample; PAS is illegal in that territory.) Since the number of eligible members from PAS-legal states totaled 401, the entire PAS-legal population was used in the overall sample. A random sample of 401 members from PAS-illegal states was pulled and combined with the PAS-legal population for a final sample size of 802.

Instrument

The survey was created by AAN staff and the Ethics, Law, and Humanities Committee in winter 2014. The Member Research Subcommittee reviewed and revised the draft in April and a final draft was agreed upon in May.

Data Collection

The survey link was sent to the entire sample via email on June 26th. The entire sample also was sent a fax or mail version of the survey. All versions included a cover letter signed by Daniel G. Larriviere, MD, JD, FAAN, Chair of the Ethics, Law, and Humanities Committee. Follow-up distributions were sent on July 10th and July 24th, and data collection was closed on August 7th.

Anonymity

To encourage respondents to share their honest opinions on this sensitive topic, members were informed that internal controls would be used for anonymity. Four-digit, randomly generated IDs were used on the surveys in place of AAN IDs, which can be linked to members' identities, and only one AAN staff member had access to any files where identifying information and survey responses were linked. These files were stored in a password-protected folder and were deleted at the conclusion of the project.

Response Rate

A response rate of 30.3% (243/802) was achieved for the *Physician-Assisted Suicide Survey*. The margin of error for respondents from PAS-illegal states at a 95% confidence level is ±9.7%. Since it was a population, rather than a random sample, a margin of error could not be calculated for the PAS-legal portion of the survey sample.

Frequencies

The Frequencies section begins on page 7. Overall frequencies for each of the survey's questions are reported. Frequencies are also broken out by PAS-legal and PAS-illegal respondents.

Mean Attitude Score and Significance Testing

For the first eight questions of the 2014 Physician-Assisted Suicide Survey, participants were asked to answer 'Yes', 'No', or 'Uncertain' to questions regarding the legalization and morality of PAS. This provided an opportunity to create an attitude score for each participant. For all questions, 'Yes' earned a score of 1; 'No' earned a score of -1; and 'Uncertain' earned a score of 0. For question 5, "Do you believe your state's existing laws regarding PAS conflict with your professional obligation to your patients?", scores were flipped for participants who currently practice in PAS-legal states, (-1 for 'Yes'; 1 for 'No', 0 for 'Uncertain'.) A positive mean attitude score indicates a group's positive attitude towards PAS; a score of 1 is the maximum. A negative score indicates a negative attitude; -1 is the minimum. A score near 0 indicates a neutral attitude.

For each of the 8 scale questions in the Frequencies section, mean attitude scores for PAS-legal, PAS-illegal, and combined respondents are reported. T-tests were completed to test for significance differences in mean attitude score between the two groups, and are reported for each question. For this report, a *p*-value of under .05 is considered statistically significant.

To find overall mean attitude scores of PAS-legal and PAS-illegal respondents, scores for each respondent to the 8 scale questions were summed and divided by the number of attitude scale questions answered (those who responded to fewer than 6 were removed from this analysis.) Each group's mean score was then calculated. See Table 3 in the Additional Analysis section for a comparison of overall attitude scores between PAS-legal and PAS-illegal respondents.

Demographic Characteristics of Sample

Demographic information on the survey sample was pulled from the AAN internal membership database. The average age of survey participants is 50.3 years and the majority is male. As seen in Table 1, the differences in gender and age between respondents and non-respondents did not have strong statistical significance. Differences in member type between respondents and non-respondents, however, were significant. Results should not be generalized, therefore, to the entire population of AAN-member U.S. neurologists.

One of the survey's goals was to test for differences in opinion between physicians who practice in PAS-legal versus PAS-illegal states. To test for confounding factors, demographic comparisons of the two groups were made. Table 2 shows that differences in age, member type, and gender between respondents from PAS-legal and PAS-illegal states did not reach statistical significance. This means that age, gender, and member type were not likely confounding factors in the variance of survey results between PAS-legal and PAS-illegal respondents.

Table 1. Demographic characteristics of survey respondents and non-respondents

Demographic characteristics		**Survey respondents** (n=243)	**Survey non-respondents** (n=559)	***p*-value**
Age[1] (mean)		50.3 years (SD=10.2)	48.9 years (SD=9.9)	.08[3]
Gender[2] (%)	Male	68.7	63.8	.18[4]
	Female	31.3	36.2	
AAN member type	Active	83.1	88.2	<.01[4]
	Associate	5.8	7.0	
	Fellow	11.1	4.8	

[1]Data missing for 4% of respondents and 8% of non-respondents
[2]Data missing for 0% of respondents and 2% of non-respondents
[3]t-test
[4]Pearson's chi-squared

Table 2. Demographic characteristics of survey respondents from PAS-legal states and PAS-illegal states

Demographic characteristics		**PAS-legal respondents** (n=145)	**PAS-illegal respondents** (n=98)	***p*-value**
Age[5] (mean)		51.4 years (SD=9.6)	48.8 years (SD=10.8)	.05[7]
Gender[6] (%)	Male	67.6	70.4	.64[8]
	Female	32.4	29.6	
AAN member type	Active	83.4	82.7	.98[8]
	Associate	89.0	6.1	
	Fellow	11.0	11.2	

[5]Data missing for 6% of PAS-legal respondents and 1% of PAS-illegal respondents
[6]Data missing for 0% of PAS-legal respondents and 0% of PAS-illegal respondents
[7]t-test
[8]Pearson's chi-squared

Data Summary

Overall Attitudes

Two-thirds of all respondents believe there are circumstances in which society should consider physician participation in PAS for terminally ill adult patients to be ethically permissible, while just half that amount (32%) believe the same for pediatric patients. On an individual level, slightly under half (48%) of all respondents would consider participation in PAS for terminally ill adult patients, if it were legal in their jurisdiction.

In the event that a terminally ill patient with decision-making capacity requests that life-sustaining treatment be withheld, most respondents believe physician compliance with this request should be ethically obligatory (58%) or ethically permissible (39%). Only about 3% of all respondents believe complying with this request should be ethically prohibited.

Exactly half of all respondents believe PAS, with appropriate protection safeguards, should be legalized in all states, while 30% think it should not be legalized (one-fifth of respondents are unsure.)

Response Factors

When asked to indicate which factors influenced their responses, participants most frequently selected personal ethical beliefs (90%), professional experience (82%), and personal religious beliefs (30%).A significant portion of respondents provide some form of palliative care for ALS patients (28%), brain tumor patients (21%), and/or all terminally-ill patients (32%).

Comparisons

For 7 out of the 8 attitude scale questions, respondents from PAS-legal states displayed a higher mean attitude score than respondents from PAS-illegal states; these differences in score were statistically significant. The largest difference between the groups was seen in question 1 (Are there any circumstances in which society should consider physician participation in PAS for terminally ill adult patients to be ethically permissible?), with 20% more participants from PAS-legal states responding 'Yes' than did participants from PAS-illegal states. The groups agreed only on question 7, which asked about a physician's compliance with a patient's request to withhold treatment; responses did not vary by state.

Although the mean attitude scores of respondents from PAS-legal states was consistently higher than the scores of PAS-illegal respondents for most individual scale questions, the overall attitude scores (the average of the sum of all scores for the 8 questions) were not statistically significant at a 95% confidence level. They were, however, significant at a 90% confidence level.

Confliction with State Law and the AAN's Position

Respondents from PAS-illegal states tended to feel more conflicted their state's laws: for question 5, 'Do you believe your state's existing laws regarding PAS conflict with your professional obligation to your patients?', 30% of respondents from PAS-illegal states said 'Yes", while half that many (15%) of PAS-illegal respondents said the same.

Under half (42%) of all respondents believe the AAN's current position statement on PAS, where PAS is stated to be ethically prohibited, conflicts with their professional obligation to patients. Almost two-thirds (64%), however, favor changing the AAN position to state that PAS be ethically permissible for terminally ill patients.

Trending

The *1998 End-of-Life Care Survey* was conducted on a population similar to the *2014 Physician-Assisted Suicide Survey*, however, data cannot be compared demographically across the two years; the AAN collected different demographic data in 1998 than it does today. Furthermore, the 1998 survey was formatted into case studies, unlike the 2014 survey, and was worded differently. Any comparisons, therefore, between the 1998 and 2014 survey are purely speculative and cannot be proven scientifically. With those warnings in mind, attitudes from the 2014 appear to be consistent with those from the 1998 survey; half of respondents for both favored legalizing PAS, and just under half (44% in 1998; 48% in 2014) would participate in PAS if it were legal.

Comments

Respondents were asked to share open-ended comments on the survey's topic, and responses run the gamut of pro-PAS to anti-PAS. A large portion of the comments display respondents' conflicted feelings towards its legalization. Many of the comments on the suffering of terminally-ill patients mentioned comfort care, where terminally ill patients may stop receiving treatment in favor of being made as comfortable as possible during the dying process, as an adequate alternative to PAS.

For qualitative analysis, all comments have been coded into themed categories beginning on page 12.

Survey Frequencies

Frequencies are broken out into three categories: responses from the PAS-legal portion of the sample, responses from the PAS-illegal portion of the sample, and responses from the overall sample. P-*values represent the likelihood that differences in mean scores between PAS-legal and PAS-illegal states are due to chance.* P-*values were calculated using t-tests. Statistically significant* p-*values are* ***bolded****.*

For this survey, the following terms are defined:

- **Physician-assisted suicide (PAS)**: the prescription of a pharmacological agent by a physician, to be administered by the patient (and not the physician), with the expressed intent of expediting death.

- **Terminally ill patient**: an individual with an incurable illness that will inevitably lead to their death within a short period of time, typically within 6 months, as suggested by existing state law and as defined by Medicare guidelines.

- **Ethically obligatory:** an action, or lack of action that is always perceived to result in a greater benefit to an individual patient, than harm to society.

- **Ethically permissible**: an action, or lack of action, considered permissible (allowed but not obligatory), ethical permissibility exists on a spectrum from ethically permissible as a last resort, to ethically preferable, depending on individual context. For an action to be considered ethically permissible, it would have to be perceived as resulting in a greater benefit to an individual patient, than the proportionate, potential harm to society.

- **Ethically prohibited:** an action, or lack of action, that is always ethically wrong and should not be done under any circumstance. The action would always be perceived to result in a greater harm to society than any potential benefit to an individual patient.

1. Are there any circumstances in which *society* should consider physician participation in PAS for terminally ill *adult* patients to be ethically permissible?

	n	Yes	No	Uncertain	Mean attitude score	*p*-value
PAS-legal	*146*	73.3%	15.1%	11.6%	.58	**.00**
PAS-illegal	*96*	54.2%	34.4%	11.5%	.20	
Overall	*242*	65.7%	22.7%	11.6%	.43	

2. Are there any circumstances in which *society* should consider physician participation in PAS for terminally ill *pediatric* patients to be ethically permissible?

	n	Yes	No	Uncertain	Mean attitude score	*p*-value
PAS-legal	*146*	35.6%	28.8%	35.6%	.07	**.04**
PAS-illegal	*95*	27.4%	43.2%	29.5%	-.16	
Overall	*241*	32.4%	34.4%	33.2%	-.02	

3. Are there any circumstances in which ***you* might personally consider participation in PAS for terminally ill ***adult*** patients, ***if legal*** within the jurisdiction in which you work?**

	n	Yes	No	Uncertain	Mean attitude score	*p*-value
PAS-legal	*144*	52.8%	35.4%	11.8%	.17	**.03**
PAS-illegal	*95*	41.1%	50.5%	8.4%	.09	
Overall	*239*	48.1%	41.4%	10.5%	.07	

4. Do you believe the AAN's position on PAS conflicts with your professional obligation to your patients? *(Note: PAS is ethically prohibited in the current AAN position statement)*

	n	Yes	No	Uncertain	Mean attitude score	*p*-value
PAS-legal	*143*	49.7%	35.7%	14.7%	.14	**.01**
PAS-illegal	*95*	30.5%	48.4%	21.1%	-.18	
Overall	*238*	42.0%	40.8%	17.2%	.01	

5. Do you believe your state's existing laws regarding PAS conflict with your professional obligation to your patients? *(Note: PAS is currently legal only in Montana, Oregon, Vermont, and Washington)*

	n	Yes	No	Uncertain	Mean attitude score	*p*-value
PAS-legal	*144*	15.3%	79.2%	5.6%	.19	**.04**
PAS-illegal	*95*	30.5%	49.5%	20.0%	-.64	
Overall	*239*	21.3%	67.4%	11.3%	-.31	

6. Should physician participation in PAS for terminally ill patients, with appropriate protection safeguards as established in Oregon (view at aan.com/view/Oregon), be legalized in all states?

	n	Yes	No	Uncertain	Mean attitude score	*p*-value
PAS-legal	*143*	55.2%	23.8%	21.0%	.31	**.01**
PAS-illegal	*95*	42.1%	38.9%	18.9%	.03	
Overall	*238*	50.0%	29.8%	20.2%	.20	

7. If a terminally ill patient with decision-making capacity requests that any and all life-sustaining treatment be withheld, including artificial nutrition and hydration, then a physician's compliance with this request should be considered to be:

	n	Ethically prohibited	Ethically permissible	Ethically obligatory	Mean attitude score	*p*-value
PAS-legal	*144*	2.8%	39.6%	57.6%	.55	.88
PAS-illegal	*93*	4.3%	37.6%	58.1%	.54	
Overall	*237*	3.4%	38.8%	57.8%	.54	

8. Do you favor changing the AAN position statement to PAS being ethically permissible for terminally ill patients in limited and clearly specified circumstances?

	n	Yes	No	Uncertain	Mean attitude score	*p*-value
PAS-legal	*144*	68.1%	20.1%	11.8%	.48	
PAS-illegal	*95*	57.9%	33.7%	8.4%	.24	**.04**
Overall	*239*	64.0%	25.5%	10.5%	.38	

9. If you answered yes to question 8, would you feel a personal need for further training/education regarding any aspect of PAS before you would be willing to participate in PAS?

	n	Yes	No	Uncertain
PAS-legal	*96*	61.5%	27.1%	11.5%
PAS-illegal	*55*	80.0%	16.4%	3.6%
Overall	*151*	68.2%	23.2%	8.6%

10. Would you consider attending an Ethics Colloquium on the subject of PAS if it were held at the 2015 AAN Annual Meeting in Washington, DC?

	n	Yes	No	Uncertain
PAS-legal	*143*	49.0%	23.1%	28.0%
PAS-illegal	*95*	54.7%	15.8%	29.5%
Overall	*238*	51.3%	20.2%	28.6%

11. What influenced your responses to this survey? *Check all that apply*.[1]

	PAS-legal	PAS-illegal	Overall
n	*144*	*96*	*240*
Professional experience	83.3%	79.2%	81.7%
Institutional policy	10.4%	8.3%	9.6%
Personal religious beliefs	25.0%	35.4%	29.2%
Personal ethical beliefs	88.9%	92.7%	90.4%
Risk of your beliefs being publicized	2.8%	4.2%	3.3%
Risk of legal action	7.6%	10.4%	8.8%

[1]Due to some participants marking more than one response, totals exceed 100%.

12. Please share any comments you have on the topic of this survey or additional explanation of any of your responses:

Comments begin on page 12.

13. In which state do you currently practice?[2] (n=243)

AL	0.4%	IN	0.8%	NE	0.0%	SC	0.0%
AK	0.0%	IA	0.4%	NV	0.4%	SD	0.4%
AZ	0.8%	KS	1.2%	NH	0.0%	TN	0.4%
AR	0.0%	KY	0.0%	NJ	0.8%	TX	1.2%
CA	2.5%	LA	0.0%	NM	0.4%	UT	0.0%
CO	2.1%	ME	0.8%	NY	4.9%	**VT**	3.7%
CT	0.8%	MD	1.2%	NC	0.8%	VA	0.8%
DE	0.0%	MA	1.6%	ND	0.0%	**WA**	30.5%
FL	2.1%	MI	1.2%	OH	1.6%	WV	0.0%
GA	2.5%	MN	0.8%	OK	0.4%	WI	0.8%
HI	1.2%	MS	0.0%	**OR**	**22.2%**	WY	1.6%
ID	0.0%	MO	0.0%	PA	2.1%	PR[3]	0.4%
IL	2.1%	**MT**	3.7%	RI	0.0%		

[2]PAS is legal in bolded states.

[3]PAS is illegal in the U.S. territory of Puerto Rico.

14. Please identify the nature of your specialty practice. *Check all that apply*.[4]

	PAS-legal	PAS-illegal	Overall
n	*141*	*94*	*235*
Neurologist who provides continuous or palliative care for ALS patients	29.8%	25.5%	28.1%
Neurologist who provides continuous care or palliative care for brain tumor patients	20.6%	21.3%	20.9%
Neurologist who provides continuous or palliative care for terminally-ill patients without consideration of specific diagnosis	31.2%	31.9%	31.5%
Pediatric neurologist or neurologist who cares for pediatric patients	13.5%	4.3%	9.8%
Neurointensivist or stroke neurologist	20.6%	21.3%	20.9%
Other neurologist categories	58.9%	57.4%	58.3%

[4]Due to some participants marking more than one response, totals exceed 100%.

Additional Analysis

To find overall mean attitude scores of PAS-legal and PAS-illegal respondents, scores for each to the 8 scale questions were summed and divided by the number of attitude scale questions answered by each respondent (per industry standards, those who responded to fewer than 4 were removed from this analysis.) The average score for PAS-legal respondents was then compared to the average score for PAS-illegal respondents with a t-test (see Table 3 below.)

Table 4 compares the mean attitude score (MAS) of respondents in each of the neurology subcategories from question 14 to all other respondents. The difference in MAS compared to all other respondents, as well as the significance of this difference, are reported.

Table 3. Comparison of overall mean attitude score between PAS-legal and PAS-illegal respondents

	PAS-legal respondents	PAS-illegal respondents	Test for significance in difference of scores
Mean attitude score	.21	.09	*p*=.08

Table 4. Comparison of mean attitude score between subspecialists

	n	Difference in MAS compared to all other respondents	*p*-value
Neurologist who provides continuous or palliative care for ALS patients	*66*	+.10	.17
Neurologist who provides continuous care or palliative care for brain tumor patients	*49*	+.07	.39
Neurologist who provides continuous or palliative care for terminally-ill patients without consideration of specific diagnosis	*74*	+.07	.33
Pediatric neurologist or neurologist who cares for pediatric patients	*23*	-.02	.83
Neurointensivist or stroke neurologist	*49*	-.04	.63
Other neurologist categories	*137*	-.06	.37

Comments

Comments from question 12 are listed below. Comments have been grouped by theme. Comments that fall into more than one category are underlined.

Please share any comments you have on the topic of this survey or additional explanation of any of your responses:

IN SUPPORT OF PAS (13)

- As long as the patient is terminally ill and has 0 chance of improving and the patients themselves wanted it, then their wish should be followed as long as there are no legal ramification. Most important thing is if the patient is in a lot of pain that cannot be relieved by any type of narcotics, then they should be allowed to die. If there is a right to live, there should also be a right to die.
- During residency in Oregon while rotating through inpatient palliative care, my experience as part of the team providing PAS was rewarding in that we helped terminally ill patients achieve the more peaceful death that they chose. I was glad we were able to give that choice and provide that comfort to the dying by complying with their wishes to end suffering.
- I am so happy that the American Academy of Neurology is looking at this issue. It is long overdue. I live in Vermont and I am so happy that we have passed PAS. I would welcome further discussion about this issue and would definitely attend a colloquium at the 2015 meeting. Thank you.
- I believe the one principle that binds together my entire ethical view of my profession is "primum non nocere". Withholding assistance in suicide may cause more harm. It may prolong unjustifiable suffering, of course, and it can force a patient into inadvertently causing non-lethal harm to themselves.
- I can certainly envision circumstances where I might elect physician assisted suicide for myself if permissible (it is in my state, Washington). The principle of personal autonomy and the right to do what one wishes with one's own body is I believe the highest of ethical principles, that should be honored, and it should not be undermined by those with opposing, I would call, arbitrary ethical views.
- I do live/work in Oregon. Although I personally have not prescribed the medications utilized I have had patients participate in PAS. They were satisfied with the choice they made and had full family support. It clearly needs very strict guidelines and restrictions.
- I personally would only do it very occasionally but would clearly like that option for myself in the certain situations and probably plan to do myself if presented in some situations in later life.
- I think anyone who has witnessed true suffering at the end of life would agree that in some (limited) circumstances PAS is ethically permissible.
- I think neurologists should address this issue proactively and responsibly. There are situations which we are in the BEST position to assess, where the ethically permissible and compassionate choice is PAS.
- If a patient has capacity, they should be able to engage in end of life care decisions
- Our duty is to help patients be the agents of their destiny, as they define that. If a patient is mentally competent to make a decision regarding life sustaining treatments, we have a moral obligation to assist them in achieving their stated wishes.
- PAS maximizes autonomy. Most people I talk to are more interested in preserving quality of life over longevity with severe disability and definitely find a life of complete dependency, unrelenting pain, and/or unable to communicate as worse than death. It is not clear to me why the values we apply to ourselves are not the ones that we consider to be normative for others. This is

not a value imposed on others who desire to keep on living but an alternative for those that consider living as contributing to others, achieving personal goals, interacting with others, etc. It's a shame that neurologists would want make people live out their time curled up in a nursing home bed with all the degradation that frequently comes with it. The role of the physician is as much for compassion as it is for preserving life.

- PAS is legal in Washington State and in my experience has been a very positive process for patients (and their families) with terminal diseases.

MORALLY CONFLICTED, IN SUPPORT OF PAS (6)

- Although it is unlikely that I would personally participate in PAS, I am not willing to prohibit a well-informed patient with decision making capacity and his/her well-informed physician from making well thought-out decision to do so (including appropriate time for both to reconsider).
- I answered no to the following question "Do you favor changing the AAN position statement to PAS being ethically permissible for terminally ill patients in limited and clearly specified circumstances?" The reason I answered no was that this statement is too restrictive. I fear that the AAN position statement if revised according to the parameters of this statement, would be too limiting to be meaningful in clinical practice. Had it said, "Do you favor changing the AAN position statement to PAS being ethically permissible for terminally ill patients?" I would have answered yes.
- I have complex feelings about these issues, but I feel that we are obligated to ease our patients through end of life issues, and must be compassionate and knowledgeable in order to do this well. Patients deserve a good death.
- I think there may be very limited situations where this might be acceptable, but on a personal basis I would not have interest in being a provider who provides this service.
- I work in Oregon. I am a general neurologist. I have never had a patient request PAS and I am not certain whether I could honor that request but I do think there are circumstances in which it is ethical.
- To better understand my stance, the question that was presented was "Is there ANY circumstance that PAS would be ethically permissible?" My decision to choose yes is based on a worst case scenario such as a patient who has severe pain with a fatal condition with no chance of recovery and no available medications other than something that could be given in a fatal dose. This would include not having any analgesics.

MORALLY CONFLICTED, OPPOSED TO PAS (5)

- Ethically there is an argument for assisted suicide, but I do not think that physicians ought to be involved with the act
- Even though I can imagine situations in which it may seem more merciful to assist with bringing an earlier end to a life, I believe there should continue to be some absolutes in that we, as physicians, do nothing willingly or intentionally to CAUSE death.
- I do not believe in PAS but I also believe in withdrawing or withholding medical prescriptions in a terminally ill patient
- I live and work in the state of Washington and feel there is nothing to prepare you for the medical discussion of PAS and in fact am relieved to be employed by a company that shares the same religious values I personally hold—thereby exempting me from participation
- I would accept a cognitively intact, terminally ill patient's request to withhold life-sustaining treatment. It would be much more difficult to participate in the pharmacologically mediated suicide by even a terminally ill patient.

WOULD WITHHOLD MEDICATION, OPPOSED TO PAS (3)

- I do not believe in PAS but I also believe in withdrawing or withholding medical prescriptions in a terminally ill patient
- I would accept a cognitively intact, terminally ill patient's request to withhold life-sustaining treatment. It would be much more difficult to participate in the pharmacologically mediated suicide by even a terminally ill patient.
- I'm ok with the ethical principle of 'double effect', but not physician assisted suicide. For instance, I took care of a patient where the patient was in status epilepticus, failing typical protocols. His parents wanted the seizures stopped, but would not allow intubation. So...after some introspection, I prescribed pentobarbital. This stopped the seizures, but obviously killed the patient. I felt ok with this. The family was most appreciative that the patient did not have to die actively seizing, which would have eventually happened.

OPPOSED TO PAS (3)

- Endorsement of physician assisted suicide by the AAN will make me quit the society and avoid future meetings.
- I don't think killing patients can be part of the profession of medicine
- We can relieve suffering (as we should) but must not participate in suicide

AAN'S POSITION STATEMENT SHOULD BE CHANGED (2)

- I strenuously object to the AAN's current position with regards to PAS. Please change your policy.
- The alarmist rhetoric surrounding the topic of PAS is balanced by the Oregon experience since the state's Death with Dignity Act. I hope AAN changes its position.

OPPOSED TO CHANGING AAN'S POSITION ON PAS (1)

- Endorsement of physician assisted suicide by the AAN will make me quit the society and avoid future meetings.

SUFFERING OF TERMINALLY ILL PATIENTS (13)

- As long as the patient is terminally ill and has 0 chance of improving and the patients themselves wanted it, then their wish should be followed as long as there are no legal ramification. Most important thing is if the patient is in a lot of pain that cannot be relieved by any type of narcotics, then they should be allowed to die. If there is a right to live, there should also be a right to die.
- Comfort care measures for terminally ill and futile situations I feel is adequate and humane. I do care for many critically ill stroke patients and I feel that comfort care measures are humane and many families are grateful through the process.
- I do not believe in PAS but I also believe in withdrawing or withholding medical prescriptions in a terminally ill patient
- I practice in Oregon. While the experience with PAS in Oregon has not led to any apparent abuse, its major benefit has been to significantly improve comfort care provided to the terminally ill. I believe as a professional organization and society we need to be providing high quality comfort care to the terminally ill. If we do that, the rationale for PAS largely disappears.
- I think anyone who has witnessed true suffering at the end of life would agree that in some (limited) circumstances PAS is ethically permissible.
- I work as a neurohospitalist and see many terminally ill patients

- I would accept a cognitively intact, terminally ill patient's request to withhold life-sustaining treatment. It would be much more difficult to participate in the pharmacologically mediated suicide by even a terminally ill patient.
- It is often claimed that proper management of pain should alleviate suffering in terminal patients. This would be true if all physical suffering were pain, but it is not. As an example, "air hunger" in an ALS patient can be severe suffering for which there is no reasonable treatment.
- PAS maximizes autonomy. Most people I talk to are more interested in preserving quality of life over longevity with severe disability and definitely find a life of complete dependency, unrelenting pain, and/or unable to communicate as worse than death. It is not clear to me why the values we apply to ourselves are not the ones that we consider to be normative for others. This is not a value imposed on others who desire to keep on living but an alternative for those that consider living as contributing to others, achieving personal goals, interacting with others, etc. It's a shame that neurologists would want make people live out their time curled up in a nursing home bed with all the degradation that frequently comes with it. The role of the physician is as much for compassion as it is for preserving life.
- Question #7 [If a terminally ill patient with decision making capacity requests that any and all life-sustaining treatment be withheld, including artificial nutrition and hydration, then a physician's compliance with this request should be considered to be:] was very difficult to answer since it involves not just "decision-making capacity", but equally important, emotional stability. In responding, I thought of a terminal ALS patient who refused a G-tube, but was forced to undergo surgery because an ethicist (not her physician) insisted upon it. This was cruel and inexcusable. She had "decision-making capacity" and was emotionally stable. She suffered considerably in the end.
- Suicidality is a symptom of depression. We should focus on improving pain relief for emotional and physical pain.
- We can relieve suffering (as we should) but must not participate in suicide
- Withdrawing care or limiting care seems more difficult for the patient and family than PAS, though hospice setting is acceptable to the vast majority

COMMENTS ABOUT SURVEY (7)

- FYI, I practice in Washington State (PAS legal), but work at a Catholic hospital (PAS ethically prohibited), so even if AAN changed its policy, I could still one day experience "moral distress" over this issue.... (You did not ask, but this would be: "Do you believe your institution's existing policies regarding PAS conflict with your professional obligation to your patients?"...)
- I answered no to the following question "Do you favor changing the AAN position statement to PAS being ethically permissible for terminally ill patients in limited and clearly specified circumstances?" The reason I answered no was that this statement is too restrictive. I fear that the AAN position statement if revised according to the parameters of this statement, would be too limiting to be meaningful in clinical practice. Had it said, "Do you favor changing the AAN position statement to PAS being ethically permissible for terminally ill patients?" I would have answered yes.
- I live in Oregon, and have experience with patients requesting PAS for long-term chronic disease without short-term terminal prognosis. That is a much more difficult ethical question and should be addressed by the AAN in the future.
- Question #7 [If a terminally ill patient with decision making capacity requests that any and all life-sustaining treatment be withheld, including artificial nutrition and hydration, then a physician's compliance with this request should be considered to be:] was very difficult to answer since it involves not just "decision-making capacity", but equally important, emotional stability.

In responding, I thought of a terminal ALS patient who refused a G-tube, but was forced to undergo surgery because an ethicist (not her physician) insisted upon it. This was cruel and inexcusable. She had "decision-making capacity" and was emotionally stable. She suffered considerably in the end.

- Questions were not well stated, e.g., 4th question. May want to query the state a member resides in or if they reside in one of the states where PAS is permissible. Do you believe the AAN's position on PAS conflicts with your professional obligation to your patients? (Note: PAS is ethically prohibited in the current AAN position statement)
- Several attempts to access this survey online were unsuccessful, including a search of AAN website or "physician assisted suicide survey", and use of the link in this letter.
- Survey is of limited value when you have defined ethical decision making only in terms of harm or benefit.

PARTICIPATED IN PAS (6)

- I am a neurologist in the state of Washington and have participated in Death with Dignity. We are hoping to summarize our experience in our ALS clinic.
- I do live/work in Oregon. Although I personally have not prescribed the medications utilized I have had patients participate in PAS. They were satisfied with the choice they made and had full family support. It clearly needs very strict guidelines and restrictions.
- I have been directly involved with PAS on two occasions in WA state.
- I live and work in Oregon and have participated in decision making for a patient who wanted PAS
- I live in Oregon and have participated in PAS.
- PAS is legal in Washington State and in my experience has been a very positive process for patients (and their families) with terminal diseases.

RELIGION (4)

- FYI, I practice in Washington State (PAS legal), but work at a Catholic hospital (PAS ethically prohibited), so even if AAN changed its policy, I could still one day experience "moral distress" over this issue....(You did not ask, but this would be: "Do you believe your institution's existing policies regarding PAS conflict with your professional obligation to your patients?"...)
- I live and work in the state of Washington and feel there is nothing to prepare you for the medical discussion of PAS and in fact am relieved to be employed by a company that shares the same religious values I personally hold— thereby exempting me from participation.
- It is irresponsible and unethical for a physician's religious beliefs to conflict with the express wishes of a patient. A physician's duty is to treat the patient first, and if a physician's religious beliefs are in conflict with this, he or she should recuse themselves.
- Very sensitive issue where you can't separate your culture/religion belief from practice. Even if legalized it will be hard to execute by some physicians.

PAS IS AN IMPORTANT ISSUE (4)

- I am so happy that the American Academy of Neurology is looking at this issue. It is long overdue. I live in Vermont and I am so happy that we have passed PAS. I would welcome further discussion about this issue and would definitely attend a colloquium at the 2015 meeting. Thank you.

- Of all the branches of medicine, neurologist should know the most about need of PAS. Every one of us has advanced cases of dementia, PD, developmentally regressing, vegetative, MS with EDSS of 9.0 and of course terminal ALS. There are no treatments on horizon (and I believe in my professional life time, I am 47) will reverse or even stop progression of those advanced cases and diseases. Happy to be wrong on the prediction if a "breakthrough" comes and changes the course of human health. I think it is AAN's duty to work on this issue. Kind of shameful for AAN to wait over 15 years to look again at this issue.
- Thank you for exploring this challenging area.
- Thank you for working on this.

PAS TERMINOLOGY (4)

- Allowing a patient to die is *not* assisted suicide
- I feel that the description of this as physician assisted suicide is a poor description of this practice. The physician is merely writing a prescription for a medication. They do not actively recommend this or initiate the process. This allows the patient to feel they have more control of their destiny. This statute requires the patient to ask for the prescription and to take it.
- I think ethics boards along with consultation from hospice/palliative care specialists must have a well-defined and obligatory role in reviewing PAS cases individually, so as to assist the physician, patient and family come to an ethically acceptable solution
- In my state, there is a conscious effort to avoid the term "Physician assisted suicide".

LOCAL LAWS (3)

- Having witnessed PAS in Europe where with "safeguards", many providers will not let their family members be hospitalized in some countries for fear of unexpected assisted deaths, ethics are as varied as people.
- I would not attend an educational session on this at the Washington DC meeting because I believe that this might best be done on a state level. The laws differ so much between the states that one needs to be trained according to local state laws.
- Regarding whether all 50 states should adopt the permissible position, I chose "Uncertain"... There is always a balance between the rights of states and Federal-national policy and law. In this, I favor a State's Right approach, letting each state determine for its citizens what they wish to develop as policy. In matters of this nature, our United States configuration allows "experimentation" which yields information for others to consider as they approach policy evolution and new policy adoption.

SUICIDE (3)

- Allowing a patient to die is *not* assisted suicide
- I am concerned that a person who wants suicide will change that view with treatment with antidepressants.
- Suicidality is a symptom of depression. We should focus on improving pain relief for emotional and physical pain.

OTHER (2)

- I'm in Oregon
- PAS is not overused.