The impact on patient trust of legalising physician aid in dying

M Hall, F Trachtenberg, E Dugan

Objective: Little empirical evidence exists to support either side of the ongoing debate over whether legalising physician aid in dying would undermine patient trust.

Design: A random national sample of 1117 US adults were asked about their level of agreement with a statement that they would trust their doctor less if "euthanasia was legal and doctors were allowed to help patients die".

Results: There was disagreement by 58% of the participants, and agreement by only 20% that legalising euthanasia would cause them to trust their personal physician less. The remainder were neutral. These attitudes were the same in men and women, but older people and black people had more agreement that euthanasia would lower trust. However, overall, only 27% of elderly people (age 65+) and 32% of black people thought that physician aid in dying would lower trust. These views differed with physical and mental health, and also with education and income, with those having more of these attributes tending to view physician aid in dying somewhat more favourably. Again, however, overall views in most of these subgroups were positive. Views about the effect of physician aid in dying on trust were significantly correlated with participants' underlying trust in their physicians and their satisfaction with care. In a multivariate regression model, trust, satisfaction, age, and white/black race remained independently significant.

Conclusion: Despite the widespread concern that legalising physician aid in dying would seriously threaten or undermine trust in physicians, the weight of the evidence in the USA is to the contrary, although views vary significantly.

After decades of debate, the core ethical issues regarding physician-assisted suicide (PAS) and euthanasia remain unresolved. Although most physicians and medical organisations remain steadfastly opposed, significant voices of dissent continue to be heard. Public opinion polls remain deeply divided, and legislatures continue to deliberate over key questions such as whether terminal pain relief is permissible. Throughout this debate, positions are frequently asserted about the impact on patient trust of legalising physician aid in dying. The United States Supreme Court, in upholding states' criminalisation of assisted suicide, noted that PAS could "undermine the trust that is essential to the doctor–patient relationship by blurring the time-honoured line between healing and harming". Similarly, leading physician and nursing organisations and ethicists are adamant in claiming that physician aid in dying (either PAS or euthanasia) would lower patients' trust in physicians. They assert, for instance, that the "ramifications are too disturbing for the patient–physician relationship and the trust to sustain it", and that physician aid in dying would cause patients "great difficulty believing their doctor intends their best interests". Others hold contrary opinions but, as Becky Cox White has noted, neither side in this empirical debate cites any evidence for these competing assertions about impacts on trust. The debate is simply too important to be conducted in the absence of empirical data. The effect on patient trust of physician aid in dying is not an abstract question that should be debated entirely as a matter of ethical theory or personal opinion. Trust worthiness—that is, whether one deserves trust—is an ethical or value-laden construct. Trust itself, however, is a psychological state that is subject to objective measurement. During the last 5 years, a number of research teams, including ours, have developed validated research tools to study trust. So far, however, these empirical tools have not been brought to bear on the core question of PAS and patient trust.

There are only two published studies from the USA on the impact on trust of physician aid in dying (PAS or euthanasia). One study, from Iowa, reported that the vast majority of primary care patients (85–90%) thought that a physician who assisted with suicide or performed euthanasia would still be trustworthy and capable of being a caring provider. Only 5% said they would probably change to another physician if they knew their physician assisted in suicide, 8% said they would definitely do so. Two-thirds indicated they would definitely not change physicians who assisted with suicide, but only one-third said they would definitely keep a physician who carried out euthanasia. A second study, from Massachusetts, found greater levels of concern: 37% of oncology patients and 44% of the general public thought that explicit discussions with a physician about euthanasia or PAS would reduce trust in the physician; 19% of oncology patients and 26.5% of the public said they would change physicians if they learned that their current physician had performed euthanasia or assisted suicide.

These studies are informative, but they suffer from a number of limitations. First, they report conflicting results, which have not yet been reconciled. One possible explanation is that each was conducted within a single state with study populations that differed sharply on key factors such as religion, age, or race, which have been shown to be significantly related to attitudes about euthanasia. For
instance, 53–66% of the Massachusetts sample were Catholic, a religion that strongly opposes euthanasia, whereas only 26% of the Iowa sample were Catholic and 23% were “agnostic”. Secondly, these studies only describe views about the impact of PAS on trust but do not analyse many or any factors that could affect these views. In particular, response rates were not reported for different races. Thirdly, these studies did not use any of the validated multi-item measures of trust that now exist. The present study was designed to improve our understanding of the relationship between trust and physician aid in dying by addressing many of these limitations.

SAMPLE, MEASURES, AND METHODS
A random national sample of 2637 households was selected in 1999 from a proprietary database of working residential telephone exchanges in the continental USA. A minimum of 15 attempts were made to reach numbers that were not answered. Households with no-one over the age of 20 years were excluded ($n = 66$). Respondent selection within eligible households was done using the next birthday method.25 Because this survey was part of a larger study of recent experiences with physicians and health insurors,18 22 respondents were further screened to select only those with some type of public or private health insurance and those who had been to a doctor or other health professional at least twice during the previous 2 years. Health insurance was defined broadly to include any source of third-party payment, even government facilities and indigent care programmes at clinics or hospitals. A total of 151 individuals (6%) did not have health insurance and 248 (9%) had not been to their doctor twice in the previous 2 years. Contacts with the 2172 potentially eligible individuals resulted in the following dispositions: 1117 (51%) were interviewed; 571 (26%) refused; 484 (22%) were unable to participate (not home, ill, non-English speaking). Data used in the following analyses were from 956 (86%) people who answered the core questions on physician aid in dying and trust.

The telephone interviews lasted approximately 25 minutes and were conducted by trained interviewers at the Survey Research Center of the University of South Carolina using computer assisted telephone interviewing. Verbal informed consent was obtained at the start of the telephone interviews and the study protocols were reviewed and approved by the Wake Forest University Medical Center Institutional Review Board. Data were collected on a range of topics, including views about PAS, trust in the person’s regular physician or health care provider, demographic characteristics, satisfaction with care, and physical and mental health. Trust was measured by a 5-item scale, the validation and properties of which are reported elsewhere.16 23 Satisfaction with care was measured using a 12-item scale on asking about health care received from all sources over the previous few years.24

Attitudes about physician aid in dying were measured by response to the following statement:

The last question has to do with euthanasia or the right to die, which is a very controversial topic. Assume for the purpose of this question that euthanasia were legal. If doctors were allowed to help patients die, you would trust Dr [the person’s doctor] less.

Response categories were on a 5-point Likert scale of strongly agree to strongly disagree. Although this question did not clearly distinguish between or define euthanasia (where the lethal agent is administered by the physician) and PAS, prior studies have found that attitudes are essentially the same for both,4 16 20 so it was not necessary to distinguish the two concepts. The concept was defined by the wording of the item above, which refers simply to doctors “help[ing] patients die”.

Owing to the particular selection criteria and survey method, this random sample is not fully representative of US norms (table 1). There is a somewhat greater representation of white people (83%) and women (68%) because they are more likely to have insurance and have visited a physician during the required period. Otherwise, about half of the participants (48%) had an income above $40 000, and the majority were aged between 30 and 60 years (60%) and were college educated (64%). The sample composition is therefore sufficient to analyse most major demographic and socio-economic groups, even though overall sample means may be somewhat skewed towards majority and higher socio-economic groups.

In order to assess the level of agreement that physician aid in dying would lower trust, frequencies of response categories were calculated for the general study population and for key subgroups: men, elderly people, and black people. $\chi^2$ tests were used to determine whether these views varied by sex, race, and older age, and Wilcoxon rank sum tests were performed to determine whether these views varied by physical health, mental health, education, income, and concordance of doctor/patient race, age, and sex. To test whether views about trust and physician aid in dying varied by underlying trust in the physician and satisfaction with medical care, Spearman’s correlation coefficient was calculated. Finally, a multivariate regression analysis was performed to determine the most significant predictors of views on trust and physician aid in dying (on the 5-point Likert scale).

RESULTS
Overall, almost three times as many participants disagreed (58%) as agreed (20%) that legalising euthanasia would cause them to trust their personal physician less (table 2). The remainder were neutral. These attitudes were the same in men and women, but older people and black people agreed more that euthanasia would lower trust (table 2). Additionally, views about the impact on trust were negatively correlated with age ($-0.078$ Spearman’s correlation coefficient; $p = 0.016$). However, overall, only 27% of elderly (age 65+) and 32% of black participants thought that physician aid in dying would lower trust.

<table>
<thead>
<tr>
<th>Characteristic Value</th>
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<tr>
<td>Range</td>
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<tr>
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<td>Race (%)</td>
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<tr>
<td>Other</td>
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views about trust and physician aid in dying differed significantly with physical and mental health, and also with education and income, with those having more of these attributes tending to view physician aid in dying somewhat more favourably (tables 3 and 4). Again, however, overall views in each of these subgroups were positive, except for the very small category (n = 11) of poor mental health.

Wilcoxon rank sum tests
Views were also found to be significantly more favourable (p = 0.001) for participants whose doctor was of the same race (3.55, n = 675) compared with those whose doctor was of a different race (3.28, n = 281). However, no significant differences were found according to age or sex matches with physicians. Finally, views about the effect of physician aid in dying on trust were significantly correlated (p < 0.001) with participants’ underlying trust in their physicians (Spearman’s correlation coefficient = 0.204) and satisfaction with care (Spearman’s correlation coefficient = 0.169).

In the multivariate regression model (table 5), physical and mental health were not significant factors, nor was race concordance with the physician. Education was only borderline significant (p = 0.062). (Income was dropped from the model because it was highly correlated with education.) Trust, satisfaction with medical care, age, and white/black race each remained independently significant.

### DISCUSSION
It is critically important to maintain patients’ trust in their treating physicians and in the medical profession as a whole. This is especially the case in end of life care. However, public policy advocates often overstate their case that physician aid in dying would seriously threaten or undermine trust, the weight of the evidence from the USA is to the contrary, although views vary significantly. This study shows that only 20% of Americans believe they would trust their physician less if euthanasia were legalised. The majority of respondents in most population groups thought there would be no negative impact on their trust in their personal physician. Although views among black people were less favourable, they were still positive on balance. One subgroup that believed trust would be harmed comprised those in poor mental health, who, on average, thought that physician aid in dying would lower trust. However, this subgroup was very small in this study (n = 11). Another study demonstrated that people with depression or in “psychological distress” had significantly more favourable views of physician aid in dying and its impact on trust.
These findings are consistent with the two other US studies previously mentioned. The study carried out in Iowa showed that fewer than 10% of people thought that a physician who assists with suicide would be less trustworthy, and fewer than 15% said this for physicians who performed euthanasia. The study from Massachusetts, which was heavily represented by Roman Catholics, showed a higher level of concern, but still fewer than half of oncology patients (37%) and the general public (44%) thought that discussing PAS or euthanasia with their physician would lower trust, and roughly the same proportions (42% and 33% respectively) believed that such discussions would increase trust. It is important to note also that the Massachusetts study did not ask participants to assume that PAS or euthanasia was legal, so their responses were clouded by the fact that many respondents may have assumed that their physicians would be considering an option that would be a serious crime.

Our finding that legalising physician aid in dying would not seriously undermine trust in their doctor for most Americans is also corroborated by two more indirect studies of the relationship between trust and attitudes in the USA about end of life care. Unlike the present study, these participants were not asked directly whether physician aid in dying would lower trust. Instead, such a relationship was inferred by observing whether differences in general attitudes about PAS, euthanasia, or living wills (for example, whether or not PAS should be permitted or whether the person wants to write a living will) correlated with self-reported trust in physicians or the medical profession. Both studies showed no relationship between trust and attitudes about end of life care in the USA. However, in contrast, participants in the current study were asked explicitly about the effect of physician aid in dying on trust, which may have made trust issues more salient in respondents’ minds. In addition, we used different, and perhaps more sensitive, measures of trust. In contrast with earlier studies, we found that views about the effect of physician aid in dying on trust were related to underlying attitudes about physicians and participants’ experiences with medical care. Those with more trust in their physician, and who were more satisfied with their care, were more likely to believe that physician aid in dying would not lower trust. Considering that trust and satisfaction are highly correlated with each other, it is notable that each remained a significant predictor of attitudes about physician aid in dying when controlling for the other. This is further evidence that trust and satisfaction are distinctive, and suggests that they contribute in different ways to patients’ views about how they would react to potential threats to trust.

Consistent with other studies, we found that both black and elderly people in the USA have significantly less support for physician aid in dying. In the present study, this relationship persisted even after controlling for both trust and satisfaction, which suggests that the views of black and elderly people are based on some aspect of their attitudes and/or experiences with health care that are independent of general trust in their physician and their satisfaction with care. In the case of elderly people, it may be that being closer to death increases their concerns about physician aid in dying, or this may reflect a generational difference related to other factors such as religious conviction.

For black people, others have speculated that a general distrust of the medical system (which is distinct from trust in a particular physician) may lower their confidence in physician aid in dying. To explore this possibility, we performed an additional analysis (results not shown) on a subgroup (n = 487) for which we also measured trust in the medical profession. Controlling for that additional dimension of trust, we found that black people still have more negative views about the impact on trust of physician aid in dying (p = 0.009). On balance, then, these findings contradict the conventional wisdom that reduced trust by African-Americans is the primary explanation for their lower support for PAS. This finding is supported by a similar study that showed that the decreased willingness of black people to complete living wills was not explained by differences in trust.

This study is limited by its focus being only on the USA. Differences in the social and religious attitudes, medical systems, history and laws in other countries could produce substantially different results elsewhere. Another major limitation of this and other studies is that they rely on self-report about trust and also on hypothetical questions about how trust might be affected by legalising euthanasia. The study used only a single, newly created item to solicit views on this issue. Under real conditions of legalised physician aid in dying, actual trust-related attitudes and behaviours could be markedly different from what people imagine when they are asked hypothetically. However, the evidence so far is comforting from Oregon, the only US jurisdiction that allows PAS. No direct studies of the impact on trust have been carried out in Oregon, but there is indirect evidence from a comprehensive survey of all physicians in that state. Only 7% of the Oregon physicians reported having one or more patients who were concerned about the physician’s position on assisted suicide; this rate was significantly greater (11% versus 4%) for physicians who oppose PAS than those who support it. Comparing the Oregon physicians who supported PAS with those who opposed it, approximately the same proportion (21% and 28%) reported that their patients responded positively when they learned of their position on PAS. Only 1% of the Oregon physicians who supported PAS reported having one or more patients leave their care because of their position, whereas 4% of those against PAS lost one or more patients because of this opposition. The authors concluded that ruptures of doctor–patient relationships “were more likely if the physician opposed assisted suicide”.

None of these findings should be taken as conclusive evidence that legalising physician aid in dying would not seriously harm trust in the general population, in more vulnerable or less trusting subgroups, or in other countries. Studies are too few and tentative to reach any such conclusion. In this study, significant proportions (20–30%) of each major US population group thought that legalising physician aid in dying would lower trust. We should not be cavalier about potential threats to trust because, once it is lost, it is far harder to rebuild than it is to sustain. Banning PAS or euthanasia could thus still be justified as a measure to avoid any diminution in trust. Moreover, there are other sound reasons to oppose physician aid in dying, such as the difficulty in assuring truly voluntary consent, or the belief that purposefully ending life is morally wrong, regardless of the circumstances. However, on balance, the empirical support is weak for those who confidently assert that legalising PAS or euthanasia would undermine trust in physicians for most people in the USA.
REFERENCES


Notice

2006 EACME Annual Meeting – Call for abstracts

The 2006 EACME Annual meeting will be taking place on 28-30 September 2006 at the Catholic University of Leuven, Belgium. The focus of the conference is on four new developments in European bioethics: social sciences and bioethics; care ethics; bioethics, law, and politics; and new technologies and bioethics. Persons wishing to present papers at the conference are invited to submit an abstract addressing the ethical dimensions of the conference topics (500 words maximum) before 1 March 2006. For further information please contact Chris Gasmans, Centre for Biomedical Ethics and Law, Faculty of Medicine, K.U.Leuven, Kapucijnenvoer 35, 3000 Leuven, Belgium; tel: 0032 16 33 69 51; fax: 0032 16 33 69 52; email: Chris.Gasmans@med.kuleuven.be.