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The acceptability of ending a patient's life

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Objectives: To clarify how lay people and health professionals judge the acceptability of ending the life of a terminally ill patient.

Design: Participants judged this acceptability in a set of 16 scenarios that combined four factors: the identity of the actor (patient or physician), the patient's statement or not of a desire to have his life ended, the nature of the action as relatively active (injecting a toxin) or passive (disconnecting life support), and the type of suffering (intractable physical pain, complete dependence, or severe psychiatric illness).

Participants: 115 lay people and 72 health professionals (22 nurse's aides, 44 nurses, six physicians) in Toulouse, France.

Main measurements: Mean acceptability ratings for each scenario for each group.

Results: Life ending interventions are more acceptable to lay people than to the health professionals. For both, acceptability is highest for intractable physical suffering; is higher when patients end their own lives than when physicians do so; and, when physicians are the actors, is higher when patients have expressed a desire to die (voluntary euthanasia) than when they have not (involuntary euthanasia). In contrast, when patients perform the action, acceptability for the lay people and nurse's aides does not depend on whether the patient has expressed a desire to die, while for the nurses and physicians unassisted suicide is more acceptable than physician assisted suicide.

Conclusions: Lay participants judge the acceptability of life ending actions in largely the same way as do healthcare professionals.

Whether physicians should intervene to end patients' lives, either directly (euthanasia) or indirectly (physician assisted suicide (PAS)), is highly controversial both among the public and among healthcare providers. Passive euthanasia— withholding or withdrawing treatment needed to sustain life—is widely practiced and condoned,^{1–7} even in countries, such as France, where it is not legally permitted.^{8–10} In contrast, active euthanasia and PAS— intervening in order to end a patient's life or providing the patient with the means to do so—are in most countries condemned by physicians' organisations and against the law.^{1 3 7 11 12} Legislation been passed recently to permit and regulate euthanasia and PAS in the Netherlands, euthanasia in Belgium, and PAS in the state of Oregon.^{13 14} Such legislation is increasingly under discussion in other US states and in other countries, including France.^{7 8 15–17} It is important, therefore, for policy makers and caregivers around the world to appreciate under which conditions life ending actions are and are not acceptable both to the public and to the healthcare community.

Frileux *et al*¹⁸ examined the joint impact of several key factors on lay people's judgments of the acceptability of physicians' interventions to end patients' lives. In line with other studies,^{4 19–21} their participants' judgments of the acceptability of physician assisted suicide or euthanasia depended additively on four factors: the age of the patient, the degree of curability of the patient's illness, the level of the patient's suffering in spite of treatment, and, most importantly, the extent to which the patient requested the life ending procedure. When the patient had not requested a life ending procedure, the level of acceptability was slightly higher when the patient was mentally impaired than when in good mental condition.

As expected,²² the participants judged euthanasia as less acceptable than PAS. The type of technique did not alter the

basic additive cognitive schema, but did modify the impact of situational factors. The participants attached greater importance to the patient's age and to the curability level of the illness when considering PAS than euthanasia. The difference in acceptability was maximal when the patient did not request a life ending act, but disappeared when the patient requested it repetitively. In agreement with Dixon,²³ Frileux and colleagues¹⁸ suggested that PAS implies, by definition, that the patient him or herself wills and performs the life ending act and can, until the ultimate moment, refrain from performing it.

The age of the participants also had an impact on situational factors while not altering the additive schema. Older adults placed more importance than middle aged adults on the patient's age, and middle aged adults more than young adults. By contrast, older adults placed less importance than the middle aged on the number of patient requests, and the middle aged less than young adults.

The current study was intended to explore other factors likely to have an impact on people's judgments of acceptability of physicians' interventions to end the lives of their patients. Firstly, since the emotional significance of the terms "euthanasia" and "physician assisted suicide" may, in the study by Frileux and colleagues,¹⁸ have obscured the real differences to people between the two types of interventions, we phrased the issue merely as in terms of which person performs the act, the patient or the physician. Secondly, to investigate the significance for people of the difference between active and passive euthanasia, we distinguished between active means (lethal injection) and passive means (disconnection of life support). Thirdly, as terminally ill patients suffer in multiple ways,^{24–27} the type of suffering— identified as physical suffering by Frileux *et al*¹⁸—may

Abbreviations: PAS, physician assisted suicide.

be important to people. Accordingly, we compared the impact of physical pain, psychiatric illness, and complete dependence.

Fourthly, healthcare providers differ from lay people in their experiences with and attitudes towards end-of-life care;²⁸ as a result, they may weight and combine the various factors differently from the public. We gave the same scenarios, therefore, first to lay people and subsequently to healthcare providers. In addition, we wanted to look at three levels of healthcare workers—physicians, nurses, and nurse's aides—who differ in their decision making responsibility, their medical training, and the intimacy of their interaction with the patient.

Finally, we were interested in knowing the interaction of these above factors with the extent of the patient's expressed desire to have his or her life ended. Frileux *et al*¹⁸ identified the extent of the patient's request for a life ending procedure as the primary determinant of acceptability. In line with Rogers'²⁹ conceptualisation of right to die terminology in terms of two dimensions, the locus of the decision to die and the locus of action, we saw patient's desire as a more general factor than request, implying PAS and voluntary euthanasia if the patient asks the physician to facilitate this desire and suicide (or involuntary euthanasia) if the patient does not inform the physician.

METHODS

As in the previous study by Frileux *et al*,¹⁸ the current study was conducted and analysed in accordance with the Functional Theory of Cognition of Norman Anderson.³⁰ Unlike typical questionnaires, this methodology (in which participants make judgments about a series of scenarios composed of all possible combinations of several key factors) allows the researcher to discover precisely how the participants weight and combine these pieces of information when making judgments.

Participants

The lay participants were unpaid volunteers recruited and tested individually by one of the co-authors (A Maudet). She contacted 200 people walking along city sidewalks of Toulouse, a city of a million inhabitants in southwest France; explained the study and asked them to participate; and, if they agreed, arranged where and when to administer the experiment. One hundred and fifteen (58%) participated, and all declared that they were not currently experiencing any suffering. Fifty six per cent were female; their ages ranged from 18 to 60 years, with a mean of 34.5 years (standard deviation 11.7); 62% completed secondary studies (and 38% did not); and 80% believed in God. For comparison, in the French population as a whole, among people 18 years and older, approximately 30% in 1999 had completed secondary studies,³¹ and among people 15 years and older, 75% reported in 1996 either going to church at least occasionally or having "a feeling of belonging to a religion".³²

The health professionals were also unpaid volunteers, recruited and tested individually by two other co-authors (M Guedj and M Gibert). They contacted 200 professionals working in the two main hospitals of Toulouse; explained the study; asked them to participate; and, if they agreed, arranged where and when to administer the experiment. Seventy two (36%) participated: 22 nurse's aides (all females, aged 27–55 years, with a mean age of 42.9 years), 44 nurses (42 females and two males, aged 20–54 years, with a mean age of 40.6 years), but only six physicians (four females and two males, aged 35–58 years, with a mean age of 46.3 years). They all declared that they were not currently experiencing any suffering.

Material

The material consisted of 16 cards containing a story of a few lines, a question, and a response scale. The cards were arranged by chance and in a different order for each participant. They depicted terminally ill male patients who, as the experimenter told the participants, were receiving the best possible care.

The scenarios had a four within-subject factor design. The patients had one of four types of life ending procedures, the combinations of who performed the act (patient or doctor) (factor 1) and whether or not the patient had told the doctor he desired to have his life ended (factor 2): (1) PAS (the patient had informed the doctor of his desire to have his life ended, and, with the assistance of the doctor, he committed the act); (2) suicide (the patient had not informed the doctor of his desire to have his life ended, and he committed the act); (3) voluntary euthanasia (the doctor killed the patient in accordance with the patient's stated desire to have his life ended); and (4) involuntary euthanasia (the doctor killed the patient even though the patient had not told the doctor of his desire to have his life ended). These two factors corresponded to the two dimensions used by Rogers²⁹ to define right to die concepts, the locus of action and the locus of the decision to die. In addition, the procedures were either active (injecting a toxic substance) or passive (disconnecting life support) (factor 3). The result was a basic set of eight scenarios ($2 \times 2 \times 2$). In addition, the scenarios depicted three types of suffering (factor 4): intractable physical pain, serious untreatable psychiatric illness, and complete physical dependence with mental confusion. All eight scenarios were appropriate for the pain condition. The four passive scenarios were implausible for the psychiatric condition, and the four patient activated scenarios were implausible for the totally dependent patients; these were deleted.

Under each story was a question: "To what extent does this procedure appear acceptable to you?", followed by a 24 cm response scale with a left hand anchor of "Not at all" and a right hand anchor of "Completely". Four examples are given in the Appendix, which can be viewed online (see <http://www.jmedethics.com/supplemental>).

Procedure

The site for the lay participants was a vacant university classroom or the private home of the adult participant. The site for the health professionals was a vacant room in the hospital. The session had two phases. In the familiarisation phase, the experimenter explained to each participant what was expected and presented him or her with the 16 stories. The participant read each story out loud, after which the experimenter reminded him or her of the items of information the story contained. The participant then made a rating of the acceptability of the specified life ending procedure for the patient in the story. After completing the 16 ratings, the participant was allowed to compare responses and change them. In the experimental phase, the set of 16 stories was presented again. Each participant provided ratings at his or her own pace, but was allowed neither to compare responses nor to go back and make changes. In both phases, the experimenters routinely made certain that each subject, regardless of age or educational level, was able to grasp all the necessary information before making a rating.

The participants took 10–30 minutes to complete both phases. The experimental phase went quickly because they were already familiar with the task and the material. The participants knew in advance how long the experiment would last. None of them complained about the number of vignettes they had to evaluate or the credibility of the proposed situations.

Brief post-experimental interviews were conducted with the last 11 lay participants when it was realised that the previous participants had made no distinction between the active and passive modes of ending life. They were asked if injecting a toxic substance and disconnecting life support were different and, if so, which was more acceptable.

Data analysis

In accordance with Anderson's methodology,³⁰ the data were analysed, at the group level, by performing analysis of variance and by constructing graphs (using Statistica 5.0).

For the lay participants, four analyses of variance were performed. The first ANOVA was conducted on the eight scenarios involving physical suffering; its design was Active/passive mode \times Actor \times stated Desire to have his life ended, $2\times2\times2$. The second ANOVA was conducted on the eight scenarios involving physical suffering or complete dependence where the physician is the actor; its design was Type of suffering \times Active/passive mode \times stated Desire, $2\times2\times2$. The third ANOVA was conducted on the eight scenarios involving physical suffering or psychiatric disease where the mode of ending life is active; its design was Type of suffering \times Actor \times stated Desire, $2\times2\times2$. A fourth ANOVA was conducted on the four scenarios corresponding to complete dependence and psychiatric disease where the mode is active and the actor is the physician; its design was Type of suffering \times stated Desire, 2×2 . Participants' age (younger versus older) and sex were also systematically introduced as between-subject factors in these four designs.

For the health professionals, the data were analysed in the same way as for the lay people. In addition the data were directly compared with the data for the lay people through two additional ANOVAs, including either lay participants versus nurse's aides or lay participants versus nurses as a between-subjects factor; this analysis was not performed on the data from the group of physicians because there were only six of them.

RESULTS

The results observed in the sample of lay participants are shown figure 1. In the case of physical suffering, the overall acceptability level was high except when the act was performed by the physician without any expression by the patient of a desire to have his life ended (involuntary euthanasia); the Actor \times stated Desire interaction was significant, $F(1, 111) = 92.81$, $p < 0.001$. In the case of complete dependence without physical suffering, the acceptability

levels were slightly lower (11.13) than in the corresponding cases of physical suffering (13.68); this effect of the type of suffering was significant, $F(1, 111) = 51.57$, $p < 0.001$. In the case of psychiatric disease, the acceptability levels were also lower (12.67) than in the corresponding cases of physical suffering (16.40), but they were higher than in the corresponding cases of complete dependence (11.00). The effect of type of suffering was significant in both cases: $F(1, 111) = 63.70$, $p < 0.001$ and $F(1, 111) = 12.87$, $p < 0.001$, respectively. The mode of ending life (active versus passive) had no effect.

In the post-experiment interviews, all 11 lay participants said that disconnecting life support was different from and more acceptable than injecting a toxic substance.

The results for the health professionals are shown in figure 2. In the case of the nurse's aides (top panels), the overall pattern is similar to the one observed among the lay participants: the Actor, stated Desire, and Type of suffering factors were significant as well as the Actor \times stated Desire interaction ($p < 0.01$). The ranges of the mean values of acceptability for each scenario were, however, reduced: among the nurse's aides, the mean values ranged from 5.95 to 14.86, while among the lay people, they ranged from 4.84 to 19.90. The difference between the overall means (11.25 v 14.01) was significant, $F(1, 135) = 6.88$, $p < 0.01$. Complementary ANOVAs with nurse's aides versus lay people as an additional between-subject factor did not show significant interactions involving this factor.

For the nurses (centre panel), the overall pattern is less similar to that of the lay participants. In cases of both physical suffering and psychiatric disease, most acceptable to the nurses was when the patient committed the act without telling the doctor about his desire to have his life ended (suicide), and least acceptable was when the doctor performed the act when the patient had not informed the doctor of a desire to have his life ended (involuntary euthanasia). The Nurses/Lay participants \times stated Desire \times Actor interaction was significant, $F(1, 157) = 5.31$, $p < 0.01$. The stated Desire \times Actor interaction was stronger among the nurses than among the lay participants. As in the sample of nurse's aides, the range of mean values was less among the nurses (from 4.02 to 17.98) than among the lay people (from 4.84 to 19.90), and the difference between the overall means was significant (10.03 v 14.01), $F(1, 157) = 28.65$, $p < 0.001$.

The participating physicians (bottom panel) were more similar to the nurses than to the lay participants in their

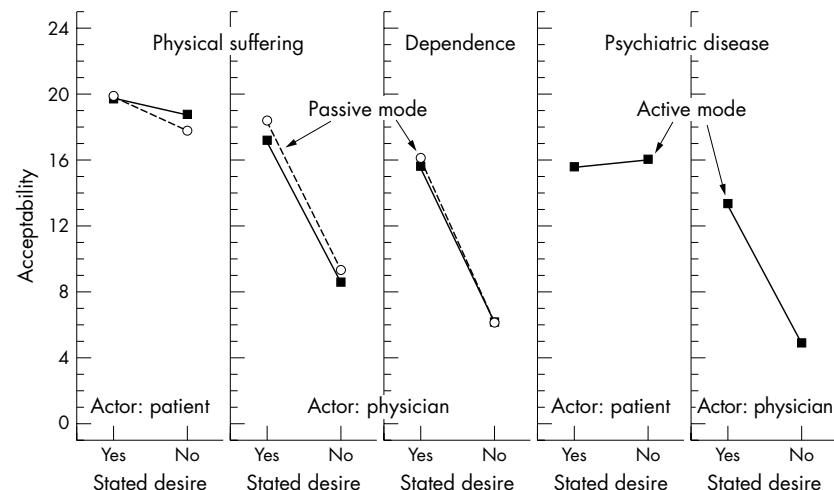


Figure 1 Lay participants' judgments of the acceptability of life ending actions. On vertical axis, mean acceptability ratings (on 0–24 response scale) of lay participants ($n = 115$). On horizontal axis, statement by patient in scenarios of desire to have his life ended (yes or no). First panel: patient with physical suffering (pain), patient as actor. Second panel: patient with physical suffering, physician as actor. Third panel: patient with complete dependence, physician as actor. Fourth panel: patient with psychiatric disease, patient as actor. Fifth panel: patient with psychiatric disease, physician as actor. Mode of ending life: filled squares = active (injecting a toxic substance), open circles = passive (detaching life support).

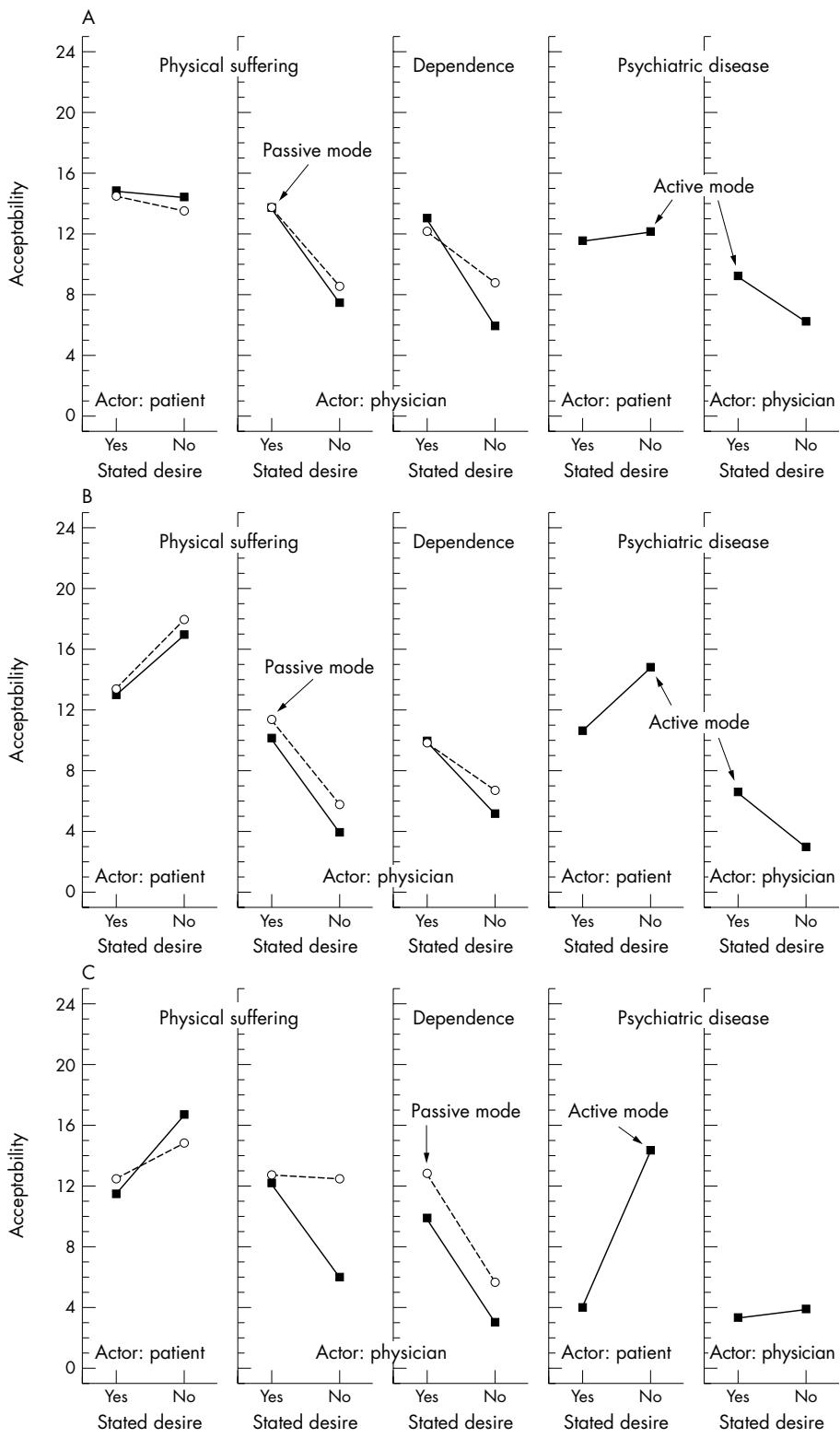


Figure 2 Health professionals' judgments of the acceptability of life ending actions. Composition of graphs as described in figure 1. Judgments of nurse's aides ($n=22$) on top row, of nurses ($n=44$) on middle row, and of physicians ($n=6$) on bottom row.

overall pattern. The main difference concerned the case of psychiatric disease. The only situation in which the physicians considered ending life as somewhat acceptable was when the patient performed the act without informing (or getting assistance from) the physician (suicide). As compared to the lay participants, the range of mean values (from 4 to 16.67) was lower, and the overall mean was

considerably lower (9.73 v 14.01). The small sample size (only six physicians), however, prevented us from performing any meaningful statistical analyses.

The age and sex of neither the lay participants nor the health professionals had any significant main effects, nor significant interactions with the other factors (though only four of the health professionals were male).

DISCUSSION

Lay participants

The acceptability for the lay people of a physician's intervention to end a patient's life was highest in situations of intractable physical pain, intermediate in ones of complete dependence, and lowest in ones of severe psychiatric disease. Similarly, prosecutors in the Netherlands were less likely to recommend an inquest in the case of intractable pain than in the case of loss of dignity (for example, complete dependence),²⁰ and numerous studies have underlined the importance of physical pain in people's end of life decision making.^{19 24 33 34} The other factors can, however, assume great importance for patients. Even if treatment of pain is often still inadequate,³⁵ improvements in palliative care may cause terminally ill people to seek assistance in dying more because of loss of autonomy, loss of dignity, and psychological distress than because of pain.^{25 36}

Acceptability was higher when the patient rather than the physician was the actor and when the patient informed the physician rather than not doing this. Thus, as expected,^{18 22} participants found PAS more acceptable than active euthanasia, even though some ethicists question the ethical validity of distinguishing between them.^{23 37} The most important determinant of acceptability in Cuperus-Bosma and colleagues²⁰ and Frileux and colleagues¹⁸ was the extent of patient requests for a life ending procedure; in the current study it was the patient's statement (or not) of a desire to have his life ended (as also found by Darley *et al*³³).

The patient's expression or not of a desire to have his life ended had a much stronger effect when the actor was the physician than when the actor was the patient. When the actor was the patient, the acceptability level was hardly modified by the presence or absence of a stated desire to die. Thus, for patients with intractable pain and severe psychiatric disease, suicide was as acceptable as PAS, and voluntary euthanasia (but not involuntary euthanasia) was nearly as acceptable as PAS. Some ethicists^{23 37} and other groups of lay people and patients^{18 27 39 40} also appear to make little moral distinction between voluntary euthanasia and PAS.

The mode of euthanasia—whether by passive means (withdrawal of treatment) or by active means (lethal injection)—had only a very small, non-significant effect on the judgments of acceptability. This finding is in accordance with the further contention of some medical ethicists that there is no moral difference between stopping a life preserving treatment and giving a life ending medication.^{37 41 42} The effect of mode may have been small in our study, as in real life, because it was examined in conjunction with other factors—notably, the type of suffering and the expression or not of a desire to die—that had much more impact on participants' views. Such an effect does not need to be very large when people are asked to judge between two factors; even if they prefer one by only a slight margin, it is enough to produce a choice. The post-experiment interviews showed that these participants did judge the mode of euthanasia as relevant when it was considered in isolation (with passive favoured over active). This finding illustrates that functional methodology, unlike other methodologies, enables researchers to infer, indirectly through participants' judgments of combinations of *a priori* relevant factors, the actual hierarchy of importance of the individual factors.

In summary, lay participants' responses were close to the "completely acceptable" end of the response scale (a) when a physically suffering patient performed the act him or herself, with or without requiring help from a physician, using passive or active means, and (b) when a physician directly ended the life of a physically suffering patient, using passive or active means, in accordance with the expressed desire of the patient to have his or her life ended. Their responses were

close to the "not at all acceptable" end of the response scale when, using passive or active means, a physician ended the life of a patient with a severe psychiatric disease or in complete physical dependence without the request of this patient.

Health professionals

Health professionals, as expected,⁴³ judged life ending actions as less acceptable than did lay people (whose mean rating was 14.0). The acceptability judgments of the nurse's aides were the highest (11.25), followed by those of the nurses (10.02) and of the physicians (9.72). Similarly, in Finland, 50% of the general public, 46% of the nurses, and 34% of the physicians agreed that euthanasia would be acceptable in some situations.⁴⁴ Nurses in neonatal intensive care units across Europe were slightly more likely than physicians to approve of the administering of drugs to end life (22% v 18%, $p = 0.009$).⁷ People may find it easier to accept life ending actions, especially morally questionable ones, when they are ordered or performed by others; the physicians would thus seem most likely to feel the emotional burden of such decisions. Physicians and, to a lesser extent, nurses would be more likely than nurse's aides to know about possible other treatments for patients' suffering. Nurse's aides receive the least medically oriented training; they are likely, therefore, to share the point of view of lay people, although altered by their more intimate interaction with patients and their families.

The highest acceptability was in cases of intractable physical suffering. This is in accord with US physicians' descriptions in 1996 of the patients whose requests for assistance in dying (by injecting or by writing a prescription for a lethal substance) they did and did not honour. Severe pain and physical discomfort other than pain were significantly associated with providing assistance in dying, whereas recent deterioration in functional status, dependence for most or all of personal care, and being bedridden were not.⁴⁵

The effects of three factors—the type of suffering (physical suffering, dependence, or psychiatric illness), the identity of the actor (patient or physician), and whether or not the patient expressed a desire to have his life ended—were significant and were, with the partial exception of stated desire, similar in pattern to the effects among the lay people. The nurse's aides had virtually the same pattern of judgments as the lay people. In contrast, among the nurses, stated desire had an overall weaker effect because of its opposite impact on the acceptability of physicians' and patients' actions. On the one hand, like the lay participants and nurse's aides, the nurses judged a physician action as more acceptable if the patient had told the physician about his desire (voluntary euthanasia) than if he had not (involuntary euthanasia). On the other hand, for the reasons discussed in the first paragraph of this section, the nurses, unlike the lay participants and nurse's aides, considered a patient action as more acceptable if the patient had not told his physician about his desire (unassisted suicide) than if he had asked and obtained assistance (PAS). The nurses judged a life ending action as acceptable only in the cases in which a physically suffering patient performed the act himself, without informing a physician, using passive or active means. Similarly, the six physicians in the study also judged unassisted suicide as the only acceptable procedure.

All three groups of health professionals judged it as unacceptable—that is, gave ratings close to the "not at all acceptable" end of the scale—when a physician ended the life of a patient suffering from physical pain or in complete dependence, using passive means (disconnecting life support) as well as active (giving a toxic injection), without knowing if the patient intended to end his life. They also

judged it as unacceptable when a physician ended the life of a patient suffering from a severe psychiatric disease, using active means, whether or not the patient had expressed a desire to have his life ended. In addition, the physicians (but not the nurse's aides or the nurses) judged it as unacceptable when, using active means, a patient suffering from a severe psychiatric illness ended his own life.

This study has several limitations. Firstly, the sample was only moderate in size (a total of 115 lay people and 72 healthcare professionals) and was restricted in geographical and cultural identity (as all were recruited in the city of Toulouse, France). Generalisation to people in France as a whole and in other countries must, therefore, be done with care. More particularly, the sample size of only six physicians makes it impossible to draw any conclusions about physicians' attitudes.

Secondly, the scenarios had limitations. The participants made judgments about hypothetical rather than real patients; it would be useful to study actual end of life decision making. The scenario patients were all men; to have added patient sex to the factors under study would have overburdened our participants, but it would be important in the future to learn how patient sex affects the acceptability of life ending procedures. Furthermore, it was impossible to include in the scenarios all of the important variables and their nuances. In particular, the representative of a "passive" type of intervention in the study—disconnection of a life support machine—still involves some action, in contrast to never starting a treatment (such as not inserting an endotracheal tube or not prescribing or administering an antibiotic). Physicians in various countries usually,^{46–48} though not always,⁴⁹ consider withholding life sustaining treatment as different from, and more acceptable than, withdrawing it. Future studies can investigate the impact on acceptability of these gradations between an active and a passive role.

In addition, the broader scope of this study prevented a direct comparison with Frileux *et al*¹⁸ about the impact on acceptability of the patient's stated wishes. Frileux *et al* asked to what extent the patient "requested" a life ending procedure. We asked instead whether the patient had stated a "desire" to have his life ended. Expressing a desire would seem a more general activity than making a request—the patient who desired to have his or her life ended could either tell the physician about this desire or not. At the same time, a direct request from a patient for a life ending intervention would be emotionally more intimate and powerful than a statement of the patient's desire. Further studies can clarify the importance of different aspects of a patient's expression of a desire to have his or her life ended.

CONCLUSIONS

In our sample of lay people and health professionals in France, life ending interventions—unassisted suicide, PAS, voluntary euthanasia, and involuntary euthanasia—are more acceptable to lay people than to health professionals. For both groups, however, acceptability is highest for patients with intractable physical suffering, intermediate for those in a state of total dependence, and lowest for those suffering from severe psychiatric disease, and acceptability is higher when patients end their own lives than when physicians end their patients' lives. When physicians perform the life ending actions, acceptability is much higher when the patients have expressed a desire to die (voluntary euthanasia) than when they have not (involuntary euthanasia). In contrast, when patients perform the action (in the cases of both physically suffering and psychiatrically ill patients), acceptability for the lay people and nurse's aides does not depend on whether the patient has expressed a desire to die (PAS) or not (unassisted suicide), while for the nurses and physicians unassisted

suicide (where the physician is unaware of the patient's desire) is more acceptable than PAS. Whether the life ending action is more active (injecting a toxic substance) or less active (discontinuing life support) has no impact on its acceptability.

It will be important to be aware of these differences in attitudes and in the salience of patient variables as patients, families, health professionals, and ethics consultants make decisions in individual cases; as medical ethicists and others prepare position statements; and as politicians, interest groups, and the public debate legislation about ending patients' lives.

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