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Legalised active assistance in dying: palliative care stakeholders' national e-consultation

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ABSTRACT

Objectives There is a growing debate surrounding the legalisation of medical assistance in dying (MAID). MAID is currently prohibited by the French law; however, the debate has recently been reinvigorated in France. This study aims to collect opinions of palliative care stakeholders (PCS) regarding the legalisation of MAID and to identify the factors associated with their opinions.

Methods We performed a transversal survey between 26 June 2021 and 25 July 2021, on PCS who were on the French national scientific society for palliative care. Participants were invited by email.

Results 1439 PCS took part and expressed an opinion about the legalisation of MAID. 1053 (69.7%) were against the legalisation of MAID. When forced to choose which option should be privileged if the law had to change, 3.7% favoured euthanasia, 10.1% favoured assisted suicide with provision of lethal drug by a professional, 27.5% favoured assisted suicide with prescription of a lethal drug and 29.5% favoured assisted suicide with provision of a lethal drug by an association. The opinion regarding legalisation of MAID was statistically different depending on the participant profession ($p<0.001$) and when comparing clinical and non-clinical positions ($p<0.001$). A quarter of participants (26.7%) believe that legalising MAID might lead them to change their current position.

Conclusions Overall, French palliative care professionals are against a modification of the current legal framework for legalising MAID but some might change their current position if a law was voted. This might destabilise the PCS demography that is already worrying.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ There is a growing worldwide debate surrounding the legalisation of medical assistance in dying, but the opinion of palliative care stakeholders remains unclear.

WHAT THIS STUDY ADDS

⇒ French palliative care stakeholders are in majority against a legalisation of any modality of medical assistance in dying.
⇒ If medical assistance in dying was voted, they would favour the legalisation of assisted suicide with the provision of a lethal drug by an association.
⇒ Whatever type of medical assistance in dying is voted, this could lead a third of the surveyed participants to consider quitting their positions.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Policymakers should consider avoiding the direct implication of healthcare professionals if they legalise medical assistance in dying.
⇒ Policymakers should consider the palliative care stakeholders' demography when deciding whether to legalise medical assistance in dying.

INTRODUCTION

There is a growing debate surrounding the legalisation of physician-assisted dying across the world.¹

Active assistance in dying encompasses various practices including (1) euthanasia, corresponding to the voluntary termination of a person's life at their request and (2) assisted suicide,

defined as suicide carried out with help of another person.¹ Euthanasia is currently legal in four European countries, including the Netherlands, which was the first country in the world to legalise euthanasia in 2002 followed by Luxembourg, Belgium and Spain.^{2,3} Assisted suicide is now legal in the Netherlands, Luxembourg, Switzerland, Austria and Spain.³ In addition, some countries have decriminalised assisted suicide or euthanasia without having explicitly legalised these practices.^{4,5} For many other countries, this remains highly debated.¹

In France, the Claeys-Leonetti law France, the Claeys-Leonetti law (2016) prohibited medical assistance in dying (MAID) but allowed doctors to provide continuous deep sedation until death as a form of symptom control when no other solution was available.^{6,7} Since sedation until death cannot be granted to patients with life-threatening disease without unbearable suffering, nor to patients with average life expectancy, this right cannot address all issues of end of life. In addition, the Claeys-Leonetti law is still poorly understood by the public and many health professionals, which results in unmet needs at the end of life. For these two reasons, the legalisation of a form of active assistance in dying remains a hot topic in French social debates, periodically fuelled by high-profile situations. To illustrate that point, when voting the law *for a free and chosen end of life*, the French parliament succeeded in passing article 1 without being able to fully adopt the law, preventing it from any practical application.⁸

The French presidential elections of May 2022 and the legislative elections of June 2022 have revived the debate. For this reason, it is essential to question health professionals working on a daily basis with patients potentially concerned by these new rights, in particular, palliative care professionals (PCP), to be able to hear their voices in the debate.

Our study aimed to survey PCPs on their acceptance of a possible change in the legislative framework to legalise active assistance in dying and to identify the factors associated with their opinion.

METHODS

We carried out a mixed-method cross-sectional study between 26 June 2021 and 25 July 2021 on the PCP to assess and explain the acceptability of a change in the legal framework to legalise MAID in France.

Objective

The main objective of the study was to assess the opinion of palliative care providers—professionals and volunteers—regarding a change in the legal framework to legalise MAID in France.

The secondary objectives were to identify the factors associated with a position regarding the legalisation of

MAID and the expected consequences it might have on the practice of palliative care.

Participants

The French Society for Support and Palliative Care (SFAP) is the French national scientific society bringing together all palliative care providers. The SFAP regularly updates the list of PCPs who have been members of the SFAP, have participated in an event organised by the SFAP or have contacted the SFAP for any reason. The result is a list of 39 000 professionals and volunteers involved in the palliative care movement.

All participants received an email in June 2021.

Procedure

Participants were invited by email in June 2021 to participate in the survey anonymously. A reminder was sent 2 weeks later.

The survey was conducted on the internet. It was open from 26 June 2021 to 25 July 2021.

Survey

The scientific committee of the SFAP developed the survey. This committee is composed of various professional backgrounds and professionals strongly involved in the provision, research or teaching of palliative care.

The survey was designed to avoid leading questions, but some questions were intended to force participants to express an opinion on legalising active assistance in dying and, if so, which option they would prefer. It was divided into four sections.

The first section collected the sociodemographic data. SFAP membership status was also recorded to analyse any selection bias.

The second section focused on participants' opinions and knowledge of the current legal framework for end-of-life care. The third sought to gauge participants' views on any changes to the current legal framework legalising MAID and, if so, which option they would prefer. The final section explored whether participants wonder whether the current legal framework would change to legalise MAID, and whether participants think this might affect their work and their decision to stay in their current position.

The English translation of the survey is provided in the supplementary files (online supplemental file 1).

Analyses

Statistics

Descriptive statistics were carried out to describe the sample and the opinion on a modification of the current legal framework legalising MAID.

Then, we used a χ^2 test to assess the association of several sociodemographic and professional factors with the opinion on a modification of the current legal framework legalising MAID.

For the static analysis, and in order to explain the position on a modification of the current legal framework

legalising MAID, the participants who answered 'yes' and 'conditional yes' were grouped together. Missing data were excluded from the analyses.

We applied Bonferroni's correction to modify the significance level based on multiple comparisons. As we had planned to perform 13 tests and set the baseline statistical significance at 0.05, the threshold for statistical significance was set at 0.004.

If a comparison revealed a significant difference, then we defined a virtual modality corresponding to the average results of the other modalities. We used this virtual modality to compare each variable pair by pair to highlight which variable is statistically different from the average.

We applied the Bonferroni correction for each sub-comparison.

IBM SPSS Statistics V.21.0 software was used to perform the statistics.⁹

RESULTS

There were 1871 participants, 348 were non-professionals, or 1523 participants involved in palliative care who answered the questionnaire.

Eighty-four participants did not comment on the legalisation of MAID and were, therefore, excluded from the statistical analyses, that is, 1439 surveys analysed.

The characteristics of the participants are described in [table 1](#).

Opinion concerning a modification of the legal framework to legalise MAID in France

The vast majority of participants were against the legalisation of MAID (N=1053; 69.7%). Three hundred and eighty-six (25.5%) participants were in favour of a change in the legal framework to legalise a form of MAID. Among them, 324 (83.9%) were in favour of such a change but only under certain conditions. Seventy-two (4.8%) had no opinion on that matter ([table 2](#)).

When forced to choose which option would be preferable if the law changed, participants were 3.7% in favour of euthanasia, 10.1% in favour of assisted suicide with the provision of a lethal drug by a professional, 27.5% in favour of assisted suicide with provision of a lethal drug by an association (as in Switzerland) and 29.5% in favour of assisted suicide with prescription of a lethal drug with self-administration by the patient.

Factors associated with taking a position regarding the legalisation of MAID and the expected consequences it could have on the practice of palliative care

Sociodemographic and professional variables

The opinion on the legalisation of MAID is not significantly dissimilar between the different age groups nor on the status of affiliation to the SFAP (online supplemental file 2).

Table 1 Description of the population (missing data were excluded)

| Characteristic | Number (%) |
|---------------------------------------|------------|
| SFAP members | 620 (43.1) |
| Others | 819 (56.9) |
| Age (years) | |
| <30 | 79 (5.5) |
| 31–45 | 433 (30.1) |
| 46–60 | 503 (35) |
| >60 | 420 (29.2) |
| Position | |
| Physician | 383 (26.6) |
| Nurse | 477 (33.1) |
| Nurse assistant | 45 (3.1) |
| Psychologist | 145 (10.1) |
| Social worker | 15 (1.0) |
| Volunteer | 279 (19.4) |
| Other healthcare provider | 95 (6.6) |
| Place of work | |
| Palliative care unit | 361 (25.1) |
| Palliative care consultation team | 360 (25.0) |
| Other hospital ward | 142 (9.9) |
| Identified palliative care bed | 96 (6.7) |
| Nursing home | 100 (6.9) |
| Hospital at home | 109 (7.6) |
| Palliative care network | 95 (6.6) |
| Other | 176 (12.2) |
| Experience in palliative care (years) | |
| < 2 | 139 (9.7) |
| 2–10 | 523 (36.3) |
| > 10 | 519 (36.1) |

Participants' opinion was significantly different by participants' occupation ($p<0.001$; [table 3](#)); however, none had a significant difference with the average opinion represented by a virtual modality. Professionals practising in clinics were 78% against a modification of the current legal framework, while those exercising non-clinical functions were 66% ($p<0.001$) ([table 3](#)).

Knowledge of the current legal framework for end-of-life care and the limits identified

Nine hundred and two (62.7%) believe that they know precisely the legal framework in force, 13 (35.6%) believe that they know it well and eight (0.6%) do not know it.

Sixty-three (4.4%) feel that other professionals know it precisely, 1187 (82.5%) that other professionals know it extensively and 146 (10.1%) that other professionals do not know the applicable law. Thirty-eight (2.6%) answered that they do not know how the current legal framework is known to other professionals.

Four (0.3%) feel that patients know the law in vigour precisely, 739 (51.4%) that patients know it

Table 2 Opinions on the different options for medical assistance in dying (MAID) if there were the legalisation of MAID (no missing data)

| Type of MAID | N (%) |
|--|-------------|
| Euthanasia | |
| For | 53 (3.7) |
| Against | 1386 (96.3) |
| Assisted suicide with provision of lethal drug by a professional | |
| For | 145 (10.1) |
| Against | 1294 (89.9) |
| Assisted suicide with prescription of a lethal drug | |
| For | 396 (27.5) |
| Against | 1043 (72.5) |
| Assisted suicide with provision of lethal drug by an association | |
| For | 424 (29.5) |
| Against | 1015 (70.5) |

extensively and 651 (45.2%) that patients do not know it. Forty-one (2.8%) answered that they did not know how the current legal framework is known by patients.

Two (0.1%) feel that the public knows it precisely, 499 (34.7%) that the public knows it extensively and 906 (63.0%) that the public does not know the current law. Twenty-seven (1.9%) answered that they did not know how the current legal framework is known by other professionals.

Three hundred and four (21.1%) estimate that they have encountered situations at the limit of the current legal framework (where the current law was not able to respond correctly to the needs of patients) in their daily practice. Six hundred and fifty-eight (45.7%) believe that they have sometimes encountered these situations, 284 (19.7%) feel that they have never been confronted with such situations. One hundred and seventy-nine (12.4%) feel that they are not concerned by this statement.

Most participants believe that a new law on end-of-life care will soon be adopted, 99 (6.9%) have no doubt about it while 959 (66.6%) think it is likely. Only 19 (1.3%) are sure that no law will be passed in the near future and 341 (23.7%) think it is unlikely.

Estimated impact on working life

Four hundred and four participants (26.7%) feel that they could quit their job if the current legal framework changed in favour of medical assistance, 407 (26.9%) would invoke their conscience clause to avoid applying the new law but would remain in their current position.

Factor associated with the opinion on a modification of the current legal framework for the legalisation of MAID

The workplace is statistically associated with the opinion concerning a change in the legal framework ($p < 0.001$). Professionals working in palliative care units, beds dedicated to palliative care, and home hospitals are more than 80% against a modification of

Table 3 Association of the occupation with the opinion on a modification of the current legal framework for legalising medical assistance in dying (missing data were excluded)

| | Occupation | | | | | | | Overall comparisons χ^2 ; ddl (p*) |
|---|------------------|-------------------|-----------------------|----------------------|----------------------|-------------------|------------------------|--|
| | Nurse (N=477) | Physician (N=383) | Care assistant (N=45) | Psychologist (N=145) | Social worker (N=15) | Volunteer (N=279) | Other caregiver (N=95) | |
| In favour of legalising MAID | 95 (20%) | 93 (24%) | 15 (33%) | 46 (32%) | 4 (27%) | 97 (35%) | 36 (38%) | 30.5; 6 (p<0.001) |
| Comparison with the virtual modality (27% of yes and 73% of no) (χ^2 ; ddl (p †)) | 382 (80%) | 290 (76%) | 30 (67%) | 99 (68%) | 11 (73%) | 182 (65%) | 59 (62%) | |
| | 2.49; 1 (p=0.11) | 0.31; 1 (p=0.57) | 0.60; 1 (p=0.44) | 0.63; 1 (p=0.43) | <0.01; 1, p=0.98 | 2.0; 1 (p=0.15) | 2.6; 1 (p=0.10) | |

*Statistical significant level following the Bonferroni correction $p < 0.004$.

†Statistical significant level following the Bonferroni correction $p < 0.007$.

MAID, medical assistance in dying.

the current legal framework. Professionals working in mobile palliative care consultation services and other hospital services are less than 70% against a modification of the current legal framework (table 4).

The professional experience in palliative care was not associated with an opinion (online supplemental file 3).

DISCUSSION

Our objective was to gather the opinion of PCPs and volunteers on a possible evolution of the current legal framework for legalising MAID in France. Second, we sought to highlight the factors associated with positive or negative opinions concerning this potential change, and the impact it could have on the practice of palliative care in France. To our knowledge, this is the first time that a study has reported the opinion of professionals working in palliative care on the legalisation of MAID.

Our study has shown that, in the current context, most French PCPs and volunteers are statistically opposed to legalising any form of MAID. In the current legal framework medical aid in dying, if the participants had to choose an option, most of them would go for assisted suicide with the provision of a lethal drug by an association and less than 5% for euthanasia.

The context of end-of-life support is changing around the world, and many countries where no form of medical aid in dying exists are now being pushed to legislate by increasingly favourable public opinion.¹ The situation has recently been reinforced by the presidential and legislative elections this year, 2022. Following the electoral promises, the current French president called for a public consultation to legally debate whether or not the MAID should be granted. Unfortunately, no specific professional consultation is yet planned. Our study highlights the opinion of professionals and will, therefore, introduce their point of view into the public debate: the majority of PCPs are opposed to the legalisation of MAID while a quarter would be in favour of it. In the event of current legal framework changes, professionals would prefer assisted suicide supported by an association (as is currently the case in Switzerland). Very few favoured the option of euthanasia. The work in progress has also collected a huge amount of qualitative data that will be analysed to shed light on the motivations of the participants on this point.

This result aligns with other reports on the PCP but¹⁰ contrasts with French surveys on doctors where 42% said they were favourable to a form of medical assistance to death, and 29% would be favourable depending on some conditions.^{11 12} We believe that, as indicated by the European Association for Palliative Care in 2015, this could be due to different ‘incompatible normative frameworks’ between professionals who do not take care of end-of-life patients daily and those who are PCPs.¹³ We think that this result can be

Table 4 Association of the place of work with the opinion on a modification of the current legal framework for legalising medical assistance in dying (missing data were excluded)

| | Geographical location of the place of work | | | | | | | | | | |
|------------------------------|--|---------------------------------------|---|----------------------------------|-----------------------------|--------------------------|---------------|---------------|---------------|-------------|--------------------|
| | Palliative care unit (N=361) | Dedicated palliative care bed* (N=96) | Mobile palliative care consultation service (N=360) | Palliative care network † (N=95) | Other hospital ward (N=142) | Hospital at home (N=109) | Other (N=176) | Urban (N=630) | Rural (N=282) | Mix (N=500) | χ^2 ; ddl (p) |
| In favour of legalising MAID | 68 (19%) | 15 (16%) | 113 (31%) | 25 (26%) | 52 (37%) | 17 (16%) | 63 (36%) | 168 (26.7%) | 83 (29.4%) | 127 (25.4%) | 1.5; 2 (p=0.47) |
| | 293 (81%) | 81 (84%) | 247 (69%) | 70 (74%) | 90 (63%) | 92 (84%) | 113 (64%) | 462 (73.3%) | 199 (70.6%) | 373 (74.6%) | 44, 8; 7 (p<0.001) |

* The French healthcare system has bed in the medical units that are dedicated to palliative situations outside of the Palliative Care Units which are dedicated to the most complex situations.

† The French healthcare system has palliative care networks in some regions. The network act as coordinating teams for the care of palliative patients. MAID, medical assistance in dying.

explained by the fact that the framework of palliative care is deeply rooted in accompanying life to its ending and fundamentally seen as incompatible with practising MAID. This incompatibility in the paradigms of palliative care and MAID has also been identified by others.¹³ In a study examining the involvement of palliative care teams in euthanasia requests in Flanders, Dierickx *et al* note that euthanasia and palliative care are not contradictory in practice.¹⁴ Although we agree that palliative care could be involved in the care of patients asking for euthanasia, we assume that the involvement of palliative care teams in almost 60% of requests to Euthanasia requests for euthanasia does not indicate the lack of fundamental incompatibility. Nevertheless, it remains very difficult to define the right place of palliative care in the MAID processes and a very large panel of relations between palliative care and the MAID exists in countries where MAID is legal.¹⁵ In our opinion, we believe that during the MAID requests, palliative care plays a role in the evaluation of patient suffering and support to provide patients with complete information on their therapeutic options. This role contributes to helping the patient to make his/her choice.

As our study involved professionals working in palliative care establishments, they have experience in the field to support dying patients. Interestingly, most of them said they met situations where the current legal framework was insufficient; however, they were opposed to changing this restrictive framework. Curiously, this experience in the field has not led professionals to wish for a change in the law. As previously indicated by others,¹⁶ we assume that most professionals may fear that this option is an awkward response to the question of providing equal and largely available palliative care. Indeed, following more than 20 years of failure of French policies promoting palliative care,¹⁷ legalising MAID could undermine the development of palliative care in already unequal territory.¹⁸ Such concern has already been reported by PCP in countries where MAID is legal,^{19 20} and arguments, such as the large increase in MAID in European countries where it is legal, support this idea.^{21 22} However, counterexamples exist,^{21 23} such as in Oregon where palliative care has grown alongside a rather stable rate of medically assisted deaths.²¹ For these reasons, along with others,²¹ we plead for the widening of access to palliative care as a priority before any modification of the legal framework for supporting the dying patients.

The limits of palliative care to the cessation of suffering have been questioned elsewhere as an argument against MAID. Above all, existential suffering, one of the main reasons for requesting MAID,²⁴ is often mentioned. However, as others have argued, the lack of palliative care research and therapies could lead to this problem.²⁵ Therefore, we would argue that an adequate answer to such issues would be to promote

palliative care research and education to enable mitigating patient suffering.

We looked for factors that would be associated with an opinion of MAID. In our cohort, palliative care experience or age was not associated with opinion. However, professionals had different opinions on MAID; nurses and doctors were statistically more reluctant towards MAID than other professionals. Another factor associated with an opinion was the workplace, while workers in palliative care units identified palliative care beds (beds dedicated to the provision of palliative care in services that are not labelled as palliative care) and home hospital structures were reluctant to MAID. While mobile palliative care teams, palliative care networks and other hospital services were more likely to MAID, both results raise the question of whether there might be a commonality that would explain these results. Our hypothesis is that clinical proximity to palliative care patients (having clinical work or providing daily care to end-of-life patients) is the key to interpreting these results; professionals in closer contact with end-of-life patients would be more reluctant to legalise MAID. This should only be taken as a hypothesis as we have specifically explored this point and especially since we have not identified a statistical association between opinions on MAID and the fact of having experienced situations that come up against the limits of the current framework.

Furthermore, our study raises concerns about the demographics of PCPs. The opinion of the participants cannot be interpreted as an opposition without consequence but rather as a fundamental opposition to the MAID. Indeed, most participants expressed that they would not participate in MAID if they were legalised, and some would even quit their jobs if they were. This is a turning point as the current demography of PCPs on French territory is decreasing worryingly while the expected population requiring palliative care continues to increase in many countries.^{26–28} Therefore, a change in the current legal framework represents an additional risk of undermine a health sector that is already struggling to provide quality and equal care to patients who need it.

Finally, this overall defiance of our participants towards MAID questions the perception they have of their duties in the context of MAID and their duties to patients and the society. In a quite old, but still enlightening opinion, Randall discussed the impact of medical involvement in MAID requests assessment and of the action of euthanasia.²⁹ She defends that legalising euthanasia might challenge the basic principles of beneficence when they are balanced with the principle of autonomy.

Additionally, she argues that the involvement of doctors in euthanasia decisions would imply a series of judgement on the patient's ability to be fully able to make such a decision without external influences (such as the feeling of being a burden for others), which

should not rely on one individual judgement. She finally questioned the potential threats to the patient–doctor relationship all along the disease trajectory if doctors were involved in MAID decisions.

In addition to Randall’s remarks, we would also add another ethical principle that could be tricky to be addressed in the eventuality of a modification of the law: the principle of equity. In the eventuality of a legalisation of MAID, it would be implied that the society should offer access to MAID all over the country. Informed by our results, it is very unlikely that patients all over the country will have equal access to MAID if the law reaffirms the right of withdrawals for professionals that do not want to participate in MAID processes. It looks like an unsolvable issue as this would entail forcing the professionals to participate which, in return, could be considered as threatening the medical autonomy. All above-mentioned considerations might have been, at least partially, involved in our participants’ opinion.

Our study suffers from an important limit that is related to the restricted options to several questions. This was led by two different strategies from the steering committee, the first one was to discuss only the options currently considered by the French government in the perspective of a change of the current legal framework, and the second one was a wish to force the participant to take a choice rather than avoiding taking a decision.

Limitations

Our study reports on a transversal survey collecting only the opinions of participants who consented to participate in the study. The topic is so controversial that selection bias may have been introduced into the sample of participants to support the results.

Furthermore, due to the way the study was disseminated, we were unable to ascertain why many of the invited participants chose not to participate in the study. This information was important for further interpretation of the results.

CONCLUSION

Palliative care officials in France are overwhelmingly opposed to legalising all forms of medical euthanasia. However, if the current French legal framework was to change, they would support the legalisation of assisted suicide by the provision of lethal drugs by associations.

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