Pressure in dealing with requests for euthanasia or assisted suicide. *Experiences of general practitioners*

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ABSTRACT

The majority of Dutch physicians feel pressure when dealing with a request for euthanasia or physician-assisted suicide (EAS). This study aimed to explore the content of this pressure as experienced by general practitioners (GP). We conducted semistructured in-depth interviews with 15 Dutch GPs, focusing on actual cases. The interviews were transcribed and analysed with use of the framework method. Six categories of pressure GPs experienced in dealing with EAS requests were revealed: (1) emotional blackmail, (2) control and direction by others, (3) doubts about fulfilling the criteria, (4) counterpressure by patient's relatives, (5) time pressure around referred patients and (6) organisational pressure. We conclude that the pressure can be attributable to the patient–physician relationship and/or the relationship between the physician and the patient's relative(s), the inherent complexity of the decision itself and the circumstances under which the decision has to be made. To prevent physicians to cross their personal boundaries in dealing with EAS request all these different sources of pressure will have to be taken into account.

INTRODUCTION

Since 2002, euthanasia or physician-assisted suicide (EAS) is regulated in the Dutch law (the Termination of Life on Request and Assisted Suicide Act). The act entails that physicians may go unpunished if they perform EAS according to the formulated criteria of due care, of which criteria 1–4 are the main patient-related criteria (see box 1).[1] Even if all criteria are met a physician is never obliged to perform EAS.

Another crucial aspect of the Dutch euthanasia act is that it, to a large extent, consists of 'open norms'.[2] For example, answering questions like 'what is unbearable suffering?' or 'what is a voluntary and well-considered request?' is left to the interpretation of the physicians applying the law. Although physicians might find some guidance in literature, earlier court decisions and decisions by the review committees on prior cases, physicians do experience difficulties in interpreting the criteria in practice.[3] The act mentions no restrictions relating to the cause of suffering. Although most requests for EAS come from patients with cancer or other physical diseases,[4 5] over the years an increase of requests of also patients with early-stage dementia and psychiatric conditions is seen. In the latter cases assessing the requirements of the voluntary nature of the request and the lack of a reasonable alternative is much more difficult. However, it is thought that people with these conditions may also suffer unbearably and might also fall within the scope of the law.[6 7] In 2017, of all reported cases of EAS in the Netherlands, 2.5% suffered from early dementia, and 1.3% from a psychiatric disease.[8]

The Netherlands is a country among the top in Europe with regard to public euthanasia acceptance.[9] Yet the voices of advocates of EAS in the society are still becoming stronger[10] and the general public is found to have a more permissive attitude towards EAS than physicians, in the exceptional cases just mentioned, and in patients who are 'tired of living' (in the absence of severe disease).[11–13]

Against this background, situations may arise in which physicians feel pressure to deal with EAS requests.[10–12] Although physicians feel that dealing with this pressure is part of their professional obligation, the impact is high,[14 15] and it leads many general practitioners (GP) to want to avoid this demanding experience.[16] A survey performed in 2014 among 455 participating physicians (response rate 13%) showed 70% of them experienced pressure to grant a request for euthanasia, and 64% of them felt an increase of this pressure over the last years.[17] However, little is known about the content of this pressure. In practice, of all physicians, GPs are those most confronted with euthanasia requests. Approximately 85% of all reported euthanasia cases to the review committees come from GPs.[18 19] Therefore, this study focused on exploring the pressure experienced by GPs, hereby contributing to a better understanding of its complexity in the work of GPs.

METHODS

Explorative qualitative interviews with Dutch GPs, focusing on cases in which they experienced pressure in dealing with an EAS request. The experience of pressure was left to the interpretation of the interviewee. It could be anything, in relation to EAS requests, that caused him or her to experience discomfort, unease or sleepless nights.

Participants

GPs were recruited through the academic networks of general practice of the departments of general practice of Amsterdam UMC (Vrije Universiteit Amsterdam), University Medical Center Utrecht and Leiden University Medical Center, reaching a total of approximately 420 GPs. Direct mailings and additional information in newsletters invited them to complete a short questionnaire about characteristics of the GP and their practice, their experience with EAS and willingness to participate in an interview about this topic. The questionnaire

Box 1 Criteria of due care

The statutory due care criteria say that the physician must:
1. Be satisfied that the patient's request is voluntary and well considered.
2. Be satisfied that the patient's suffering is unbearable, with no prospect of improvement.
3. Have informed the patient about their situation and prognosis.
4. Have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation.
5. Have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out above have been fulfilled.
6. Have exercised due medical care and attention in terminating the patient's life or assisting in the patient's suicide.

was used to maximise variation (years of experience, solitary or group practices, urban vs rural areas). Data collection for the interviews took place on the basis of the principles of constant comparison and the purposive selection of participants (purposive sampling),[20] that is, those who would be able to provide specific information relevant to the subjects of investigation. Exclusion criteria for the interview were: principle objections against EAS (eg, for religious reasons) and no experience with EAS.

Interview

The participating GPs were invited to talk about each case in which they had experienced some sort of pressure in dealing with an EAS request. The semistructured in-depth interviews were guided by a topic list which included: when the pressure was experienced, what the source of the pressure was and how this affected the GP in question. GPs were also asked about their general views on pressure generated by EAS requests. The interviews were all conducted by the same researcher (MEdeB) between March and November 2016. All interviews were recorded and anonymously typed verbatim.

Analysis

Data are analysed with use of the framework method,[21] consisting of the following steps: (1) transcription, (2) reading and re-reading interviews, (3) coding of the text segments by two researchers independently (MEdeB and MdenB), (4) development of an analytical framework (consensus is reached about codes and categories in repeated discussion of the researchers (MEdeB and MdenB)), (5) applying the framework to all interviews (MdenB and MEdeB), (6) structuring data in a 'framework matrix' (tables including GPs, categories and summarised data) (MdenB and MEdeB) and (7) interpretation of data (from the matrix plus additional notes) (MEdeB and MD). Data analysis is supported by atlas.ti (for coding) and Excel (for matrixes). Findings were presented to the other members of the research team (BDOP and CMPMH) and discussion resulted in further clarification, verification and interpretation of the results.

RESULTS

The questionnaire was returned by 44 GPs of which 22 were eligible for an interview. After 15 interviews (see table 1 for characteristics) saturation with regard to the sorts of pressure described by the GPs was reached.

The 15 GPs described a total of 36 cases of EAS request in which they experienced pressure. In the analysis process and the development of the framework all expressed feelings of pressure were taken into account regardless of their effect on how the EAS request was dealt with. Profound analysis of all transcripts revealed the following categories of pressure GPs experienced: (1) emotional blackmail, (2) control and direction by others, (3) doubts about fulfilling the criteria, (4) counterpressure by patient's relatives, (5) time pressure around referred patients and (6) organisational pressure.

Table 1 Characteristics of interviewed GPs

GP	Sex	Age group	Working year categories	Practice type	Urban/rural area	Performed euthanasia?	Experienced pressure around EAS request
1	F	51–55	11–15	Health centre	Urban	Yes	Multiple times
2	M	51–55	16–20	Health centre	Moderate urban	Yes	Once
3	M	46–50	11–15	Multiple GPs	Urban	Yes	Once
4	M	56–60	26–30	Health centre	Urban	Yes	Once*
5	F	46–50	16–20	Multiple GPs	Urban	Yes	Multiple times*
6	F	41–45	6–10	Group practice	Urban	Yes	Multiple times
7	M	56–60	31–35	Multiple GPs	Rural	Yes	Multiple times
8	M	46–50	16–20	Multiple GPs	Moderate urban	Yes	Multiple times
9	F	36–40	6–10	Multiple GPs	Moderate urban	Yes	Multiple times
10	F	61–65	31–35	Multiple GPs	Rural	Yes	Multiple times
11	F	51–55	21–25	Multiple GPs	Moderate urban	Yes	Multiple times
12	M	46–50	11–15	Multiple GPs	Moderate urban	Yes	Multiple times
13	M	61–65	36–40	Multiple GPs	Moderate urban	Yes	Multiple times
14	M	36–40	6–10	Health centre	Moderate urban	No**	Once
15	M	51–55	21–25	Health centre	Moderate urban	Yes	Multiple times

*Including pressure not to perform euthanasia.
**In contrast with what was specified in the questionnaire, the interview revealed this GP did not perform euthanasia, but did experience pressure around an EAS request he was professionally involved in.
EAS, euthanasia or physician-assisted suicide; GP, general practitioner.

Emotional blackmail

GPs experienced pressure in cases where they felt emotionally blackmailed to perform EAS as if it were the patients' right. This may be patient's threatening to commit suicide: 'If you do not help me this week I will have to jump' (Case 2.3); family members threatening to murder the patient: 'Well, will I have to do it myself then, will I have to put a pillow over her head? And then you will be the guilty one' (Case 9.1); or jointly by patient and family: The patients says: 'I want it [euthanasia] now, or else I will hang myself from the bridge,' to which the partner of the patient reacts by saying: 'he will do it for real' (Case 6.2). Another example was formed by patients and/or families who tried to question the GP's integrity. GPs are reminded of their earlier promises in such a way that it is implicitly suggested they are unreliable doctors if they do not fulfil these earlier promises. For example: 'You have promised me back then to help me when I asked for it [euthanasia], and now I ask for it you want time to think it over or something like that. What is it that you want at this point?' A last example came from a patient who challenged his GP: 'You are scared to do it, aren't you?' (Case 3.1).

Control and direction by others

There are also situations where the patient feels so convinced that he/she is in control of the euthanasia process that they take direction right away, without any prior efforts to persuade the GP, such as the ones described above. For example, in the case where the GP was still in the process of willingness to discuss euthanasia in due time and the patient suddenly said: 'I have made up my mind, I want it [euthanasia] after my birthday, because I still want to celebrate my birthday.' At this point, this GP started 'feeling pressure, because she [the patient] very much took over control' (Case 5.1). In another case, a 'well-educated lady with a strong character' made it clear to the GP that she had organised herself very well. Her advance directive for euthanasia was ready and handed to a notary and she notifies the GP: 'My daughter is also present at the meeting [discussion about euthanasia] and she works for the Dutch Health Care Inspectorate (IGZ), and my other daughter is married to a professor, and he will be there too' (Case 8.1). The GP in this case felt 'You get less space to form your own judgement, which makes it less easy to get the feeling that you also support this [euthanasia]' resulting in 'quite a disturbing experience.' Even after the decision to grant the euthanasia request a GP may feel herself 'entering a theatre play' on the day of the euthanasia: 'The whole table was surrounded with friends who were smoking and drinking. On the table lay all sorts of jewelry that were to be divided; whether K [trainee GP] and I [GP] would want to select a nice necklace as well?' (Case 5.1). Another GP described his unpleasant feeling when the patient who was about to receive euthanasia opened the door himself and led the GP into the living room which was full of people as if it was a birthday party: 'Everybody had a glass of wine in his hands, while I was preparing the euthanatica' (Case 13.3).

Doubts about fulfilling the criteria

GPs reported also to experience pressure, in case they had doubts about fulfilling the legal criteria for EAS. One GP provided the example of a patient who was suffering from increasing dependency and loss of control: 'I needed multiple meetings and time for myself to feel this [type of suffering] was enough for euthanasia.' Looking back she felt forced to make a decision in a situation which to her felt as 'too soon' (Case 11.2). Another GP told about how she questioned herself whether the request for euthanasia of a patient with metastatic colon cancer was perhaps grounded in fear and 'Can unbearable fear be a ground for euthanasia?' She sighed: 'In the acute moment you are actually on your own [to decide]' (Case 6.3). How difficult it can be to make such decisions is also illustrated by a situation in which the patient withdrew his request for euthanasia in the very last moment. Instead of a feeling of relief for this GP 'in doubt,' the GP explained she felt 'used' to the extent that she could no longer continue to be the patient's GP (Case 11.1).

Counterpressure by patient's relatives

Another reported form of pressure arises when there is counterpressure by the patient's relatives, which potentially complicated the decision-making process. In these cases, the GP is in principle prepared to grant the request of the patient, but experiences pressure of the patient's relatives who oppose strongly to the euthanasia. One GP counteracted this pressure by encouraging the patient to explicitly state to her partner: 'I am dying, not you, and I am the one making this decision' (Case 4.1). Another GP decided ultimately to not grant the EAS request because she did not want to 'give your [the patients] wife a unacceptable problem and huge grief to [his] children,' but was left with the feeling 'we could have saved him [the patient] from dreadful weeks' (Case 5.3).

Time pressure around referred patients

There are cases where the GP feels pressured by the circumstances of a referred patient, with whom he/she lacks time to develop a trusting relationship. Looking back a GP reacted by saying: 'Like this, I will never do it [euthanasia] again' (Case 6.1). While the patient felt 'I have already talked this through and I want it [euthanasia] now,' the GP found herself at the beginning of the decision-making process because this patient was just referred to her. Another GP described a patient who had 'moved' to one of his colleagues because they did not bond very well. Unfortunately, this colleague was not able to work around the moment the euthanasia was planned to be performed. The GP told: 'Then I took back the euthanasia case of this patient, and I experienced it as a very annoying euthanasia.…I rather had not performed this euthanasia' (Case 4.3). The GP felt he had no other option than to continue the euthanasia process his colleague already started.

Organisational pressure

Many GPs made reference in general terms to the difficulty of combining a euthanasia case with the daily work in their GP practice. All the arrangements to be made with regard to the pharmacy and the planning of consultations with other patients are referred to as 'organizational hassle.' GPs also remarked: 'It [euthanasia] takes more time than we get refunded and 'it takes a lot of energy and thinking.' One GP remarked: 'I have not yet dared to do 'a euthanasia' in the morning, and then do consultations in the afternoon. I always plan it in the afternoon. I make sure I have the afternoon off for it.'[3] Euthanasia may also interfere with a GP's family life, as explained by a GP who became very introvert and not very nice around the time cases took place, even to the extent that his wife had told him, 'I do not want you to do that anymore.'[7] Or a GP who described how he tried to be available for a patient even during a 3-day training course elsewhere: "(I had) to go back to do this euthanasia. […] I traveled to G in the morning, a 2-hour train ride, I arranged in the train everything was done and all things were ready to proceed, I went to perform this euthanasia, and the same evening I returned [to the training course]. And I thought 'never again like this'" (Case 12.2).

DISCUSSION

This article gives insight into the variety of forms of pressure GPs experience in dealing with EAS requests, which is highly relevant in the light of the reported increase of this pressure.[17]

One main source of pressure is coming from either the patient or his/her family members and is reflected in the categories 'emotional blackmail' (1), and 'control and direction by others' (2). These forms relate to behavioural expressions of patients, such as anger, manipulation or high demands, which are known factors to potentially contribute to difficult patient–physician encounters,[22] also in regular clinician decision-making. However, because EAS requires in particular a good patient–physician relationship, based on reciprocity and mutual understanding,[23] this behaviour may be specifically disrupting in the complex setting of EAS decision-making. Our research shows that absence or misbalance of these valued aspects forms an important source for the experience of being pressured in EAS decision-making. It is important to realise that the decision-making process around EAS is influenced by the patient and the physician and by the relatives involved.[24] Awareness of these influences, along with communicating and clarifying expectations throughout the process,[24] may help in the prevention of complex situations and the reduction of pressure around EAS requests.

Another source of pressure relates to a process going on in the minds of GPs themselves, which is closely related to the inherent complexity of the deliberation process around EAS requests, and described under the categories 'doubts about fulfilling the criteria' (3) and 'counterpressure of patient's family' (4). The requirement with regard to the unbearable suffering of the patient is known to be challenging, as the open norms require interpretation[2 25] and perceptions of unbearable suffering and the focus on symptoms of suffering are found to potentially differ among patients and physicians.[26 27] Physicians are found to also differ in the way they assess the suffering of the patient, by either imagining how they themselves would experience the situation of the patient or by trying to adopt the patient's perspective in relation to the suffering.[28] It is also known that physicians are more at ease with classifying actual pain or physical symptoms as unbearable suffering than irreversible loss and 'existential' kinds of suffering.[29] Determining the latter forms of suffering within the scope of the 'open norms' of the law is bound to be much more difficult. One can imagine EAS requests based on these specific forms of suffering are therefore more likely to put pressure on physicians. In addition to fulfilling the legal requirements, this process also asks physicians to find a 'balance between the necessity to shorten a patient's suffering through euthanasia and their own personal values,'[16] which may include their views on what 'good dying' entails.[30] This implies that, even if the GP thinks the requirements are legally met, this deliberation can still lead to feelings of pressure in case a GP struggles to find this balance. In our society where the emphasis on patient autonomy 'as a right' is increasing it becomes more difficult for a physician to balance this with their own professional responsibility.[31] In terms of reducing or managing feelings of pressure around EAS requests, (the education of) physicians may benefit from an increase in knowledge about their own personal norms and values on suffering, along with awareness on how they assess the suffering of the patient. In addition, the debate on what the boundaries of unbearable suffering are within the Dutch euthanasia law deserves ongoing attention, especially in the light of physicians possibly becoming less willing to consider EAS requests,[32] or an increase in perceived pressure around EAS request by physicians.

We found this balance to be also disturbed, in cases where granting the EAS request, was in disagreement with the patient's family or other relatives. The issue of opposition of family members to euthanasia has been acknowledged in literature.[33] We found pressure of family members to be more influential in the decision-making process than perhaps anticipated, especially in cases where the GP sympathises with the opposing feelings of the family. It shows that family members are an essential partner in the shared decision-making process, although the prevalence of pressure of family members to reject a euthanasia request is found to be very low among GPs.[5]

The final source of pressure around EAS requests is found to have its origin in organisational factors, summarised in the categories 'time pressure around referred patients' (5) and 'organisational pressure' (6). Here it is not the decision itself which is complicated but primarily the circumstances under which the decision has to be taken or EAS has to be performed. First of all, EAS requests of referred patients cause organisational issues resulting in GPs experiencing pressure to act too soon. The main problem here is that the physician lacks time to get to know the patient and to take all the necessary steps in the deliberation process. Despite the fact that the patient may have a long-lasting wish for euthanasia, creating a good patient–physician relationship takes time, and without it shared decision-making about EAS will not be possible. Other organisational factors causing pressure for GP go beyond the patient–physician relationship and include issues with pharmacy delivering the necessary drugs, and the impact EAS has on the GP and his ability to combine it all with the rest of his practice and private life.

Strengths and limitations

The main strength of this article is the fact that it is, to our knowledge, the first to explore the content of the pressure experienced by GPs around EAS requests. Hereby it contributes to the wish of the interviewed physicians to raise awareness among society about the emotional burden that euthanasia (requests) may impose on them,[14 16 34] and to which experiences of pressure may contribute. And it shows how, based on the content, different strategies are needed to reduce this pressure on GPs. Our research is limited by the fact that it is focused on the Dutch euthanasia practice, which is not representative for GP practices in most countries. However, its findings add to the euthanasia debate, also in countries with different euthanasia law and practices.

CONCLUSION

We conclude that the pressure experienced by GPs in dealing with EAS requests can be attributable to factors associated with the patient–physician relationship and/or the relationship between the physician and the patient's relative(s), the inherent complexity of the decision itself and the circumstances under which they have to make the decision to (not) grant EAS requests or perform EAS. Our results and the reported increase in the pressure GPs experience in granting EAS requests[17] call for further investment into raising awareness on this topic in order to prevent physicians to cross their own personal boundaries in dealing with EAS request. This investment may include further education of the general public on euthanasia, but also support for GPs and other physicians in recognising sources of pressure, identifying their own personal values and boundaries in granting EAS requests and guiding them towards adequate use of sources of support.

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