

Supporting GPs around euthanasia requests from people with dementia:

a qualitative analysis of Dutch nominal group meetings

Abstract

Background

Euthanasia has been regulated by law under strict conditions in the Netherlands since 2002. Since then the number of euthanasia cases has constantly increased, and increased exponentially for patients with dementia (PWD). The number of euthanasia requests by such patients is even higher. Recently, an interview study showed that physicians who are confronted with a PWD's euthanasia request experience problems with communication, pressure from relatives, patients, and society, workload, interpretation of the law, and ethical considerations. Moreover, if honoured, the physician and patient may interpret the right moment for euthanasia differently.

Aim

To identify ways of supporting GPs confronted with a PWD's euthanasia request.

Design and setting

Two expert nominal group meetings were organised with Dutch care physicians for older people, GPs, legal experts, a healthcare chaplain, a palliative care consultant, and a psychologist.

Method

A total of 15 experts participated in the meetings. Both meetings were audio-recorded, transcribed verbatim, and analysed using thematic analysis.

Results

Four themes emerged from the meetings: support provided by healthcare professionals, influencing public opinion, educational activities, and managing time and work pressure. The need for support was considered highest for GPs for all of these themes.

Conclusion

Consensus was reached with the help of experts on support needs for GPs confronted with euthanasia requests from PWD. A concise and clear explanation of the law is strongly desired. Changing public opinion seems the most challenging and a long-term aim. Communication training for finding the right balance between the physician's professional responsibility and the patient's autonomy should be made available, as a short-term aim.

Keywords

dementia; euthanasia requests; general practitioners; health services, primary health care; support.

INTRODUCTION

Euthanasia has been regulated in the Netherlands since 2002, as stated in article 2 of the Termination of Life on Request and Assisted Suicide Review Act.¹ There are strict conditions: only a physician can perform euthanasia and the statutory due-care criteria have to be met. Moreover, after euthanasia has been carried out, physicians are obliged to send a report describing the entire procedure to a review committee.¹ Until 2015, the physicians' professional standard, endorsed by the Royal Dutch Medical Association (KNMG), was that a person with a euthanasia request should verbally non-verbally confirm their actual wishes, and also when an advance euthanasia directive (AED) was available. This standard was adapted following criticisms that it was more conservative than the law itself. Recently, an extensive interpretation of the law was published that confirmed the importance of an AED in view of 'precedent autonomy'.² This new guideline resulted in not only an ongoing professional debate, but also a public one, on euthanasia in patients with dementia (PWD).³⁻⁶

Recently, a Dutch euthanasia case fuelled this public debate. It was one of the few euthanasia cases in an advanced stage of dementia where no verbal or non-verbal confirmation was provided by the patient.^{7,8} This case led, for the first time since the implementation of the euthanasia law, to a

criminal court case. This controversial case demonstrates the challenges and ethical concerns of euthanasia and AEDs in PWD, as AEDs are seen as an ultimate possibility to take autonomous decisions before the autonomy, because of the loss of cognition, disintegrates. Moreover, in Dutch society, a growing number of people think they have a right to die;⁹ a public initiative aiming to legalise assisted suicide of older people who consider their life completed already has over 100 000 declarations of support.¹⁰ Also one of the political parties, D66, a Dutch social liberal party, is pleading for extension of the euthanasia law.¹¹ These developments have impact on physicians. A recent study on developments in euthanasia practice in the Netherlands recommended to (re)discover the right balance between the physician's professional responsibility and the patient's autonomy.⁹ It underlines the importance of looking at means to support the difficult decision-making process GPs have to go through.

In the past decade, an exponentially growing number of actual cases of euthanasia in PWD has occurred: from 25 cases in 2010 (of the total 3136 performed euthanasia cases in 2010) towards 146 in 2018 (of 6126 cases in total).¹² As not every request results in euthanasia,¹³ the number of requests for euthanasia from PWD, which do not always result in euthanasia, will have increased too and will further increase. However, exact figures are unknown.

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How this fits in

The number of countries that have a euthanasia law is increasing, as well as the number of euthanasia cases and requests. Previous studies show that physicians confronted with euthanasia requests experience pressure from patients, relatives, and society. Where people with dementia are concerned, they also experience problems with communication, workload, interpretation of the law, and ethical considerations. Influencing public opinion and better training of healthcare professionals were also advised by the experts. Moreover, if honoured, the physician and patient may interpret the right moment for euthanasia differently.

Although euthanasia in case of dementia is possible, GPs do not take these complicated requests lightly.^{5,14,15}

In a recent interview study with GPs who had experienced pressure around dealing with euthanasia requests in general, the risk of crossing their own personal boundaries if not being able to stand up for their own values was reported, for which education and support were recommended.¹⁶ A recent qualitative study on Dutch physicians' experiences in dealing with euthanasia requests of PWD confirmed this experienced pressure.¹⁷ GPs experience problems with communication, pressure from relatives, patients, society, workload, interpretation of the law, and ethical considerations. Moreover, if honoured, the GP and patient may interpret the right moment for euthanasia differently. Furthermore, dealing with the decreased cognition, also in relation

to AED, was considered problematic in this patient group.

There are different sources of support for GPs dealing with euthanasia requests, such as Support and Consultation on Euthanasia in the Netherlands (SCEN), GPs or other colleagues, practice guidelines, and clinical ethical support (CES) services.¹⁷⁻²¹ Moreover, with regard to euthanasia requests from PWD, improving existing conditions, for example, interdisciplinary team meetings and support groups, and increasing awareness of alternatives for euthanasia, for example, palliative care or assisted suicide, were mentioned.¹⁷ GPs are particularly in need of support, as they are responsible for approximately 85% of all euthanasia cases.²²

The overall aim of the current study therefore was to identify and prioritise forms of support that should be used or implemented to help GPs confronted with euthanasia requests from PWD.

METHOD

Study design

This study is reported in accordance with the COREQ guidelines²³ (see Supplementary Appendix S1). A qualitative consensus study was performed using the nominal group technique (NGT). This technique was chosen because of its structured and evaluative method for obtaining group consensus and is often used to generate, clarify, and prioritise ideas and/or solutions around a specific topic within a small-group discussion.²⁴⁻²⁶

Participants

Because the debate about euthanasia in cases of dementia has ethical, medical, political, and juridical aspects, the authors invited a diverse group of experts covering these fields to participate. Experts were recruited through the first and last authors' professional networks. They were approached by email, telephone, or face to face. Experts who expressed interest in the meeting, and were available to participate, received additional information that included the study goals, the research question, and the procedure of the NGT meeting. A total of 15 experts from a variety of professions took part in this study: eight participated in the first meeting and seven in the second. Participant ages ranged from 31-74 years; see Table 1 for participant characteristics. No financial or other compensation was provided for participation.

NGT meetings

Two NGT meetings were conducted in September 2018. Both meetings, each

Table 1. Participant characteristics

Characteristic	Group 1 n	Group 2 n
Sex		
Male:female	5:3	4:3
Occupation		
GP	2	1
Care physician for older people	1	1
Professor in geriatric medicine	1	-
Professor in care medicine for older people, especially long-term care	1	-
Physician and palliative care consultant for older people	1	-
Professor-emeritus in jurisprudence	1	-
Jurist	1	-
Healthcare chaplain in palliative care and consultant spiritual care	-	1
Healthcare psychologist	-	1
Assistant professor in care ethics	-	1
Professor in religion and care	-	1
Professor in medical care and decision making at the end of life	-	1

Box 1. Nominal group process

Phase	Description
1. Introduction and explanation	Experts were introduced to the main objective of the study using a PowerPoint presentation, namely identifying and prioritising forms of support, presented with the problems as reported by GPs and care physicians for older people in a qualitative interview study on the same topic. ¹⁷ These problems concerned pressure from and expectations of relatives, the consequences of society's negative view of dementia on their practice in combination with the growing 'right to die' conviction of many people, the interpretation of the law and of AEDs, ethical considerations, communication with PWDs and their relatives, timing, and workload. The experts were asked to approach the period from the moment a patient expresses a euthanasia wish or request until a decision has been made as one process, regardless of the outcome. Furthermore, the different phases of the NGT were explained.
2. Silent generation	The research question was presented: <i>'What forms of support should be used or implemented to help GPs confronted with euthanasia requests from PWDs?'</i> Experts were asked to individually make a list of favourable forms of support, such as (improvement of) existing conditions, as well as new alternatives. Suggestions based on the present qualitative study ¹⁷ and other literature on this topic were in both meetings presented to the group on a large screen.
3. Round robin	Experts were asked to share their favourable forms of support one at a time, which were then written on a flipchart. When every idea was shared and no new ideas were mentioned, this phase ended. Explanation and discussion during this phase were kept to a minimum.
4. Discussion/clarification	Experts were invited to clarify and discuss all suggested forms of support. Items were removed, reworded, merged, or added to the list. At the end experts were asked if they agreed with the final list.
5. Voting	Experts were provided with a ranking sheet and asked to select and rank their top five favourable forms of support as presented in phase 4 from 5 to 1 points. The moderator specified and emphasised that higher numbers represented more importance.

AED = advance euthanasia directive. NGT = nominal group technique. PWD = patients with dementia.

lasting about 2.5 hours, consisted of five structured phases and were led by two experienced moderators: a female professor in spiritual health care, experienced in facilitating NGTs and focus groups (last author), and a male psychologist, nurse, and PhD candidate in advance care planning for PWD with previous experience in conducting focus groups (fourth author).²⁶⁻³²

All expert participants were asked to sign informed consent. It was explained that the meetings would be audio-recorded and processed anonymously.²⁸ In addition, the second and third authors kept detailed minutes of the meetings. All written records were sent to the participants in order to obtain consent.

The five steps (phases) that were followed during both NGT meetings are described in Box 1.

Analysis

A combination of qualitative and quantitative methods was used.³¹⁻³⁴

Two strands of data were obtained from the NGT meetings:

- a qualitative list of discrete ideas, which were organised into *in-situ* categories (original categories generated during the meeting) and refined based on the transcript of phases 3 and 4 obtained from the audio-recording; and
- a quantitative list of individually scored favourite forms of support.

The steps of the analysis process are described in Box 2.

RESULTS

Identified and prioritised forms of support: overall group analysis

During the first NGT meeting 10 *in-situ* categories of potential forms of support emerged, and five *in-situ* categories during the second meeting. Almost all categories mentioned in both meetings were similar or overlapping. Only one category (time and work pressure) was not mentioned during the second meeting.

Themes

Thematic analysis revealed four themes with a total of 10 categories of support, as displayed in Table 2. The four themes, ranked in descending order, were: support provided by healthcare professionals, influencing public opinion, educational activities, and managing time and work pressure (Table 2).

Support provided by healthcare professionals. Direct support from other healthcare professionals of various expertise was considered the most important form of support in both groups and consisted of three categories (Box 3):

a) Support during the decision-making process by individual healthcare professionals: this was often mentioned. In both groups a buddy system was suggested. This is a service where a physician can ask a healthcare professional to assist and support them during the entire communication and decision-making process and, if applicable, during the euthanasia process. An expert added:

'That the GP can always count on someone else for support ... That it is actually always a two-person job.'

Several types of professionals were mentioned to be suited for this buddy function: an end-of-life clinic physician or nurse, a care physician for older people,

Box 2. Analytical process

Step	Description
1. Content analysis	<p>Content analysis of the qualitative data in two phases with two approaches was used.</p> <p>First, conventional thematic content analysis of raw data generated during the first meeting was conducted. Suggested forms of support ranged from very detailed to quite general. For that reason, the second and third researchers independently grouped similar suggested forms of support into themes and categories, using ATLAS-ti (version 8), and then discussed differences until consensus was reached.</p> <p>Second, the same two researchers added the forms of support mentioned during the second nominal group meeting into this thematic list. This list was then presented to the entire research team and discussed until consensus was reached, resulting in a final thematic list of ideas.</p> <p>To obtain information about the decision-making process and insights into the argumentation regarding each statement, audio-recordings of the round robin phase and discussion/clarification phase were transcribed verbatim and analysed using direct content analysis, again independently, by the first and second authors using ATLAS.ti (version 8). This also enabled the addition of ideas not written down during the meeting.</p>
2. Nominal group ranking	<p>Quantitative analysis of the nominal group ranking.</p> <p>First, individual group scores, that is, the top five priorities, were calculated separately for both meetings. The researchers ranked a top four by calculating the summed score and relative importance of each <i>in-situ</i> category as obtained from the voting phase. When two categories obtained the same score, the categories were ranked not only via scores but also via frequency (the number of times a category was voted for).</p> <p>Next, the themes were ranked based on the scores of the five overarching themes. The total score per theme was calculated by summing the scores of the <i>in-situ</i> categories (calculated in the first step) falling under the new (overarching) theme.</p>

a SCEN physician, and a spiritual care provider (healthcare chaplain). Experts also mentioned support by healthcare professionals in organisations and teams, such as the Netherlands Comprehensive Cancer Organisation (IKNL), ABC-teams (geriatric consultation teams), palliative

Table 2. Themes and their ranking of importance

Overarching themes (from content analysis)	Sum of scores	Ranked priority (using scores)	Relative importance (%)	Ranked priority (using %)	Voting frequency	Ranked priority (using scores and frequency)
Support provided by healthcare professionals	101	1	46.1	1	29	1
Influencing public opinion	76	2	34.7	2	27	2
Educational activities	40	3	18.3	3	15	3
Managing time and work pressure	2	4	0.9	4	2	4

Relative importance = score for the overarching theme / maximum points for groups x 100. The maximum points for groups = 219.

consultation teams and groups palliative care at home (PaTz). The PaTz groups are teams consisting of GPs and community nurses, who, supervised by a physician with expert training in palliative care, discuss their palliative patients five to six times a year.³⁵ Furthermore, multidisciplinary team meetings were mentioned, such as interdisciplinary consultation and moral case deliberation. Ethical discussions or moral deliberation services are not easily available and accessible in primary care in the Netherlands, hence they may be unaware of these options.

b) Emotional-moral guidance and care (for the confronted physician) by a healthcare professional: for example, a spiritual care provider or existential counsellor, was considered to be very important. One participating physician commented:

'The emotional guidance for the doctor, after euthanasia. That is quite [silence] ... I have experienced it myself; no attention is paid to that.'

Another expert added support via reflection meetings for GPs in which *'not only complex dilemmas are discussed in which you got stuck, but also cases which did not result in euthanasia'*.

c) Awareness and easy access: experts stated that awareness of the availability of these healthcare professionals and their specific roles is of great importance. One expert emphasised the future professional role of the spiritual care provider (existential counsellor) in primary care as follows:

'At short notice, the financing of primary care spiritual care providers will be arranged ...'

Furthermore, easy access to such healthcare professionals and an up-to-date list with contact details of available healthcare professionals per region was suggested.

Influencing public opinion. Experts mentioned the need of indirect support through influencing public opinion and raising awareness about the different aspects related to decision making around euthanasia and its impact, with the aim of reducing the burden experienced by the physician. This theme consisted of the following three categories (Box 3):

a) Provision of accurate and valid information via campaigns, brochures,

Box 3. Forms of support mentioned by experts during both NGT meetings, themes, and categories

Support provided by healthcare professionals

- Support during decision-making process, for example, by individual healthcare professionals, organisations/teams, moral case deliberation
- Emotional-moral guidance and care for physician, for example, by spiritual care provider, reflection meetings
- Awareness and easy access

Influencing the public opinion

- Provision of accurate, valid information, for example, campaigns, brochure
- Activities, for example, 'Nursing Home Open Day', café 'Death is normal'
- Legislation clarification

Educational activities

- Training, for example, communication skills, signalling existential questions
- Tools, for example, vision paper, observational tools assessing (unbearable) suffering

Managing time and work pressure

- Time and space availability, for example, regular time for weekly reflection
- Facilitators, for example, administrative assistant

NGT = nominal group technique.

flyers, movies/commercials, and books: Using a brochure was deemed particularly important:

'I seriously plead for a clear, in layman's terms, brochure, with pictures.'

According to the experts, various topics should be addressed in this brochure. Many topics were mentioned and explained. For example, dementia does not necessarily mean suffering: *'dementia automatically stands for suffering. And that is — often — not necessarily the case'*, and euthanasia is not a right:

'Make clear that euthanasia is no right. That there is no right to euthanasia, but that it must remain an exception, and you cannot just decide about this.'

Also, the impact of euthanasia on a physician was stressed:

'It's not like: "ask and we deliver"; there should also be awareness of the professional consequences for the physician.'

Another expert added:

'I can imagine that it would be pleasant for the physician if there was more attention in the public debate for the "amazon.com mentality" (ordered today, delivered tomorrow): take it down a notch.'

Moreover, advance care planning, fear of the future, for example, loss of autonomy,

'Who will take care of me?', and attention to alternatives to euthanasia, such as palliative care and assisted suicide, were important topics.

b) Activities: some experts mentioned influencing the public opinion through activities, for example, influencing the negative image of nursing homes (*'which is hardly ever correct'*) via a 'Nursing Home Open Day', a day where nursing homes open their doors for the local community. Two experts mentioned the concept of 'Café Doodgewoon' (café 'Death is normal'), an informal meeting place for expert volunteers, people, and their close family members to discuss end-of-life issues. One of the experts added:

'This is a model that works excellently... within this framework, you can raise the whole issue of euthanasia, suffering and death.'

c) Legislation clarification: this was widely discussed. In both NGT meetings experts stated that there is a need for a clear and understandable explanation of the law, including of AEDs, for the general public and for physicians. They again emphasised the need for a brochure on the legislation and AED in layman's terms:

'More clarity with regard to the AED, within what timeframe, how often, what should be in it ...'

and

'The awareness that, with the writing of an AED alone, you're not there yet.'

Experts discussed methods to obtain guidance in clarifying the law. Collaboration and deliberation between the notary and the KNMG came forward: *'this is very necessary ... because notaries give the impression that an AED is just the same as a will, and therefore valid'*, as well as linking knowledge and sharing experience with other disciplines dealing with euthanasia requests and mental incapacitation.

Educational activities. Experts stated that it was important that GPs acquire skills that are necessary to properly deal with euthanasia requests from PWD and the decision making related to this. This theme consisted of two categories (Box 3):

a) Training: during (medical) education and as post-academic training was recommended. First, acquiring communication skills,

for example, specialised conversational techniques, discussing end-of-life issues, and conducting family meetings:

'I have learned that there is a need for support in conducting conversations with patients, also to be able to really give good information about the possibilities and impossibilities. Also, broader than just euthanasia alone. We often hear from confronted physicians, that they are in need of support ... How to cope with this?'

Next, signalling existential questions and learning to deal with uncertainties, which was emphasised by the following statement:

'I think that many questions about euthanasia come from not being able to deal with uncertainty, like prognosis and all kinds of aspects, which we are insufficiently trained.'

Experts argued for expanding knowledge related to this topic, such as attention to the impact on and nature of suffering that PWD can experience. One of the experts explained this:

'Nowadays in our society, people experience great difficulties with relating to and dealing with suffering. We have a strong tendency to solve, and otherwise we tend to look away. While recognition of this tragic, insoluble side of suffering is of great importance for both the patient and the physician.'

Further, the following topics were discussed: advance care planning and multiculturalism with regard to death, suffering and person-centred end-of-life care: *'these issues are so culturally defined'*.

b) Tools that facilitate and support the decision-making process: Experts mentioned the following options: First, observational tools for assessing (unbearable) suffering, such as a discomfort scale or existential distress. Next, a service for GPs where euthanasia decisions can be reviewed prospectively among a group of (legal) experts, as a solution for *'the tension between the jurist who says: "I can only review it in retrospect" and the physician who says: "Yes, but if I could know in advance about what I can do and what I cannot ..."'* In both meetings a vision document by the KNMG was considered to be important:

'In 2018 the KNMG started a project in which a vision on euthanasia and the different stages of dementia will be developed. This joint project of the KNMG and its federation partners is among other things intended to provide doctors with guidance during the decision-making process in this complex matter.'

Managing time and work pressure. Particularly in the first meeting, experts mentioned forms of support that could reduce time and work pressure, related to euthanasia requests, especially in case of dementia. They described that these difficult requests require more time than is currently available in regular care. A financial incentive was not seen as a solution; one expert explained this clearly:

'I do think this should not be done with a financial incentive. I would be terrified of that. You see, wherever there is a financial incentive, it will be used ... That seems incredibly harmful to me. So, you have to support this problem in a different way.'

This theme consists of the following two categories (Box 3):

a) Time and space availability: one solution was discussed in the form of scheduling regular time for weekly reflection. Another expert emphasised:

'Time and space for moral case deliberation under the supervision of an ethicist.'

b) Facilitators: an administrative assistant during the decision-making process, *'someone who has experience with the procedure and who will make sure that the administration is handled correctly'*, and colleagues to take over routine tasks of the [confronted] physician were mentioned.

DISCUSSION

Summary

This explorative study has taken the first step to reduce the current knowledge gap regarding sources of support for GPs who are confronted with euthanasia requests in dementia cases. Four themes of forms of support were identified and prioritised: support provided by healthcare professionals — which was considered most important, influencing public opinion, educational activities, and managing time and work pressure. Four concrete examples were emphasised: the possibility of a buddy who is available for the physician throughout the entire decision-making process, moral

case deliberation, a spiritual care provider for emotional moral guidance for the confronted physician, and a brochure in layman's terms about the different aspects related to euthanasia in PWD including legislation clarification.

In this study the nominal group technique was used to further explore forms of support for GPs confronted with euthanasia requests from PWD. Not all recommended sources of support appeared to be specifically targeted at dealing with euthanasia requests from this specific patient group. Particularly, a specific focus on dementia was evident in 'influencing the public opinion', 'dealing with AEDs and legislation', 'training GPs in dementia-related aspects', and 'managing time and work pressure'. Moreover, the experts in this study mentioned that it was essential to make the public aware that euthanasia is not a right, as well as the impact of euthanasia on a physician.

Strengths and limitations

The inclusion of a multidisciplinary group of experts, including healthcare professionals, care physicians for older people and GPs, legal experts, an ethicist, and researchers is one of the main strengths of this study. The fact that they all had a professional background related to this topic provided a broad perspective. Another strength of this study was the use of the NGT, which ensured time efficiency and encouraged equal participation and discussions among experts.²⁸ In addition, the method directly facilitated researchers in making a prioritised list of solutions to answer the research question. It also provided an efficient approach to construct a survey for further research.²⁹

However, the present study also has some limitations. Because of last-minute cancellations, no politician participated. Besides this, group dynamics and the absence of anonymity might have influenced the responses and discussions.³⁶ The last phase of the NGT process consisted of prioritising the generated forms of support. All experts cooperated during this phase, though some experts felt reluctance when prioritising owing to the different aspects of the generated solutions. The small number of GPs among the participants is also a limitation as the study aim was to find support needs for GPs, and warrants further research among these professionals.

Comparison with existing literature

To the authors' knowledge, this study is unique in exploring existing and new forms of support for GPs confronted with

euthanasia requests from PWD. Generally, in studies on euthanasia, 'support provided by other healthcare professionals' has already been suggested.^{19,37-40} For example, in a qualitative survey, Hanssen-de Wolf *et al*¹⁹ found that GPs value due-care criteria discussions with other professionals. In the present study, experts expressed not only the need for support provided by other professionals in a short consultative way, but also the possibility of a more long-term form of assistance. Examples they mentioned were a buddy who is available for the physician throughout the entire decision-making process, or support by taking part in regular meetings of GPs and nurses on proactive palliative care. In general, within such PaTz groups, members indeed receive informational and emotional support from each other.⁴¹

Furthermore, moral case deliberation (MCD), a specific form of a clinical ethical support (CES) service, was deemed important and seen as a form of multidisciplinary moral support during the decision-making process. It is known that CES services are increasingly available in Dutch health care.^{37,38} A qualitative interview study among Dutch care physicians for older people and GPs described that only care physicians for older people mentioned MCD as a form of support when dealing with a PWD's euthanasia request.¹⁷ The fact that this form of support was hardly mentioned by GPs was probably due to the unfamiliarity and unavailability of MCD in general practices.¹⁷ In addition, a former ethicist of one of the regional euthanasia review committees recently stated publicly that in complex cases, like euthanasia in PWD, ethical and moral reflection is largely lacking. The former ethicist called for a 'more severe proactive review' that is 'broader in scope' for complex cases using a multidisciplinary approach.⁴² This implies that there is also a need for a proactive, broader, multidisciplinary decision-making process for complex euthanasia requests from PWD, for instance supported by a CES service.

Emotional and moral guidance and care for the physician by a healthcare professional was emphasised by several experts during the meetings. This is in line with a previous study that recommended that physicians who are confronted with euthanasia should be aware of their own needs.⁴⁰ A recent study specially focused on support for GPs and other physicians in recognising sources of pressure and recommended investment in support for GPs, and guiding them towards adequate use of sources

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Competing interests

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of support. During the present meetings, but also in earlier research,^{17,43-45} the spiritual care provider was characterised as someone who could provide such emotional and moral support. However, awareness of spiritual care providers' availability for general practice and clear job descriptions including the provision of non-denominational spiritual support are lacking and limit their involvement in euthanasia requests. The Dutch Ministry of Health Affairs currently invests €7.5 million per year in this domain.^{46,47} Hence, the authors propose to increase the awareness of the possibility to consult a spiritual care provider among GPs and patients. This awareness should be an important element within the Dutch Minister of Health's project concerning the implementation of spiritual care in primary care.

'Influencing the public opinion' has also been mentioned in the Discussion summary as a recommendation of recent research (further education of the general public).⁴⁸ This theme was considered important by the experts as the public's opinion is coloured and misinterpreted about multiple aspects related to euthanasia and dementia, such as 'euthanasia is a right', 'dementia necessarily means suffering', and a negative perception of nursing homes. Furthermore, an important topic and category within this theme in the present study was 'legislation clarification', including the value of an AED. In line with previous research,⁴⁹ experts stated that there is a discrepancy between the general public's and GPs' view about the possibilities, or impossibilities, of AEDs in PWD. As stated in the study by van Wijmen *et al*,⁵⁰ people have a wide variety of reasons and aims for drafting an AED and the AED should, therefore, always be discussed in detail by the patient and physician. Besides, the KNMG is currently developing a tool that will give physicians guidance during the complex decision-making process

regarding euthanasia and the different stages of dementia.⁵¹ Finally, GPs might profit from interactive communication training to find the right balance between the physician's professional responsibility and the patient's autonomy.

Implications for research and practice

Because of global ageing, GPs in high-, intermediate-, and low-income countries will have to serve a rapidly increasing number of persons with dementia and their caregivers. As no effective treatment of any form of dementia is available or within reach, the number of persons with severe dementia and questions around end-of-life care will also rise. The forms of support for GPs in the difficult task of handling ethical dilemmas in the group of patients described in this study may thus be relevant for GPs globally, even though legislation on euthanasia in the Netherlands is currently different from the rest of the world.

Moreover, the number of countries where euthanasia and physician-assisted suicide is legalised is increasing, though legally replacing verbal communication by an AED if a patient can no longer express their own wishes is only possible in the Netherlands.⁵² The increasing negative society view of dementia and the process of dying for PWD may also raise similar discussions on AED in other countries.⁵³

It would be very interesting to compare the present qualitative research findings on end-of-life care for persons with dementia across other countries, as cultural, medical, and legislative differences may result in different end-of-life care questions in dementia care.

Currently, a large-scale survey study among GPs is taking place to quantify experienced problems and support needs.⁵⁴

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