

Opinion Piece

Perhaps the subject of the questionnaire was too sensitive: Do we expect too much too soon?

Wishes for the end of life in Huntington's Disease - the perspective of European physicians

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In The Netherlands euthanasia and physician-assisted suicide (PAS) have been legal since 2002 albeit under strict conditions [1–3]. This enabled patients who were suffering from a neurodegenerative disease, such as Huntington's Disease (HD), to make plans for the future. In our out-patient clinic specialized in HD we have experienced an increase in the number of requests for euthanasia and the use of advance directives. Further investigation has revealed that many HD patients and identified gene carriers do have some ideas about what they want regarding the end of their life [4]. We then wondered if physicians in other European countries, who are familiar with HD, have made similar observations and whether they are willing to discuss the subject with their patients. We were also interested in the actual content of the patients' wishes

and what the physician's reaction is to these or related questions.

In an attempt to gain insights into the European perspective, we developed a questionnaire which we sent to participants/investigators/physicians who participate in the European Huntington's Disease Network (EHDN). 540 questionnaires were sent out in February 2013 and a reminder in April 2013 to participants in 17 European countries, all by email. The questions addressed the end of life options and aimed 1. to investigate if physicians know about these options in their country, 2. to investigate if physicians ever have conversations with their patients about their wishes regarding the end of life and 3. what their opinion is about the possibilities in their own country. In addition, some biographic and demographic data were collected.

Only 53 questionnaires were returned, i.e. a response rate of 10%. Another 10 respondents indicated that they did not want to complete this questionnaire or

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participate in this study, for different reasons: lack of time, lack of interest, not enough contact with HD patients or not willing to participate because of the nature of the topic. Due to the low response rate, we cannot draw any firm conclusions, but we will make some general comments and wish to speculate on the reason for the low response.

The responses were derived from physicians in 15 European countries. Forty respondents were neurologists; just over half considered themselves to be religious. Most respondents answered that advance directives concerning: not to resuscitate (DNR), treatment limitations or the appointment of a representative are valid in their country.

Half of the respondents, representing 12 European countries, reported that their patients do express wishes for the end of life. These involved all aspects of care, administration of fluid and food, admission to a hospital or nursing home, DNR and euthanasia and PAS in countries where it is legal (The Netherlands, Belgium, Luxemburg and assisted suicide in Switzerland). In the majority of cases the patient or a relative took the initiative to discuss the wishes with the physician. In a minority of cases the physician actively asked the patient about his/her thoughts and feelings about the end of life. Physicians reported that the reason for having these wishes were related to fear of future suffering, having witnessed suffering in a relative, and the fear of loss of control, independence and dignity. Most patients were in the early or advanced stages of the disease when the discussion about their wishes for the end of life took place.

Considering the management options for the end of life some respondents reported that "quality of life could also mean quality of dying, and thus, euthanasia or PAS": several other respondents indicated that their focus is on quality of life. "I am against any kind of assisted suicide as this is a reflection of giving-up, or an example of a missed diagnoses. It is far from my professional attitude to let an event like that pass" and "I'll fight for the health of my patients and their quality of life. I'll never take someone's life." For these respondents, assisting in euthanasia or PAS is not an option.

Several respondents indicated that they would like to see management options for patients being expanded in the future, because patients do have end-of-life wishes. It would seem, however, that others ignore this fact. "It should be recognised by our law" and "I hope that our law could change. They ignore the problem, but these patients exist" and "there is a strong opposition from some sectors of the society, such as the church." One

physician expected "there would be a decrease in the number of suicides in the HD population if wishes for end of life could be expressed and euthanasia or PAS legalised."

Reviewing the responses we did receive, we can only speculate about the reasons for not being willing to participate in this study. From the questionnaires returned, we can deduce that many physicians probably do get questions from patients about their choices for the end of life, treatment limitations and retaining a certain quality of life. Perhaps the nature of the questionnaire was too delicate, although we did not direct our questionnaire towards euthanasia and PAS solely, but towards wishes for the end of life in a broader perspective. It may be that talking about euthanasia, PAS or other life-limiting actions is still difficult in parts of Europe, but we feel that our questionnaire was drafted in such a way as to invite physicians to talk about wishes for the end of life in general.

A second reason could be that physicians perceived it to be not important or irrelevant to their practice to answer. Other studies asking about practices surrounding the end of life in general reported higher response rates [5, 6]. None of these studies were directed towards a specific disease. A reason for a higher response rate in one study could be that physicians in this study were selected because of their involvement in the treatment and death of a specific patient instead of our choice to send the questionnaire to every physician treating patients with HD and asking general questions about the end of life. Some physicians may consider that it is not part of their professional duty to talk about care at the end of life. But, is it not the responsibility of the physician to care for his patient until the end of the disease? Is caregiving not always synonymous with quality of life which can also mean quality of dying for an individual patient? [7–9]. As some physicians say: "I am always glad when the patients are admitted to a nursing home, then I do not have to discuss the end of life issues."

A third reason might be that physician receive many requests by email. However our study group was not randomly selected, but approached because of their involvement with HD, their participation in HD research and their membership of EHDN. From this point of view it is even more remarkable that response rate was so low, which could support our hypothesis that the issue might have been too delicate.

Ways to improve response rate could be for example to hand out the questionnaire during the international congresses on HD and ask physicians to fill in the questionnaire during the congress.

From our studies we concluded that HD patients do have wishes and do want to talk about their wishes with their physician [4]. Talking about thoughts and wishes for the end of life and talking about quality of life and all that quality of life encompasses can be very helpful and reassuring for patients [10]. As patient's autonomy attracts an increasing amount of attention in the public debate, choosing not to be treated will become part of doctor-patient conversations [11]. Studies have shown that families rely on physicians to help in the decision-making process [11]. A research paper reported that patient autonomy could even be transferred to the physician when the patient was no longer competent according to the family [12]. Furthermore, other research has indicated that some form of acceptance and regulation of euthanasia and physician-assisted suicide is gaining increasing support from the general population in most western countries [13].

Are we expecting too much at this moment by drawing attention to this topic or should doctors prepare themselves better for this conversation with their patients? Thus are we expecting that we can ask these kind of questions to physicians in other countries, because we are so used to talking about this topic and discussing these wishes in The Netherlands? Is the time not there yet, is it too soon to ask questions about this topic to physicians in other countries, should we wait a couple of years? Or should doctors consider taking care of their patient in all aspects of their disease, the patient's welfare and best interests, including quality of dying, as part of their job?

In our opinion doctors will receive questions from patients about this topic more frequently in the near future. Other studies already concluded that physicians with training in palliative care were more inclined to make end-of-life decisions [6]. We do not suggest that other countries should legalize euthanasia or PAS in the near future. Nevertheless, the first step towards helping patients is to make the topic of end-of-life wishes open for discussion. We think that the awareness that HD patients have end-of-life wishes and the awareness that a physician and patient (together) should make end-of-life decisions, can increase the realization that this is indeed a very relevant topic for every physician treating patients with HD and thus to respond to these kinds of questions.

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CONFLICT OF INTERESTS

The authors have no conflict of interest to report.

ETHICAL APPROVAL

The study protocol was approved by the Medical Ethics Committee of the Leiden University Medical Centre. (MEC LUMC registration number P11.035).

DATA SHARING

no additional data available.

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