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Though we think we're in control
Questions that besiege us in life
Are testament of our helplessness

No Control – Bad Religion

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Managing the end of life: observations at consultation hours on Advance Directives

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Submitted

ABSTRACT

Background

Advance Directives (ADs) are often used as a tool to lay down patients' end-of-life care preferences. Right to Die-NL organizes consultation hours on the topic of ADs for their members.

Aim

Our research question is threefold: (1) what are the aims and expectations of people visiting the consultation hours, (2) what is the consultation about and what advice is given during the consultations, and (3) do users follow up with their GP on talking about their ADs?

Methods

Non-participant observation study.

Results

In total, 29 appointments with 36 members were observed during ten separate consultation hours, with eight different consultants. The main reason for visiting was a need for assurance and control over their future death. The advice they got was to focus on communicating with their physician. The consultants emphasized that the refusal of treatment document is of greater importance than the euthanasia directive.

Conclusion

Talking about euthanasia does not necessarily imply an active request for euthanasia or physician-assisted suicide. The need for control combined with a focus on communication with the physician should be seen as attempts to manage the end of life.

INTRODUCTION

Advance Directives (ADs) can be used to lay down patients' end-of-life care preferences for the future. In the United States, according to the Patient Self-Determination Act, patients should be informed about their right to have ADs.(1) A systematic review showed that 36.7% of US adults had an AD.(2) Although the consistency of patients' preferences is questioned(3-4), having an AD is associated with a more stable treatment preference compared to no AD.(5-6)

To our knowledge, initiatives to discuss ADs supported by non-medical professionals are scarce. We found one study that looked into a volunteer-based advance directive team “providing personalized, timely, and accurate information about advance directives and assisting patients with their completion”.(7) In the Netherlands, provision of information about ADs outside the medical circuit exists for over several years, but, up until now, had never been studied.

In the Netherlands, although only 7% of the population have an AD, of the people who do not have an AD 22% are sure they will have one in the future and another 64% are perhaps going to.(8) Right to Die-NL (NVVE) provides ADs for their members, as shown in box 1. NVVE is a society that provides information, consultation and education about euthanasia and physician-assisted suicide in the Netherlands. Their goals are “advancement of social acceptance and legal regulation of free choice for the ending of life in situations that fall both in- and outside the scope of the existing legal possibilities”.(9)

Box 1 Advance directives issued by Right to Die-NL (NVVE)

1. *Legal representation (surrogate decision making when the patient is no longer competent)*
 2. *Do-not-resuscitate (DNR) necklace*
 3. *Refusal of treatment*
 4. *General euthanasia directive*
 5. *Euthanasia directive in case of dementia*
 6. *Refusal of treatment in case of being tired of living*
-

For questions about these directives NVVE offers support over telephone or via a house visit. Over the years, the number of members asking support grew and in 2014 the society started a new initiative to meet the growing demand: consultation hours on ADs. Members can register themselves to have a consultation. A consult takes about half an hour. The consultants (101 in total) are trained members of NVVE, often with previous experience on lecturing about NVVE. There are 33 locations in the Netherlands where the consultation hours are held. Around 200-300 members visit these consultations every quarter of a year.

We were interested in the way people prepared for and informed themselves about their end of life by attending these consultation hours. Since the consultation hours are a service of NVVE, we also wondered if there was unbalanced attention for the option of euthanasia in the consultations. Our research question is threefold: (1) what are the aims and expectations of people visiting the consultation hours, (2) what is talked about and what advice is given during the consultations, and (3) do users follow up with their GP on talking about their ADs?

METHODS

We wanted to study consults first hand, not retrospectively. For this, we chose to conduct non-participating observations and tried to follow the participants throughout the process of talking about their ADs with their GP.

Our study was not burdensome for the participants and did not pose any risk to them. Therefore, according to the Dutch legislation, review by the medical ethical committee was not required. Information letters and informed consent forms were used to ensure prudent research.

NVVE provided M.C.S. with a schedule of where and when upcoming consultation hours were planned and how many visitors had registered themselves. M.C.S. chose which hours to observe based on location, and number of expected visitors. NVVE would then contact the consultants to ask their consent for M.C.S. to be present. If the consultant agreed to this, NVVE would (e)mail the visiting members an information letter about the research to which the members could reply if they did not want to participate. When no decline was received, M.C.S. would be present when visiting members arrived for their appointment. M.C.S. would then check if they read the information letter and if they were willing to participate. If they had not read the

information letter beforehand, M.C.S. would hand it out and inform them verbally. If consent was given, M.C.S. would stay present and take notes during the conversation. Most consultations were also audio-taped, unless participants asked not to do so.

After the observation, M.C.S. would verify if the visitors agreed to a follow-up two weeks later in order to ask if they planned to talk to their physician about the directives and to ask whether they agreed to have that conversation observed as well.

If consent was given, M.C.S. would email or phone in two weeks and if a doctor's appointment had been made, M.C.S. would send an information letter to the physician. Consent from physicians was either obtained verbally or by signing an informed consent form.

M.C.S. wrote field notes in detail as soon as possible. D.L.W. and B.D.O.-P. read these as the study continued. We analyzed data using open coding. Codes were discussed between M.C.S., D.L.W. and B.D.O.-P. We then grouped the codes into larger themes.

In total, 29 appointments with 37 members were observed during ten separate consultation hours, with eight different consultants. Most often, people came alone, however seven people were accompanied by their partner or child(ren). Five consults did not lead to talking to their physician in the near future, and four led to observations of conversation between patient and physician. The remaining 20 members dropped out of our study.

RESULTS

We grouped our findings in chronological order, beginning with the general impression and reasons for visiting, continuing with what was discussed during these consultations, ending with whether or not the consultation resulted in a conversation with a physician. Box 2 provides a description of one of the observations.

Members visiting the consultation hours varied in sex, age (58-92 years), and education (intermediate vocational education to university). All of them were white and native Dutch. Most of the participants had prepared themselves thoroughly in advance for the consultation — either by writing down questions in advance, or by having written down their preferences concerning the last phase of life. However, some of the members just came in 'blank' and used the consultation as a way of orientation.

The consultant and I are sitting at a large, wooden table with room for about 12 people. It is placed near a window that overlooks the garden. At the other side of the room are more tables, unoccupied. We're inside an old monastery in the heart of the city. It is winter; the room is just warm, but by occasion you feel a cold breeze coming through the cracks of the door.

The consultant is an older lady: calm, sensitive and emphatic. We are chatting about nothing in particular when we see an older couple walking by the window. "Ah, there they are, I presume", says the consultant. We hear knocking on the door and the couple enters: "Is this the right place for the advance directives?"

We introduce ourselves to each other and I tell them something about my research and that I would like to observe the conversation they're about to have. Mr. and Mrs. de Boer agree to have me present. While talking about this, they already started unpacking and soon after the table is filled with all kinds of documents. The different directives that NVVE provides are spread out, all in fourfold: one copy for the member him/herself, one for their GP, one for their legal representative, and one for either a second representative or the treating specialist.

"So, what should we write down?", they ask the consultant. Mrs. de Boer asks the consultant about the difference between a request for euthanasia and a refusal of treatment. The consultant explains that euthanasia is the active ending of the life of a patient, by injecting a lethal substance. "And which of these documents do I need to fill in as complete as possible? Which one is the most important?" The consultant says that even if you only put a signature on them, they are valid. "So I'm already covered now?", Mrs. de Boer asks.

Then Mr. de Boer interferes and start telling about his late wife (he remarried with Mrs. de Boer). He took care of his wife for seven years and it was a painful experience. She wanted to die, but their GP said it was already too late to perform euthanasia. When she was admitted in a regional hospital, the staff was also not cooperating, because the hospital has a Christian foundation. While he finishes the story, he starts to cry, softly.

After a while, the couple talks about the death of a friend of theirs. He was able to die by euthanasia and they both describe this experience as "beautiful and peaceful".

The subject switches to dementia. Mrs. de Boer says that above all, she wants to be "covered" in case of dementia. She fears she will be suffering from dementia in the future, because it runs in her family. The consultant asks if her mother suffered severely, but it turns out the mother of Mrs. de Boer was a rather cheerful woman, even when no longer competent. It's not that Mrs. de Boer fears she will become aggressive or anything like that: she explains that she just does not want to live in a nursing home, no matter what. The picture of living in a nursing home, for her, is terrible. At the same time, she's struggling to describe where she wants to draw the line: she does not know yet when life is not worth living.

The couple and the consultant talk about dementia and euthanasia a bit more. It turns out Mrs. de Boer thought that her legal representative should be able to arrange the performance of euthanasia when she becomes mentally incompetent. As the consultant explains, this is a tricky topic and there won't be many physicians who are willing to help patients under these conditions.

Next, they also ask questions about the legal regulations: whether or not a necklace stating they do not want to be resuscitated is binding and if physicians are obliged to follow refusal of treatment. The consultant tells that these two are legally binding for care professionals, but that euthanasia directives are always a request, and not something they can demand from their physician. "But, don't physicians have a more relaxed attitude towards euthanasia nowadays?" The consultant says that they should really talk to their own physician about these advance directives, because it is not that simple.

(participants 8.1, 8.2 (couple) and consultant 3)

Aim of visiting

Previous experiences of people close by who had died were a motivation participants often mentioned for wanting a consultation. A positive experience motivated the participants to arrange a similar kind of death, whereas negative experience motivated participants to do their best to prevent the struggles they had seen other people endure. Both experiences incited people to deal with their ADs. The case description in Box 2 also shows these both sides.

During their visit, many participants mentioned a high profile documentary showing people requesting and receiving euthanasia; participants were either very compassionate with the people asking for euthanasia or felt that a line was crossed by granting the requests for euthanasia. This last reaction might be unexpected, since the visitors are members of NVVE and probably have a somewhat more liberal view on euthanasia than the general population.

Notes: She starts talking about the documentary she's seen this week and says she finds it unbelievable that euthanasia was performed to a woman suffering from dementia who was still able to drive a car. "My husband died a few years ago by euthanasia, and that went very differently. We had a conflict with the physician to come to terms. His physical suffering was enormous — being seriously weakened and having to wear diapers for weeks." The woman tells us this had made a lasting impression.

(Participant 4, consultant 2)

The words the participants used — making sure, arrange, certainty — reveal the most prominent reason for visiting: being in control. Participants wanted to do everything within their power to be able to die the way they wanted and planned. This became apparent in statements like “*I want to make sure I’ve arranged it well, before my disease catches up with me and I’ll be no longer able to do so*” (participant 7), but also in their need to let the consultant check if everything was in order: “*Is the living will I have written down okay like this?*” (participant 26). Taking care of one’s ADs can be difficult, and some participants used the consultation hour as a sort of incentive to take matters into their own hands. “*I needed something to start dealing with these ADs*” (participant 3).

What is said and advised?

What was actually being said and done during these consultations? A lot of time was spent on providing factual information to the members. For instance about the legal value of ADs, or about legal representatives. Information also concerned the reasons for requesting euthanasia or physician-assisted dying that physicians regard as valid, or the ADs that were relevant for the visitor. Although the meetings were organized by NVVE, all consultants placed emphasis on the refusal of treatment and the do-not-resuscitate (DNR) necklace, over the directives concerning euthanasia. The argument for this was that refusing treatment is a right of the patient while physician-assisted dying is merely a request.

Notes: The consultant says that refusing treatment is a right of the patient. She links this to the experience of the father of the member, who died because of pneumonia that wasn’t treated, and also gives an example of her own experience. She continues: “It can be a good alternative to euthanasia, in some cases”, which is not further specified. “Euthanasia, on the other hand, is a request, not a right. I think you both know this?”

(participants: 1.1, 1.2 (couple) and consultant 1)

Next to this, all consultants stressed the importance of talking to a physician. Only this way a member could make their fears and wishes known to the person who will most likely deal with it in the future.

Visitors were often in search of certainty and control, however at the same time they were still in doubt under what conditions their life would no longer be worth living.

“I don’t know what I should write down in the open spaces of the directives [where you write down your own thoughts and wishes concerning the end-of-life]. I don’t know what the conditions are under which I find life no longer worth living.”
(participant 10)

Some participants feared that their physician might not be willing to perform euthanasia or physician-assisted suicide. This fear was not shared by all members — some of them were very confident their treating physician would help them if it would come to that — but it was important for people who were not sure about this. They wanted to know what other options were available if the physician would decline their request. An option that was mentioned was to find a different physician, or to register at the End-of-Life Clinic.

Although not the objective of the consults, on request, some consultants gave advice on ways outside the medical route to organize your own death: non-medical assistance in dying. Other consultants felt that it was not up to them to provide this kind of information, and referred the member back to NVVE. Non-medical assistance in dying is providing information on ways to organize your own death in a humane and non-mutilating way — for instance by taking a lethal substance. One of the reasons mentioned by members to be interested in this option, was *“not to be dependent on their physician and not to bother their physician with a request for euthanasia in an early stage”* (participant 19).

Taking the next step?

All visitors were strongly advised to go talk to their physicians about their ADs. Although the non-response was high in follow-up, of the people who did respond, five out of nine did not go to see their doctor. For one couple, this was because they had already discussed this topic with their physician. Others were procrastinating to have a conversation with their physician about this subject.

In the end, we were able to observe four conversations between physician and patient(s): three couples and one single man. All felt a sense of relief after the conversation with their physician and were content about the conversation itself. It was mentioned that this was — for now — the last conversation about the subject, because it was not pleasant being reminded on, and having to think about, the disease and the end of life over and over. Uneasiness became apparent during the observations; fiddling with a chair or trying to close the conversation.

During the conversation, physicians tried to understand the patients in their wishes, but were unable to answer clearly when asked if they were willing to perform euthanasia or physician-assisted suicide, since it is impossible to foresee the future circumstances.

Woman: "I don't ever want to go to a nursing home."

Physician: "As a person, I can relate to that."

Woman: "But if I have to go to a nursing home, it's not like there won't be anything wrong with me [then there will be medical grounds]."

Physician: "It's possible that there will be a situation that I don't sympathize [with an euthanasia or physician-assisted dying request], while you do want to. I can't and won't just say 'yes' to it."

Man: "We wouldn't want to put you in a difficult position."

Physician: "If that happens, I'll refer you to another physician."

(participants: 18.1, 18.2 (couple) and general practitioner 3)

In the conversation with the physician, more attention was paid to complex situations. Like above, the physician showed that there is no easy answer to a request for physician-assisted dying. The following notes of an observation show the importance of managing expectations and avoiding miscommunication, although, despite the best efforts, this remains difficult.

Notes: Physician asks the couple if they understand what a refusal of treatment-directive entails. He starts to explain it: not providing life-prolonging treatment, but still comfort care. The GP explicitly asks what to do in case of pneumonia: does the patient want to be treated with antibiotics or not? The couple does not provide a clear answer to this question. The GP gives it another try. The couple's response is that the man has no further treatment options. The couple takes 'no treatment options' literally, while it means that there is no curative treatment for that primary disease of the patient. The physician tries to unravel whether the patient doesn't want treatment no matter what, but doesn't seem to reach the couple.

(participants: 14.1, 14.2 (couple) and general practitioner 2)

DISCUSSION AND CONCLUSION

Our research question was threefold: we wondered what the aim of people visiting the consultation hours is, what the consult is about and what advice is given, and if users follow up with their GP on talking about their ADs.

The observations showed that the main reason for visiting was that members were looking for assurance and control over their future death. The advice they got was to focus on communicating with their physician and an emphasis was placed on the directive of treatment refusal. The rationale for this being that refusing treatment is a right of the patient, but receiving euthanasia is not. Although members sought assurance and control, often there was no follow up with their treating physician about the ADs.

Overall, wanting to be in control and the focus on communication, shows that participants want to come to terms with their physician: a strategy to reduce the uncertainty — think for instance about the advice of consultants on what reasons for euthanasia are more often granted than others, and the emphasis on refusal of treatment. In this management of the end of life, an ongoing conversation between patient and physician is most important. The importance of communication between patient and physician was stressed in previous studies on end-of-life preferences.⁽¹⁰⁾ However it seems this remains a barrier, since our study showed that several people had no immediate plans to do so. Previous research showed that only 24% of people with an AD had discussed this with their physician, while 81% had discussed the AD with their relatives.⁽¹¹⁾ Research on the topic of communication about ADs and advance care planning showed comparable numbers: 83% had talked about future health care wishes with their partner, while 23% had discussed this with their physician.⁽¹²⁾

The people that did discuss their AD with the physician were overall satisfied with the outcome of the conversation, although the physician did not make any promises concerning euthanasia or physician-assisted suicide. Research on the topic of the effect of discussion about ADs on patients' satisfaction with their GP also showed that discussing ADs was associated with a greater feeling of satisfaction of the patients.⁽¹³⁾

The emphasis on refusal of treatment and DNR shows that the consultations are apparently not used as by NVVE as a way of advertising the option of euthanasia. This might come as a surprise from an advocacy group that strives for a less reluctant attitude of physicians towards physician-assisted dying. Apparently, their goals as an association

do not reflect directly in the recommendations they give on an individual level where a more pragmatic approach is seen — for patients it is more important to have their physician on their side than to make a claim to the right to die. It can be questioned if the focus of refusal of treatment as a patient's right is a correct reflection of practice. Research in the Netherlands has shown that ADs to forgo treatment are followed in approximately half of the cases.(14)

The need to be in control of the end of life is no surprise, since our participants all were members of NVVE, and it could be expected they are more actively involved in end of life choices than the general public. The need for assurance and control also became apparent in research about non-medical assistance in dying. A study showed there are several reasons for people to seek this form of assistance, but seeking reassurance seemed important in all of them, according to the authors.(15) Other previous research on the notion of control has also strongly associated the need for control to the value of autonomy.(16-18) However, autonomy and control in this context can also mean granting leeway in decision-making to someone else, for instance a surrogate or physician.(19) This challenges a notion of autonomy that relies on independence. Even talking about one's wishes with family and friends would provide both parties with a sense of control.(20)

Despite the participants having a specific interest in influencing their end of life, it also became apparent that talking about euthanasia and physician-assisted dying does not imply an active request for physician-assisted dying.(21-23) None of the members had an active wish to die by euthanasia or physician-assisted suicide, they just wanted to do everything within their power to avoid future suffering and physician-assisted dying would be a future option to arrange this.

Strengths and limitations

A limitation of the study is that despite trying to inform all possible participants beforehand, many of them had not read the information letter sent to them. Because of this, the observant had to explain the research and inform the participants on the spot. This caused participants to have little time to consider their options and in turn may have had influence on their decision to participate or not. This could also explain the high non-response in follow-up.

It is not likely our study reflects the way the general population addresses (concerns about) ADs, since our participants were all members of NVVE. However, a strength

of our study is the fact that the observations give a direct and unique insight into an exceptional initiative, because it concerns provision of information on medical practice of end-of-life care outside the professional medical domain.

Conclusion

People visiting the consultation hours expressed a need for control, whereas the consultants focused on communication with the physician. These two things combined show a tendency to manage the end of life. Despite the need for control, patients felt satisfied if they talked to their physician about their ADs, even though the physician would only reassure them and not make any solid promises.

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