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Autonomy and dying: Notes about decision-making and “completed life” euthanasia in the Netherlands

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ABSTRACT

Euthanasia in the Netherlands is based on the notion that the person seeking assistance to die is able to make an autonomous decision. The objective of this study is to explore this notion, in particular, in the case of “tiredness of life.” The article is mainly based on two qualitative researches and two selected case histories that provide an in-depth insight into the complex process of (not) reaching a clear decision. We found three obstacles that cast doubt over autonomous decision-making in the face of death: (1) Doctors – not patients – have the final say in “measuring” the “amount” of pain and suffering that entitles a person to be granted euthanasia. (2) Human decisions are always taken in a context of complex circumstances involving relatives, friends, and medical professionals. Decisions may therefore be changed, mitigated, or not taken at all. (3) People lose much of their autonomy when they grow old and fragile, and will be increasingly inclined or forced to leave decisions to others.

Introduction

Starting in the 1970s, public discussion about euthanasia and physician-assisted suicide in The Netherlands led to increasing support for euthanasia under certain conditions. In 2002, the government issued the “Termination of Life on Request and Assisted Suicide Act,” which states that euthanasia and physician-assisted death will not be punished if the attending physician acts in accordance with criteria of due care. This law stipulates that in order to allow euthanasia, there must be unbearable suffering without prospect of improvement, and a voluntary and well-considered request from the patient who is competent to express his/her will. A second physician must be consulted, and the euthanasia has to be carried out with due medical care and attention. Most requests for euthanasia come from people whose suffering is unbearable and who regard a self-chosen death to be the only way out. The suffering almost always has a physical basis. In 2016, in 67% of cases, the requests concerned cancer patients in the final stages of their illness (Onwuteaka-Philipsen et al., 2017).

Dutch legislation on euthanasia, as mentioned earlier, is firmly based on the notion that the person

seeking assistance to die is able to make an autonomous decision (it is “a voluntary and well-considered request from the patient who is competent to express his/her will”). The person’s request should be clear and unambiguous and there should be no pressure from others. This principle is intended to prevent a person from being pushed by others in some way to ask for assisted death. A “free” decision is a logical condition for what is called “voluntary death.” “It is the sole right making characteristic” of choosing euthanasia (Gastmans & De Lepeleire, 2010, p. 82). The apparent assumption is that a human subject is an independently thinking and acting being who is able to make rational autonomous decisions, even in matters of life and death and at an advanced age.

Discussions about the legal criteria for euthanasia have continued in the Netherlands ever since euthanasia was legalized. Some criticize the limitations of the present regulation. They argue, for example, that people who are tired of life without being seriously sick should be considered eligible for euthanasia. This criticism forms the starting point of this article.

In 1991, H. Drion – a former professor of civil law and member of the Supreme Council – initiated the

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debate on “completed life” in an article in a Dutch newspaper about older people’s desire to end their life and in an English article one year later (Drion, 1992). He wrote that many older people are looking for an acceptable way to end their lives when they feel tired of living and no longer want to go on. His plea prompted the emergence of the concept of a “Drion pill”, a euthanasia pill that people could have at their disposal and could take without the interference of a doctor. Drion’s proposal did not directly lead to policy decisions, but it did draw public attention to euthanasia as a possibility, even in the case of tiredness of life.

The concept of the autonomous individual choosing death took a drastic turn and gained more prominence in 2010 when a petition (called “Of Free Will”) was signed by more than 100,000 people asking to allow assisted voluntary death for people who are not suffering from a serious sickness but who consider their life to be “complete.” The petition was discussed in the House of Representatives, after a motion calling on the government to involve the citizens’ petition in its evaluation of the existing euthanasia law. The government responded by stating that the citizens’ petition did not relate well to the current system, but that further consideration of the issues it raised was important. It decided to conduct a study of the legal possibilities and social dilemmas of assisted suicide for people who deem their life “complete.” An advisory committee, chaired by the sociologist Paul Schnabel, was set up to carry out the study.

In January 2016, the committee reported that the number of people who wish to die while in a good state of health is probably very small and that such a wish usually arises with an accumulation of physical and/or mental health complaints. They concluded therefore that the existing euthanasia regulation could also accommodate most people who consider their life to be “complete” and that no additional legislation was needed (Adviescommissie Voltooid Leven, 2016). Nine months later, however, in October 2016, two government ministers proposed that new legislation should be made to help older people who wish to die after a “completed life.” The advice of the Schnabel committee was apparently ignored. The new government that took office in 2017, and which included a strict religious party, nevertheless decided to shelve the issue of “completed life” euthanasia. As it stands now, no decision will be taken in the coming years, certainly not before new elections.

An exploratory qualitative research study into the motives and expectations of nine people who signed

the “Of Free Will” petition (Satalkar & Van der Geest, 2019) and extensive research conducted by Van Wijngaarden and colleagues among persons who were preparing for voluntary death because of “completed life” (e.g. Van Wijngaarden, 2016) provide most of the data on which this article is based.

The purpose of this article is to explore in depth the notion of “autonomy” in older age and to critically examine the optimistic view that older people can be expected to take independent decisions about ending their life.

Research

The exploratory study was carried out in 2011, shortly after the launch of the “Of Free Will” petition. It aimed to understand the reasoning and decision making of individuals who had endorsed the petition. During the conversations, ideas of “free will” and autonomous decision-making were central in the reasoning of the respondents.

Semi-structured in-depth interviews were carried out with nine Dutch citizens living in the western part of the Netherlands, six women and three men. Seven of the nine respondents had a university degree, which is of course a very high percentage. The average education level of the signatories of the petition is not known, though it may have been rather high as well. The first respondent was identified through personal contact. The other eight were enrolled using the snowball technique. All interviewees gave oral informed consent. The respondents were engaged in a conversation and had the freedom to speak about anything that they deemed relevant to the topic. Their narratives guided further questions. Each conversation lasted for about 90–120 min. All were audio recorded and transcribed verbatim. The transcriptions were sent to the respondents for their feedback, clarifications and comments.

The data was coded manually to highlight the recurring themes. Data analysis was done by both authors independently and the themes of analysis were discussed, especially regarding differences in interpretation and to triangulate the relevance and consistency of the themes. A consensus was reached between the two authors in case of differing interpretations. The research was carried out by the second author. The first author provided comments throughout the research and was the main author of the present article.

Van Wijngaarden and colleagues carried out qualitative research, using a phenomenological or

“lifeworld perspective” as the authors call it (Van Wijngaarden, Leget, & Goossensen, 2016b). Their aim was to capture the views and lived experiences of older people who are confronted with the acute feeling that their life is complete. Their various publications are based on diverse research techniques and “samples” of people, for example in-depth interviews with 25 older people, the analysis of two vignettes of older people, and a focus on one case of an elderly couple.

Our concern over autonomous decision-making about voluntary death among older people is echoed by Van Wijngaarden and colleagues, who noticed the paucity of research into people’s experiences of living between the intention and the execution of self-directed death. On the basis of their research, they questioned “the concept of ‘rational suicide’ as an autonomous, free decision without pressure” (Van Wijngaarden, Leget, & Goossensen, 2016a, p. 9).

Two extended case histories, one from our own research and one from Van Wijngaarden’s study, form the ethnographic backbone of this article, complemented by shorter quotations from the conversations with our nine respondents.

Two case histories

Gertrude’s mother

Gertrude¹, one of the nine signatories of the “Of Free Will” petition, is 60-years old. She is married to Bas and has one daughter. One of her reasons for signing the petition was that she had witnessed the long suffering of her mother before she died. Gertrude believes that everyone should have the freedom to choose death without the interference of others. To clarify her position, she told us what had happened to her mother.

My mother suffered from depression for many years. We do not know exactly when it started but I think it could be partly from her childhood experiences and the war. She was in her late 50s when it started and she died when she was 80, and by that time she was in her seventh hospitalization for depression. Each time the depression hit her harder [sighs].

For the last couple of years, she hinted that there was a secret in her life, something so bad that she did not dare to tell us about it. But in her last year, she finally admitted that she wanted to die. She did not want to live any longer. Then she asked me for help with euthanasia. At that time, I thought it was a simple thing. I thought, you go to the NVVE [Dutch Association for Voluntary Euthanasia], sign the contract and you get the help. Forget it! It was not at

all that simple. She was living with my father and then she stopped eating. My father got really mad. This was the seventh time. He was also at the end of his patience. My mother’s illness had taken a huge toll on him as well and their relationship was becoming difficult. In his despair and distress, he began maltreating her. He used to pull her out of bed, hit her and kick her. One day when I visited them, my mother told me that he had hit her that morning. I looked at my father and I saw despair in his face. I knew I had to intervene. I called up the physician and asked him if my mother could be hospitalized. I was also afraid that if the situation remained the same, my father would die out of despair and physical exhaustion, since he had a severe heart condition.

She was taken to a hospital. That is when she said she wanted euthanasia. The hospital staff immediately reacted: “No, we don’t do euthanasia here. If you want euthanasia, we can’t admit you here. So, if you want to stay here, you have to sign the paper that you will refrain from euthanasia.” She did so. She had no other option. She could not go back home. We visited her every week. We used to have weekly meetings with the health staff. A month after her admission, in one of those weekly meetings, the psychiatrist told me that she was not doing well. I said, “I am not surprised, because she wants to die. What do you expect from her?” He reacted, “Oh no, that is not the case. She has never said it. If she wants to die, she just has to ask, and I have a syringe ready”. That conversation scared my mother. It was too strong a confrontation for her. He turned to her and asked in a threatening voice, “Do you really want to die?” She denied it vehemently. I was so mad about what had just happened.

It was not just the anger towards this psychiatrist and his attitude, but I was also mad at my mother. There had been so many times when she got me into trouble. I stood up for her and she would back out. The psychiatrist said, “You see, she doesn’t want to die. It is you who is pushing these thoughts.”

I asked myself, “Why did I get into this again?” I felt extremely upset. He left the room and I said to my mother, “If you really want to die, you have to be persistent and consistent and repeat your wish to several people.” That is what she did after that, but it did not help her anymore. The psychiatrist went away, and a new psychiatrist came in his place. We had to start all over again. He was also against euthanasia. Looking for another facility was not an option for her. And if you tried to commit suicide and you failed, you were punished.

The last months of my mother’s life were extremely hard. She broke both her arms while she was in that institution. We tried to find other solutions for her since she was not going to get euthanasia. She could

not stay in that hospital. She could not go back to my father. So, she had to go to an old people's home. The institution said that if she wanted to go to an old people's home, she had to wash herself, dress herself and we would have to practice it with her. They said it in such an unfriendly way. They did not want to help her get into her pants or tie her shoes, and she was extremely afraid that she might tumble over and fall. Because she had broken her arms, the fear of falling was understandable, and also the anxiety that she might be facing if you are an 80-year-old with osteoporosis.

We were on holidays and it was the end of September. My mother had been hospitalized since the end of March. She had been there for 6 months already. I came back and saw her very thin, her hair was unkempt. It was hard and scary to look at her, all skin and bone. I asked her if she still wanted to die and she told me that she had stopped eating. They tried to force-feed her. My mother was innocent, sometimes to the extent of being naive. That is when I realized that they were giving her packed astronaut's food, dense in energy. She did not know that it was that food that was keeping her alive. For her it was not food, it did not feel like food and they told her that it is not food, it is a drink. I realized what was happening there.

I explained to my mother, "These drinks, as long as you take them, you are not going to die. You are keeping yourself alive. Do you realize that?" She asked "What to do? I feel thirsty". That was understandable. She stopped taking those drinks. Then they [the hospital staff] said, "As long as you take your medicines, you are not going to die. Why are you still taking your medicines? That means you do not really want to die." I saw something in her face and the very next day she refused to take her medication. She had lot of conditions for which she was being medicated. She had a heart condition with leaking valves, she had high blood pressure and she was also on antidepressants. She had to take at least 15–20 tablets a day.

The hospital called us for an emergency meeting for she refused to take any medicines. I said to them that this is what you told her in clear words: "If you want to die, you would stop taking medicines." "But we can't allow this to happen," they said. "She will die in a week's time." That did not happen. Rather the opposite, she became lucid again. She started talking again [laughs]. It was so amazing. She almost came alive. I found my mother after many years. It was good to see her like that without the influence of any drugs.

The hospital again tried to treat her. That is when I intervened, and I said that we have a written statement and contract that you will not treat her against her will. That was the only document we had

on our side. They threatened to take us to court. I sought legal assistance. We tried to get her out of the institution, and they wouldn't let her go. They asked for a second opinion from another psychiatrist. He talked to her and he said, "It is clear that this woman doesn't want to live anymore." But he advised shock therapy as a last resort. We said that under no circumstances would we allow the hospital to put her through shock therapy. Her declaration had immense value in that situation. What would they gain by putting an 80-year-old through shock therapy who has been hospitalized for depression seven times? We did not expect that they could offer her anything in terms of improvement of any sort, let alone a better quality of life. They were really convinced that the shock therapy was in my mother's best interest and that our struggle to let her die was causing harm to her. They also tried to talk to her behind our backs to change her mind. Oh, I was so angry, so angry. I can't describe in words my anger and frustration with the system.

We were afraid that she might change her mind again. But this time, she was so determined, and she spoke to all of us, including to my eldest brother, who did not like the idea of her wanting to die, and she even convinced him. By then, I was also convinced that she was ready to go.

She had stopped eating but she was still taking fluids. Stopping to drink is the hardest part. You can't do it on your own and that is when you need good palliative care. We needed assistance from a physician. We made an agreement with the GP, who was against euthanasia, but she agreed to home care and palliative sedation. The part of palliative sedation was not clear to us in those days and that part went wrong. The doctor told my mother that she would give her medication to put her to sleep and that she would not wake up again. It seems she gave a very low dose which was not enough. After a few hours, my mother was wide awake and completely confused about where she was and if she was alive or dead. We all were flabbergasted. We did not expect that at all. We tried to contact the physician again and it turned out that she had gone on a course.

We did not know what to do. We called the group practice and they said she [the doctor] is not here and the other doctors did not know anything about the case. We found out that she would come back on Monday and we were really put out. Fortunately, we had good help in those days for everyday assistance and nursing care. The nurse said that she would take it up with the center and ask for more morphine plasters, and she helped us. Finally, on Sunday night, she died. There were no repercussions, no legal hassles. We had no troubles. It happened during the night. The nurse was there, our father was asleep.

This dramatic account of Gertrude's mother's road to voluntary death shows the mother shifting from

one position to another depending on the position and pressure of influential others such as her daughter and medical professionals. We were not able to speak to the mother in order to ascertain her own deepest convictions, but according to Gertrude she really did want to die. The case also brings out the fact that a “decision” to end one’s life may remain futile until the physician in charge agrees. This case will be analyzed more extensively in the next section.

Peter and Suzan

This case is taken from an article by Van Wijngaarden et al. (2016b) that describes the experiences of an elderly couple who chose to end their lives together, which the authors call “spousal self-euthanasia.” The article is based on three conversations, first with the wife and the husband apart and the third with both together, totaling 4.25 hr. Shortly after the last meeting, the couple died. We have chosen this case (with the permission of Van Wijngaarden) because spousal self-euthanasia seems an extreme example of autonomous decision-making which could provide important insights for the central question of this article.

Peter and Suzan, both in their 70s, were married for over 40 years. They raised four children, and both worked as university lecturers. In his spare time, Peter was an artist. They looked back on their lives “with satisfaction” and evaluated their marriage as “happy and intimate.” In his 40s, Peter went into therapy because he suffered from a childhood trauma and separation anxiety, which had quite an impact on their family life, as his problems caused mental suffering to their children as well. Things went “all right after all,” but with one child personal contact remained rather difficult.

Short after retirement, both had to face physical problems. Suzan was diagnosed with severe, progressive arthritis, while Peter suffered from several transient ischemic attacks (TIAs), a sensory disorder and impotence. Because of decreased mobility, they had decided to move to a town nearby their children, but they were unable to take root in their new environment. The development of their wish to die was closely associated with deteriorated health and age-related losses. To their children, they spoke about their strong aversion toward ending up in a nursing home and their intention to terminate life before losing their independency. With regard to their death wish, no mental health therapies were sought, as Peter and Suzan did not perceive themselves as being mentally ill and having a pathological wish to die. They rather perceived themselves as “normal” citizens, with a “reasonable” wish to die, in search for what they call “a dignified death.” For decades, they

had been active members of two Dutch right-to-die organisations. Both organisations provide information on how to perform a self-chosen death. The couple planned to perform the self-euthanasia in their home, by taking lethal doses of medicine. Within a few months after member check, they died together at a self-directed moment (Van Wijngaarden et al., 2016b, pp. 1065–1066).

The authors provide an extensive reflection on the views and experiences of the couple leading to their self-chosen end of life, to which we will refer in the next section.

Dependence and autonomy

The two cases differ in several respects, and two differences are notable. The first case is a narrative by a daughter about her mother’s wish to die; the second is based on the couple’s own account of the experiences and emotions that made them long for their lives to end. A second crucial difference is that Gertrude’s mother was suffering from grave physical and mental problems, while Peter and Suzan were not; neither of them had a life-threatening illness or severe depression. Their wish to die had developed from their struggles with ageing (alienation from their body and identity, a growing emptiness of life due to the loss of contacts and the ability to do certain activities, and an inability to reconcile themselves with their changed ‘being-in-the-world’, Van Wijngaarden et al., 2016b, p. 1069). Taken together, the two cases present complementary pictures of decision-making when it comes to voluntary death, in the first case in the context of severe physical and psychic suffering, in the second without such complaints.

Medical domination

Peter and Suzan did not speak about doctors on whom they depended for the realization of their wish to die. From personal communication with Van Wijngaarden, we know that they had approached their general practitioner, who refused to get involved. After that, doctors did not play any role in their decision. Doctors were (and still are) legally barred from granting euthanasia to people who declare their life to be “complete” without suffering any terminal disease.

Gertrude’s account of her mother’s final years presents in detail the chaos and conflicting opinions that may arise around a person’s death wish. In this case, the mother seemed to be pulled back and forth between what she wanted and what others believed was the right choice for her. Her husband was upset

by the thought that she did not want to continue living and used verbal and physical violence to force her to eat and get out of bed. Her daughter, on the other hand, believed that her mother had a real death wish and supported her when facing the pressure of the professional caregivers, doctors and psychiatrists who wanted to keep her alive. Their rejection of euthanasia for someone who was not terminally ill and whose death wish was seen to be the result of pathological depression became the main stumbling block for Gertrude when helping her mother to die with dignity.

To portray doctors as persistent opponents of a dignified death is of course unjust and unfair. Most doctors who are approached for euthanasia are cooperative and attentive to patients' complaints about pain and suffering, but they are restricted by the law. In 2015, 55% of requests for euthanasia or assisted suicide were granted (Onwuteaka-Philipsen et al., 2017, p. 94). The fact that during the interviews with the nine signatories of the 'Of Free Will' petition medical domination was continuously mentioned and criticized is, however, understandable, since the interviews were focused on cases where doctors did not – or did not immediately – agree with the request. The narrative of Gertrude's mother was in fact presented as a gripping confirmation of that domination. The respondents differed, moreover, in their complaints about their forced dependence on doctors. Some insisted that doctors should listen to them and take their reasons for wanting to die seriously. Others suggested that doctors should be excluded from the decision-making process and called instead for self-euthanasia. Marjan, 64, never married, no children, explained:

I do not agree with the fact that the doctors decide whether I should live for another week because they do not want to pull the plug [life support]. We live longer... because the doctors keep us alive. That is not my decision, it is their decision. They don't want to discuss it with me.

Lia, a woman of 53 years, told us that both her parents had died after refusing to receive further treatment. She and her dying parents had remained polite but firm with the doctors. She described her views on doctors' interference as follows:

We must be realistic about a patient's condition, open and honest in communication with the patient about his life and death, not just say, "Be strong you can fight this out." I expect that the patient will be an equal partner in deciding his last course of life and death. If a patient feels that he is not getting better and does not want to suffer the pain, why can't we

believe him? Why do doctors feel compelled to do everything to prolong the life of a patient even when the patient doesn't want it?

Dirk is 67-years old and a retired medical doctor, who sometimes had to give a second opinion about euthanasia requests. His observation captured the bitter irony of medical domination:

I have had patients who said that they would be happy to get diagnosed with cancer as "now I can ask for euthanasia. I was ready for it but now I have a valid reason to get help." The only possible way out is a solid diagnosis like cancer.

Jenny, 65-years old, the mother of two daughters and divorced, commented:

Nobody, not even my GP, can or may tell me if my life still has sense or not. He may know me very well, but he can't make decisions about my life. That is *the whole point*. How dare he?

The "whole point," however, is that Jenny's GP is likely to have a decisive voice when, in a near or distant future, she chooses to die because she is tired of living. For Jenny, using such strong terms when talking about doctors making decisions against her personal wishes may seem a little premature and gratuit, since at the age of 65 it will likely be a long time before she will in fact make a request for euthanasia. Ultimately, most of the respondents insisted, the only way out would be to bypass the GP altogether. Marjan was very clear on this:

Independence is the most important value in my life choices. I do not want to be dependent on doctors who keep me alive when my body wants to die. I want to decide that for myself. I want to be more in balance [autonomous] instead of doctors having the total say on how my life should continue or end.

And Gertrude, who told us about her mother's death, also rejected doctors' interference at the end of life:

Death is the final thing you want to have control over. It starts with life (abortion or not, marriage or not, children or not). Now it is time to include death in this list.

Despite this, and as we mentioned before, it proved quite difficult for her to actually keep the doctor out and allow her mother to decide for herself.

Are autonomous decisions possible at all?

Gibson (1993) has made a useful distinction between independence and autonomy in old age. Very briefly summarized, she states that independence is the

ability to decide and act without anyone's help (which from a sociological and psychological perspective seems impossible to us, anyway). Autonomy is the ability to decide and act, usually with the help of others. Autonomous decisions in this sense are possible if the person – in this case the older person – is able to command assistance from others (cf. Winance, 2007). This ability again depends on reciprocity, for example social credit built up during one's life, but it can also be financial capital that buys assistance, as Gibson shows. Limiting ourselves for a moment to reciprocity through social capital, we see that if older people can call upon children or others to help them when making decisions or carrying out certain actions, they are autonomous because they are able to do what they want to do. In contrast, those who want to remain independent and refuse to ask for help deprive themselves of activities that they would like to carry out. In this case, the wish to remain independent becomes an obstacle to autonomy. For example, an older woman wants to visit a concert but is unable to go there on her own. If she can ask her son to accompany her (or can afford to take a taxi), she can in fact realize her wish with the help of someone else. But if she wants to be independent and does not dare or want to ask her son for help, she has to give up on the idea of going to the concert.

If we apply this distinction to the situation of older people who want to make and follow their own decision regarding voluntary death, autonomy turns out to be more complex. Especially in such a sensitive matter as voluntary death based on the consideration of a "completed" life, children and others may be unwilling to help older people carry out their death wish, and may even actively obstruct them in spite of the fact that they love them and want to help them. Van Wijngaarden and colleagues observed this dilemma in the case of Peter and Suzan, but also in other cases they described.

Peter and Suzan's son felt upset and powerless when his parents told him about their plans, and strongly disagreed with them:

It's just absurd. It's absurd that they apparently believe that their life is over. Though we, as children, totally disagree with this idea. They have grandchildren who love having a grandma and grandpa. And they have children who love them (...) but apparently that plays no role in their decision (Van Wijngaarden et al., 2016b, p. 1069).

Peter seemed undeterred by his son's objections. He was determined to carry out his and his wife's mutual promise, which they had made 10 years

previously, that they would seek a dignified death together before they reached a stage of total dependency and their lives were reduced to an empty passing of time (as they had seen happen to Peter's parents). But Suzan hoped that her life could still be meaningful and that she could contribute something to her children and grandchildren in spite of her deteriorating health condition. She was not in a hurry, but Peter wanted to take the "shortcut" as soon as possible. In her interview, Suzan complained, "Damn, why can't he wait a little longer for me?" (p. 1068). At the same time, she felt guilty about not staying faithful to the promise they had made to one another. Tension arose and the topic of "when" became a silent split between the two and caused an impasse. Not long after, however, Suzan had apparently given up her resistance, since the researchers received the message that the couple had ended their lives together. Suzan's subjective wishes had to be compromised due to differences in her and Peter's past experiences, their present conditions and their perceived prospects.

Van Wijngaarden and colleagues observed similar obstacles to autonomous decision-making in their interviews with 25 older Dutch citizens who had decided to end their lives in the near future because they no longer found life worth living. The article (Van Wijngaarden et al., 2016a) focuses on "what it means to live with the intention to end life at a self-chosen moment from an insider perspective" (p. 2). They conclude that their respondents had a "constant feeling of being torn." They expressed this in words like "dilemma," "doubt," "struggle," "balancing act," "quandary," "split position," and "a contradictory process" (p. 4). The authors distinguish five polarities in this uncertainty about what would be the right decision, two of which are particularly relevant for this article: detachment versus attachment and resisting interference versus longing for support (p. 4). One of the respondents said: "It's about freedom. Total freedom. And now I want to keep that freedom, which I've always had, to die in my own way." Another one said: "I just want to keep it under control. (...) I think you shouldn't burden someone else. It's my decision, so I'm fully responsible" (p. 7).

Ari Gandsman (2018) opens his article on autonomy and right-to-die activism in North America and Australia with an apocryphal story that he heard three times in three different versions. An elderly couple in New Zealand had decided to end their lives together and told their children about their plan. They had acquired the medicines and would take them in the near future. The children protested vehemently, and

one daughter demanded that her parents give her the medicines so that she could flush them down the toilet. She threatened to call the police if they refused. She said this out of love, someone commented. In making an autonomous decision to die, a person may encounter several obstacles that in fact destroy autonomy. Gandsman (2018, p. 330) writes that the insistence on autonomy “limits critical self-reflection in how this issue necessarily involves one’s relationship with others.” Among these others are loved ones as well as medical doctors. Van Wijngaarden et al. (2016a, p. 7) conclude:

Despite the fact that most participants clearly stated that they regarded their choice to end life as their “own responsibility” and “an autonomous, independent decision,” preferably made without any interference from others, the majority of participants at the same time paradoxically wanted interference with proper (medical) assistance to actually carry out the act to end life, and they felt closely dependent on medical professionals for support and assistance.

Many still consider medical professionals indispensable in terms of safeguarding a successful and painless end of life, but the agreement and support of loved ones, in particular children, is also crucial for making a self-chosen death a “good death.” The following quotation from a man who was concerned about the emotions of his children illustrates this:

If they all show the same emotions as my daughter, I don’t think I can handle it. Then I’ll probably give up my freedom to decide on my own life. Because then I will see so much sadness, I just can’t handle that... (...) You hurt someone while it’s not necessary, because I don’t have to commit euthanasia. No one forces me. (...) It’s voluntarily (p. 5).

The final words of this quotation encapsulate the paradox of making autonomous decisions. The man had initially chosen for a voluntary death, but was prepared to “give up his freedom” if his children opposed it. But, he added, they would not be forcing him to give up. It would still be his own decision to take his children’s emotions into account and change his mind. “When I see their sorrow, then well, I actually think, I’m a bit of a coward. (...) I am choosing the path of least resistance,” he added. Freedom and autonomy are ambiguous concepts. So-called free decisions are never made in splendid isolation.

Une personne autonome n’est pas une personne qui décide et agit seule, mais dont le pouvoir décisionnel et les capacités d’action sont soutenus par de multiples relations (sociales, techniques, institutionnelles, symboliques ...) (Winance, 2007, p. 84).

But Van Wijngaarden et al. (2016a, p. 8) also observed that communication with others about this delicate topic sometimes proves impossible:

The idea of a self-chosen death was not only rejected by close family, but also by other older people like neighbours or occupants of the same nursing home who “got mad” at them: “I cannot talk about it with people. They say: ‘Are you crazy!’ (...) I’d better keep it to myself.”

The simplistic popular notion of equating autonomy with independence is a typical product of a society in which Ego is declared sacred, as if not every decision of an individual involves other people and inevitably asks for consultation with others. This so-called autonomy of the individual is not only considered one of the main cultural values in Dutch society; it is also seen as a real possibility: the free person who “stands on his/her own two feet” and walks around in the market of well-being and happiness buying what he/she wants. Janzen (1978), in his classic study of therapy choice in Zaire (now D. R. Congo), suggested the concept of a ‘therapy management group’ in order to contrast the Congolese style of decision-making in medical situations (family-based) with the “Western” style (individual-based). But – as we have argued above – “Western” individuals can also rarely detach themselves completely from their relatives and other significant others when making decisions regarding life and death. Certainly not when they have grown old and fragile.

Decisions in times of fragility

The obstacles to autonomous decision-making with regard to euthanasia that we have discussed in the two previous sections assume greater momentum when physical and mental fragility increase when growing older. It is true that the number of older people who are physically and mentally fit and competent to make decisions is growing, but it is also true that for many, life in the present world has become too complex to oversee the many options and choose the best ones. The technical and administrative routes to the various options may also pose problems and force older people to seek the help of others. The ability to reflect on their situation in the context of a rapidly changing world is also a major challenge.

The case of Gertrude’s mother illustrates this well. The mother may have expressed her wish to die to her daughter, but she also seemed uncertain about this wish. She felt lost in the context of institutional organizations and existing rules and legislation.

Moreover, the people around her had conflicting views on what was the right thing for her in her situation. Most of Van Wijngaarden and colleagues' respondents, who had at an earlier point made clear and assertive statements about their determination to choose death when life became meaningless to them, later expressed doubts about their previous decisiveness.

Despite all efforts to ensure the course of their end, the majority of participants still expressed feelings of worry and uncertainty about the dying process; especially about the extent to which they would be able to stay in charge up to the end, about whether they would succeed in avoiding a painful death, and about the "right method" for self-euthanasia (Van Wijngaarden et al., 2016a, p. 6).

The irony of progressing fragility is that the need to make a decision becomes more urgent (before it is too late), but the ability to make such a decision actually diminishes. The thrust of our argument is to question the over-optimistic expectation that human beings at an advanced age are always able to take their destiny into their own hands. The crumbling subject loses his/her confidence in personal competence and feels increasingly dependent on others, who may now decide over matters that have slipped away from them. The tragedy of this loss of various competences is of course that the ability to maintain control also disintegrates. There is too much confidence in the expectation that people can make sovereign decisions when they have become totally dependent on others. Even if they have made self-confident advance decisions, it is uncertain whether they will be able to implement them at a later stage. Their ability to endorse and persuade in order to ensure that their advance decision is carried out may have evaporated. Being in charge of one's own decline may prove a painful contradiction, as the case of Gertrude's mother shows.

Conclusion

Our study revealed three aspects of decision-making with regard to voluntary death that cast doubt over the assumption that one can make a free decision in the face of death, in particular voluntary death as a solution to being tired of life:

1. Doctors – not patients – have the final say in "measuring" the "amount" of pain and suffering that entitles a person to be granted euthanasia.
2. Human decisions are never fully autonomous; they are always taken in a context of complex

circumstances and the presence of relevant others such as relatives, friends, and medical professionals. Decisions may therefore be changed, mitigated or not taken at all.

3. People lose much of their autonomy when they grow old and fragile, and will be increasingly inclined or forced to leave decisions to others.

This qualitative exploration of the views and expectations concerning "completed life" euthanasia among nine signatories of the petition "Of Free Will" and the extensive study by Van Wijngaarden among 25 older people who had reached the moment of ending their lives based on their feeling that their life was "complete" both suggest that choosing to end one's life is more uncertain and complex than most people anticipate.

As long as ethicists and Dutch politicians remain undecided about how to respond to this new call for a facilitated self-chosen death, the complexities surrounding the case of people who consider their life to be complete will continue. They can receive no assistance from medical doctors, and relatives and friends are likely to discourage them from making a decision that they view as premature and unauthorized. "While suicide is generally an individual act, a medically assisted death involves by definition the assistance of others and a legal framework" (Gandsman, 2018, p. 331). The present conditions under which older people could end their life, without the support of a doctor and against the wishes of their loved ones, does not feel like the good and dignified death that many envisage. Autonomy in this case proves to be but an illusion (Gandsman, 2018).

Ethical approval

No formal ethical approval was needed, but all research participants gave their full informed consent to being interviewed.

Disclosure statement

No potential conflict of interest was reported by the authors.

Note

1. All respondents' names in this article are pseudonyms to protect their identity and privacy.

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