Patients Who Seek to Hasten Death by Voluntarily Stopping Eating and Drinking: A Qualitative Study

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ABSTRACT

PURPOSE Voluntary stopping of eating and drinking (VSED) is a controversial method to hasten death. Little is known about why and how people come to VSED. This study assessed patients' motives, how patients decide on VSED, and the ways in which they prepare for VSED and involve others.

METHODS We conducted a qualitative study in the Netherlands of 29 patients; 24 started VSED and 19 died. Thirteen patients were included before or during VSED and 16 afterward. We interviewed 17 patients, 18 relatives, and 10 professional caregivers. Inductive ideal-type analysis was used to describe typologies.

RESULTS Three patient groups emerged. The first group (12 patients) were older people who felt life was completed, for whom control was important. They prepared well for VSED, but could overlook the need for help and the emotional burden their decision could place on relatives. The second group (11 patients) were older care-dependent patients with a poor quality of life. They sometimes started VSED suddenly, and they relied heavily on (informal) caregivers to prepare and execute their plan. The third group (6 patients) were psychiatric patients with a long-standing but fluctuating death wish, most of whom were younger. They often prepared for VSED in secrecy or started VSED unprepared.

CONCLUSIONS Patients embarking on a trajectory toward VSED are a very diverse group, with different care needs. Guidance for care during VSED needs to be applicable to all 3 groups.

Ann Fam Med 2023;21:534-544. https://doi.org/10.1370/afm.3037

INTRODUCTION

Physicians around the world are confronted with patients who want to hasten death by voluntary stopping of eating and drinking (VSED). Studies showed that 46% of Dutch general practitioners (GPs) and 43% of Swiss GPs provide care to patients during VSED in their career.[1,2] In Oregon, 41% of hospice nurses have experience with VSED.[3] Studies from the Netherlands and Switzerland estimated 0.5% to 2.1% of people who die do so by VSED.[4-6]

Patients do not need approval by their physician, or others, to start VSED. With adequate care, VSED can lead to a relatively comfortable death.[7,8] Experts stress, however, the importance of involvement of professional and informal caregivers and good preparation.[7,8] Some patients do not involve others in VSED.[9] In former research, patients informed their GPs in a timely manner in merely 50% of VSED cases, and only a minority involved their GP (21%) or relatives (44%) before their attempt.[1] Most physicians and nurses in the western world seem willing to support patients during VSED,[1,3,10,11] although they can feel unease over aiding someone to hasten death.[7,11-13] Relatives who provide care to a patient during VSED can feel satisfaction as well as a heavy responsibility, exhaustion, and doubts. Their experience is related to their level of acceptance of the patient's decision.[14-16]

General practitioners and relatives describe patients' motives to initiate VSED as diverse. The motives can be related to somatic, psychosocial, and existential suffering; loss of independence; loss of self; and a wish to control the end of life.[5,8] Because studies involving patients are lacking, it is unknown why this group with such diverse motives to hasten death choose this method and what happens before they start VSED.[17,18]

This study aimed to describe why and how patients come to VSED. First, what are their motives and how do they decide on VSED? Second, how do they prepare and in what way do they involve others? Is it a homogenous patient group? To fully

Conflicts of interest: authors report none.

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explore the subject, we performed a qualitative study and included the perspective of patients, relatives, and professional caregivers.[17]

This study took place in the Netherlands, where most end-of-life care is provided by GPs, to patients dying at home (33% of nonsudden deaths), in homes providing low-level care, and in hospices (20% of nonsudden deaths).[19] Much as in the United States and other western countries, aiding a patient during VSED is legal. According to professional standards, patients are entitled to care to relieve suffering during the process.[4] Caregivers can use guidance on care during VSED. In the Netherlands, physician-assisted dying (PAD) or euthanasia can be an alternative for patients with unbearable and incurable (physical or psychological) suffering; however, physicians can decline requests for PAD on personal grounds. Requests for PAD from patients with psychiatric or existential suffering are mostly declined.[20]

METHODS

Design

We performed a qualitative study using interviews with patients, relatives, and professional caregivers. To be included, individuals had to be (1) people who seriously considered or decided to hasten death by VSED in the near future or recent past, (2) relatives who had a close relationship with a deceased patient who attempted VSED, or (3) professional caregivers (primary treating physicians, nurses, or nursing aids) involved in VSED. When possible, we explored cases from 2 or 3 perspectives. The study protocol was reviewed by the medical ethics committee of the VU University Medical Center, Amsterdam, the Netherlands. We used the Consolidated Criteria for Reporting Qualitative Research (COREQ) for this article.[21] The 3 (female) researchers are a practicing GP (E.E.B.), a former nurse and social scientist (H.R.P.), and a health scientist (B.D.O-P.). Two (H.R.P. and B.D.O-P.) are experienced qualitative researchers, and 1 (E.E.B.) completed a master's course on qualitative research. This study followed a quantitative study on VSED that highlighted a need for more in-depth qualitative data on the practice.[1]

Recruitment and Sampling

Because VSED is rare, we used convenience sampling. We used various sources to recruit participants to increase validity. The sources were a website designed for the project (3 patients); the magazine, newsletter, and helpdesk of NVVE (Nederlandse Vereniging voor Vrijwillige Euthanasie, the Dutch Right-to-Die Association) (16 patients); and professional caregivers (11 patients). General practitioners with special interest in palliative care and hospice physicians were informed about the study at a conference and through personal e-mails. Professional caregivers asked eligible patients and relatives permission for the researchers to contact them. Participants received written and oral information about (the motives for) the study from the researchers before they decided to participate.

The inclusion period lasted 18 months (January 2020-June 2021). We were approached by 27 patients, 49 relatives, and 9 professional caregivers. If the patient gave consent, we invited their relative and professional caregiver to participate after death. In 2 cases, the patient was too weak to participate and their relative gave an interview on their behalf. In many cases, the patient was already deceased at recruitment. We included all of the 12 patients who had an active wish to end life, because they were expected to be the most valuable sources of information. For additional participants, we strove for maximum variation in the sample with respect to source of information, age and sex of the respondent, and source of recruitment.

Setting and Data Collection

We selected 33 cases for an interview, interviewing multiple sources per case when possible. We conducted 54 interviews with 17 patients (with multiple interviews in 6 cases), 18 relatives, 8 physicians, and 2 nurses. One-on-one interviews were conducted face to face at the participant's chosen location (17 participants, mostly at home) or by telephone (37 participants, because of COVID-19 restrictions) by E.E.B. and H.R.P. A relative was present during the patient interview in only a single case (case 16). Interviews lasted 29 to 100 minutes and were audio recorded and transcribed verbatim.

Before the interviews, all 3 researchers made a topic list. After 5 interviews, they discussed and adapted the topic list; for instance, questions about burdening relatives and expectations of others were added. The topic list was used as a reminder of issues to be addressed during the semistructured interviews. The interviewer made a mind map and summary directly after the interview and expanded them after reading the interview transcript.

Data collection and data analysis were done simultaneously; new interviews were continued as long as new codes came up. When interviews no longer added new codes, data collection stopped. We excluded 4 cases from analysis because the interviewed patients had not attempted VSED and were not considering it in the near future.

Data Analysis

The data were first analyzed by the principles of inductive thematic analysis.[22] Interviews were transcribed and coded using Atlas.ti 8 (Scientific Software Development GmbH). First, E.E.B. familiarized herself with the data by reading 5 interviews and keeping notes. Two interviews were coded inductively by 2 researchers (E.E.B. and H.R.P.) independently and then discussed by all 3 researchers. Thereafter, codes were refined and an initial coding tree was made by E.E.B. After 5 interviews, the coding tree was discussed by the 3 researchers and adjusted. Two interviews were coded by E.E.B. and R.P. using the new coding tree and discussed. The coding tree was further developed during the study, and interviews already coded were recoded using the new coding tree by E.E.B. Two researchers (H.R.P. and B.D.O-P.) critically judged the findings.

For this study, the research group further explored the 22 codes involving the period up to VSED and rearranged them into 4 categories: background and motive; considerations and expectations; role of others; and trajectory. In the process of analysis, 3 distinct patient groups emerged from the data, with within-group similarities and between-group differences for each of the 4 categories. From this point onward, we changed our approach to an ideal-type analysis as described by Stapley et al,[23] to develop and check typologies.

On the basis of the case summaries and mind maps, and after rereading (parts of) the interviews, each patient's story was described in a case reconstruction. Key features were systematically compared using color codes in Excel (Microsoft Corp), and the within-group similarities and differences were summarized. Next, we constructed 3 groups that shared fundamental features (ideal cases). Finally, we identified the cases best exemplifying each group (optimal cases). To check credibility, each case reconstruction was reread and outliers were identified.

RESULTS

We included in our analysis 29 cases of patients who used or contemplated VSED. Their characteristics are summarized by group in Table 1 and detailed in Table 2. Nine cases were included before VSED was initiated (of whom 4 made an attempt during the 1-year study period), 4 cases were included during VSED, and 16 cases were included after a VSED attempt. The patients' ages ranged from 26 to 97 years.

Patient Groups

Through ideal-case analysis, we identified 3 groups of patients, each with similar background and motive, considerations and expectations, roles of others, and trajectories: those using VSED to remain in control (group 1), those using it to accelerate a natural death (group 2), and those using it as a more acceptable suicide (group 3). Figure 1 gives narrative descriptions of each group, and Figures 2, 3, and 4 present the cases that best exemplify each group (optimal cases). We discuss each group in detail below, noting supporting quotes from interviews that are given in Table 3.

Group 1: VSED to Remain in Control

Background and motive. The first group consisted of 12 cases, of whom 6 died before study inclusion and 3 died after inclusion. For this group, VSED was a method to maintain a sense of control over life and/or death. These cases were characterized by the absence of severe physical and mental suffering, and the absence of a strong death wish (Table 3, quote 1.1). Participants described physical discomforts related to old age and loss of loved ones, but the main reason they wanted to end their lives was to prevent physical or cognitive decline and loss of independence (quote 1.2). They felt they were already losing parts of their identity: they reported feeling disconnected from the world and a loss of interest in others, describing this interest as an integral part of their identity. Typically, these patients were used to being in charge and wanted to exercise control over their own death (quotes 1.3 and 1.4).

Considerations and expectations. All of the patients in this group had considered PAD and some had discussed it with their GP, but most discarded it as an option. They assumed it was not within reach, and some did not want to depend on, or burden, their physician (Table 3, quote 1.5). Some considered collecting medicine but found it too risky, or discarded it because they did not want to hide their actions (quote 1.6).

Although most preferred a faster and easier death, VSED seemed the most autonomous method. A few patients saw it as an interesting venture or a final challenge, or preferred VSED over PAD as a more gradual and natural death (Table 3, quote 1.7). Patients in this group expected that VSED would not be easy, but were confident that they would succeed (quote 1.8). They did not expect to need much help, and would get help if needed (quote 1.9). Some relatives described afterward how VSED turned out to be harder and lengthier than expected (quote 1.10).

Role of others. Patients in this group rarely included others in their decision making. Most did not inform relatives and caregivers until they had made up their minds and had prepared for VSED by themselves (Table 3, quote 1.11). Relatives could be shocked by the news and have a hard time understanding how the patient came to this decision. The patients were open about their motives (quote 1.12). Both interviewed patients and interviewed relatives described how

Table 1. Summary of Patient Characteristics for Each Group (N = 29)

Characteristic	Group 1: VSED to Remain in Control (n = 12)	Group 2: VSED to Accelerate Natural Death (n = 11)	Group 3: VSED as a More Acceptable Suicide (n = 6)
Age at death/inclusion, median (range), y	82 (64-93)	92 (78-97)	47 (26-82)
Sex, female, No. (%)	5 (41.7)	7 (63.6)	5 (83.3)
Requested PAD, No. (%)	9 (75.0)	7 (63.6)	5 (83.3)
Attempted VSED, No. (%)	8 (66.7)	10 (90.9)	6 (100)
Died during VSED attempt, No. (%)	8 (66.7)	9 (81.8)	2 (33.3)

PAD = physician-assisted dying; VSED = voluntary stopping of eating and drinking.

Table 2. Detailed Patient Characteristics (N = 29)

Case No.	Recruit-ment	Interview Source(s)				Age Decile at Death/ Inclusion, y	Sex	Timing of Inclusion[a]	Request for PAD?	VSED Attempt?	Time Between Attempt and First Interview	Died During Attempt?
		Patient	Relative	Physician	Nurse							
Group 1: VSED to remain in control (n = 12)												
2	NVVE		x			60s	M	After	Yes	Yes	3 Months after	Yes
4	NVVE	x		x		80s	M	During	No	Yes	Day 4 of attempt	Yes
5	NVVE	x	x	x		90s	M	During	Yes	Yes	Day 8 of attempt	Yes
6	Other		x			80s	F	After	No	Yes	2 Years after	Yes
7	NVVE	x				80s	M	Before	Yes	No	...	NA
10	NVVE		x			80s	M	After	Yes	Yes	1 Year after	Yes
11	NVVE	x				70s	F	Before	Yes	No	...	NA
13	NVVE		x			90s	F	After	Yes	Yes	2 Years after	Yes
20	Other				x	70s	F	After	Yes	Yes	4 Years after	Yes
21	Caregiver	x				70s	F	Before	Yes	Yes	Day 1 of attempt	Yes[b]
25	NVVE	x				70s	M	Before	Yes	No[c]	(4 Months before PAD)	NA
27	Caregiver			x		70s	M	After	Yes	Yes	3 Weeks after	Yes
Group 2: VSED to accelerate natural death (n = 11)												
8	NVVE		x			90s	F	After	Yes	Yes	8 Months after	Yes
9	NVVE		x			70s	F	After	No	Yes	8 Years after	No
12	NVVE		x			80s	F	After	Yes	Yes	15 Months after	Yes
14	Caregiver	x	x	x		90s	F	During	Yes	Yes	Day 1 of attempt	Yes
15	Internet		x	x		80s	F	Before	Yes	Yes	4 Months before	Yes
17	NVVE		x			90s	M	After	No	Yes	10 Months after	Yes
18	Caregiver		x	x		90s	M	After	No	Yes	7 Days after	Yes
19	Other		x			90s	F	After	Yes	Yes	2 Years after	Yes
24	NVVE	x				80s	M	Before	Yes	No	...	NA
28	Internet		x			90s	M	After	Yes	Yes	4 Months after	Yes
29	Caregiver		x	x	x	80s	F	Before	No	Yes	Day 9 of attempt	Yes
Group 3: VSED as a more acceptable suicide (n = 6)												
1	Caregiver	x	x	x		60s	F	During	Yes	Yes	2 Days before	Yes
3	Other	x				20s	F	After	Yes	Yes	4 Days after ending VSED	No
16	NVVE		x			80s	M	After	No	Yes	9 Years after	No[b]
22	NVVE	x				30s	F	Before	Yes	No	...	NA
23	NVVE	x				40s	F	After	No	Yes	17 Months after	No
26	Internet	x				30s	F	Before	Yes	Yes	2 Months before	No

F = female; M = male; NA = not applicable because VSED was not attempted; NVVE = Nederlandse Vereniging voor Vrijwillige Euthanasie (the Dutch Right-to-Die Association); PAD = physician-assisted dying; VSED = voluntary stopping of eating and drinking.

[a] Relative to VSED attempt.
[b] Died by suicide (ingestion of lethal substances).
[c] Died by PAD.

some relatives tried to talk the patient out of VSED but were unable to do so (quote 1.13).

Trajectory. Patients described their decision making as a gradual process. It started with a growing dread of losing independence, leading to the intention to take matters into their own hands. Patients took their time, and some studiously explored different options to hasten death.

For those who initiated VSED, there was no identifiable trigger for doing so. Rather, patients described how the balance between positive and negative aspects of life had slowly tipped toward the negative. They took a practical approach to planning initiation of VSED, starting after the holiday season or after a family celebration (Table 3, quote 1.14).

Patients took time to prepare. All but 2 prepared well for VSED and their death, and over a longer period of time (Table 3, quote 1.15), and all who started died (although one ultimately died by ingesting lethal substances). Three patients did not start VSED during our 1-year follow-up: 1 died after

PAD, 1 was waiting for her cat to die first, and 1 could not say if and when he would want VSED.

Group 2: VSED to Accelerate a Natural Death

Background and motive. The second group consisted of 11 patients who were care dependent because of old age and/or severe disease and had a poor life expectancy. In general, they had had a low quality of life for years. Disability and loss of relatives made their world small (Table 3, quote 2.1). As in the first group, loss of independence played an important role in their motivation to end their lives. But in contrast to the first group, who were still largely independent but feared becoming dependent, patients in this second group had already lost more of their independence than they could bear. These patients had had a passive death wish for a long time, and had been patiently waiting for death until a certain trigger activated them (quote 2.2).

Considerations and expectations. Although most patients in this group preferred PAD, they did not make a formal request, their request was denied, or the process would take too long (Table 3, quote 2.3). Patients wanted to hasten their death as soon as possible, and VSED was seen as the only option within their reach (quote 2.4). Relatives described patients with unrealistic expectations about prognosis or care (quote 2.5). They did not seem to worry about symptoms or problems during VSED (quote 2.6), and trusted their physician to relieve their suffering and their relatives to support them. These patients were described by relatives and caregivers as passive and, as a result, others (relatives and professional caregivers) took over the preparations (quote 2.7).

Role of others. These patients had a strong network of informal caregivers around them and were used to others arranging things for them. In line with this situation, they depended on their relatives and GP to gather information about methods to hasten death. Typically, the decision to start VSED was made together with (and sometimes at the suggestion of) their relative(s) and their GP (Table 3, quote 2.8).

Figure 1. Narrative descriptions of the 3 groups.

Group 1: VSED to remain in control. These patients were older adults (aged older than 70 years) who were still largely independent and highly valued their autonomy. However, they had lost interest in the world around them or wanted to prevent becoming dependent because of physical or cognitive decline. Physical or social suffering could be present, but was not the main motive for VSED. They did not have a strong wish to die, rather, they had lost the will to live. For most, VSED was a way to exercise control over their end of life. The decision to start VSED was a gradual process that could take a long time because these patients were not in a hurry. VSED was carefully planned, but others played no or only a small part in the decision making and were informed late in the process.

Group 2: VSED to accelerate a natural death. These patients were the oldest old (aged older than 80 years) or severely ill, who were care dependent because of old age or somatic disease. Their quality of life appeared poor. Their life-world had already become very small because of immobility and loss of loved ones, and they could experience a lack of autonomy. They could be suffering or even waiting for death for a long time. If their passive death wish changed into an active one after a life event or decline in functioning, they suddenly decided on VSED and did not want to postpone it. They were dependent on others to prepare and arrange well for VSED and expected others to help. Relatives and caregivers could understand their wish to die and helped them to be successful in VSED.

Group 3: VSED as a more acceptable suicide. These patients were physically healthy and younger individuals (aged younger than 70 years) who had severe chronic psychiatric disease(s). They had a long history of psychiatric suffering, an enduring wish to die, and fluctuating suicidal ideations. Their main motive was to end their enduring mental suffering. VSED seemed the most humane and socially accepted method of suicide. There was a risk that these patients would start VSED (or attempt suicide) in a psychiatric crisis, without preparation, and without help because they did not expect caregivers to help them.

VSED = voluntary stopping of eating and drinking.

Figure 2. Optimal case of VSED to remain in control: Mr Jansen, a man in his 90s (case 5).

Patient: Mr Jansen was a widower with a large social network and a good relationship with his children. Over the last years, he slowly contemplated the idea of hastening death. His body deteriorated and this annoyed him. He lost his interest in the world around him and felt his life was complete. He wanted his children to remember him as the strong man he was instead of the weak man he was becoming. He decided he wanted to hasten his death. Mr Jansen expected his GP would not perform euthanasia in his case. Also, he did not want to depend on approval by others. He read about VSED and decided it was the only acceptable way to have control over his death. It seemed a somewhat uncomfortable death, but he was certain he would succeed and he assumed that his GP would sedate him after some days. He would have preferred ingesting lethal medication, because he would not have burdened his children with a prolonged death process, but did not know how to obtain this medication. After his decision, he informed his family, expecting them to understand. He waited until some celebrations and life events in his family passed, and stopped eating and drinking. He died after 15 days.

Daughter: On her weekly visit to her father, he suddenly announced that he would stop eating and drinking before the year was over. Although over the years he had repeatedly mentioned his wish to end his life before he became care dependent, this announcement came as a bolt from the blue. In the conversations that followed, his children could not persuade him to change his mind, nor could they fully understand his motives. They felt burdened that his wish not to burden them with his decline was one of their father's motives to hasten death. His steadfastness forced them to accept his decision, and they decided to support him in the process. They felt enormous unease about helping to end a life that was still so valuable to them, however.

General practitioner: Mr Jansen had discussed his wish to die multiple times, but had never talked about acting on this wish and had never requested euthanasia. On the first day of VSED, he called the doctor's office to inform them he had stopped eating and drinking. The general practitioner felt he could understand the patient's motives and visited him daily until his death. He saw it as an interesting experience.

VSED = voluntary stopping of eating and drinking.

In general, interviewed relatives saw the patients' suffering and supported the decision (Table 3, quote 2.9). Relatives said they preferred euthanasia, however, because it seemed less burdensome for the patient. This preference could lead to friction between relatives and the physician (quote 2.10).

Trajectory. Patients in this second group had a long-standing death wish but refrained from action for a long time (Table 3, quote 2.11). Factors such as not wanting to hurt relatives or unavailability of home care could lead to postponing or abandoning the idea of VSED. Finally, almost all patients in this group attempted VSED, and all but 1 (a patient with dementia) succeeded.

In this group, patients sometimes suddenly decided not to wait any longer (Table 3, quote 2.12). This abrupt decision could be triggered by a sudden drop in quality of life due to an acute illness or a realization that death was not imminent (quote 2.13). Once they had made up their mind, relatives described how patients were suddenly impatient to initiate VSED. This could lay a heavy burden on relatives, who needed to prepare everything in little time (quote 2.7).

Figure 3. Optimal case of VSED to accelerate a natural death: Mrs van Vliet, a woman in her 80s (case 12).

Daughter: Her mother, a widow, was unhappy for a very long time and she had had a death wish for years without acting on it. She lived in an elder care home and suffered from pain in her bones and joints due to arthritis and vertebral fractures. After a sudden increase in pain, she was again admitted to the hospital and a rehabilitation center. She did not improve and was continuously in pain and progressively bedridden. After some time, she told her daughters she wanted to end her life as soon as possible. She did not want to deteriorate even further.

The daughters consulted the general practitioner about euthanasia, but the physician was reluctant and said she needed some time to consider this request. Mrs van Vliet responded that she would not wait and would start VSED instead. She was determined. A family member had died after VSED and she would do the same. The close family collected information about VSED and called other relatives to give them the opportunity to say goodbye. They were unable to arrange sufficient and quality home care in time, so the family members needed to take on some of the care themselves. Six days after starting VSED, Mrs van Vliet died.

VSED = voluntary stopping of eating and drinking.

Figure 4. Optimal case of VSED as a more acceptable suicide: Ms van As, a woman in her 20s (case 3).

Patient: Ms van As had experienced psychiatric illness all her life, leading to severe anxiety, and had had a strong death wish for as long as she could remember. Her social network was small and she had never been able to work. Her burden of disease was very high and she had attempted suicide multiple times; however, she disapproved of suicide, viewing it as a painful death that would burden others and prevent her loved ones from saying goodbye to her. Over the years, she had gathered a lot of information about nonviolent methods to end her life, and she preferred euthanasia as the most comfortable method, with VSED a second best.

Two years ago, Ms van As looked into euthanasia at the Expertisecentrum Euthanasie (an organization that in some cases performs euthanasia), but they told her to try more psychiatric treatment before they could start the process to determine whether she fulfilled the criteria for euthanasia. She also requested euthanasia from her general practitioner, who initially seemed to consider this option but then suddenly closed the door on it. That message prompted her to start VSED, unprepared. She read it would be very difficult for a physically healthy young woman like her, but she saw this as her only option.

Only her best friend knew about her decision, and this friend helped her by taking her in. After 4 days, Ms van As started to experience pain and extreme thirst. She sought admission to a hospice but was declined. Also, her general practitioner did not support her in her effort. She gave up and started eating and drinking again. One year later, she still intended to reattempt VSED, but not until she was certain that a hospice was willing to admit her. Although her suicide risk remained high, she reported that the prospect of euthanasia and VSED, ways to die with her loved ones close to her, prevented her from committing suicide.

VSED = voluntary stopping of eating and drinking.

Group 3: VSED as a More Acceptable Suicide

Background and motive. The third group of patients was characterized by a long history of psychiatric problems. They were generally physically healthy and were often young. Because of their lifelong psychiatric problems, they had been unable to build their lives as they would have wished and had a small social network (Table 3, quote 3.1). Patients could have little confidence in professional caregivers, although some had a good relationship with their GP or mental health nurse. They had a long-standing death wish (quote 3.2).

Considerations and expectations. Like the other groups, these patients said they preferred PAD. Some of them requested PAD, but their caregiver denied the request or postponed the decision (Table 3, quote 3.3). The risk of violent suicide seemed high, especially when they were in psychiatric crisis. This patient group preferred VSED over other methods of suicide, because it seemed more morally acceptable, less painful, and less burdensome for others (quotes 3.3 and 3.4).

The younger patients in this group were warned that their physical fitness would make VSED extremely difficult and that they could expect a prolonged dying process with severe physical problems and thirst sensation (Table 3, quote 3.5). This information sometimes led to a decision not to start VSED (yet). Fear of a crisis intervention sometimes led to starting VSED in secret, but without elaborate preparation (quote 3.6). These patients occasionally backed out of their decision because of physical discomfort.

Role of others. Professional caregivers and relatives could disapprove of VSED because of the patient's young age and a hope for improvement of the psychiatric disease, and could try to prevent the patient from initiating VSED (Table 3, quote 3.7). Some in this group kept their plan a secret because they assumed others would not be supportive (quotes 3.6 and 3.8). Some reported that professional caregivers declared they would intervene if the patient initiated VSED (quote 3.9). When the patient persisted in the death wish,

however, some relatives and professional caregivers decided they would help (quote 3.10).

Trajectory. Patients in this group had a persistent death wish and had contemplated methods to hasten death for years. They often described suicide attempts in the past. Their death wish could fluctuate over time, however, and could disappear for longer periods (Table 3, quote 3.11). Some patients in this group showed signs of ambivalence of VSED to their professional caregivers and relatives, and even to the interviewer.

In 5 out of 6 cases, VSED was initiated. One of these patients, the only patient who was supported by a caregiver, died by VSED. The other 4 initiated VSED in a psychiatric crisis, without much preparation and/or without informing others or seeking help (Table 3, quote 3.12). They restarted eating and drinking after some days. They described VSED as a lonely and uncomfortable process. Some reported that they sought help during their attempt, but did not receive the care needed to continue.

This patient group often kept VSED as a back-up plan, however. Some commented that knowing they could hasten death by VSED with help from their relatives and/or physician gave them the strength to keep on going and try another treatment. In this way, the availability of VSED as an option prevented these patients from attempting violent suicides (Table 3, quote 3.13).

Differences and Similarities Between Groups

The 3 groups differed in ways beyond patient demographic and clinical characteristics. The VSED decision-making process ranged from last-minute decisions in response to a trigger (in the second and third groups) to trajectories that were spread out over years (in the first group). Preparations, too, could be spread out over years (first group), be a rush job for caregivers (second group), or be absent in patients who started unprepared (third group). Relatives could be closely involved in the trajectory toward VSED (second group). But involvement was minimal when patients saw no role for relatives (first group) or expected no support (third group).

The groups also had similarities. In all groups, most patients preferred PAD over VSED. Also, patients described VSED as a better, more morally acceptable method to hasten death than ingesting drugs or other methods of suicide.

Some patients had characteristics of multiple groups. For instance, case 1 (third group) had both physical ailments and psychiatric problems. The former made the patient care dependent, whereas the latter was the reason for her death wish. During preparation, she relied heavily on others and trusted others to take care of her, as is described in the second group. Others, however, could not understand her death wish coming from psychiatric suffering, which led to many problems before and during VSED. Case 23 had chronic psychiatric disease, but she started VSED well prepared and out of a wish to retain control, so she fit in the first group. During the process of VSED, however, she described a growing distrust between her and her caregivers, and she committed suicide by ingesting lethal substances (much like patients in the third group).

DISCUSSION

Major Findings

Our study shows that patients considering and/or using VSED are diverse, but we were able to distinguish 3 groups

Table 3. Quotes From Participants in Each Group, by Theme

Theme	Group 1: VSED to Remain in Control
Background and motive	1.1. I'm done with it, I'm throwing in the towel. I'm 73. I've had a good life. I don't really feel like having to spend a few years somewhere sitting and watching the credits to what's been a beautiful film. (case 25, patient)
	1.2. My life is beautiful. But I'd rather leave. So that my children will remember a father who is still the father they know. Always a strong man who can do everything, instead of someone who is wasting away…. (case 5, patient)
	1.3. During my life, I have always been in control over everything. And that's exactly what I want at the end of life. (case 11, patient)
	1.4 [It is important to me] to remain the same person, and not to wither away. I've seen that happening too many times, and I don't need that. You wither away and you no longer are allowed to decide whether you want to live or die. (case 21, patient)
Considerations and preparations	1.5. That's why this method appealed to me: you can do it yourself and aren't dependent and you don't have to ask anyone anything. (case 4, patient)
	1.6. I also saw how you could collect medicines, you know, but I find that such a hassle. You're dependent on having to get them, or should you lie? ... And then I think to myself, [in VSED] I'm completely in control here. (case 11, patient)
	1.7. I feel like stopping eating and drinking gives you the opportunity to work through a process. A winding-down process. Living with the end in sight, in 1 week or 2. And I can't prove it, because I've not yet experienced it, but I think it's a good thing. (case 7, patient)
	1.8. I can manage that. ... If I'm doing something, then I'll do it. Then I'm fully behind it. And of course it's not a spur-of-the-moment thing. (case 25, patient)
	1.9. [What you need is] perseverance. And a few people around them who come and check up on them every now and then. (case 5, patient)
	1.10. He was so adamant about that: It takes 4 days and then it's over. And by God I don't know where he got those 4 days from, but it was so forceful that we all, including him, thought "This takes 4 days." That wasn't true. ... And I had an image in my head, from the stories about an Indian sitting down leaning against a tree and his soul flying out. I think I had a bit of a romantic image. (case 6, daughter)

GP = general practitioner; PAD = physician-assisted dying; VSED = voluntary stopping of eating and drinking.

in our patient population. The group seeking to retain control consists of older people who highly value autonomy, a group that is quite visible in the Netherlands as an advocacy group.[24,25] The 2 other groups identified in this study are less well represented in the debate on self-termination of life.[26] These are (very) old patients who are in poor health and care dependent, and often younger patients with severe psychiatric suffering. These groups seem less well equipped to prepare well for VSED; they likely need the most guidance before and during the process.

Comparison With Existing Literature

Similar to our study, studies among caregivers and relatives have shown that existential and psychosocial suffering are important reasons for VSED.[1,6] We are not the first to describe the need to approach VSED as a diverse phenomenon. Stängle et al[9] described different types of VSED. They saw concealed VSED in patients who initiated the process in secret because of objections from caregivers, and implicit VSED in patients who reduced food and fluid intake but did not openly state a wish to die.[9] We found concealed VSED in our third group, albeit only in cases with psychiatric suffering. We did not come across implicit VSED, possibly because this was not recognized as VSED.

Because we included patients with unsuccessful VSED attempts and even some who never initiated VSED, our sample captured patients who were not included in many previous studies.[1,3,4,6,20] In particular, these were often young psychiatric patients.[1,6] A Dutch study among people preparing for and seeking demedicalized assistance in suicide (for instance by VSED) included some psychiatric patients.[27]

VSED in Relation to PAD and Other Methods to Hasten Death

An important similarity across most patients in all 3 groups was the preference for PAD. Only patients in the first group described preferring VSED over PAD. In previous studies, 19% to 49% of patients who died by VSED had requested PAD before they started VSED.[1,4,5,20] Our study, as well as the study by Hagens et al,[27] indicates that the number of patients preferring PAD is higher. Interestingly, in cases in which we included multiple perspectives, patients or relatives sometimes

Group 2: VSED to Accelerate a Natural Death	Group 3: VSED as a More Acceptable Suicide
2.1. She can't do her make-up anymore, she can't style her hair anymore ...that deterioration is awful for her. No longer being able to do anything. She can't write anymore. She loved shopping but that's no longer possible, or maybe for a little while every now and then. Other than that, she doesn't really have anything left. (case 15, relative) 2.2. For years my mother has been thinking she wouldn't mind if it was all over tomorrow. Her health is really bad all the time, so much so that we keep thinking it's over, and every time she still manages to recover. (case 12, daughter)	3.1. It's not that I don't want to live, it's that I can't live. (case 3, patient) 3.2. I haven't wanted to keep on living for a very long time. Quite a long time, and that thought just became stronger and stronger. (case 23, patient)
2.3. She wanted euthanasia. But every time the doctor visited her, she didn't give a clear signal that she was really ready for euthanasia. She always gave the impression that she was enjoying the small things in life. (case 19, relative) 2.4. He said: "If I don't get euthanasia, if I don't get an injection, then this is an option that I still find acceptable and dignified." (case 28, daughter) 2.5. Her expectations were, because that is what we read, that after 2 days a moment of happiness would arise, and then you calm down and softly fade into unconsciousness. (case 29, daughter) 2.6. At that moment, I don't think she'd thought further about whether she'd be able to stick with it, she just wanted for it to be over, the end. (case 8, relative) 2.7. She made her announcement very late, so we had to take care of everything in very short order. So yeah, there's a whole situation first. For us, the hardest thing was that you couldn't find good home care services at that time. (case 12, daughter)	3.3. Euthanasia ... in my view that's still the most humane way. ... I wanted to go back to the end-of-life clinic [for euthanasia], but then I'd have to go back on the waiting list, which is very long. (case 3, patient) 3.4. (About suicide using medicines): My body gets taken over, there's a lot of hassle, and the family I have, the police, the nurse who gets a shock when she finds me... I just want to do it properly. (case 1, patient) 3.5. Because I'm young, and physically there's nothing really wrong with me, I'm scared it will take too long. Not the usual average of 2 weeks. But I'm also very scared of delirium. (case 3, patient)

continues

said that they requested PAD from their GP, but the involved GPs could not remember this request. Possibly, the request for PAD was done more implicitly, or these patients assumed their request would be denied and therefore did not formally make the request.[27] This can be especially true for patients with psychiatric or existential suffering, who are least likely to have their request for PAD granted.[28-30]

In our study, patients with psychiatric suffering often did not succeed in VSED. Explanations found included impulsiveness associated with their disease, a lack of support in their small social network, and objections by professional caregivers. As a result, these patients undertook lonely and poorly prepared VSED attempts. If psychiatric patients with a strong death wish assume they cannot obtain assistance in dying both by PAD and by VSED, they may see no other option than committing suicide by less humane options, such as ingesting lethal substances or using violent methods. In this study, patients described how knowing that VSED was an option helped them to continue living. The same was seen in patients who requested PAD in a study by Pronk et al.[31] In their study, however, a request for PAD was sometimes a cry for help, and the same could be true for psychiatric patients who ask for assistance with VSED.

Table 3. Quotes From Each Group, by Theme *(continued)*

Theme	Group 1: VSED to Remain in Control
Role of others	1.11. [He said,] "I have a plan and this is what I'm going to do and this is what I'm expecting from you and this is how we'll do it." And that's exactly what he did. (case 4, GP) 1.12. He was very clear, he said there's no room for discussion. ... "This is my decision." But he really was willing to explain it to all his children and grandchildren. (case 6, daughter) 1.13. [We said,] "Why are you doing this? There's nothing wrong with you, you're healthy!" You try everything to persuade him. ... There's nothing that convinced us he had to take this step. At some point, my sister and I resigned ourselves to it, because we were fighting a losing battle. But my brother dug his heels in until the very last moment. (case 5, son)
Trajectory	1.14. December, I didn't think that was a good month to say goodbye because of the Saint Nicholas festivities. ... So I thought January would be a good month. When I had a business, that was the month for clearing up. (case 4, patient) 1.15. Now I'm going to take control. But when you have nobody, you have to arrange things very well. But it doesn't have to be done on the spot either. (case 11, patient)

GP = general practitioner; PAD = physician-assisted dying; VSED = voluntary stopping of eating and drinking.

Strengths and Limitations

This study is the first to describe how patients come to VSED, detailing 3 different patient groups. Reducing the patients into 3 groups is a simplification of reality, however, and some patients had characteristics that fit in more than 1 group.

Although we tried to obtain maximum variation, it is possible that we failed to include certain types of patients. Most patients and relatives were recruited via the NVVE (the Dutch Right-to-Die Association). Although this association is large, having 170,000 members, members are more likely than the general population to have overthought their death and methods to hasten death. We therefore put extra effort into recruiting patients via hospices and GPs to find unprepared and younger patients. In all 3 groups, we succeeded in recruiting participants through different sources. Still, we found few patients who stopped eating and drinking without help. It is possible that for these patients, the trajectory toward VSED looks different from the trajectories described in this study. Although we included some cases in which patients were less well prepared by interviewing relatives after the patient's death, there is a risk of recall bias in these cases because years could have passed between VSED and the interview.

By interviewing some patients at different time points, we were able to better understand the decision-making process. We explored the trajectories toward VSED from the perspective of patients, relatives, and professional caregivers to include a larger variety of cases and gain a more complete picture. In 16 cases, however, the patient perspective was missing. We saw many similarities between the interviews of the patient and of their relatives and caregivers, but there were also inconsistencies. For instance, some patients said that their relatives understood their decision, whereas interviewed relatives said this was not the case.

Group 2: VSED to Accelerate a Natural Death	Group 3: VSED as a More Acceptable Suicide
2.8. Then the doctor came up with the fact that you can also just stop eating and drinking, because that's not a bad way to go. (case 15, relative) 2.9. We told her, "Mom, if this is what you want, we will be there for you. We will get over this, don't worry about that." Because she said, "I don't want to do this alone, I want to do this together with you." (case 29, daughter) 2.10. Bizarre. Well, who decides [whether you are eligible for euthanasia]? We were quite annoyed by it. You've already been through a lot and then you get that on top of it all. Isn't it bad enough? Who decides how much someone is suffering and when it's done? (case 14, daughter)	3.6. It was around 8 o'clock; he came home and said, "I don't need dinner, I'm going straight to bed, I'm tired." For 4 days I didn't realize that he wasn't eating or drinking. (case 16, partner) 3.7. [The carers] were also given the freedom to refuse to be involved, but to the great surprise of the head of care they said unanimously that they refused. (case 1, GP) 3.8. I thought I'm not going to drag people into this, they're not going to support me ... no one is going to support me in this. ... Because I'm too young and because they think I'm going to get better. (case 26, patient) 3.9. The plan was to gradually eat and drink less and lose weight. And then to stop altogether. But the psychiatrist said, if you do that I will have you admitted. So they throw bombs on your plan. (case 22, patient) 3.10. It's been a whole process to get to the point where I wasn't trying to stop him anymore, ... it's been hard to be able to finally say, "I'm with you from now on." (case 16, partner)
2.11. It's a battle with myself. On the one hand, I think it's ... well cowardly to end it, and on the other hand there's that huge pain where you say, well folks, I'm very sorry, but now I'm going to do what's right for me. It's a constant dilemma. (case 24, patient) 2.12. One day, he was sitting at the dinner table, downstairs in the dining hall (of the elderly care home) ..., and he pushed away his plate and said he wanted to go back upstairs. They brought him back to his room and called me [to tell me] that he had stopped eating and drinking. (case 17, relative) 2.13. To everyone's surprise, she was doing much better [she recovered from a heart attack] ... R. [patient] then immediately says, "Well, but I want to die, give me a shot or whatever." "No ma'am, this is a hospital, and we don't do euthanasia in hospitals." I understand that R. has had a big discussion with the doctor and the nursing staff, saying she wanted to die. And at some point she said, "Then I'll stop eating and drinking." (case 8, relative)	3.11. I really thought oh, I don't want to go through another winter. Not another ... well, eventually you just keep going or something. (case 23, patient) 3.12. That was in a psychiatric crisis. ... I felt a lot of turmoil inside, about wanting to end it all, and I was somehow trying to stay in control, well then I'd do it this way ... so that I can still say goodbye. (case 26, patient) 3.13. Especially because my GP supports me, my family supports me. Then I don't really need to commit suicide so to speak. It's a good source of strength for me. (case 23, patient)

Although our study took place in the Netherlands, these findings are interesting for readers from other countries as well. Voluntarily stopping eating and drinking may be an even more important topic in countries where PAD is not a legal option. The Netherlands is unique because clinical guidance on VSED is available, published by the Royal Dutch Medical Association and the Dutch Nurses' Association.[7] Although not all professional caregivers are familiar with this guidance, care for patients undertaking VSED in the Netherlands may be better organized than that in other countries.

Practical Implications

Our study illustrates the diversity of patients considering VSED. It is likely that the 3 patient groups have different care needs. We recommend future research to focus on these care needs, as well as the needs of relatives because they can experience a large burden during and after VSED.[15,16] These studies could add to the knowledge base needed for clinical guidance for professional caregivers.

There is an increasing call for clinical guidelines for professional caregivers in different countries, similar to the Dutch and American guidelines.[7,32-34] In our study, we found a need for guidance among patients and relatives as well. It is important that professional and patient guidelines apply to the full spectrum of patients considering VSED. In overview articles, patients pursuing VSED are described to be mostly old and in poor health (based on quantitative studies, from the perspective of caregivers).[18,35] Our study shows that this description does not fit all patients. Moreover, the decision-making and preparatory processes differ distinctly for the different groups of patients. These differences call for a personalized approach to patients considering and initiating VSED.

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Key words: voluntarily stopping eating and drinking; VSED; palliative care; pain; suffering; death; aged; aged, 80 and over; elderly; geriatrics; psychiatric illness; end of life; physician-assisted suicide; euthanasia; ethics; primary care

Submitted November 13, 2022; submitted, revised, July 21, 2023; accepted August 1, 2023.

Funding support: This study was funded by a grant from the Dutch Research Agenda (NWA), issued by the Dutch Research Council (NWO).

Disclaimer: The views expressed are solely those of the respondents and do not necessarily represent official views of the authors' affiliated institutions or funder.

Previous presentations: The results of this study were presented as a poster presentation at the NHG wetenschapsdag (Dutch College of General Practitioners Science Day) June 10, 2022, Leiden, The Netherlands (title: Hoe besluiten mensen bewust te stoppen met eten en drinken?/How Do People Consciously Decide to Stop Eating and Drinking?). The results were also presented as a poster presentation at the European Association for Palliative Care 18th World Congress on June 17, 2023, Rotterdam, The Netherlands (title: How Do People Decide to Stop Eating and Drinking to Hasten Death? A Qualitative Interview Study).

Acknowledgments: We would like to thank all study participants for sharing their personal stories with us.

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