



# Perspectives of people accompanying a person during voluntary stopping eating and drinking: a convergent mixed methods study

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**Background:** Voluntary stopping eating and drinking (VSED) is an option for people wishing to bring about premature death. In Switzerland, VSED is considered a controversial action at the end of life in the guidelines for “Management of dying and death,” which states that the decision to support or oppose VSED must be made individually by health care professionals; so far there are no instructions for action. The aim of this research was to explore the experiences of people who play an important role in VSED accompaniment, and to explain how the people involved in the process deal with VSED.

**Methods:** This convergent mixed methods study included a national survey (n=1,681) and five focus group interviews (n=47). Data integration was conducted using the four-stage pillar integration process.

**Results:** Given Swiss society interest, VSED has already established itself in the health system without the institutions having addressed the issue, whereupon health professionals make individual decisions when a person willing to die comes to them with a VSED wish. Health professionals are open to VSED, but are also ambivalent and would like to know more about it before being confronted with a VSED case.

**Conclusions:** In Switzerland, VSED has become a rare but desired option for ending life prematurely. While health professionals are already being confronted with the phenomenon, there is a lack of discussion at the level of health institutions about how to deal with it.

**Keywords:** Data integration; convergent mixed methods; survey; focus group interviews; voluntary stopping eating and drinking (VSED)

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## Introduction

Voluntary stopping eating and drinking (VSED) is an emerging global topic (1-8). Data from the Netherlands (9,10) and Switzerland (11,12) show that between 0.4% and 2.1% of annual deaths are attributable to VSED; unreported cases are likely (3,11,12). VSED is an option when a person consciously and voluntarily decides to bring about death by

stopping eating and drinking (1,13). It differs significantly from other forms of food refusal (14), where the person has no intention of dying (13,15,16). In Switzerland, VSED was first included in the Swiss Academy of Medical Sciences' (SAMS) guidelines for “Management of dying and death” in 2018 (17). The guidelines clearly distinguished three situations.

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The first situation describes people whose life expectancy is limited to a few days or weeks due to an illness (17). In this phase, feelings of hunger and thirst often decrease and the desire to shorten the dying process can arise (18), which is a generally accepted action in Switzerland (17), Germany (19), Austria (2), and the Netherlands (20).

The second situation concerns the person's judgement. The guidelines (2,17,19,20) equally emphasize that the "voluntariness" in VSED presupposes a person's ability to make decisions (1,13); if that ability is limited (e.g., in the early stages of dementia), it must be clarified exactly how the situation should be assessed (2,17,19,20). There are currently international scientific discussions (21–27) on whether a decision once made by a person with decision-making competence should still apply if this person loses the capacity in the further course of his or her life. The SAMS (17,28) explicitly rejects such behavior; food and liquid must be offered in any case, but not forced.

The third situation focuses on people without a terminal illness (17). Between 24% and 29% (1,9,29) of all people who follow the VSED path do not have a terminal disease. The unbearable suffering of those people is described as life fatigue, fullness of life, the senselessness of continuing to live, and low quality of life (1,29). In Germany and Austria, these situations are not covered by guidelines (2,19). In the Netherlands, no distinction is made between terminally ill and healthy people; the desire to die and the ability to judge are central (20). In Switzerland, the person's motives and health status are considered, but the health professionals' opinions are decisive (17).

Internationally, controversial discussions (7,21,30,31) on VSED classification (suicide or something else) and the legitimacy of accompaniment are ongoing, but a liberal stance has been adopted in Switzerland, similar to that in the Netherlands (20). Depending on the person's health condition and the health professionals' discretion, accompaniment is possible, since Swiss law allows that choice if the wish to die persists. However, a person has no binding right to accompaniment (Article 115 Swiss Penal Code). This leads to questions about what health professionals themselves think about VSED.

Quantitative studies with health professionals have confirmed that VSED is an internationally known phenomenon. Many participants had accompanied people during VSED; overall, patients are granted the right to medical and nursing care, and VSED is often considered an autonomous and "good" way to die (1,8,11,12,32). Although there are few qualitative studies (13), previous research

indicated that accompanying a person during VSED is an individual decision (33), and that there is an implicit or unspoken form of VSED where the person does not talk about their intention or even hides it from others (14). The existing evidence is not sufficient to derive practical recommendations for health professionals.

Therefore, we aim to apply a mixed-methods design to explore the VSED knowledge and experience of Swiss family physicians and heads of outpatient and long-term care facilities, and to explain the current professional culture and handling of VSED as an emerging phenomenon. To the best of our knowledge, no previous mixed-methods studies on VSED have been conducted. We present the following article in accordance with the MDAR reporting checklist (available at <http://dx.doi.org/10.21037/apm-20-1339>).

## Methods

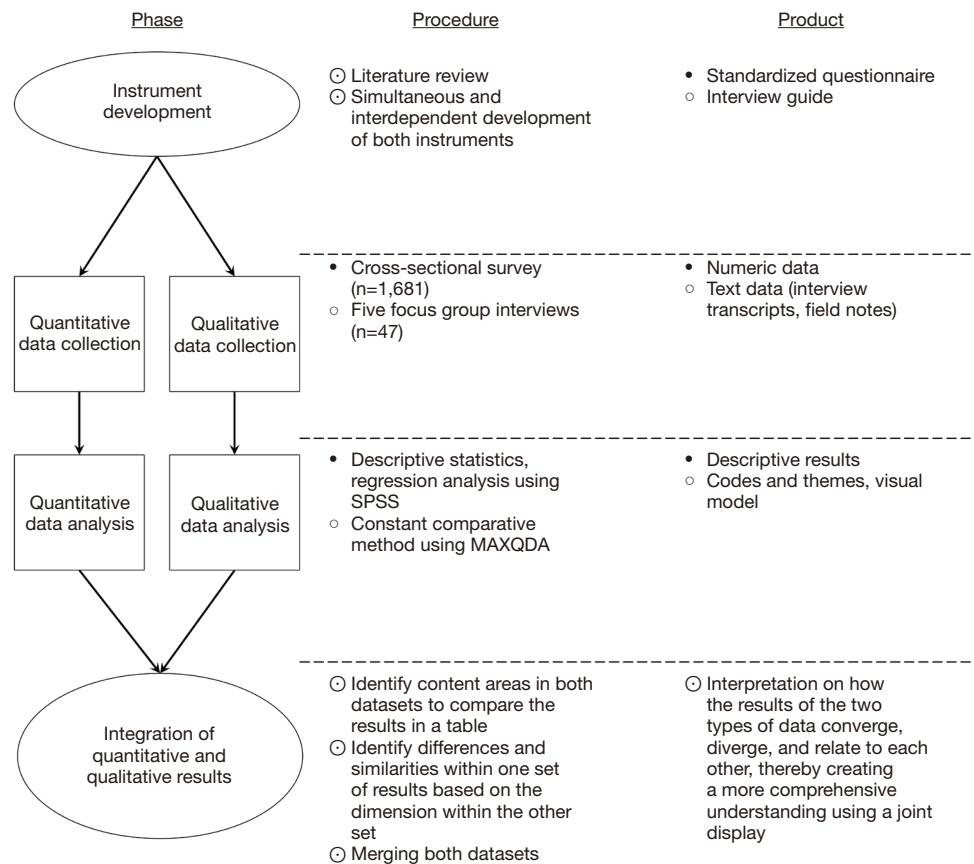
### *Study design and research paradigm*

A convergent mixed methods study was chosen to answer the research question. As described in our study protocol (34) we conducted a national, cross-sectional survey and focus group interviews (*Figure 1*).

By integrating the exploratory and explanatory research strands (35), the contradictory aspects and open questions could be answered using abduction (36,37). The limitations of each research approach are balanced by the strengths of the other, and the combined strengths of both approaches lead to an extension of knowledge (38). The study design was directed by Dewey's pragmatism, in which knowledge is continually re-generated by an oscillating movement between action and experience (39). Quantitative and qualitative data were collected simultaneously, with equal priority (40,41).

### *Rationale*

The rationale for using a convergent mixed-method study was that the instruments' development could be carried out simultaneously to ensure comparable methodological data sets. The approach allowed us to explore and explain the breadth and depth of the VSED phenomenon, especially the data integration it provides when the unexpected occurs, which can relativize the separate analyses. This approach promoted examining the national appearance and importance of VSED in Switzerland to better understand the phenomenon (42).



**Figure 1** Visual model for convergent mixed methods design procedures about voluntary stopping eating and drinking in Switzerland. • = information regarding the quantitative study; ○ = information regarding the qualitative study; ⊙ = information regarding both studies.

### *Design, participants and statistical analysis of the survey*

A cross-sectional survey was conducted, including heads of outpatient and long-term care facilities, and family physicians in Switzerland. All three professions are very well organized through professional organizations. We took advantage of this and asked the management of the individual professional organizations whether they would support us in sending the questionnaires to the target groups and received their approval from all of them. We have invited a total of 4,589 health professionals (1,562 heads of long-term care; 1,616 heads of outpatient care, and 1,411 family physicians) in a staggered invitation between January 2017 and July 2018. Due to the recruitment strategy it is likely that participants who have already participated in the focus groups in 2016 will also be invited to participate in the survey. Due to the anonymous survey, however, we are not able to determine this. This is the case for at least 29 of the 47 participants in the focus

groups who have the same profession as those surveyed.

The questionnaire for the survey and the interview guides for the qualitative interviews were developed simultaneously. In February 2016, a literature search was conducted in the following databases: PubMed, EBSCOhost CINAHL, Ovid PsychINFO, followed by an open search on the internet. Literature-based categories were formed to capture the phenomenon. Subsequently, questions were formulated and assigned to the research strand. Care was taken to ensure that similar questions were recorded both quantitatively for the questionnaire and qualitatively for the interview guide. The questionnaire was tested for intelligibility and manageability using a standard pre-test (43). After revision, the questionnaire was validated in two rounds using the content validity index (CVI) (44,45). All items had an item-CVI value greater than 0.90 and a scale-CVI of 0.97, which corresponds to excellent values. The literature review, and the development, psychometric testing (43-45) and the forward/backward translation (46)

(from German into French, Italian, and English) of the questionnaire and the questionnaire itself has been published (47). A questionnaire with 41 items was developed to record the occurrence of the VSED and the experiences, attitudes and stances about it. The answers are given in free text fields and on five-point Likert scales.

The questionnaire was created online based on the survey software Questback (EFS 10.9). On the front page, the project and its objectives were described. Participation was voluntary and anonymous, and the participants had to actively give their consent to the study. Due to the low response rate among family physicians, which is described in more detail elsewhere (11), we created a paper-and-pencil questionnaire. The answered questionnaires were scanned and then read in, edited and exported as SPSS files using the EVASYS software.

Descriptive analysis was conducted using SPSS (IBM, Armonk, NY, USA; Version 25 and 26). To describe participants, and the attitudes and professional stance of the participants, appropriate statistical methods were used, such as means, standard deviations, percentages, and frequencies. Missing values were coded as such and automatically excluded from the analysis. The number of missing values in the analyses is indicated by the number of values included.

### *Design, participants and data analysis of the focus group interviews*

We conducted a qualitative focus group study. We used a constructivist grounded theory methodology (48), that supports the inductive, emergent and constant comparative approach (49). The grounded theory is particularly suitable for phenomena whose conceptual framework has not been clearly identified and for which there is a lack of understanding to development a theory about VSED. The grounded theory was underpinned by a pragmatic philosophical perspective, which assumes that our knowledge is developed through our actions and interactions, which are shaped and developed by our social environment (39). For pragmatic research reasons the theoretical sampling as an instrument to reach theoretical saturation could not be performed.

In autumn 2016, 50 people involved in accompanying a person during VSED were invited for focus group interviews. The invitation to the focus groups followed an expert meeting organised by “Palliativ Zug” ([www.palliativ-zug.ch](http://www.palliativ-zug.ch)). At each meeting one topic is discussed intensively with the participants of the meeting. The participants are

either practitioners with a focus on palliative care, work in politics, are relatives of palliative patients or are affected themselves. On this day VSED was the main topic of discussion. All participants (n=50) of the meeting were invited to the focus groups, 47 of whom took part. One participant found it unpleasant to talk about the topic in a focus group, two participants did not have time. The interview guides were developed simultaneously with the questionnaire, after reviewing the literature described above. We performed five focus groups (50), starting with an open question, in which participants were asked to talk freely about their attitudes, experiences and stances regarding voluntary stopping of eating and drinking. As soon as the flow of speech stagnated, impulses were given to discuss the perspective of the person willing to die, relatives or health professionals; to talk about communication about voluntary stopping of eating and drinking or about the unspoken or unrecognized form of refusal to eat. Five focus group interviews were conducted and after the consent of the participants were obtained, the focus groups were digitally recorded and transcribed verbatim. Focus groups are suitable for exploring experiences and attitudes within the group on a given topic, taking into account the participants' interaction and group dynamics and incorporating them into the analysis (51). Each interview lasted 60 minutes. Field notes were taken during and immediately after the focus groups. The data were evaluated inductively using a modified ground theory approach that uses guidelines for systematic, theory-driven data analysis by Charmaz (48). MAXQDA (Analytics Pro 2018) software was used to simplify data coding and memo writing. Each interview was read and re-read in its entirety, one after the other and then the data were selected, separated and sorted by coding them inductively line-by-line (initial coding) using comparative methods. Then, we focused for frequently initial codes or codes with a high significance and searched for relationships between the initial codes, connected them and built up categories (selective coding).

### *Analysis of the integration of quantitative and qualitative data*

The results of the quantitative and qualitative studies were integrated in an interactive synthesis by comparing them and focusing on the similarities. The synthesis was performed by oscillating the inductive and deductive data and generating the results in an abductive manner (36,37). The results were then visualized in a joint display (52-54)

based on the four stages of the pillar integration process: listing, matching, checking, and pillar building, which promotes the abduction process (55). First, raw coded or grouped data are listed (listing). Next, the data are matched with the opposite side and the system searches for parallels, similarities, or other relationships (matching). Subsequently, the data quality must be checked for completeness and correctness (checking). At the final stage, the findings are compared and contrasted; then, they are conceptualized to analyze the themes in a cross-analysis manner with abduction to generate a central phenomenon that answers the research questions. Conclusions are drawn about patterns, insights, or issues that emerged and possible explanations (pillar building).

### **Ethical approval**

The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by the Institutional Review Board of the Greater Region of Eastern Switzerland (EKOS 17/083).

The ethical approach for the present survey is based on the principles of the “Declaration of Helsinki” and “informed consent”. Anonymity and respect for human dignity is guaranteed at all times during the research process. Drawing any conclusions about the respondents will not be possible at any time. After a brief introduction about the necessity and the aim of this study, the participants got informed about their safety and anonymity and reasons where named why they should answer this questionnaire. Participation was voluntary and could be discontinued at any time. All participants included in this research have given written informed consent to participate in the study.

## **Results**

A total of 1,728 participants were included in the survey (n=1,681) and focus group interviews (n=47). Participants’ demographics are shown in *Table 1*.

The results of both lines of research are presented in the outer columns (*Table 2*) and are described and discussed elsewhere (11,12,56). The results form the basis of the data integration, which is presented in the following.

Data integration involved the social-institution level, the professional-individual level, and the family level. Overall, it was striking that the survey statements and the interview statements were consistent or complemented each other.

The quantitative data and the qualitative codes underlying the pillar building themes are shown in the joint display (*Table 2*).

### **VSED at social and institutional levels**

*VSED penetrates the consciousness of Swiss society and influences the health care system (theme 1)*. Of all deaths in Switzerland, between 0.5% and 0.7% are attributable to VSED. It is therefore a rare phenomenon whose presence has already assumed a very wide range. This was confirmed in the interviews, and compels a closer look at the issue. “*VSED does not occur so extremely often now. That maybe before having a case, one should deal with the topic*” (FG 2\_105). Society is showing an increasing willingness to discuss taboo subjects, such as dying and death, and seeking advice on them. It is therefore not surprising that the interested Swiss population, where assisted suicide is already possible, openly discusses VSED as well. This is reflected in the finding that about one in two health professionals currently considers VSED to be of great relevance in their daily work; this proportion is expected to increase in the future. In sum, the VSED option is already firmly anchored in the population, even before the health care institutions have actively addressed the issue.

*There is a chance to anchor VSED in the institution, as it does not contradict its culture (theme 2)*. Nearly every health care professional stated that VSED does not contradict the culture of their institutions. However, on closer inspection, it is obvious that the institutions have not yet taken a position on the issue. As long as this does not change, VSED will remain in the grey zone and it remains uncertain whether accompaniment will be systematized and professionally implemented.

### **VSED on professional-individual levels**

*Ambivalent classifications are an expression of uncertainty in dealing with the topic (theme 3)*. Most participants characterized VSED as natural because of the slow and familiar dying process. Much less often it was viewed objectively and classified as suicide because of the deliberately induced death. Some vehemently objected to classifying VSED as suicide, because VSED is more a process and not an impulsive act. Above all, it was emphasized that the possibility of breaking off VSED and eating again makes VSED an undescribed form of dying.

*More knowledge is required to develop a common*

**Table 1** Participants' characteristics

Participants' characteristics by study phase	Part I—Participants' characteristics of the cross-sectional survey		Part II—Participants' characteristics of the focus group interviews		Total	
	Mean (SD), range	Absolute (relative %) frequencies	Mean (SD), range	Absolute (relative %) frequencies	Mean (SD), range	Absolute (relative %) frequencies
Total participants		1,681		47		1,728
Professional background (missing Part I: n=0; Part II n=0)						
Family physicians		751 (44.7%)		2 (4.3%)		753 (43.6%)
Heads of long-term care		535 (31.8%)		14 (29.8%)		549 (31.8%)
Heads of outpatient care		395 (23.5%)		13 (27.7%)		408 (23.6%)
Counsellor, ethicists, politician, volunteer, relatives		–		18 (38.3%)		18 (1.0%)
Age (in years; missing Part I: n=50; Part II n=8)	54.6 (9.5), 25–87		48.6 (10.6), 24–64		54.5 (9.6), 24–87	
Gender (missing Part I: n=37; Part II n=7)						
Female		870 (52.9%)		35 (87.5%)		905 (53.7%)
Diverse		2 (0.1%)		–		2 (0.1%)
Male		772 (47.0%)		5 (12.5%)		777 (46.1%)

SD, standard deviation.

*understanding of VSED (theme 4).* The great difference in classification was also reflected in the unequal level of knowledge about VSED among the participants. Just under half felt familiar with the topic. The rest had no knowledge or felt their knowledge was insufficient. There was criticism that nothing is currently being done to increase the existing knowledge.

*Both the pronounced VSED of a person capable of judgement and the unspoken food refusal of a person who is not capable of judgement are anchored in the Swiss health care system and are equally tolerated (theme 5).* In the opinion of most participants, VSED decisions are bound to the judgement of the person who is willing to die. It is an act that cannot be carried out without this ability to rationally make decisions. It is therefore astonishing that almost a quarter of the respondents did not consider that determining a person's ability to judge was important. It was described as relying on one's gut feeling and the person's gestures. This discrepancy illustrates the current arbitrary treatment of people who stop eating or refuse to eat, regardless of the underlying reasons.

*VSED is only compatible with the moral and ethical attitudes*

*of health professionals at first glance (theme 6).* Behind the superficial compatibility between VSED and moral and ethical attitudes lies a lack of alternatives to deal with the situation. VSED is considered more justifiable than, for example, jumping in front of a train. The *good* about VSED is therefore a *better* compared to a suicidal act and not actually *good* in the true meaning of the word. A general ethical and moral stance cannot be taken at all, because the "situation of a young person who is not sick is quite different from when someone has cancer and certain diagnoses" (FG 3\_23).

*Recommendations on VSED are made with restraint; information is gladly passed on (theme 7).* Approximately one in two health professionals could imagine recommending VSED, provided the person willing to die requests it or a terminally ill person expresses the wish to die several times.

*More important than individual willingness to accompany a person during VSED is the joint decision within the healthcare team (theme 8).* The wish to die through VSED was generally accepted and respected by the participants, provided that the person willing to die is capable of judgment and has an incurable disease. In this case, most participants were willing to accompany the person on this

Table 2 Joint display

Quantitative data	Quantitative categories	Pillar building themes	Qualitative categories	Qualitative codes
Voluntary stopping of eating and drinking (VSED) at institutional level				
The occurrence of VSED among all deaths in Switzerland in the years 2016 to 2017 was between 0.5% and 0.7%	VSED is not an isolated case, but will influence the everyday working life of nearly every second health professional	VSED penetrates the consciousness of Swiss society and influences the health care system (theme 1)	Swiss society is more concerned with dying and death	“Advanced directives are becoming more frequent than in the past.” “Younger ones also say quite clearly and know what they want. Not only [reject] life-prolonging measures, but also [write down] sometimes quite detailed information.”
How would you judge the relevance of explicit VSED for your daily work? (n=1,681): (very) relevant: 52.4% vs. not/less relevant/don't know: 47.6%			VSED is getting better and better known	“Well informed people know about the alternative [VSED]” “The topic [VSED] is brought to me [by patients and relatives], I work in the counselling center.” “VSED does not occur so extremely often now. That maybe before having a case, one should deal with the topic.”
How would you judge the relevance of explicit VSED in the future? (n=1,681): rise (considerably): 47.1 vs. rise not/a little/don't know: 52.9%			VSED gets a momentum of its own	“As an institution and professional, we cannot avoid this issue. This takes on a momentum of its own.” “Although, I think it will come anyway (...) even if we say now that we don't want it. (...) well, I think we are talking about it now, because our culture is going in that direction.” “The people who are involved in this feasible medicine, I'm now talking about cancer, they are also confronted with the feasible death.”
Contradicts culture of institution (n=1,661): agreement: 16.1% vs. disagreement/neutral: 83.9%	VSED does not contradict the culture in health institutions	There is a chance to anchor VSED in the institution, as it does not contradict its culture (theme 2)	The attitude towards VSED must be anchored within the institutions	“It needs guidelines and a discussion of the topic [within the institution].” “I think it is important there that the institution has a clear role and also clearly documents what its attitude is.” “[The described attitude within the institution] can also protect the employee. The employee can say whether he or she can agree with the attitude.” “The attitude of the institution is adopted and lived by the staff.” “Everyone within the institution must talk about the same thing [must understand the same thing about VSED]”
VSED on a professional-individual level				
VSED is... (n=1,651): (physician assisted) suicide: 4.7%; passive euthanasia: 26.5%; (physician and nursing assisted) natural dying: 63.5%; something else: 5.3%	VSED is usually classified as natural death	Ambivalent classifications are an expression of uncertainty in dealing with the topic (theme 3)	Suicide Natural character Something else	“If you look at it objectively, it's nothing more than suicide. Deliberately ending life. Deliberately! There is no difference [between VSED and suicide]” “It's an assisted suicide” “I think it's something natural, and I would never consider it suicide.” “It feels like a natural dying process. He [the person] gets sleepy, doesn't like it anymore, falls asleep, so it's actually something nice” “It [VSED] is to be distinguished from everything else. You still have the option to turn around and say, “I'm eating again, I'm drinking again” “VSED is the logical step towards modern medicine. Dying is postponed for so long. VSED is now the conscious dealing with dying - a confrontation” “Compared to suicide, the VSED is socially acceptable. One can say goodbye.”
Familiarity with the topic VSED (n=1,716, including survey and focus group participants): unfamiliar: 15.5%; somewhat familiar: 41.5%; familiar, accompanied someone during VSED: 43.0%	The knowledge about VSED differs	More knowledge is required to develop a common understanding about VSED (theme 4)	Knowledge transfer is needed	“I would like to know more [about VSED]” “We [nurses] are not fully aware of the dimensions around VSED.” “One has to inform about VSED in nursing education.” “The subject is not yet entirely comprehensible to me.” “We have to find a way to bring the existing knowledge to the base.”
Determination of patients' ability to judge the situation (n=1,659): agreement: 77.3% vs. disagreement/neutral: 22.7%	It is important for most people to check the judgement of the person willing to die	Both the pronounced VSED of a person capable of judgement and the unspoken food refusal of a person who is not (certain) capable of judgement are anchored in the Swiss health care system and are equally tolerated (theme 5)	VSED is bound by the judgement of a person Not talking, but accompanying	“If the person is cognitively no longer responsible, so I think there it has certain limits. I would probably not support it [VSED] there or if the person then has advanced dementia.” “(…) it is important that the ability to judge is clarified, that everything is correct.” “VSED is bound to judgement. So, if someone can no longer [judge] (...), it is out of the question to decide.” “If he can no longer judge, then it is not a VSED. VSED is an active activity.” “The patient had dementia. She was not somehow consciously able to do this [renunciation of food]. It's simple, her gestures are very clear: “I've finished eating”.” “Well, we haven't really been talking about it. We just let it happen [accompany a VSED-case].”

Table 2 (continued)

Table 2 (continued)

Quantitative data	Quantitative categories	Pillar building themes	Qualitative categories	Qualitative codes
Compatible with world view or religion (n=1,673): agreement: 86.4% vs. disagreement/neutral: 13.6%	VSED is morally and ethically compatible for most health professionals	VSED is only compatible with the moral and ethical attitudes of health professionals at first glance (theme 6)	Better than other paths	“I must honestly say, I can rather be behind the fact that perhaps one dies earlier, although he would still have eaten something by means of reflexes. Than for someone to be forced” “It would actually be desirable that people would rather do that [VSED] than throw themselves in front of the train”
Have moral doubts (n=1,667): agreement: 16.8% vs. disagreement/neutral: 83.2%			It depends on the case	“The healthier the patient, the more difficult.” “If someone says he wants to die now and not eat anything more, then from my point of view it doesn't matter if someone says this is for a religious reason, or (...) because he can't stand the pain anymore. But the change should be taken seriously, no matter what the reason is. Or well, if one says then stop, I do not want to be a burden for the relatives, that wins then completely different dimensions.” “Of course, a situation of a young person who is not sick is quite different from when someone has cancer and certain diagnoses.”
Would recommend VSED (n=1,625): yes: 47.9% vs. no: 52.1%	About half of the health professionals would recommend VSED to patients	Recommendations on VSED are made with restraint, information is gladly passed on (theme 7)	Personal, cultural and religious backgrounds influence compatibility with VSED	“We also really exchange individual team members when they say quite clearly: “I can't do that yet, I can't do that. I'm too close or I know the relatives and I don't want to get into another war privately.”” “There are cultures here, or nurses here who come from a culture where death is - you don't talk about that, you just die at some point.” “So, in the case that ended yesterday, it was actually the situation that we have a woman on the team that night, she is an Islamist. In her opinion [VSED] is suicide, which she accompanied and supported. So she took up the challenge but she had a serious conflict with herself and discussed it in the team.”
Would care for a patient during VSED (n=1,655): yes: 92.9% vs. no: 7.1%			High acceptance/respect for VSED and willingness to accompany a person during VSED	More important than the willingness of the individual to accompany a person during VSED is the joint decision within the team (theme 8)
Accept decision (n=1,673): agreement: 93.9% vs. disagreement/neutral: 6.1%	Professionals are burdened during VSED accompaniment (n=1,656): agreement: 48.7% vs. disagreement/neutral: 51.3%	Complex professional support without financial coverage (theme 9)	Individual dissent must be respected by the institution/team	“I'm a nurse. (...) if I would recommend that [VSED], I would certainly have said “no”. It was like a taboo for me. (...) I would never steer anyone in that direction.” “As long as he comes himself, I'm all right, then I didn't push him towards it.” “It would probably be quick to interpret that you want to put something on him [to encourage him]”
Respect decision (n=1,674): agreement: 97.3% vs. disagreement/neutral: 2.7%			Interdisciplinary coordination and communication	“It is very important - it is a team process. It needs a good team to look after the [willing to die] person together. And there it needs a clear line.” “And I think it needs a team consensus. That really everybody sits down, takes the time and says: “Now let's talk about the subject. How does everybody feel about it?”” “So when someone expresses the wish [to die], you respect and perceive it. Personally, I have no problem with that now. I would accompany and respect it.”
Professionals are burdened during VSED accompaniment (n=1,656): agreement: 48.7% vs. disagreement/neutral: 51.3%	Professionals are burdened during the accompaniment	Complex professional support without financial coverage (theme 9)	Complex support of relatives	“The freedom of the individual stops where it restricts others” “Give employees the opportunity to change jobs for the time being.” “It is a project of an individual, the employees should be free to decide whether they want to participate or not.” “Employees must be allowed to say no, “I can't do this”, “This contradicts my understanding”. ”
			Interdisciplinary coordination and communication	“The interaction, I think, of the different people involved I find can be a challenge.” “Not only the outpatient care and not only the doctor and not only the relatives but really very different (people) and that's why I think what would be important is really: You have to organize yourself in this moment and arrange it. and really say who has the lead? and the lead is called, who calls attention watch out something is not going well. Come on, stand by each other”
			No financial coverage	“There are often round-table discussions where the doctors are present and the nurses (...) where they also inform about what happens in the body (...). I then experience the relatives in a more relaxed way.” “It needs the support appropriate to the situation. Questions after questions come up and the (...) relatives (...) do not understand what is going on. So there has to be a lay companionship, from process to process in the dying phases” “It is not only the patient who is with us but the whole family belongs to it and they also want to be noticed and heard.”
			Allow to stop VSED process	“For clarification, type and coordination, so if I were to write 15 hours of coordination lines, then the health insurance companies would immediately call and ask if I had made a spelling mistake.” “We were able to clarify all things, but we did not charge for many conversations. The whole company has then concentrated on it really, colleagues and I, what we have achieved 100%, we have all pulled together. But it is an intensive time for the team.” “This has been a very intense time. Partly it was the husband who asked questions and the daughter who asked completely different questions. And that was just done on the side.”
			Becoming an advocate for the person willing to die	“I also find it challenging, on the one hand, to still be a present, which I keep checking [whether the person still wants to die], - is that so? and on the other hand, to respect or accept that it is so [that he or she wants] to die.” “I think we must, and this is very challenging, the talks, that we must encourage him that he is on the right [VSED] path, but also in such a way that he still has the chance to turn the tide [to stop VSED]”
				“That is my task just as much as supporting or helping him or offering him services. That I also stand up for him and stand up for him and say: that is his wish (...) actually almost as an advocate.” “We need even more time, and this in the area of consulting services. Relatives, affected persons themselves and less in the basic care or treatment care also increases considerably in the end”

Table 2 (continued)



Table 2 (continued)

Quantitative data	Quantitative categories	Pillar building themes	Qualitative categories	Qualitative codes
VSED at family level				
Relatives have trouble accepting the decision (n=1,643): agreement: 61.0% vs. disagreement/neutral: 39.0%	Some relatives cannot accept the decision of their loved one	Professionals help relatives to understand the decision of the person willing to die through VSED (theme 10)	Professionals as bridge builders to the relatives	<p>“And then you become a bridge builder to the relatives. Because it’s going to be very difficult for them to support it and not bring the favorite food [of the person affected] with them.”</p> <p>“Basically, I have to get the relatives on board. Well, they have to have a say and they have to agree to some extent.”</p> <p>“How can the needs on both sides, on both sides, be met? So if everyone pulls together it is easier, I think that is also an important hint, what else can be done.”</p> <p>“I think it’s important to involve the relatives. They don’t always have to agree, but they have to understand, a little.”</p>
			Communication leads to more understanding	“So from my experience it is important that the affected persons themselves talk openly about it with their relatives. So when the wish is expressed, it can be better respected.”
			Dying, letting go is generally difficult to accept	<p>“It’s just an extraordinary situation (..) just let go, they [relatives] cannot let go”</p> <p>“But often it is the relatives who are further away from it. Well, that is not the problem of who dies, but of the relatives, that they cannot accept that someone dies.”</p> <p>“I think it is already preceded by a huge amount of suffering that people decide to do this and this suffering is also experienced by the relatives and the nursing homes. I experience it when they come to us, especially the relatives very ambivalent.”</p>
Relatives are burdened during VSED accompaniment (n=1,655): agreement: 75.9% vs. disagreement/neutral: 24.1%	Burdens on the people involved	Doing nothing makes it difficult for relatives to accompany a loved one during VSED (theme 11)	Doing “nothing”, “just” being around is exhausting	<p>“And then you’re in “action” mode I want to do something. Just sit by and watch the last breath go. I just think it’s a tremendous challenge, especially for the relatives”</p> <p>“The most difficult thing for the relatives is (...) the helplessness of only being allowed to observe. Just being present, holding hands, having conversations. This is actually what overwhelms many.”</p> <p>“I often experience towards the end of the terminal phase that drinking and eating is the task of the relatives. As soon as that is gone, they have nothing to do for the person concerned. They want to bring the cake from home”</p> <p>“So, drinking and eating has something to do with love. You can’t do that anymore and then you need an alternative.”</p>
			The “long” dying process is indeed burdensome, but it makes it possible to say goodbye	<p>“I also think it’s good when it takes a while. That it doesn’t happen so abruptly, so quickly. Well, I’m just saying this from my experience. That it’s always good for the relatives, if it lasts for a certain time.”</p> <p>“This is a relief for the relatives that they know it is not just over, but the door is still open for a long time. Where you can make (re)decisions again.”</p>
			To (co)support the decision	<p>“So it’s not an easy topic, even if you discuss it in advance”</p> <p>“They [relatives] are suddenly afraid to do something illegal.”</p> <p>“I think in the end, some people are afraid, that is, letting go, they develop a bad conscience”</p> <p>“Those willing to die give their lives into the hands of relatives and professionals.”</p>

path. However, more important than individual acceptance was the team willingness to collaborate. Every team member's decision must be respected in the same way the person's decision to die is respected: "*The freedom of the individual stops where it restricts others*" (FG 3\_24). Creative possibilities can be considered; for example, a health professional is assigned to another department for the period of VSED accompaniment.

*Complex professional support without financial coverage* (theme 9). Deciding whether to accompany a person on the VSED path and the accompaniment itself represent a challenge. Above all, good interdisciplinary cooperation is of crucial importance and must be coordinated. Especially important are discussions within the team, with the person wishing to die, and with their relatives. These require a lot of time, which poses a problem, because no financing is provided for the accompaniment—VSED is not listed in the Swiss diagnosis-related groups (DRG) used to fund care. In addition to these organizational challenges, health professionals also face burdensome situations regarding direct contact with the person willing to die. First, they must support the person on their path while not pushing them to give up food; second, they must offer the option of stopping VSED, without making it a demand. The occurrence of delirium is described as particularly challenging when the person in a state of disorientation craves to eat and drink. The expressed desire directly contradicts the previously made agreements, which are to be taken over by the professionals in case of disorientation. This places professionals in a dilemma that raises moral concerns.

### ***VSED at the family level***

*Professionals help relatives to understand the decision of the person willing to die through VSED* (theme 10). It is generally difficult to accept the death of a loved one. Therefore, special sensitivity is needed to inform relatives when a person, although still able to live, prefers to die. If relatives cannot accept a loved one's VSED decision, health professionals often serve as bridge builders to the relatives. They communicate the needs of the person willing to die and provide comprehensive information on the VSED course. The earlier and more intensively relatives are involved in the decision, the more likely they are to support it.

*Doing nothing makes it difficult for relatives to accompany a loved one during VSED* (Theme 11). Once the relatives have agreed to accompany the loved one, they are considered

vulnerable and require intensive support from health professionals. The duration of the dying process, which lasts an average of 14 days, is perceived as lengthy and burdensome, but also as positive, because it allows loved ones to say goodbye. It is also burdensome because relatives are left without a task. "*So, drinking and eating has something to do with love. You can't do that anymore and then you need an alternative*" (FG 2\_28). The relatives feel helpless by "*only being allowed to observe. Just being present, holding hands, having conversations. This is actually what overwhelms many*" (FG 2\_29). Relatives need assistance during this time, to show them the importance of their presence and to offer alternatives such as a foot massage or reading a story aloud.

The key message of data integration is that Swiss society has managed to anchor its interest in the VSED option in the healthcare system. While no actual positioning is yet taking place within the institutions, health professionals are directly confronted with it. In principle, they are open to VSED, but with some ambivalence, and they would like to have more knowledge so that they can provide professional support to those affected.

## **Discussion**

In this large, mixed-methods study, we investigated existing VSED knowledge and how the topic is currently being dealt with based on participant experiences. The analyses showed that VSED must be viewed from three levels: the social-institutional, the professional-individual, and the family levels.

The results from the social-institutional level clearly show that VSED is an important issue for the Swiss population, which is consistent with the results of Schmid *et al.* (57), who found that the Swiss show a remarkably high interest in end-of-life decisions. The consequences become apparent when health professionals are confronted by patients' desire to die through VSED, which is not common but already happens (11,12). Currently, health care professionals do not receive any guidance from their institutions on whether and how to respond to these death wishes. Nor is there any practical recommendation by which to orientate oneself, as is the case in the Netherlands (20). As a result, health professionals are on their own when asked by a patient to accompany him or her during VSED.

Most health professionals classify VSED as a natural dying process, but some equate it with suicide. These attitudes are strongly linked to the individual's reasons for wanting to die. While there is a high willingness by Swiss physicians to assist patients with unbearable pain, physicians feel very

uncomfortable when there is no physical suffering (58), which is very often the case with VSED (1,9,29,59). This highlights the challenging decisions health professionals are confronted with. Insufficient knowledge about VSED makes it more difficult for health professionals to decide how to respond.

If health professionals decide to accompany the patient, it becomes clear once again how little support is provided by the institution. The very complex care required for both the patients and their relatives, and the intensive interdisciplinary cooperation cannot be reflected in the current billing systems; therefore, work is not fully remunerated. As a result, accompanying a person during VSED is arbitrary, and the reasons that one may or may not receive support from health professionals are completely incomprehensible to patients and their families.

At the family level, it is the desire to die rather than VSED itself that leads to irritation and rejection. Wiegand (60) showed that even if relatives understand and accept the wish to die, they are afraid of the dying process and do not feel prepared for it. Heller and Wegleitner (61) asserted that, in today's society, dying is being forgotten, since it no longer takes place at home, but in institutions. Gamondi *et al.* (62) pointed out that relatives are often left out of the decision-making process at an early stage; in Switzerland they are mainly responsible for accompanying their loved ones. This was confirmed by our results.

While each level has its own major barriers, it is not yet possible to model exactly how challenges, which involve a combination of all levels and the interaction of all actors, can be dealt with. Future research needs to explore the different relationships of all actors at all levels.

This study's strength is the integration of quantitative and qualitative data, which made it possible to gain deeper insight into the attitudes of people involved in VSED. However, the study also has limitations. While the quantitative results represent participants from all over Switzerland, the qualitative results are limited to the German-speaking regions. Although these regions proportionally make up the largest share of Switzerland, the group analyses (63) showed that different attitudes were registered in the Lake Geneva region in particular, which could not be fully reflected in the present mixed-methods study. A qualitative survey in the French and Italian-speaking regions is recommended for future research.

## Conclusions

The study results show that it is necessary to discuss

the VSED issue at several levels. Given the increasing social interest, institutions should position themselves regarding accompaniment and incorporate guidelines for all employees. In addition, employees require training to provide adequate support to all the persons involved. Furthermore, the extensive services required of health professionals accompanying VSED must be remunerated. A clear VSED policy and well-trained staff will help relatives and patients with their decision and assist them through the patient's dying process.

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*Ethical Statement:* The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by the Institutional Review Board of the Greater Region of Eastern Switzerland (EKOS 17/083) and informed consent was taken from all participants.

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