Full-Length Research Report

Voluntary Stopping of Eating and Drinking in Swiss Outpatient Care

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Abstract: Besides physician-assisted suicide, there is another end-of-life practice under discussion: voluntary stopping of eating and drinking (VSED). In this study, we assess the occurrence of VSED in outpatient care and evaluate nurses' attitudes about it. We recruited 395 nurses (24% response rate) in our online survey. The occurrence of VSED in Switzerland lies at 0.5%. Most nurses (84.6%) were aware of VSED, and 39.5% had experienced it with patients. VSED was mostly (70.3%) regarded as a natural death, and nearly all (95.1%) were willing to care for these patients; however, about one-quarter (26.5%) expressed moral concerns. Our results show that VSED occurs in rare cases, and that nurses are willing to accompany patients during this VSED, but express moral concerns.

Keywords: ambulatory care, decision making, frequency, palliative care, professional attitude, refusal of food and liquid, surveys and questionnaire, terminal care, voluntary stopping of eating and drinking

Swiss health professionals are increasingly being confronted with patients' death wishes. According to a national survey, in 2001 74.5% of all nonsudden expected deaths received an end-of-life practice, rising to 82.3% in 2013: forgoing life-prolonging treatments (49.3%), intensified alleviation of pain/symptoms (29.8%), and physician-assisted death (3.1%) (Schmid et al., 2016). Since then, a further end-of-life practice was established in Switzerland and included in the guideline "Management of Dying and Death" of the Swiss Academy of Medical Sciences (2018), namely, the voluntary stopping of eating and drinking (VSED). VSED has become a relevant issue in some Western societies over the last 30 years for people who wish to die independently from health and medical systems and to maintain autonomy until death (Berry & Marcus, 2000; Cavanagh, 2014; Ganzini et al., 2003; Harvath et al., 2004; Ivanović et al., 2014; Norberg et al., 1988; Quill et al., 1997; Radbruch et al., 2019). International studies show that VSED cannot be considered an isolated phenomenon. In a survey of 307 American nurses (Ganzini et al., 2003), 33% had already accompanied a person during VSED. In The Netherlands (Bolt et al., 2015; $N = 708$), Germany (Hoekstra et al., 2015; $N = 255$), and Japan (Shinjo et al., 2017; $N = 571$), palliative care physicians and general practitioners were interviewed, and between 32% and 62% of respondents reported having accompanied at least one VSED case. In The Netherlands, VSED accounts for 0.4% to 2.1% of all deaths (Chabot & Goedhart, 2009; Onwuteaka-Philipsen et al., 2012). Similar results were obtained in a study of long-term care institutions in Switzerland: 1.7% of all deaths in Swiss long-term care institutions were due to VSED (Stängle et al., 2019a).

Background

VSED is the free decision of a person to refuse the intake of food and fluids with the intention of ending their life prematurely (Bernat et al., 1993; Byock, 1995; Ivanović et al., 2014; Mattiasson & Andersson, 1994; Quill et al., 1997). It is not equivalent to, for example, loss of appetite during the dying process, refusal to eat due to mental illness (e.g., dementia, anorexia), eating disorders (e.g., dysphagia), or hunger strike (Stängle et al., 2019c). According to the definition of Ivanović et al. (2014), an essential prerequisite for being able to carry out VSED is the ability of the person to wish to die (Grisso, & Appelbaum, 1998). Voluntariness stands for the willpower of a person to make a conscious decision out of various choices, taking into account personal motives and preferences, and to act accordingly. The person also is able to appropriately resist any attempt to influence someone else's will (Zürcher, Elger, & Trachsel, 2019). Contrary to this demand, the results of Lamore et al. (2017) show that a person's decision-making capability is significantly influenced by relatives and healthcare professionals. Relatives may try to dissuade the person who wants to die. But also the expressed willingness of relatives and professionals to accompany the person during VSED can lead to the decision

not being reconsidered, even if doubts arise (Lamore et al, 2017; Stängle et al., 2020).

Previous surveys showed that, although people of all ages opt for the VSED, the most common age group are persons over 80. Most (73%) suffer from an underlying disease (including cancer, cardiovascular diseases, and neurological diseases), while about one-quarter (27%) have no underlying disease other than old age (Bolt et al., 2015; Chabot & Goedhart, 2009; Stängle et al., 2019b; van der Heide et al., 2012). The reasons for the decision to VSED are associated with the age and the underlying diseases of the person willing to die. Common reasons are pain, the lack of prospects for improvement, fatigue, the fear of being dependent, and the feeling of having finished life (Bolt et al., 2015; Stängle et al., 2019b). While at the beginning of the VSED the affected person retains his or her independence, the body becomes weaker and weaker over time, and delirium can also occur, resulting in a dependency on care (Fringer et al., 2018; Gärtner & Müller, 2018; Wax et al., 2018). The person generally dies within 7 to 14 days (Ivanović et al., 2014). The involvement of professionals is therefore important from the outset in order to inform affected persons and relatives about the course of events, to ensure the provision of nursing care (e.g., oral hygiene, pressure ulcer prophylaxis) and to draw up a plan for dealing with side effects (e.g., the occurrence of delirium) (Lachman, 2015; Saladin, Schnepp & Fringer, 2018).

About 40% of all VSED cases in Switzerland take place at home, which means that outpatient care is provided for those affected and their relatives. A guideline such as the one developed in The Netherlands (Royal Dutch Medical Association & Dutch Nurses' Association, 2014) does not yet exist in Switzerland. In Switzerland, as in the international discussions (Alt-Epping, 2018; Fringer et al., 2018; Herzog, 2017; Jansen, 2004, 2015; Requena & Andrade, 2018; Simon, 2018), VSED is the subject of controversial debate (Swiss Academy of Medical Sciences, 2018). Depending on the professional's attitude, VSED is considered to be suicide (Birnbacher, 2015; Gärtner & Müller, 2018; McGee & Miller, 2017), or as physician-assisted suicide (Quill, 2015; Requena & Andrade, 2018), based on the similarities with the act of suicide and the individual's intention to die as well as the involvement of a professional. Another classification is passive euthanasia (Bernat et al., 1993; Simon & Hoekstra, 2015), which emphasizes the right of a patient to discontinue life-support measures, something health professionals must accept. VSED is also described as an alternative end-of-life decision (Ganzini et al., 2003; Lachman, 2015), and because eating and drinking are not therapies or interventions, passive euthanasia doesn't apply. The only way to prevent VSED would be by force-feeding the patient, which is illegal (Wyss & Breitschmid, 2018).

It is not yet known how VSED is classified by professionals in outpatient care in Switzerland, nor are empirical data on the occurrence of VSED in Swiss outpatient care available.

Purpose and Aims

This article reports the findings of a national study on VSED in Switzerland and clarifies its importance in outpatient care settings. We asked the following research questions: How high is the occurrence of VSED in Swiss outpatient care? What are nurses' attitudes toward VSED?

Methods

Design

We developed an evidence-based questionnaire (Stängle et al., 2019d) as part of a mixed-methods project according to our research protocol (Stängle et al., 2018). We wanted to determine the occurrence of and attitudes toward VSED among health professionals; this was used in this cross-sectional study. As described in the study protocol, we interviewed three target groups: outpatient care, nursing homes, and family physicians. Results of nursing homes have already been published (Stängle et al., 2019a). This article reports on the results of outpatient care. The questionnaire was activated for online answering by the survey software Questback (EFS 10.9).

Sample

Switzerland has 2,035 outpatient care service providers (Federal Statistical Office, 2018b), which are very well organized through their respective professional associations. We contacted the management of the three largest professional associations for public, private, and freelance outpatient care to help us distribute the questionnaires to their members, all of whom assured us of their willingness. This recruitment strategy allowed a total of 79% ($n = 1{,}616$) of all outpatient care services providers to be included in the study, among others:

- *Spitex*, a professional association for public outpatient care with 426 members (https://www.spitex.ch);
- *Associations Spitex privée Suisse*, a professional association for private outpatient care with 175 members (https://spitexprivee.swiss/de/);
- *CURACASA*, a professional association for freelance outpatient care with 1,015 members (https://www.curacasa.ch).

Between January and August 2017, participants were invited to complete the survey. Since freelance outpatient nurses work alone, we contacted them individually. For the public and private outpatient care services, we included the head of each institution. Depending on the size of the institution, the job titles vary, including nursing director, institute director, or head nurse. We focused on the head of public and private institution as they are always involved in difficult decisions, such as accompanying a person during VSED, and we excluded registered nurses, nursing assistants, and other professions. In other words, we wished to prevent the multiple reports of the same incident by more than one nurse within the same institution. In the following, we use the term "nurse" to stand for all included participants from public, private, and freelance outpatient care services.

We sent all documents digitally to the management of the professional associations to forward to their members. They distributed the invitations to the survey via email, newsletter, and a website specifically developed by the authors for this project. In order to ensure that no more than one person from the same institution participated in the survey, we queried sociodemographic data on the profession as well as the postal code. Duplicate entries from a postal code would have led to the verification and possibly exclusion of the datasets, but this did not happen. A response rate of 20% was targeted throughout Switzerland as well as for the seven major regions, consisting of one or more cantons with an average population density of 1,041,144 people (Schuler et al., 2005).

Instrument

This study used a questionnaire (Stängle et al., 2019d) that was based on a literature search and was psychometrically tested after development (Colton & Covert, 2007; Polit & Beck, 2006; Polit et al., 2007) and then translated from German into French and Italian (Acquadro et al., 2012; Mahler & Reuschenbach, 2011). We developed a questionnaire with 41 items to record the occurrence of the VSED and the experiences, attitudes, and stances about it. The answers are given on Likert scales: 1 (*never*), 2 (*rarely*), 3 (*occasionally*), 4 (*often*), and 5 (*very often*); or 1 (*strongly disagree*), 2 (*disagree somewhat*), 3 (*neutral*), 4 (*agree somewhat*), and 5 (*strongly agree*); or 1 (*no*), and 2 (*yes*). It took about 15 minutes to answer the questionnaire.

Institutional Review Board

The responsible institutional review board of the Greater Region of Eastern Switzerland (EKOS 17/083) approved this study. All participants provided written informed consent to complete the online survey.

Statistical Analyses

Descriptive analyses were performed with SPSS 25.0 (IBM, Armonk, NY, USA) and considered 95% confidence intervals. Participants' characteristics were described with absolute and relative frequencies, means, and standard deviations.

The following approach was taken to calculate the occurrence of VSED: All participants were asked whether they had already accompanied a person during VSED; those who answered positively were additionally asked about the number of accompaniments in the past year (2016). The percentage of accompanied cases in 2016 was calculated on the basis of the number of all deaths in Switzerland in 2016, with a total of 64,649 deaths (Federal Statistical Office, 2018a) and on the basis of all persons who died at home or in an accident, with a total of 18,102 deaths (Federal Office of Public Health, 2016).

Results

Description of Participants

A total of 395 of the 1,616 participants answered the questionnaire (response rates = 35% public, 26% private, 20% freelance, and 24% total). As can be seen in Figure 1, five major regions achieved a return of more than 20%, while the Lake Geneva region and Espace Mittelland only achieved a total return of 16% and 17%, respectively. Associations Spitex privée Suisse has no members in Ticino. The participants' demographics are shown in Table 1.

Relevance and Occurrence of VSED in Swiss Outpatient Care

Two-thirds (66.9%, n = 260) of the participants felt that VSED is a relevant topic in outpatient care, and 63.6% (n = 231) assumed that the relevance of the topic will increase in the future. Using a dichotomous scale (*yes* or *no*), most (84.6%, n = 334) participants were aware of the topic, about half (49.1%, n = 194) felt familiar with it, and 39.5% (n = 156) had accompanied at least one person during VSED. Of the subsample of 156 nurses with VSED experience, 143 of them provided information on the number of patients (see Table 2).

The data of the subsample of nurses with VSED experience (n = 143) show that, in 2016, VSED was the cause of 1.7% of all deaths at home or in an accident and accounted for 0.5% of all deaths in Switzerland. The cases were often accompanied by public outpatient care services (45.5%), with the highest occurrence per all deaths in Eastern

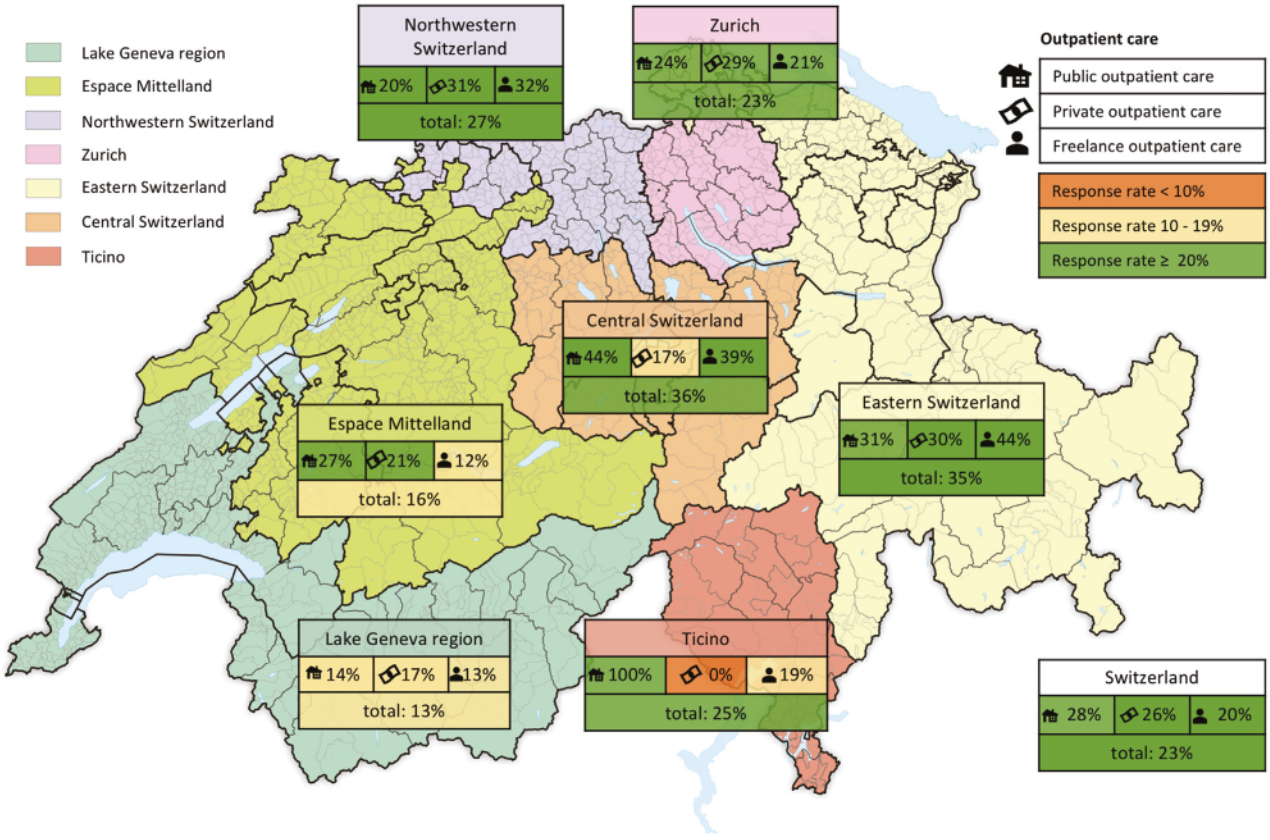

Figure 1. Response rate of public, private, and freelance outpatient care in the seven major regions of Switzerland. Source: Map from Tschubby (2019), with information on outpatient care provided by the authors.

(1.0%) and Central (0.8%) Switzerland, the lowest in the Lake Geneva region (0.1%) (Table 2).

Nurses' Attitudes Toward VSED

Nurses were asked to classify VSED, to explain their attitudes toward it, and the challenges they face in accompanying a patient. For most participants (70.3%), VSED is a "natural death." Moreover, 17.4% equated VSED with passive euthanasia in the sense of refraining from life-support measures, 6.6% considered VSED to be a person's autonomous right, while 4.9% considered it to be (physician-assisted) suicide. Lastly, 0.5% rated VSED as an expression of life fatigue and 0.3% noted it as "abandoning" a dying person.

Table 3 shows that most participants strongly agreed that VSED is compatible with their world view or religion. Half expressed no moral concerns accompanying a patient. The decision to VSED was generally accepted and respected. Almost all were convinced that people who choose VSED have a right to medical and nursing care; however, one-quarter felt that the support they receive contradicts the culture of their institution or their professional ethos. Some respondents believed that VSED would allow for dignified dying and would agree, in principle, to accompany a patient. Moreover, most could imagine VSED themselves. When asked whether they would recommend VSED as an option to patients who wish to die, a nearly equal number answered *yes* or *no*. Moreover, most attached great importance to the determination of patients' ability to judge and to reflect on their situation before deciding to stop eating and drinking. During accompaniment, many nurses felt that patients' relatives would feel burdened, and that patients' decision would be hard to accept.

Expressed or Unspoken VSED

We wanted to know whether VSED is always *expressed* clearly and unambiguously (verbally or nonverbally), or whether there are cases that are *unspoken* in which food and fluids are denied, but patients do not communicate this renunciation (neither verbally nor nonverbally). The participants (n = 392) noted that one-quarter (26%) of patients *expressed* their intentions clearly and unambiguously, and nearly three-quarters (74%) died as a result of not eating or drinking without making this clear (*unspoken*). It was also

Table 1. Participants' characteristics

	Missing	Mean (*SD*) range	Absolute (relative %) frequencies
Total participants			395
Outpatient care			
Freelance			198 (50.1%)
Private			46 (11.6%)
Public			151 (38.2%)
Age (years)	11	51 (9) 25–87	
< 30 years			5 (1.3%)
30–39 years			29 (7.6%)
40–49 years			110 (8.6%)
50–59 years			181 (7.1%)
≥ 60 years			59 (15.4%)
Sex	6		
Female			345 (8.7%)
Diverse			2 (0.5%)
Male			42 (10.8%)
Competence level in palliative care (European Credit Transfer and Accumulation System)	8		
Level A1 (1–2)			27 (7.0%)
Level A2 (2–3)			45 (11.6%)
Level B1 (5–6)			55 (14.2%)
Level B2 (17–18)			44 (11.4%)
Level C (60–180)			12 (3.1%)
No additional qualification in palliative care			204 (52.7%)
Work experiences	7	27 (9) 4–50	
< 10 years			11 (2.8%)
10–19 years			61 (15.7%)
20–29 years			131 (3.8%)
30–9 years			143 (6.9%)
40–49 years			40 (10.3%)
≥ 50 years			2 (0.5%)

of interest whether there was a connection between patients' age and whether food refusal was *expressed* or *unspoken*. The participants were asked to indicate in which age group they expect the *expressed* VSED and the unspoken food refusal (several answers were possible). Figure 2 shows that *expressed* VSED occurs at all ages but increases consistently as patients age. Further, the increase in *unspoken* food refusal was markedly stronger in patients aged 75+ years.

Discussion

This cross-sectional study sought to determine the occurrence of VSED in Swiss outpatient care and what attitudes nurses have toward this topic. All objectives were achieved, and VSED was surveyed in outpatient care for the first time.

We found that every third participating nurse had already accompanied a VSED case, and 0.5% of all deaths in Switzerland result from VSED. The results correspond to those from nursing homes (0.7%) (Stängle et al., 2019a), which were surveyed at the same time and with the same instrument, which means that the occurrence in Switzerland might possibly be higher. VSED occurrence is also comparable to that of The Netherlands (0.4–2.1%) (Chabot & Goedhart, 2009; Onwuteaka-Philipsen et al., 2012). We posit that this topic will become more relevant in the future as the Swiss population ages (Kucera & Krummenacher, 2018), since VSED occurs more frequently as patients age (Stängle et al., 2019b).

By far the most nurses say that VSED is comparable to natural death. While the statements are in line with those of nursing homes (Stängle et al., 2019a), it presents a different picture from the current discussions in Switzerland and internationally, which are particularly concerned with the question of suicidal behavior, which was classified by only a few (4.9%) nurses in this study. Although most participants recognized VSED as a natural death and said that they would be willing to provide care for said patients, about one-quarter still expressed moral concerns. This alleged contradiction can be explained by the Ethics of Care (Held, 2006): In a caregiving relationship, when the patient becomes dependent on the caregiver, the caregiver may act emotionally and make decisions for the patient that do not match their own ideals (Held, 2006). This can also occur when accompanying a person during VSED, something that must be discussed beforehand, especially if the person who is willing to die develops delirium and later demands fluids (Gärtner & Müller, 2018). The extent to which this has taken place among nurses could not be clarified within the framework of this research.

From a previous interview study (Stängle et al., 2019c) with relatives who have lost a loved one due to VSED, we know that there are other forms of VSED besides explicit VSED. These include the concealed form of VSED, in which patients consciously try to hide their intentions so that relatives or professionals cannot dissuade them from their VSED plans; or implicit VSED, in which people consciously stop eating without informing their surroundings. The intention would not be concealed if asked, but it turns out that especially very old people are not asked about it, as it probably was not recognized. In this study, the nurses expect a high number of unreported VSED cases and assume that, in addition to the expressed VSED cases, three more patients may be added who refuse to eat but do not openly communicate that they want to die. Especially in old age, a high proportion of people are expected to tacitly

Table 2. Number of patients accompanied by nurses with VSED experience (n=143)

		Number of VSED[1] cases accompanied by participants				Occurrence of VSED in Switzerland			
		Number of accompanied VSED cases in 2016 according to the outpatient care settings							
Region	n	Public cases (%)	Private cases (%)	Freelance cases (%)	Total number of accompanied VSED cases in 2016	Deaths in 2016[2]	Occurrence of VSED per all deaths	Deaths at home in 2016[3]	Occurrence of VSED per deaths at home deaths
Lake Geneva region	12	2 (14.3%)	0 (0%)	12 (85.7%)	14	11,200	0.1%	3,136	0.5%
Espace Mittelland	29	25 (58.1%)	7 (16.3%)	11 (25.6%)	43	15,924	0.3%	4,459	1.0%
Northwestern Switzerland	18	10 (23.8%)	15 (35.7%)	17 (40.5%)	42	9,127	0.5%	2,556	1.6%
Zurich	31	7 (14.6%)	12 (25.0%)	29 (60.4%)	48	10,652	0.5%	2,983	1.6%
Eastern Switzerland	28	50 (56.8%)	12 (13.6%)	26 (29.5%)	88	9,186	1.0%	2,572	3.4%
Central Switzerland	16	32 (71.1%)	6 (13.3%)	7 (15.6%)	45	5,570	0.8%	1,560	2.9%
Ticino	9	11 (50.0%)	0 (0%)	11 (50.0%)	22	2,990	0.7%	837	2.6%
Switzerland total	143	137 (45.4%)	52 (17.2%)	113 (37.4%)	302	64,649	0.5%	18,102	1.7%

Note. [1]VSED: voluntary stopping of eating and drinking; [2]Source: Federal Statistical Office, 2018a; [3]Source: Federal Office of Public Health, 2016.

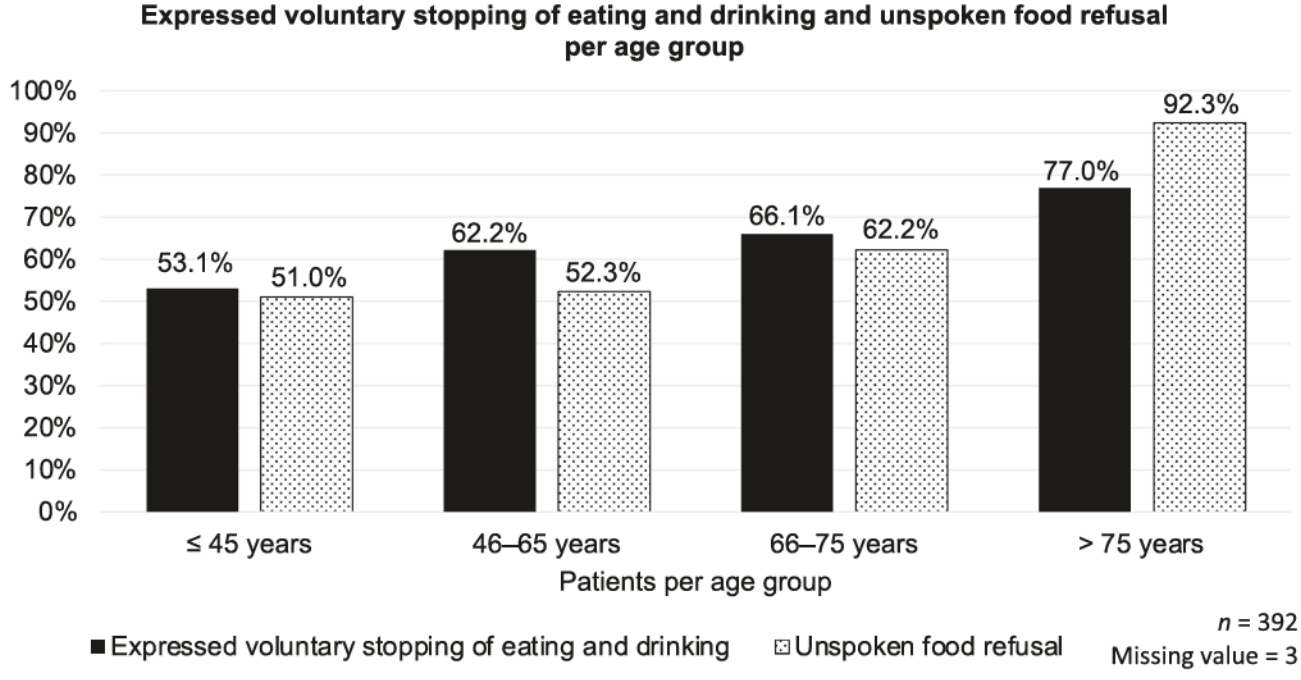

Figure 2. Expressed voluntary stopping of eating and drinking and unspoken food refusal per age group.

give up food. This may be because the outpatient care does not necessarily control the food intake and may only notice the consequences of the food shortage at a very late stage. Alternatively, it is also possible that the refusal to eat is associated with dying because of old age, so that other causes (e.g., loose teeth, pain) are not sought. Since the professionals themselves expect a high number of unspoken VSED cases, further training seems essential to ensure patient safety.

One strength of this study is that it is a large-scale national survey that, in contrast to previous studies about VSED from other countries (Bolt et al., 2015; Chabot & Goedhart, 2009; Hoekstra et al., 2015; Shinjo et al., 2017), it is the first to focus on outpatient care. The necessary response rate (20%) per our study protocol (Stängle et al., 2018) and average response rate (21.5%) of national surveys worldwide (Sax, Gilmartin, & Bryant, 2003) were exceeded. We posit that people who have already been confronted with VSED cases are more likely to answer the questionnaire; nevertheless, it was a heterogeneous sample: 15.4% had no knowledge about the topic, and most had not accompanied a VSED patient.

Regarding the response rate per major region, the expected rates in Geneva region and Espace Mittelland were not achieved. This could result from linguistic or

Table 3. Nurses' attitudes and professional stance

Nurses' attitudes and professional stance	Coding	Strongly disagree 1	Disagree somewhat 2	Neutral 3	Agree somewhat 4	Strongly agree 5
Compatible with world view or religion	*n* = 393	3.1%	3.6%	9.9%	12.0%	71.5%
Have moral doubts	*n* = 393	50.4%	23.2%	13.0%	7.1%	6.4%
Contradicts culture of institution/ professional ethics	*n* = 390	51.3%	24.1%	12.8%	7.9%	3.8%
Represents a dignified death	*n* = 392	3.3%	5.6%	19.4%	28.6%	43.1%
Entitled to medical and nursing care	*n* = 392	0.3%	0.3%	2.0%	6.4%	91.1%
Accept decision	*n* = 394	0.5%	1.3%	6.6%	9.6%	82.0%
Respect decision	*n* = 394	–	0.3%	2.5%	8.9%	88.3%
		No	Yes	–	–	–
Would personally consider it as an option	*n* = 390	23.8%	76.2%	–	–	–
Would recommend voluntary stopping of eating and drinking (VSED)	*n* = 379	51.7%	48.3%	–	–	–
Would care for a patient during VSED	*n* = 391	4.9%	95.1%	–	–	–
Challenges during VSED		Strongly disagree	Disagree somewhat	Neutral	Agree somewhat	Strongly agree
Determination of patients' ability to judge the situation	*n* = 390	3.1%	4.1%	14.4%	19.7%	58.7%
Professionals are burdened	*n* = 390	10.0%	10.5%	36.2%	24.9%	18.5%
Relatives are burdened	*n* = 389	1.3%	3.3%	22.4%	31.9%	41.0%
Relatives have trouble accepting the decision	*n* = 389	0.8%	3.1%	32.6%	34.7%	28.8%

cultural differences within Switzerland. While French is spoken in Geneva region and Espace Mittelland, and Italian is spoken in Ticino, German is the main language in the other major regions. It is assumed that, despite testing and validation, the French version of the questionnaire was not adequate. A group comparison within the major regions is recommended for further research.

Conclusions

The nurses' experience with caring for patients who embrace VSED is not uncommon in Swiss outpatient care facilities. Nurses usually classify it as a natural death and are willing to take on this new task, even if moral concerns arise. They further believe that the person has a right to medical and nursing care during VSED. In addition to the VSED cases, nurses expect a much higher proportion of patients who stop eating without this being recognized by the nurses or relatives. Especially in old age, it is assumed that there are a high number of patients who go undetected by their nurses, stop eating and die prematurely.

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