Short informative title:

- Long-term care nurses´ attitudes and the incidence of voluntary stopping of eating and drinking: a cross-sectional study

Short running title:

- Attitudes of VSED in long-term care

List of all authors

Sabrina STÄNGLE, MSc, RN (Corresponding author)

Job title: Research associate

(ORCID: 0000-0003-1664-8824)

Witten/Herdecke University

Faculty of Health, Department of Nursing Science

Stockumer Strasse 12

D- 58453 Witten

e-mail: sabrina.staengle@uni-wh.de

Zurich University of Applied Sciences

School of Health Professions

Institute of Nursing

Technikumstrasse 81

CH- 8400 Winterthur

Phone: +41 58 934 41 44

e-mail: sabrina.staengle@zhaw.ch

Wilfried SCHNEPP, PhD, RN

Job title: Head of Department for Family-Oriented and Community Care

(ORCID: 0000-0001-7856-7224)

This article has been accepted for publication and undergone full peer review (not applicable for Editorials) but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/jan.14249

Witten/Herdecke University

Faculty of Health, Department of Nursing Science

Stockumer Strasse 12

D- 58453 Witten

e-mail: wilfried.schnepp@uni-wh.de

Daniel BÜCHE, MD, MSc

Job title: Senior physician

(ORCID: 0000-0001-9922-663X)

Cantonal Hospital St.Gallen, Palliative Centre St.Gallen, House 33

Rorschacherstrasse 95

CH-9007 St. Gallen

e-mail: daniel.bueche@kssg.ch

André FRINGER, PhD, MSc, RN

Job title: Co-Head of MSc Nursing and Co-Head Nursing Science

Twitter: @AndrFringer

(ORCID: 0000-0003-4950-7788)

Zurich University of Applied Sciences

School of Health Professions

Institute of Nursing

Technikumstrasse 81

CH- 8400 Winterthur

e-mail: andre.fringer@zhaw.ch

Witten/Herdecke University

Faculty of Health, Department of Nursing Science

Stockumer Strasse 12

Author contributions

Criteria	Author Initials
Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data;	SS, AF
Involved in drafting the manuscript or revising it critically for important intellectual content;	SS, WS, DB, AF
Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content;	SS, WS, DB, AF
Agreed to be 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.	SS, WS, DB, AF

Conflict of Interest statement

No conflict of interest has been declared by the author(s)

Funding Statement

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research is sponsored by the funding program ‘‘Research in Palliative Care’’ of the Swiss Academy of Medical Sciences, supported by Stanley Thomas Johnson Foundation and the Gottfried and Julia Bangerter-Rhyner-Stiftung.

MRS SABRINA STÄNGLE (Orcid ID : 0000-0003-1664-8824)

Article type : Original Research: Empirical research - quantitative

ABSTRACT

Aims: To assess the incidence of voluntary stopping of eating and drinking in long-term care and to gain insights into the attitudes of long-term care nurses about the voluntary stopping of eating and drinking.

Design: A cross-sectional study

Methods: Heads of Swiss nursing homes (535; 34%) answered the Online-Survey between June and October 2017, which was evaluated using descriptive data analysis.

Results: The incidence of patients who died in Swiss nursing homes by voluntarily stopping eating and drinking is 1.7% and 67.5% of participants consider this phenomenon highly relevant in their daily work. Most participants (64.2%) rate voluntary stopping of eating and drinking as a natural death accompanied by health professionals and patients are also granted the right to care (91.9%). This phenomenon is expected by the participants less at a young age and more in old age.

Conclusion: Participants' overall views on the voluntary stopping of eating and drinking are very positive, whereas it is assumed that voluntary stopping of eating and drinking is a phenomenon of old age. Professionals still lack sufficient knowledge about this phenomenon, which could be clarified through training.

International Registered Report Identifier (IRRID): DERR1-10.2196/10358

Impact:

1. Voluntary stopping of eating and drinking is much discussed interprofessional, but there is a lack of knowledge on how this is perceived in the context of long-term care and about the incidence of the phenomenon.
2. Voluntary stopping of eating and drinking is rare but noticeable end-of-life practises that is considered by professionals to be mainly dignified and peaceful, although moral concerns make it difficult to accompany.
3. These findings call on long-term care institutions to discuss voluntary stopping of eating and drinking as an end-of-life practice. Positioning on the issue provides clarity for staff and patients and promotes to develop standardized care.

Key words: long-term care, nurse, food refusal, decision at the end-of-life, nursing home, VSED, advance nursing practice, self-determination, end-of-life practice, attitudes

INTRODUCTION

Switzerland cultivates a right-to-die society where the desire to die is openly communicated. Over the past 20 years, health professionals have increasingly been confronted with the desire of patients to die (Schmid, Zellweger, Bosshard, Bopp, & Swiss Medical End-Of-Life Decisions Study Group, 2016) and the number of assisted suicides is also increasing (Wiler, 2019). In Switzerland, the Swiss Academy of Medical Sciences (SAMS) (2018) issues a guideline for all health professions, which regulates the handling of death and dying. In 2018, for the first time, in addition to assisted suicide, the forgoing life-prolonging treatments, pain relief measures and sedation, a further option to end life prematurely was included and discussed. It is about the voluntary stopping of eating and drinking, VSED for short; an autonomous decision of a discerning person who would still be able to eat and drink, stops the intake of food and liquid with the intention of prematurely ending one's own life (Bernat, Gert, & Mogielnicki, 1993; Ganzini et al., 2003; Ivanović, Büche, & Fringer, 2014; Mattiasson & Andersson, 1994). It should be emphasised that VSED should be clearly distinguished from discontinuation of artificial feeding (Druml et al., 2016), treatment of people with dementia (Volkert et al., 2015), or malnutrition, including anorexia and cachexia (Arends et al., 2017; Hopkinson, 2015a, 2015b). The topic of VSED is not a marginal issue, as can be seen in international studies which showed that between 32% and 62% of the participating health care professionals have already accompanied at least one person during VSED (Bolt, Hagens, Willems, & Onwuteaka-Philipsen, 2015; Chabot & Goedhart, 2009; Ganzini et al., 2003; Hoekstra, Strack, & Simon, 2015; Shinjo et al., 2017). Empirical data on the incidence of VSED in long-term care in Switzerland has not yet been recorded.

Background

The decision to VSED is made autonomously and self-determined by the person willing to die (Bolt et al., 2015; Ivanović et al., 2014). It affects people of all ages, with an increasing frequency from the age of 60 (23 - 32%) and further from the age of 80 (48 - 70%) and an expected life span up to four weeks (32%), one year (41%) or longer (26%) (Bolt et al., 2015; Chabot & Goedhart, 2009; Stängle, Schnepp, & Fringer, 2019). Most people die through VSED in their own home (52%) or nursing home (42%) (Bolt et al., 2015). The persons frequently suffer from a somatic disease (39%) or cancer (27%) or have no previous illnesses except for

old-age fractures (24%) (Bolt et al., 2015; Chabot & Goedhart, 2009; Stängle, Schnepp, & Fringer, 2019). In the decision-making process, somatic complaints (79%), existential causes (77%), dependencies (58%), loss of autonomy (37%), loneliness (21%) or psychiatric symptoms (14%) are present among those who are willing to die (Bolt et al., 2015).

While the decision on the VSED is self-determined, a need for care develops over time (Fringer, Fehn, Büche, Häuptle, & Schnepp, 2018). It is therefore advisable to have health professionals accompany you right from the start (Lachman, 2015), which is not always the case (Bolt et al., 2015). In the preparation phase, the first step is to assess the capacity of the person who is willing to die and to prepare all persons involved in the process for the coming period (Bickhardt & Hanke, 2014; Birnbacher, 2015; Quill, 2015; Simon & Hoekstra, 2015). The Guideline of the Netherlands can serve as a basis for this (Royal Dutch Medical Association (KNMG) & Dutch Nurses' Association (V&VN), 2014).

For a long time, the course was described as predominantly positive (Ganzini et al., 2003; Ivanović et al., 2014), but in recent years some cases have been reported where the course was described as cumbersome, long and with severe side effects (e.g. delir) (Fehn & Fringer, 2017; Gärtner & Müller, 2018; Saladin, Schnepp, & Fringer, 2018). The accompaniment of a VSED case can still be seen as an unknown challenge in everyday professional life. This can lead to tensions between the professional stance and one's attitudes, resulting in fears and uncertainties in the accompaniment (Saladin et al., 2018).

THE STUDY

Aims

This study aimed to access the incidence of VSED in Swiss nursing homes and to explore the attitudes and professional stance of nurses for long-term care about VSED.

Design

A cross-sectional study on VSED in Swiss long-term care.

Sample

Switzerland has a total of 1562 nursing homes (Federal Statistical Office (FSO), 2018b), which are very well organised by the professional association CURAVIVA (CURAVIVA Schweiz, 2019). Due to CURAVIVA's willingness to send our questionnaire by e-mail and newsletter to

all members, all Swiss nursing homes were invited to participate in the survey. The study population was defined as either the nursing director, institute director or head nurse.

Data collection

According to our research protocol (Stängle, Schnepp, Mezger, Büche, & Fringer, 2018), an evidence-based questionnaire (Stängle, Schnepp, Mezger, Büche, & Fringer, 2019) was used in this study to determine the incidence of VSED and attitudes and professional stance among health professionals to VSED. In addition to the managers of nursing homes, managers of outpatient nursing and family physicians were also interviewed in this research project, but these are not dealt with in this article. The questionnaire was created with the survey software Questback (EFS 10.9) and the recruitment took place between June and October 2017. Access to the questionnaire is subject to the consent of the declaration of consent. There the research project was described, and the objectives defined. It was emphasized that participation in the study was voluntary and anonymity was guaranteed.

Ethical considerations

The study was reviewed and approved by the responsible institutional review board of the Greater Region of Eastern Switzerland (EKOS 17/083) (May 2017).

Data analysis

Descriptive analysis was carried out using statistical software IBM SPSS Statistics (Version 25). The characteristics of the study participants, as well as the results from the survey, are given in means, standard deviations, percentages and frequencies.

Validity, reliability and rigour

The questionnaire used in this study was checked and tested in advance using standard pre-test (Colton & Covert, 2007) and content validity index (Polit & Beck, 2006; Polit, Beck, & Owen, 2007).

RESULTS

Description of the participants

A total of 535 out of 1562 participants answered the questionnaire, resulting in a response rate of 34%. In addition to the overall response rate, the distribution of feedback in Switzerland is also

of interest. To calculate this, Switzerland is divided into seven major regions, consisting of one or more cantons and an average population density of 1 041 144 persons (Schuler, Dessemontet, & Joye, 2005, p. 67ff). Figure 1 shows that the response rate per region is between 21% and 48%.

The majority of the participants (59.5%) are women and on average 52(8) years old. Half of the participants (52.6%) have acquired further training in palliative care and have been working for an average of 28(10) years (Table 1).

Incidence of VSED in Swiss nursing homes

First, we wanted the nurses to assess the relevance of VSED in their daily work. For 67.5% (*n*=355) of those surveyed, VSED is already an important topic in everyday professional life and a half (55.3%, *n*=280) assume that confrontation with VSED will increase in the future. We also wanted to know if the participants knew and were familiar with VSED and how many people had already accompanied a person during VSED. It turned out (*n*=535) that most (88.2%) know VSED as an option to end life prematurely and a little less (61.3%) feel more familiar with the topic. VSED was accompanied by almost half (47.1%) of all nursing home managers surveyed.

Those who accompanied a person during VSED (*n*=252) were asked to provide more detailed information on the frequency of accompaniment. Since the beginning of their professional career, the participants have accompanied an average of 12 patients during VSED (total 3061, mean 12(19), range 1 - 100). To calculate the incidence of VSED, used the previous year of the recruitment period, in this case, the year 2016. To this end, participants were asked to indicate the number of VSED cases they accompanied in 2016. In 2016, a total of 462 patients were accompanied by nurses, which is two patients per nurse in 2016 (mean 2(3), range 0 - 30). In 2016, 64´964 deaths were reported in Switzerland (Federal Statistical Office (FSO), 2018a). To measure the incidence, the percentage of all VSED cases in 2016 was calculated based on all deaths. This leads to an incidence of VSED in Switzerland of 0.7%. While 41% (≈ 26´635 deaths) of all people in Switzerland die in nursing homes (Federal Office of Public Health (FOPH), 2016), the incidence of having died in 2016 in a nursing home as a result of VSED is 1.7%.

We also wanted to know if the nurses recommended VSED to the patients in 2016. The nurses have recommended VSED as an option to an average of one person (total 251, mean 1(2), range

0 - 20). Among these, 47 (18.7%) participants did not make a recommendation but would have done so, while 120 (47.6%) would never make a recommendation.

Classification of VSED

Nurses were asked to indicate how they felt VSED should be classified. Most (64.2%) feel that VSED is a natural death accompanied by healthcare professionals and a quarter (25.7%) feel that it is passive euthanasia in the sense of forgoing life support measures. The remaining 10.1% say that it is a self-determined decision, suicide, an alternative form of death or can be evaluated differently depending on the case (Figure 2).

Factors that influence the decision of nurses for or against an accompaniment

Basically, nurses see that people during VSED have a right to medical and nursing care (91.9% strongly agree) and most can respect the decision to VSED (87.2% strongly agree), in the sense it is not for me to judge, the person has the right to do that (see Table 2). This overlaps in most cases (72%) with the strong agreement (or 86.7% agreement) that VSED is consistent with one's worldview or religion. The acceptance for the decision is strongly agreed by 80.8% of the respondents, which means they can agree and approve the decision. Almost everyone would be willing to accompany a patient during the VSED (93.2%). In 7.7% (agreement), the accompaniment contradicts the culture of the institutions of the participants, whereas in 79.9% (disagreement) of the cases no objections are to be feared on the part of the institutions. For 77.7% (agreement) of the participants, a clarification of the patient's ability to judge is an important step that influences the decision to accompany them, 11.8% have a neutral attitude and 10.5% (disagreement) feel this step is not necessary. Two thirds (67%) of those involved can imagine recommending VSED as an option to a person and the many (72.6%) could imagine choosing VSED as an option if they wanted to end their lives prematurely.

Challenges in accompanying a patient during VSED

Most (71% agreement) consider the dying process through VSED to be dignified, 11.6% (disagreement) can only contradict this and express moral concerns (12.7% agreement) (see Table 2). Most, on the opposite, see no moral concerns during the accompaniment (74.5% disagreement). While the professionals tend to feel burdened during the accompaniment (35.9% neutral attitude, 48.7% agreement), most professionals agree (75.3% agreement) that the

relatives are burdened during this time. Also, nurses assume that relatives have problems accepting VSED decisions (61.5% agreement).

The influence of age on the decision VSED

In the following, participants should not consider the incidence of VSED, but make assumptions about how patients express their desire to forego food and fluid. For this purpose, participants should relate their assumptions about the frequency of the expressed VSED to their assumptions about the frequency of the unspoken refusal of food and fluid. The nurses (n=535) assume that the majority (75.3%) of patients unspokenly reduce and stop food intake and only 24.7% openly express their desire to die through VSED. In the next step, we wanted to know if there was a connection between the two forms of food refusal and the age of the patients. We wanted to find out where age groups the participants expect the two forms of food renunciation. As can be seen in Figure 3, both forms are expected by about half of the participants at a younger age, while almost all expect it to occur at the age of 75.

DISCUSSION

In this research project, the incidence of VSED in long-term care in Switzerland and the attitudes of managers of long-term care facilities to VSED were to be recorded, which was also achieved.

While in the Netherlands between 0.4-2.1% of all deaths can be attributed to VSED (Chabot & Goedhart, 2009; Onwuteaka-Philipsen et al., 2012), similar results could be obtained in this study, showing that 1.7% of all deaths in Swiss long-term care institutions and 0.7% of all deaths in Switzerland are attributable to VSED and that among respondents almost every second institution has already accompanied a VSED case. The proportion of participants who have already accompanied a person to the VSED with international studies (Bolt et al., 2015; Hoekstra et al., 2015; Shinjo et al., 2017) is also comparable. Especially by the assumption of the participants that for every patient who expresses the wish to die through VSED, four patients come who do not communicate their wish to die but refuse to eat. Since only two-thirds of the participants consider it necessary to check the patients' ability to judge, there is a danger that patients are wrongly attributed to the desire to die, although other causes such as pain or homesickness (Bartholomeyczik, 2019) may hinder the patient from eating.

Death by VSED is seen by most as a natural death that enables dignified dying and confirms the above-average positive attitude towards VSED (Ganzini et al., 2003; Ivanović et al., 2014). This can also be explained by the fact that nurses make a good death of relatives and health professionals acting according to the patient's wishes, dying without technical equipment and the ability to communicate till the end (Gibson et al., 2008). One quarter sees VSED as passive euthanasia, as it is also perceived in Germany (Hoekstra et al., 2015). The attitude, as it exists in the Netherlands (Bolt et al., 2015; Chabot & Goedhart, 2009), that VSED should be regarded as physician assisted suicide, is only supported by a few. There is a heterogeneous picture of the classification of VSED as found in international literature (Alt-Epping, 2018; Fringer et al., 2018; Requena & Andrade, 2018; Simon, 2018). The recommendation for VSED is rejected by most, which is also because changes in therapy are traditionally discussed with the attending physician.

Among all participants, less than half assume that expressed VSED and unspoken food refusal may occur in all age groups. Of the others, few believe that both can occur in age groups up to 75 years, while most expect both to occur from age 75. From these findings it becomes clear that the expectations of the participants are focused on people of an advanced age. This is probably since the average age of patients in Swiss nursing homes is over 80 years (Federal Statistical Office (FSO), 2019). However, international literature (Bolt et al., 2015; Chabot & Goedhart, 2009; Stängle, Schnepp, Büche, Häuptle, & Fringer, 2019; van der Heide, Brinkman-Stoppelenburg, van Delden, & Onwuteaka-Philipsen, 2012) has already shown that VSED can occur in all age groups of decision-competent persons. Even though it is the least common among the under-65s with about 7%, two thirds are 80 years and older. It seems important that health professionals are educated about these findings to be able to develop a differentiated approach to the topic.

Limitations

The strength of this study lies in the fact that all nursing homes in Switzerland invited one manager each to take part in the survey, so that in the extrapolation of the VSED accompaniment, it was not possible to duplicate a single VSED case. However, it is also possible that not every VSED case was communicated with the management level and thus remained undiscovered. Also, not all of the nursing homes we contacted answered our questionnaires,

which can lead to further cases not being discovered. Accordingly, a higher incidence of VSED cannot be ruled out.

The response achieved does not constitute a representative study. However, this time the focus was not on a sample, as in previous studies (Bolt et al., 2015; Hoekstra et al., 2015; Shinjo et al., 2017), but on a national survey of all nursing homes. With this participation, we met the expected 20% response rate according to our study protocol (Stängle, Schnepp, Mezger, et al., 2019) and were also able to exceed the average response rate of national studies worldwide (Sax, Gilmartin, & Bryant, 2003).

CONCLUSION

For the first time, the incidence of VSED in Swiss nursing homes was recorded, with the result that 1.7% of all patients die from VSED in nursing homes. Participants expect four times as many unreported cases of patients who do not eat, but do not communicate openly.

Participants view VSED very differently, but predominantly as a natural dying process and have an overall positive attitude towards VSED. In particular, the participants' assumption that VSED is only expected by a few at a young age reveals an important knowledge gap. It can therefore be expected that there will be further knowledge deficits which can be remedied by targeted further training and conferences.

Conflict of Interest statement

The authors declared no potential conflicts of interest concerning the research, authorship and/or publication of this article.

References

Alt-Epping, B. (2018). Con: Der freiwillige Verzicht auf Nahrung und Flüssigkeit ist keine Form des Suizids. [Con: Voluntary stopping of eating and drinking is not a form of suicide]. *Zeitschrift für Palliativmedizin, 19*(01), 12-15. doi:10.1055/s-0043-124167

Arends, J., Baracos, V., Bertz, H., Bozzetti, F., Calder, P. C., Deutz, N. E. P., . . . Weimann, A. (2017). ESPEN expert group recommendations for action against cancer-related malnutrition. *Clin Nutr, 36*(5), 1187-1196. doi:10.1016/j.clnu.2017.06.017

Bartholomeyczik, S. (2019). [Prevention of malnutrition in institutional long-term care with the DNQP "nutrition management" expert standard]. *Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz, 62*(3), 304-310. doi:10.1007/s00103-019-02878-1

Bernat, J. L., Gert, B., & Mogielnicki, R. P. (1993). Patient refusal of hydration and nutrition. An alternative to physician-assisted suicide or voluntary active euthanasia. *Archives of Internal Medicine, 153*(24), 2723–2728.

Bickhardt, J., & Hanke, R. M. (2014). Freiwilliger Verzicht auf Nahrung und Flüssigkeit: Eine ganz eigene Handlungsweise. [Voluntary stopping of eating and drinking: a very individual way of acting]. *DÄ, 111*(14), 590–592.

Birnbacher, D. (2015). Ist Sterbefasten eine Form von Suizid? [Is voluntarily stopping eating and drinking a form of suicide?]. *Ethik in der Medizin, 27*(4), 315–324. doi:10.1007/s00481-015-0337-9

Bolt, E. E., Hagens, M., Willems, D., & Onwuteaka-Philipsen, B. D. (2015). Primary care patients hastening death by voluntarily stopping eating and drinking. *Annals of Family Medicine, 13*(5), 421–428. doi:10.1370/afm.1814

Chabot, B. E., & Goedhart, A. (2009). A survey of self-directed dying attended by proxies in the Dutch population. *Social Science & Medicine, 68*(10), 1745–1751. doi:10.1016/j.socscimed.2009.03.005

Colton, D., & Covert, R. W. (2007). *Designing and constructing instruments for social research and evaluation* (1 ed.). San Francisco, CA: Jossey-Bass.

CURAVIVA Schweiz. (2019). Verband Heime und Institutionen Schweiz. Retrieved from https://www.curaviva.ch/

Druml, C., Ballmer, P. E., Druml, W., Oehmichen, F., Shenkin, A., Singer, P., . . . Bischoff, S. C. (2016). ESPEN guideline on ethical aspects of artificial nutrition and hydration. *Clinical Nutrition, 35*(3), 545-556. doi:10.1016/j.clnu.2016.02.006

Federal Office of Public Health (FOPH). (2016). Data situation on palliative care - evaluation of data on the place of death. Retrieved from https://www.bag.admin.ch/bag/de/home/das-

bag/publikationen/forschungsberichte/forschungsberichte-palliative-care/datensituation-zu-palliative-care.html. Retrieved 06.08.2019, from FOPH https://www.bag.admin.ch/bag/de/home/das-bag/publikationen/forschungsberichte/forschungsberichte-palliative-care/datensituation-zu-palliative-care.html

Federal Statistical Office (FSO). (2018a). 2000 more deaths in Switzerland in 2017. Retrieved from https://www.bfs.admin.ch/bfs/de/home/statistiken/kataloge-datenbanken/medienmitteilungen.assetdetail.5389171.html. (2018-0274-D). Retrieved 06.08.2019, from FSO https://www.bfs.admin.ch/bfs/de/home/statistiken/kataloge-datenbanken/medienmitteilungen.assetdetail.5389171.html

Federal Statistical Office (FSO). (2018b). Statistics of the socio-medical institutions. Retrieved from https://www.bfs.admin.ch/bfs/de/home/statistiken/kataloge-datenbanken/tabellen.assetdetail.6526711.html. (su-d-14.04.02-sm-2017-01). Retrieved 06.08.2019, from FSO https://www.bfs.admin.ch/bfs/de/home/statistiken/kataloge-datenbanken/tabellen.assetdetail.6526711.html

Federal Statistical Office (FSO). (2019). Personen in Alters- und Pflegeheimen 2017 [Persons in retirement and nursing homes 2017]. Retrieved from https://www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/gesundheitswesen/alters-pflegeheime.assetdetail.7267444.html. (1904-1700-05). Retrieved 21.03.2019, from FSO https://www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/gesundheitswesen/alters-pflegeheime.assetdetail.7267444.html

Fehn, S., & Fringer, A. (2017). Notwendigkeit, Sterbefasten differenzierter zu betrachten. [Necessity to take a more differentiated view on VSED]. *Schweiz Ärzteztg, 98*(36), 1161-1163. doi:10.4414/saez.2017.05863

Fringer, A., Fehn, S., Büche, D., Häuptle, C., & Schnepp, W. (2018). Freiwilliger Verzicht auf Nahrung und Flüssigkeit (FVNF): Suizid oder natürliche Entscheidung am Lebensende? [Voluntary stopping of eating and drinking (VSED): Suicide or natural decision at the end of life?]. *Pflegerecht, 7*(2), 76-83.

Ganzini, L., Goy, E. R., Miller, L. L., Harvath, T. A., Jackson, A., & Delorit, M. A. (2003). Nurses' experiences with hospice patients who refuse food and fluids to hasten death. *The New England journal of medicine, 349*(4), 359–365. doi:10.1056/NEJMsa035086

Gärtner, J., & Müller, L. (2018). Ein Fall von „Sterbefasten“ wirft Fragen auf. [A case of voluntary stopping of eating and drinking raises questions]. *Schweiz Ärzteztg, 99*(21), 675-677. doi:10.4414/saez.2018.06691

Gibson, M. C., Gutmanis, I., Clarke, H., Wiltshire, D., Feron, A., & Gorman, E. (2008). Staff opinions about the components of a good death in long-term care. *Int J Palliat Nurs, 14*(8), 374-381. doi:10.12968/ijpn.2008.14.7.30772

Hoekstra, N. L., Strack, M., & Simon, A. (2015). Bewertung des freiwilligen Verzichts auf Nahrung und Flüssigkeit durch palliativmedizinisch und hausärztlich tätige Ärztinnen und Ärzte. [Physicians Attitudes on Voluntary Refusal of Food and Fluids to Hasten Death - Results of an Empirical Study Among 255 Physicians]. *Z Palliativmed, 16*(02), 68–73. doi:10.1055/s-0034-1387571

Hopkinson, J. B. (2015a). The nursing contribution to nutritional care in cancer cachexia. *Proc Nutr Soc, 74*(4), 413-418. doi:10.1017/S0029665115002384

Hopkinson, J. B. (2015b). Nutritional support of the elderly cancer patient: the role of the nurse. *Nutrition, 31*(4), 598-602. doi:10.1016/j.nut.2014.12.013

Ivanović, N., Büche, D., & Fringer, A. (2014). Voluntary stopping of eating and drinking at the end of life - a 'systematic search and review' giving insight into an option of hastening death in capacitated adults at the end of life. *BMC Palliative Care, 13*(1), 1-8. doi:10.1186/1472-684X-13-1

Lachman, V. D. (2015). Voluntary stopping of eating and drinking: An ethical alternative to physician-assisted suicide. *Medsurg nursing, 24*(1), 56–59.

Mattiasson, A. C., & Andersson, L. (1994). Staff attitude and experience in dealing with rational nursing home patients who refuse to eat and drink. *Journal of Advanced Nursing, 20*(5), 822–827.

Onwuteaka-Philipsen, B. D., Brinkman-Stoppelenburg, A., Penning, C., Jong-Krul, G. J. F., van Delden, J. J. M., & van der Heide, A. (2012). Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: A repeated cross-sectional survey. *The Lancet, 380*(9845), 908–915. doi:10.1016/S0140-6736(12)61034-4

Polit, D. F., & Beck, C. T. (2006). The content validity index: Are you sure you know what's being reported? critique and recommendations. *Research in Nursing & Health, 29*. doi:10.1002/nur.20147

Polit, D. F., Beck, C. T., & Owen, S. V. (2007). Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. *Res Nurs Health, 30*(4), 459-467. doi:10.1002/nur.20199

Quill, T. E. (2015). Voluntary stopping of eating and drinking (VSED), physician-assisted death (PAD), or neither in the last stage of life? Both should be available as a last resort. *Annals of Family Medicine, 13*(5), 408–409.

Requena, P., & Andrade, A. D. S. (2018). Hastening death by voluntary stopping of eating and drinking. A new mode of assisted suicide? *Cuadernos de bioetica, 29*(97), 257-268.

Royal Dutch Medical Association (KNMG), & Dutch Nurses' Association (V&VN). (2014). Caring for people who consciously choose not to eat and drink so as to hasten the end of life. 51. Retrieved from https://www.knmg.nl/advies-richtlijnen/knmg-publicaties/publications-in-english.htm

Saladin, N., Schnepp, W., & Fringer, A. (2018). Voluntary stopping of eating and drinking (VSED) as an unknown challenge in a long-term care institution: an embedded single case study. *BMC Nurs, 17*, 39. doi:10.1186/s12912-018-0309-8

Sax, L. J., Gilmartin, S. K., & Bryant, A. N. (2003). Assessing Response Rates and Nonresponse Bias in Web and Paper Surveys. *Research in Higher Education, 44*(4), 409-432. doi:10.1023/a:1024232915870

Schmid, M., Zellweger, U., Bosshard, G., Bopp, M., & Swiss Medical End-Of-Life Decisions Study Group. (2016). Medical end-of-life decisions in Switzerland 2001 and 2013: Who is involved and how does the decision-making capacity of the patient impact? *Swiss medical weekly, 146*, w14307. doi:10.4414/smw.2016.14307

Schuler, M., Dessemontet, P., & Joye, D. (2005). Eidgenössische Volkszählung 2000 - Die Raumgliederung der Schweiz [Federal Population Census 2000 - The geographical levels of Switzerland]. Retrieved from https://www.bfs.admin.ch/bfs/de/home/grundlagen/raumgliederungen.assetdetail.342284.html

Shinjo, T., Morita, T., Kiuchi, D., Ikenaga, M., Abo, H., Maeda, S., . . . Kizawa, Y. (2017). Japanese physicians' experiences of terminally ill patients voluntarily stopping eating and drinking: a national survey. *BMJ Support Palliat Care*. doi:10.1136/bmjspcare-2017-001426

Simon, A. (2018). Pro: Freiwilliger Verzicht auf Nahrung und Flüssigkeit als Suizid? [Pro: Voluntary stopping of eating and drinking as suicide?]. *Zeitschrift für Palliativmedizin, 19*(01), 10-11. doi:10.1055/s-0043-124169

Simon, A., & Hoekstra, N. L. (2015). Sterbefasten - Hilfe im oder Hilfe zum Sterben? [Voluntary stopping of eating and drinking - help with dying of help to die?]. *Dtsch Med Wochenschr, 140*(14), 1100–1102. doi:10.1055/s-0041-102835

Stängle, S., Schnepp, W., Büche, D., Häuptle, C., & Fringer, A. (2019). Pflegewissenschaftliche Erkenntnisse über die Betroffenen, den Verlauf und der Begleitung beim freiwilligen Verzicht auf Nahrung und Flüssigkeit aus einer standardisierten schweizerischen Gesundheitsbefragung. [Nursing findings on the affected persons, the course and the accompaniment of voluntary stopping of eating and drinking from a standardized Swiss health survey]. *ZfmE, 65*(3), 237-248. doi:10.14623/zfme.2019.3.237-248

Stängle, S., Schnepp, W., & Fringer, A. (2019). The need to distinguish between different forms of oral nutrition refusal and different forms of voluntary stopping of eating and drinking. *Palliative Care and Social Practice, 13*. doi:10.1177/1178224219875738

Stängle, S., Schnepp, W., Mezger, M., Büche, D., & Fringer, A. (2018). Voluntary Stopping of Eating and Drinking in Switzerland From Different Points of View: Protocol for a Mixed-Methods Study. *JMIR Res Protoc, 7*(12), e10358. doi:10.2196/10358

Stängle, S., Schnepp, W., Mezger, M., Büche, D., & Fringer, A. (2019). Development of a Questionnaire to Determine Incidence and Attitudes to "Voluntary Stopping of Eating and Drinking". *SAGE Open Nursing, 5*. doi:10.1177/2377960818812356

Swiss Academy of Medical Sciences (SAMS). (2018). Management of dying and death. 32. Retrieved from https://www.samw.ch/en/Ethics/Ethics-in-end-of-life-care/Guidelines-management-dying-death.html

van der Heide, A., Brinkman-Stoppelenburg, A., van Delden, H., & Onwuteaka-Philipsen, B. D. (2012). Sterfgevallenonderzoek 2010: Euthanasie en andere medische beslissingen rond het levenseinde. *Reeks evaluatie regelgeving: deel, 31*.

Volkert, D., Chourdakis, M., Faxen-Irving, G., Fruhwald, T., Landi, F., Suominen, M. H., . . . Schneider, S. M. (2015). ESPEN guidelines on nutrition in dementia. *Clin Nutr, 34*(6), 1052-1073. doi:10.1016/j.clnu.2015.09.004

Wiler, J. (2019). EXIT hat mehr leidende Menschen begleitet [EXIT has accompanied more suffering people]. Retrieved from https://exit.ch/news/news/details/exit-hat-mehr-leidende-menschen-begleitet/

Table 1: Characteristics of participants

N	535
Age (in years) (24 missings)	52(8) (Range: 26 – 87)
- < 30 years	6 (1.2%)
- 30 – 39 years	48 (9.4%)
- 40 – 49 years	107 (20.9%)
- 50 – 59 years	287 (56.2%)
- ≥ 60 years	63 (12.3%)
Gender (16 missings)	
- male	210 (40.5%)
- female	309 (59.5%)
Profession (0 missings)	
- Head nurse	84 (15.7%)
- Institute director	283 (52.9%)
- Nursing director	168 (31.4%)
Competence level in Palliative Care (20 missings)	
- Level A1 (1- 2 ECTS)	58 (11.3%)
- Level A2 (2- 3 ECTS)	94 (18.3%)
- Level B1 (5- 6 ECTS)	71 (13.8%)
- Level B2 (17- 18 ECTS)	37 (7.2%)
- Level C (60- 180 ECTS)	11 (2.1%)
- No additional qualification in Palliative Care	244 (47.4%)
Work experiences (20 missings)	28(10) (Range: 1 – 49)
- < 10 years	31 (6.0%)
- 10 – 19 years	75 (14.6%)
- 20 – 29 years	139 (27.0%)
- 30 – 39 years	208 (40.4%)
- 40 – 49 years	62 (12.0%)

Table 2: Nurses´ attitudes and stance towards VSED

Attitudes (A) and stance (S) towards VSED		**Strongly disagree**	**Disagree somewhat**	**Neutral**	**Agree somewhat**	**Strongly agree**
	Coding / Mean(SD)	1	2	3	4	5
(A) Compatible with world view or religion	*n*=532 4.5(1.0)	17 3.2%	19 3.6%	35 6.6%	78 14.7%	**383** **72.0%**
(S) Contradicts culture of institution/professional ethics	*n*=532 1.7(1.1)	**307** **57.7%**	118 22.2%	66 12.4%	23 4.3%	18 3.4%
(S) Determination of the patient's ability to judge	*n*=534 4.2(1.2)	26 4.9%	30 5.6%	63 11.8%	103 19.3%	**312** **58.4%**
(S) Entitled to medical and nursing care	*n*=530 4.9(0.5)	4 0.8%	1 0.2%	4 0.8%	34 6.4%	**487** **91.9%**
(S) Accept decision	*n*=530 4.7(0.6)	4 0.8%	2 0.4%	20 3.8%	76 14.3%	**428** **80.8%**
(S) Respect decision	*n*=533 4.8(0.5)	2 0.4%	1 0.2%	13 2.4%	52 9.8%	**465** **87.2%**
		No	**Yes**	**-**	**-**	**-**
(A) Option for yourself	*n*=530 1.7(0.4)	145 27.4%	**385** **72.6%**	-	-	-
(S) Recommend VSED	*n*=521 1.3(0.5)	**349** **67.0%**	172 33.0%	-	-	-
(S) Care for a patient during VSED	*n*=529 1.9(0.3)	36 6.8%	**493** **93.2%**	-	-	-
During VSED support		**Strongly disagree**	**Disagree somewhat**	**Neutral**	**Agree somewhat**	**Strongly agree**
(A) Having moral doubts	*n*=529 1.9(1.2)	**271** **51.2%**	123 23.3%	68 12.9%	37 7.0%	30 5.7%
(A) Worthy culture of dying	*n*=528 4.0(1.1)	22 4.2%	39 7.4%	92 17.4%	148 28.0%	**227** **43.0%**
(S) Professionals are burdened	*n*=532 3.5(1.1)	25 4.7%	57 10.7%	**191** **35.9%**	139 26.1%	120 22.6%
(S) Relatives are burdened	*n*=531 4.1(0.9)	6 1.1%	15 2.8%	110 20.7%	180 33.9%	**220** **41.4%**
(S) Relatives have trouble accepting the decision	*n*=528 3.8(0.9)	5 0.9%	26 4.9%	172 32.6%	**195** **36.9%**	130 24.6%

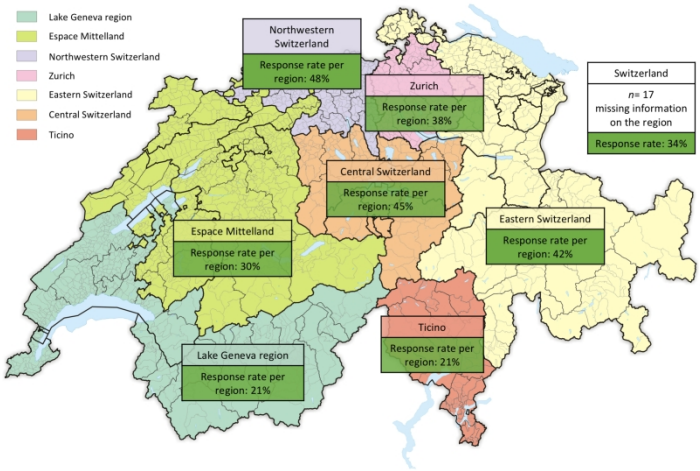

Figure 1: Response rate of long-term care facilities in the seven regions of Switzerland
Source: Map of Tschubby (2019), with information on long-term care provided by the authors.

Figure 2: Classification of VSED by nurses

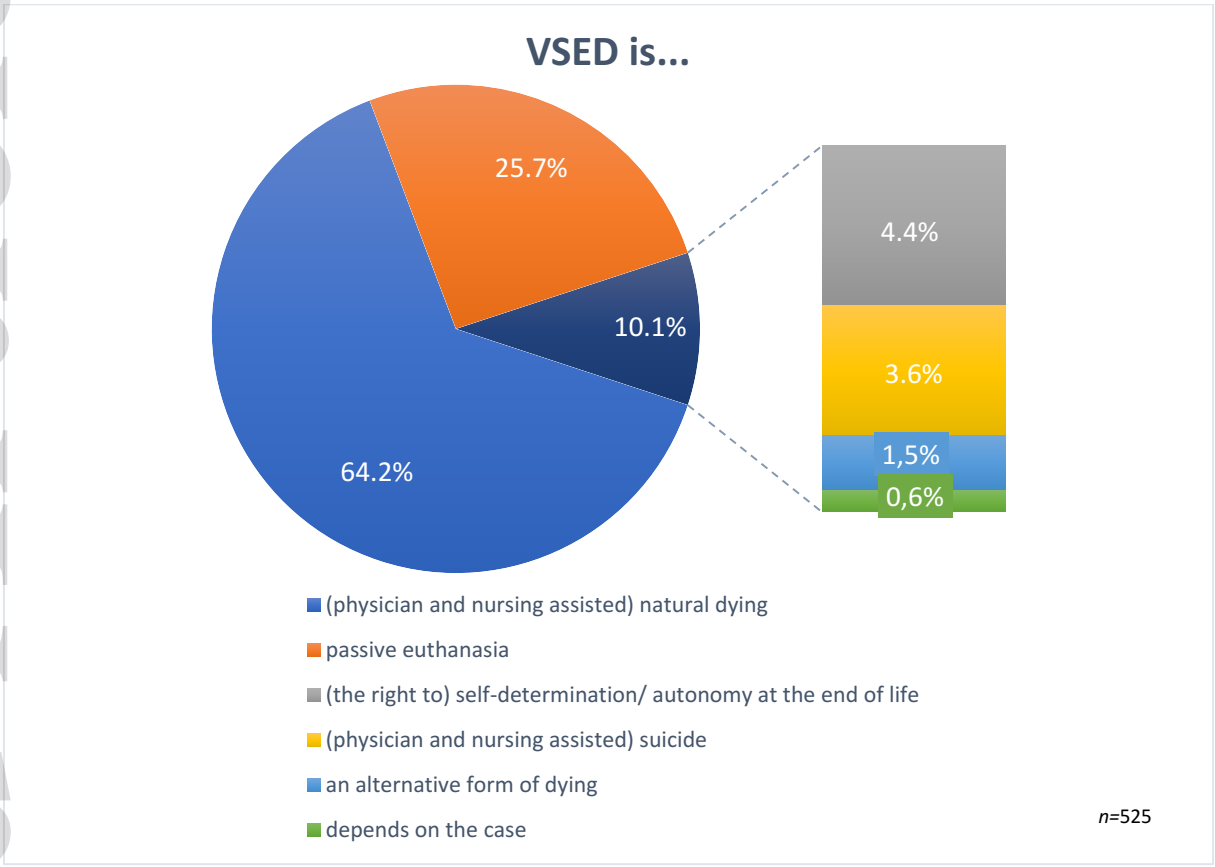

Figure 3: Participants' assumptions about the different forms of food renunciation depending on the age of the person willing to die.