

Voluntary Stopping of Eating and Drinking (VSED) in Switzerland



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Research Group & Published Articles

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Published Articles on VSED:

- 7 peer-reviewed articles¹⁻⁷
- 9 non peer-reviewed articles⁸⁻¹⁶
- 1 book¹⁷, 2 book chapters^{18,19}
- 5 newspaper articles²⁰⁻²⁴
- 1 television report²⁵
- „Uncountable“ public presentations

Upcoming Peer-Reviewed Articles:

- 3 about VARIED
- 1 about FIVE (Fokus Group Interviews Study)
- 1 about 18 Cases of Relatives
- 1 about Experiences of Palliative Experts

Background, Definition & Objectives

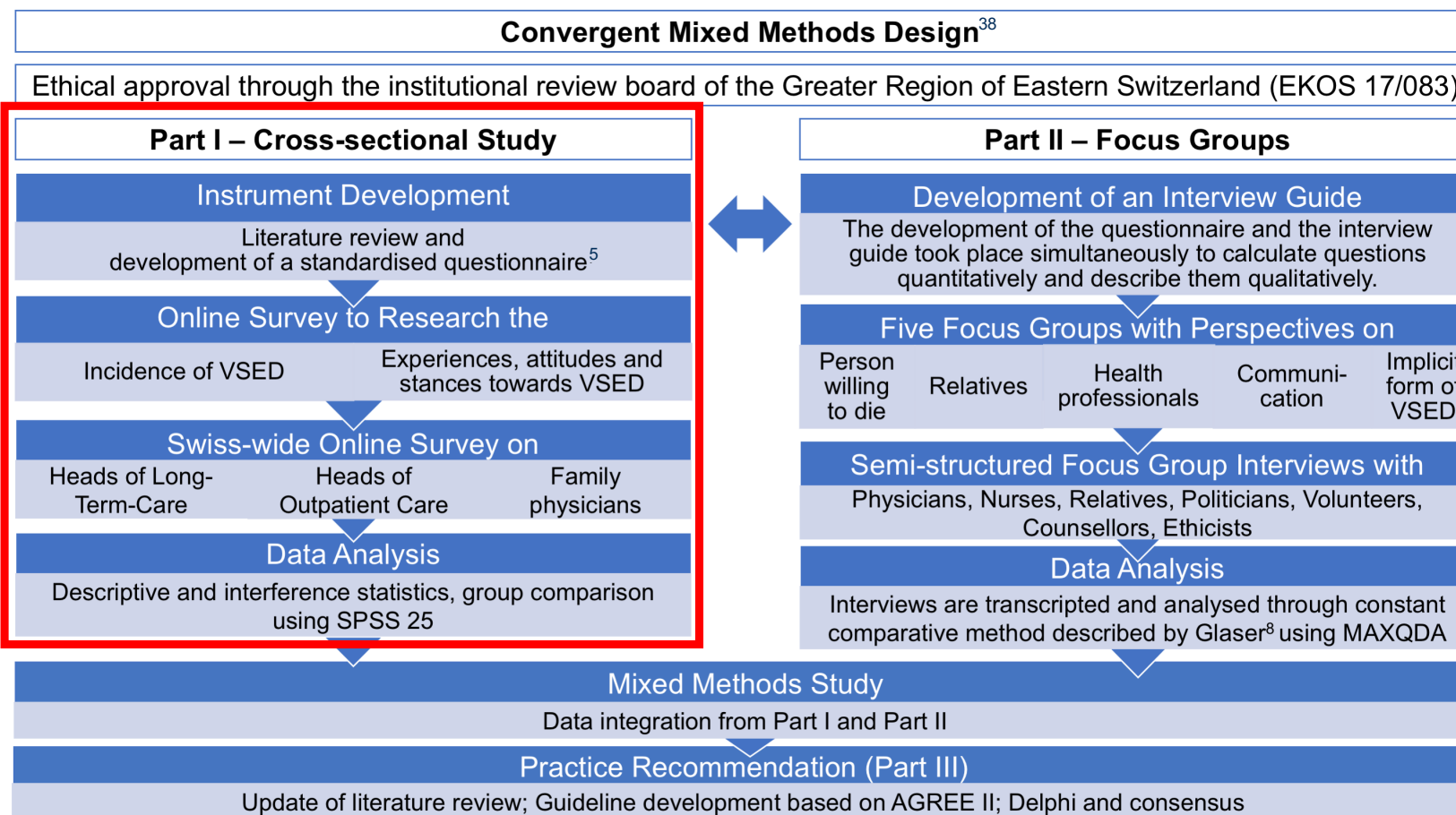
Background:

- “Voluntary Stopping of Eating and Drinking”, short VSED, has become a relevant phenomenon in decision making at the end-of-life^{14,26-30}
- Various forms of VSED have been identified, including the explicit and implicit forms⁶
- Incidence of VSED has only been studied in the Netherlands and is between 0.4% and 2.1%^{31,32}
- VSED is included in the SAMS guideline "Management of dying and death" since 2018 as a controversially discussed action at the end-of-life³³
- Still lack of empirical research^{2,4}

Definition: VSED is described as an act that is voluntarily and consciously chosen by a decent person without cognitive restrictions, to refuse to eat and drink with the intention to end one's life prematurely.^{1,2, 26-28, 34-37}

Objectives: To assess the incidence of VSED through heads of outpatient and long-term care & family physicians, and to evaluate the experiences, attitudes, and the professional stance of health care professionals towards VSED.

Overall Study Design



Study Design & Methods– Part I



Study Registration: DERR1-10.2196/10358³

Design: A cross-sectional online-survey

Instrument: Development of an evidence-based standardized questionnaire on VSED in German, French and Italian, including validation and pretest⁵.

Ethical consideration: EKOS 17/083 (May 2017)

Data collection:

- Online-Survey using Questback (EFS Survey)
- Paper-pencil survey using EvaSys
- Recruitment and two reminders by email invitation or by post, sent by professional associations

Data analysis:

- Descriptive data analysis & group comparison (e.g. age, profession) using SPSS 25.0

Setting & Participants ($n = 1,681/40\%$):

- Heads of **Outpatient Care** (Jan - Aug 2017):
 - Population $N = 1,616$
 - Recruitment through Spitex³⁹, ASPSP⁴⁰ and CURACASA⁴¹
 - Response $n = 395$ (24%)
- Heads of **Long-Term Care** (Jun - Oct 2017)
 - Population $N = 1,562$
 - Recruitment through CURAVIVA⁴²
 - Response $n = 535$ (34%)
- **Family physicians** (Aug 2017 - Jul 2018):
 - Population $N = 1,013$
 - Recruitment through FMH⁴³
 - Response $n = 751$ (74%)

Results of VSED in Long-Term Care⁷

Incidence* of VSED in Long-Term Care:

- The incidence of VSED in Switzerland is 0.7%, and for all deaths in long-term care facilities the incidence is 1.7%.

Classification of VSED:

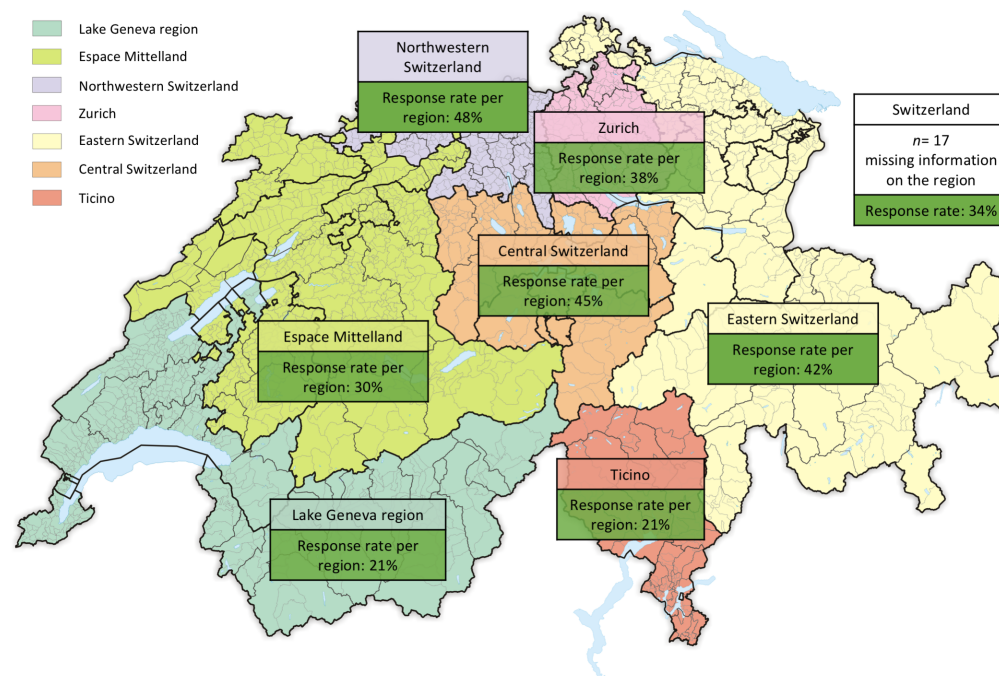
- Most (64%) nurses classify VSED as a natural dying, a quarter (26%) as passive euthanasia, other classifications are: self-determination at the end-of-life, suicide, or an alternative form of dying.

Supporting a Person During VSED:

- Having moral doubts: yes = 26%, no = 74%
- Patients have the right to medical and nursing care: yes = 99%, no = 1%
- Professionals are burdened: yes = 85%, no = 15%
- I would care for a patient: yes = 93%, no = 7%

*Calculation of the Incidence:

In 2016, 64,964 people died in Switzerland, while 41% ($\approx 26\,635$ deaths) of all people in Switzerland die in nursing homes.



Response rate of long-term care setting according to the seven major regions of Switzerland

Source: Stängle et al. 2019⁷: Map of Tschubby⁴⁴, with information on long-term care provided by the authors.

SABRINA STÄNGLE/WILFRIED SCHNEPP/DANIEL BÖCHE/
CHRISTIAN HÄUPTLE/ANDRÉ FRINGER

Pflegewissenschaftliche Erkenntnisse über die Betroffenen, den Verlauf und die Begleitung beim freiwilligen Verzicht auf Nahrung und Flüssigkeit aus einer standardisierten schweizerischen Gesundheitsbefragung

Results about VSED-Cases in Switzerland¹⁴

Background:

Embedded in the VSED survey, we asked the participants to describe their experiences with their last or most memorable VSED-Case

Intermediate Result:

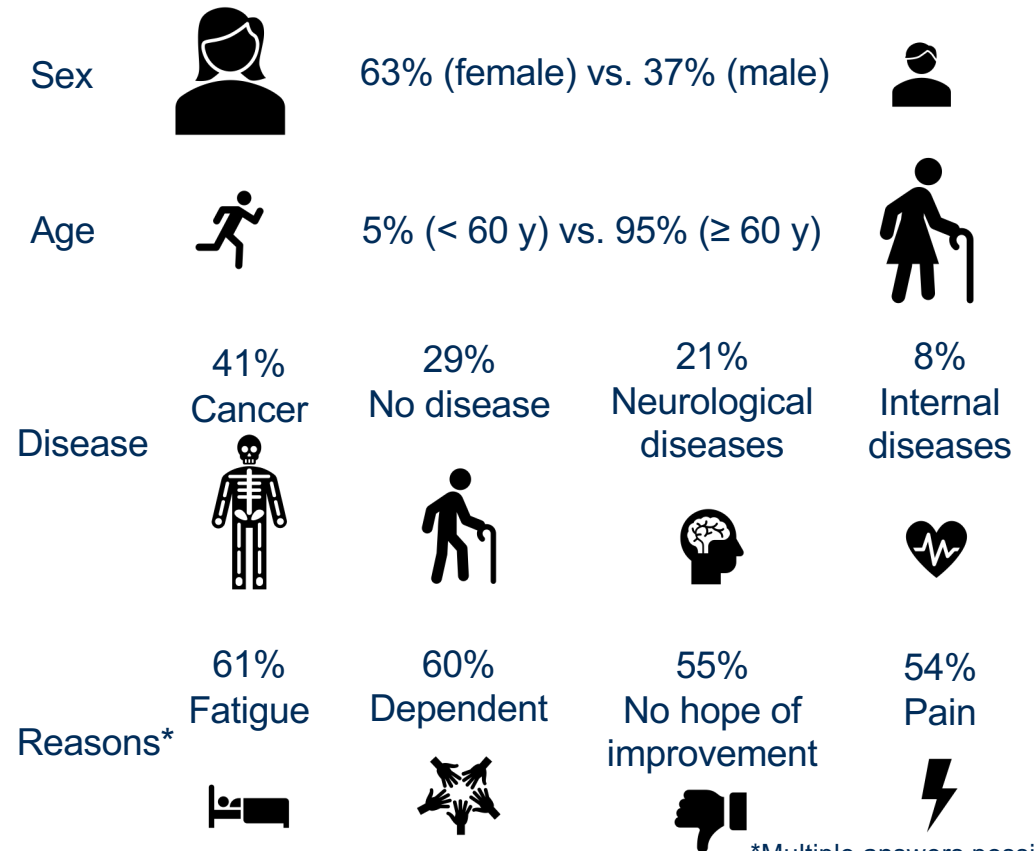
Of all 1,681 participants in the VSED survey, a total of 728 (43%) have already accompanied at least one person during VSED.

Sample:

Of these, 627 participants were willing to report on their last or most memorable VSED case:

- $n = 270$ family physicians (43.1%)
- $n = 166$ heads of outpatient care (26.4%)
- $n = 191$ heads of long-term care (29.9%)

Results about the VSED cases:



*Multiple answers possible

Lessons Learned & Next Steps

Lessons Learned:

- The spirit breaks the body and afterwards the body break the spirit
- VSED is not an isolated case in Switzerland either^{28,45}
- Despite moral concerns, almost everyone finds that individuals have the right to professional care during VSED²⁷
- But, only half of the participants feel familiar with the topic and 15% are not aware of it, so further education and training are necessary

Next Steps:

- Development of a practice recommendation (Part III) to accompany a person during VSED
- Information brochures and counselling services for patients and their relatives
- Qualitative research to develop a VSED theory (Grounded Theory)

Thank you

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- Curacasa
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