

Development of a Questionnaire to Determine Incidence and Attitudes to “Voluntary Stopping of Eating and Drinking”

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Abstract

Background: “Voluntary stopping of eating and drinking” (VSED) is an option to hasten death at the end of life. There are no data available about incidence of either the explicit VSED or implicit (V)SED nor information about experiences and attitudes of health professionals about VSED in Switzerland.

Aims: To develop, test, and translate a standardized questionnaire that measures the incidence of VSED, and physicians’ and nurses’ experiences about explicit VSED and implicit (V)SED.

Methods: The development of the questionnaire was based on a systematic search, which were updated in 2016. The questionnaire was tested by palliative care specialists using standard pretest and content validity index (CVI). Subsequently, a forward/backward translation was made.

Results: The questionnaire includes 38 items. Feedback of 15 participants in the standard pretest were positive in terms of intelligibility with an average time of 28 minutes. After adjustment, 27 experts validated the items in two rounds. The questionnaire achieves excellent item-CVI values between 0.91 and 1.00 and scale-CVI values of 0.97. The forward/backward translations were each carried out by two independent translators with subsequent building of a consensus through a consultant.

Conclusion: A multilingual questionnaire has been developed, which measures the incidence of explicit VSED and implicit (V)SED. This questionnaire is the basis for a Swiss-wide census of all physicians and nurses of outpatient and long-term care.

Keywords

voluntary stopping of eating and drinking, questionnaire, standard pretest, content validity, forward/backward translation

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Introduction

People wish to live and die with dignity. In Western societies, dignity is closely linked to autonomy and control over one’s own body. While autonomy requires self-determined medical decisions, control refers to the functionality of the body. Loss of autonomy or control directly affects the perceived dignity of a person (Birnbacher, 2015; Chabot & Goedhart, 2009; Sullivan, 2016). If current or future suffering due to degenerative disease is too high, some develop the desire to hasten death (Rodriguez-Prat, Monforte-Royo, Porta-Sales, Escribano, & Balaguer, 2016).

Review of Literature

In Switzerland, terminally ill people can choose physician-assisted suicide through the organizations EXIT (2016) and DIGNITAS (2016). Physicians and

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outpatient and long-term care nurses (Bolt, Hagens, Willems, & Onwuteaka-Philipsen, 2015; Ganzini et al., 2003; Hoekstra, Strack, & Simon, 2015; Shinjo et al., 2017) were asked about other options to end one's life prematurely. One option is through "voluntary stopping of eating and drinking" (VSED). This method occurs when a capable and informed person deliberately stops oral intake with the intention of shortening their lifespan (Haller, 2014; Klein Remane & Fringer, 2013), saving themselves from unacceptable suffering (Black & Csikai, 2015; Cavanagh, 2014; Ivanović, Büche, & Fringer, 2014; Pope & West, 2014). During the dying process caused or accelerated through VSED, which can take up to 3 weeks (Bolt et al., 2015; Chabot, 2012; Ganzini et al., 2003; Ivanović et al., 2014; Klein Remane & Fringer, 2013; Lachman, 2015; Quill, Lee, & Nunn, 2000; Simon & Hoekstra, 2015), the patient is dependent on help from relatives, as well as medical and nursing support (Bolt et al., 2015; Klein Remane & Fringer, 2013; Lachman, 2015). While medical treatment is particularly dedicated to symptom management (Bickhardt & Hanke, 2014; Bolt et al., 2015; Lachman, 2015; Pope & West, 2014), attentive nursing care is needed to prevent further suffering, such as oral care or decubitus prophylaxis (Bernat, Gert, & Mogielnicki, 1993; Haller, 2014; Klein Remane & Fringer, 2013; Lachman, 2015). Studies have shown that VSED largely takes place at home (52%) or retirement homes (42%; Bolt et al., 2015) and are often accompanied by physicians (Hoekstra et al., 2015). Surveys in the Netherlands (Bolt et al., 2015) and Germany (Hoekstra et al., 2015) have shown that between 46% and 62% of physicians have accompanied at least one patient during VSED. Therefore, the practice of VSED is not isolated (Hoekstra et al., 2015). Given the need for medical and nursing support during VSED, it is of interest to sample the rate of VSED in Switzerland, to assess current attitudes of physicians, and to determine if there is a need for education.

While VSED begins with a clearly worded desire of death, some patients exhibit an unspoken or implicit refusal of oral intake, called (V)SED (Fehn & Fringer, 2017). In that case, the person cannot or does not want to communicate their intention to die. It is, however, unclear whether health professionals understand the causes (Athlin & Norberg, 1993). There is a risk of forced eating or presuming that the person wishes to die, which may not be the case (Fehn & Fringer, 2017). Whether there is a need for further education on the different forms of VSED can only be assessed with an accurate survey of explicit VSED and implicit (V)SED in Switzerland. A detailed assessment would reveal attitudes and experiences that health professionals have had with VSED patients. Currently, there are no empirical data.

The aim of this study is to develop, test, and translate a standardized questionnaire that explores the incidence

of VSED and, in future studies, to evaluate physician and nurse attitudes and experiences about explicit VSED and implicit (V)SED.

Methods

Development of a Questionnaire

According to the research protocol (Stängle, Schnepf, Mezger, Büche, & Fringer, 2018), the researchers developed a questionnaire guided by Colton and Covert (2007). A literature search was conducted, based on the search strategy of the systematic review of Ivanović et al. (2014), and was carried out between March 2013 and February 2016 in the databases: PubMed, EBSCOhost CINAHL, Ovid PsycINFO, and an open literature search on the Internet. All articles relating to the topic of VSED, food refusal, and eating disorders were included, while articles that included people with reduced capacity, such as dementia, were excluded.

Psychometric Testing

Following a literature review, the generated items and scaling responses were tested using a standard pretest (Colton & Covert, 2007).

The validity, also referred to as measurement accuracy, ensures that an instrument elevates what it is supposed to collect (Colton & Covert, 2007). Adapted changes were further tested using a content validity index (CVI; Polit & Beck, 2006; Polit, Beck, & Owen, 2007).

Sample

In the standard pretest, 15 participants took part, included academic nurses, nurse practitioners, and nursing students. Through an e-mail link, the participants were redirected to the online survey. Their task was to check the questionnaire for intelligibility and manageability. If items were not understood or there was uncertainty, they could write a pretest comment.

In the CVI, a total of 27 experts from 3 countries (Germany, Netherlands, and Switzerland) were recruited. The participants were between 27 and 69 years old (mean 46) and 70.4% female. The participants have professional qualifications in medicine, nursing, and other health-related professions. The professional experiences were between 4 and 41 years (mean 27).

Institutional Review Board

The present investigation is neither a clinical trial nor an observational study of vulnerable groups. Thus, no personally identifiable information was collected. Participation was voluntary, and participants had

irreversible anonymity. There were no disadvantages in refusing to participate in the survey. With a letter (via e-mail, cover letter, or information on a web page), the participants were informed in detail of the aim and purpose of the study, as well as the use of the generated data and their personal rights. This ethical approach is based on the principles of the “Declaration of Helsinki” and “informed consent.” Anonymity and respect for human dignity was guaranteed at all times during the research process. Drawing conclusions about the respondents will not be possible at any time (Groves et al., 2009).

Statistical Analysis

The standard pretest (Colton & Covert, 2007) was carried out using the Questback online survey software (EFS Survey 10.9). The received pretest comments were inserted into a table and sorted for intelligibility and manageability. In a comment field, the changes were described, or nonchanges justified.

For CVI, a survey was generated using Questback. The participants of the validation process were given the task of checking the items for intelligibility, comprehensibility, and completeness. All three subcategories were calculated individually and were then equally balanced in the calculation of the item-CVI (I-CVI). Each item was assessed by all three points with a

nominal scale of *agree*, *do not know*, or *disagree*, and comments could be left in response fields. For this purpose, the response options *do not know* and *disagree* were added together, as disagreement. The assessment of the relevance of an item was required (Polit et al., 2007), which was fulfilled assessing the completeness (Brosius, Haas, & Koschel, 2016). To ensure that participation did not rely on familiarity with VSED, the intelligibility and comprehensibility were assessed (Figure 1).

To evaluate the likelihood of the math in the interrater, agreement of the items to calculate a modified kappa statistic was additionally provided (Polit et al., 2007). For obtaining information of the entire survey, the scale-CVI/average method (S-CVI/Ave) was calculated (Polit & Beck, 2006; Polit et al., 2007). Items related to participant experience values have only been validated by experts who are familiar with the phenomenon of VSED.

Translation of the Questionnaire

Due to the four national languages (German, French, Italian, and Romansh) in Switzerland, a translation of the survey was necessary. Because Romansh is spoken by only 0.5% of the population, and German is usually spoken in addition to their mother tongue, this translation was not made (Schweizerische Eidgenossenschaft,

Item 15: Which of the following opinions regarding explicit VSED do you agree with?			
<input type="radio"/>	(a)	The explicit VSED is to be equated with medically assisted suicide.	
<input type="radio"/>	(b)	The explicit VSED is to be equated with “leaving to die”.	
<input type="radio"/>	(c)	The explicit VSED is a natural death along with medical and nursing support.	
<input type="radio"/>	(d)	Other, namely _____	
Please assess the item regarding intelligibility, comprehensibility and completeness.			
	Agree	Do not know	Disagree
Intelligibility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comprehensibility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Completeness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Please justify your statement here, what you can not understand, is incomplete or not understandable.			
<input type="text"/>			

Figure 1. Item for assessing the content validity of the questionnaire.
VSED = Voluntary Stopping of Eating and Drinking.

2017). The questionnaire was developed in German and translated into French, Italian, and English (for publication). A forward/backward translation process was used (Acquadro, Conway, GirouDET, & Mear, 2012). The aim of the process was to design an equivalent questionnaire in the target language considering linguistic aspects. Through this process, the data from all languages can be evaluated together in the data analysis (Acquadro et al., 2012; Mahler & Reuschenbach, 2011).

Results

The literature search included 245 articles written in English and German screened and reviewed by S. S. and A. F. In the end, 35 articles were deemed relevant. A total of 41 questions were developed, based on Porst (2000). Response alternatives were constructed as a 5-point Likert scale (Likert, 1932). The score for an item was either 1 (*never*), 2 (*rarely*), 3 (*occasionally*), 4 (*often*), and 5 (*very often*) in the affirmative, or 1 (*strongly disagree*), 2 (*disagree somewhat*), 3 (*neutral*), 4 (*agree somewhat*), and 5 (*strongly agree*) in the negative. Last, there was a section with sociodemographic items including age, gender, profession, work setting, and work experiences.

Reduction and Modification of the Questionnaire

The feedback from the participants confirmed intelligibility and manageability of the questionnaire. Two items were redundant and therefore deleted. A definition on VSED, and about the implicit form of (V)SED, was inserted at the beginning of the questionnaire to ensure a mutual understanding for participants. Terms were modified (e.g., from *problems* into *challenges*) to avoid misunderstanding. After appropriate adaption of the questionnaire, content validation was carried out.

A total of 121 comments were submitted, most (68%) resulted in slight changes to the questionnaire. First, the comments could be mapped into five categories and then the following changes were made: 26 clarifications ($n=28$), 6 spelling/grammar ($n=6$), 13 additions ($n=30$), 15 notes ($n=28$), and 22 understanding ($n=29$). Some comments were not included because they were not relevant to the concept of VSED. As can be seen in Supplemental file 1, all items already achieved high I-CVI values ≥ 0.86 in the first round. Based on the comments of the experts, Item 11 was deleted due to redundancy. Two items (1 and 8) were fundamentally revised and presented again to the participating experts for validation. Eleven experts were recruited for the second round, at which time all I-CVI values were ≥ 0.90 , with an S-CVI/Ave of 0.97, which is also excellent. Thus, the development of the German questionnaire was completed.

Development of Four Identical Questionnaires in Different Languages

For each target language, two translators independently translated the questionnaire, which is also called forward translation. While one translator works in a medical or nursing context (informed), the other translator is not familiar in this context, but mother tongue in the target language (uninformed). This has the advantage that the professional language is used and at the same time understood by all professional groups, regardless of whether one is familiar with the topic of VSED or not. For each target language, both forward translations were analyzed and reconciled by a consultant. Unclearness was discussed between the responsible main authors (S. S. and A. F.) to the point of consensus. Subsequently, the backward translation and international harmonization took place, also with two translators (informed and uninformed) each. In addition to translating the questionnaire back into German, the task of the translators was to check the consensus regarding syntactic and semantic coherence as well as the usability of words in the context of health care. Both results from the backward translation and the international harmonization were again analyzed, discussed, and modified by a consultant and, if necessary, consulted by S. S. and A. F. Finally, the questionnaires were completed by proof-reading. The development of equivalent questionnaires into the target languages of French, Italian, and English was completed. A graphical representation of the translation process from German into French and Italian is shown in Figure 2. Furthermore, the English version of the questionnaire is included.

Discussion

The aim of the current study was to develop and test a German-language evidence-based questionnaire for exploration of the phenomena of VSED and (V)SED and to translate the questionnaire into French and Italian for nationwide use in Switzerland. It was essential to develop a questionnaire that was understandable by all involved professions (e.g., general practitioners, ambulant care services, and long-term institutions). The interdisciplinary cooperation of different groups of professions in health care is of central importance (Kränzle, 2014). There was great care in developing the questionnaire for all health-care providers and to find similarities and differences between the disciplines. However, the interdisciplinary audience poses a major challenge to the development because each profession differs in thinking process and language expression (Hollaender, 2003). Given that different professions use a different vernacular, it was vital to use language that was interpreted identically by all. Through the test

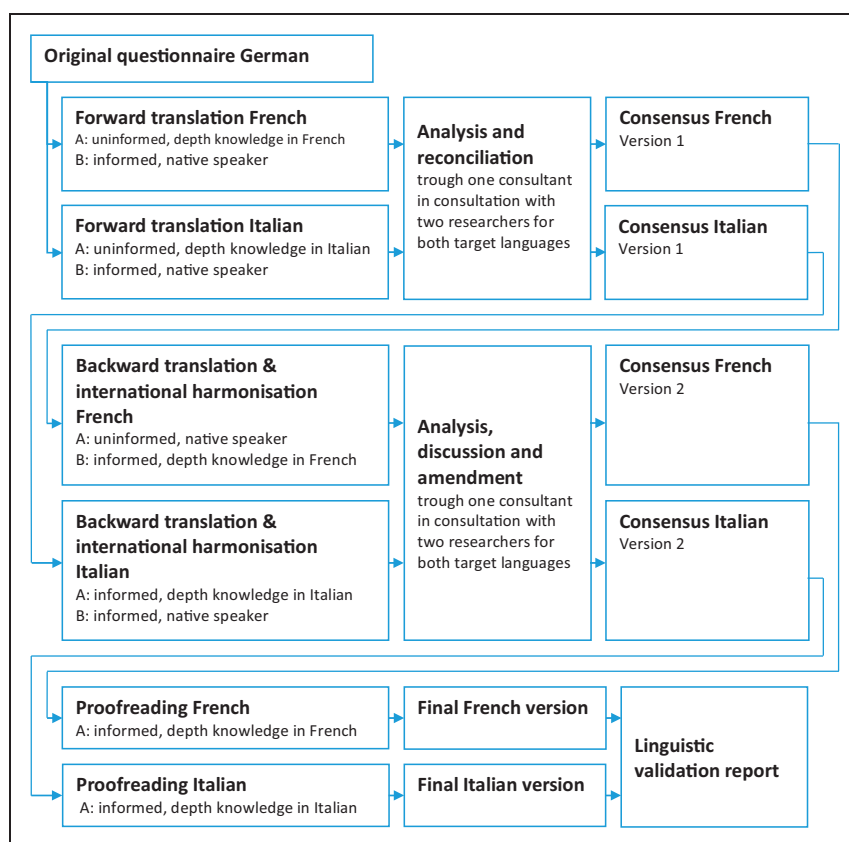


Figure 2. Diagram of translation process (Acquadro et al., 2012).

phases, in which experts and nonexperts in the target population checked the items, general comprehensibility of the questionnaire was achieved.

Strengths and Limitations

In comparison with previous surveys on the topic of VSED (Bolt et al., 2015; Chabot & Goedhart, 2009; Ganzini et al., 2002, 2003; Harvath et al., 2004; Hoekstra et al., 2015), for the first time, a questionnaire was developed and described according to content validity. Nevertheless, we wanted comparability between previous surveys and the results of the upcoming countrywide survey. Therefore, the development of the questionnaire was based on previous approaches. There are no standardized questionnaires that have been tested for validity and objectivity for explicit VSED and implicit (V)SED. The test and translation methods used in this study are established methods in nursing science. A further strength of this work is that, in addition to the target languages German, French, and Italian, the questionnaire has also been translated into English with the same scientific precision. This enables the English-speaking scientific community use of the instrument.

Conclusion

We have developed a multilingual questionnaire that surveys the incidence and attitudes toward explicit VSED and implicit (V)SED by health professionals. It assesses how prepared and willing health professionals are to assist patients with their choice. The instrument will be distributed to all physicians and nurses in outpatient and long-term care across Switzerland. With results from the survey, rates of VSED in Switzerland can be compared with the Netherlands (Bolt et al., 2015; Chabot & Goedhart, 2009) and Germany (Hoekstra et al., 2015), where VSED is a relevant issue. If it is high in Switzerland, health professionals, institutions, and the health-care system can discuss appropriate VSED patient care.

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Author Contributions

S. S. and A. F. conceptualized and designed the study. A. F. is responsible for the study, project management, and funding.

S. S. is major contributor in writing the article. M. M. is responsible for the ethical analysis of VSED. M. M., D. B., W. S., and A. F. have revised the article. All authors read and approved the final article.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Supplemental Material

Supplemental material for this article is available online. All data generated or analyzed during this study are included in this published article. The English version of the questionnaire is attached to this article (Supplemental file 2).

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