Frequency and prevalence of VSED in Switzerland:
Development, testing, and translation of a questionnaire

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Background

Autonomy and dignity are a great good for all people at all times and especially at the end of life. „Voluntary Stopping of Eating and Drinking“ (VSED) represents a serious alternative to assisted suicide for death fasting10. There are no data available about prevalence and frequency of either the explicit VSED nor the implicit reduction of food and liquid in Switzerland.

Aims

(a) The development of an evidence-based questionnaire about the phenomenon of VSED in Switzerland, i.e. a nation-wide exploration of general practitioners, home care services, and long-term facilities. (b) The performing of a standard pretest and (c) to proof content validity. (d) At least a scientific forward-backward translation process into French and Italian were conducted.

Method

The development of the questionnaire was based on a systematic search and review11, which were updated in 2016. The questionnaire was tested by Palliative Care Specialists using standard pretest and (c) to proof content validity. At least a scientific forward-backward translation process into French and Italian were conducted.

Results

The questionnaire includes 38 Items. The feedback of the 15 participants of the standard pretest were positive in terms of intelligibility with an average processing time of almost 28 minutes. After adjustment of the questionnaire 27 experts validated the items in two rounds on linguistic clarity, content comprehensibility and completeness. Overall, the questionnaire achieves excellent I-CVI values, i.e. between 0.91 to 1.00 and S-CVI values of 0.97. The forward and backward translation was carried out by two independent translators. In each case one was a medical and health expert (informed) while the other one was not (uninformed) (see Figure 1). Subsequently, the consensus was prepared by consultant and was completed with proofreading.

First results of the questionnaire with 35 experts in palliative care show that VSED is relevant (67.5%) in professional life and will increase (73%) in the future. Most participants know about VSED (81.2%) but only half of them (45.5%) is familiar with it. While VSED can occur in any age, there is a tendency, that people between 66-75 years (13.2%) and in particular from 75 years (52.6%) implicitly reduce and stop the intake of food and liquid, without talking about it (see Figure 2).

Conclusion

The high participation in the standard pretest and validation process confirms the importance of the phenomenon of VSED. The excellent I-CVI values indicate a large agreement between the literature and the experts’ experiences in VSED. Overall, very good values in content validity could be demonstrated. The scientific translation of the questionnaire is the foundation of a nationwide survey of the phenomenon in Switzerland. The results of the first pilot show a tendency and a first descriptive confirmation that there is a big gap between the prevalence of VSED and the knowledge about it. Our hypotheses have been tentatively strengthened that VSED could be seen as an deliberate option for people in any age while particular older people stop the intake of food and liquid spontaneously and without talking about it so as to naturally end their life.

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Literatur