

## Peer Review Report

# Review Report on Knowledge gaps in end-of-life care and planning options among older adults in Switzerland

Original Article, Int J Public Health

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### EVALUATION

#### **Q 1** Please summarize the main findings of the study.

This study investigates the knowledge of the elderly population (55+) in Switzerland about options and regulations in end-of-life care based on a knowledge scale in wave 6 of the Survey of Health, Ageing and Retirement in Europe in Switzerland with 2,199 respondents in this (sub)sample. The results show that knowledge tends to be limited, especially among people with lower levels of education and/or older people, men, and residents of the French- and Italian-speaking regions of Switzerland. The authors conclude that the various aspects of advanced directives and end-of-life care options need to be better communicated and explained to the general public.

#### **Q 2** Please highlight the limitations and strengths.

Strengths: representative sample; relevant research question with relevant policy implications

Limitations: 2 of the 8 items in the knowledge scale on end-of-life care (the 2 questions on palliative care) are ambiguous (neither clearly true nor false) and therefore not good items.

#### **Q 3** Please provide your detailed review report to the authors. The editors prefer to receive your review structured in major and minor comments. Please consider in your review the methods (statistical methods valid and correctly applied (e.g. sample size, choice of test), is the study replicable based on the method description?), results, data interpretation and references. If there are any objective errors, or if the conclusions are not supported, you should detail your concerns.

##### Major comments

The paper is well written, the focus clear and the topic highly relevant with respect for the future due to demographic change. The methods are appropriate except for the missing information on internal consistency of the used knowledge scale (see below). The discussion is consistent, adequate and the results well reflected against the existing literature. The conclusion is sound.

All in all I have only minor suggestions which you will find below. But to begin with, I have to admit that I have some problems with the two palliative care questions PC1 and PC2. "Palliative care means stopping all medical treatment and giving morphine to ensure a peaceful death." – From the perspective of a layperson, which most study participants are, would you really say that this statement is completely false? I know, this description is extremely narrow and highly reductive, but does that make it wrong? Concerning PC2: "Palliative care should start early in the disease course and can prolong life significantly." – I think this statement is misleading because the wording can give the impression that palliative care starts with any disease, which from my knowledge is definitely not true. Therefore, it is not surprising that so many answers are incorrect (in the definition of the authors) or answered with "Don't know". So, it sounds logic that you did not find significant associations with your explanatory variables. (line 162 f: "...knowledge regarding palliative care, which mostly displayed statistically insignificant associations with our set of explanatory variables." And, line 168 f: "Similarly, individuals from French-speaking Switzerland are more likely to give a correct answer to the statement "palliative care does not mean stopping all medical treatment and giving morphine to ensure a peaceful death (APE: 7.6,  $p < 0.1\%$ )" – Would you rule out the probability that this relationship and the given significance are random?

Did you calculate Cronbach's alpha of the Knowledge score? I suspect it won't be too high, as this is often the case with knowledge scales. Nevertheless, it would be good to know, and in particular, whether and how alpha would change if PC1 and/or PC2 would be deleted. I have a feeling that these items would be across.

#### Minor comments

In general:

Both, the terms "advance directive" and "advanced directive" are used, also in the SHARE-questionnaire. Is this by purpose, and if so, why? Is there any difference? If not I would suggest to harmonize this.

In detail:

I. 54 "advances directives" -> advanced ..

I. 124 "About one in four respondents appraised properly half of the statements (score=4)." I think I know what you mean but the sentence has potential for misunderstanding. For me it would make more sense to say "About every second respondent appraised properly at least half of the statements (score=4 and more)."

I. 130 AD = Advance directives --- AD not introduced

I. 147 f: suggestion: "the knowledge score is on average 0.4 points ( $p < 0.001$ ) higher among women compared to men." -> "the knowledge score is on average 0.4 points higher among women compared to men ( $p < 0.001$ )." In the following sentences the meaning seems clear then.

I. 168 f: "...are more likely to give a correct 169 answer to the statement "palliative care does not mean stopping all medical treatment and giving 170 morphine to ensure a peaceful death"..." - You changed the statement from the original wording in the questionnaire, but put it in quotation marks as it would be the original statement. This is a bit confusing. I would recommend sticking to the original statement and adjusting the text accordingly.

I. 187 ff: "...revealed that 82.3% of deaths in 2013 were preceded by at least one of the following EOL practices: forgoing life-prolonging treatment (49.3%); intensified alleviation of pain or symptoms (29.8%); physician-assisted death (euthanasia, assisted suicide, or ending of life without the patient's explicit request) (3.1%) (1)." - You are citing Schmid et al. who are probably using the term "euthanasia" in their paper. Since I do not know the context and their operationalisation of euthanasia in their article I would like to make you aware of one paper of Dierickx et al. (2020) <https://pubmed.ncbi.nlm.nih.gov/31297558/> who examined euthanasia by physicians in Switzerland, Belgium and the Netherlands. The paper shows that a significant number of physicians gives active support to die in Switzerland, although it is illegal. This was just drifting through my mind when I read it. You may ignore or use it; I know this is a bit far out of focus...

I. 264 "Lower knowledge of EOL care options in French- and Italian-speaking Switzerland" - This is an interesting point, and I understand that it is very difficult to find a satisfactory explanation for these regional differences. I am reading your discussion as a more culturally grounded one. You are arguing that these "attitudes may also act as barriers to communication and education...". But, from a public health perspective, couldn't it be the other way round, i.e., that public health and local authorities do not provide enough and sufficient information in French and Italian? Could it be kind of regional disadvantage in the Suisse health care system as a whole? Can you rule this out?

Table 2: "Patients with advanced dementia can make use of assisted suicide as long as they have clearly expressed this wish in their advance directive." - This is different from the item in the SHARE-questionnaire and the item in the footnote of table 3 where it is correct.

Table 3: The footnote is very overloaded. I would suggest to indicate the items AD1 to PC2 just with one or two keywords (e. g. AD1 "healthcare proxy") directly in the headline as the items themselves are fully presented in table 2.

#### PLEASE COMMENT

**Q 4** Is the title appropriate, concise, attractive?

Yes.

**Q 5** Are the keywords appropriate?

Yes.

**Q 6** Is the English language of sufficient quality?

Yes.

**Q 7** Is the quality of the figures and tables satisfactory?

Yes.

**Q 8** Does the reference list cover the relevant literature adequately and in an unbiased manner?)

Yes.

#### QUALITY ASSESSMENT

**Q 9** Originality



**Q 10** Rigor



**Q 11** Significance to the field



**Q 12** Interest to a general audience



**Q 13** Quality of the writing



**Q 14** Overall scientific quality of the study



#### REVISION LEVEL

**Q 15** Please make a recommendation based on your comments:

Minor revisions.