Perceptions and knowledge of end-of-life medical situations among older adults in Switzerland

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Background:

Perceptions and knowledge regarding end-of-life health and healthcare can influence individuals' advance care planning, such as the completion and content of advance directives (1). Key aspects to consider when planning for the end of life include the risk to suffer from dementia in old age, legal liability for medical decision-making at the end of life, the potential utility of different types of medical interventions at the end of life and considerations of place of death (2).

The complexity of end-of-life situations and the potentially negative consequences of an uninformed or misinformed decision on the quality of dying and death emphasize the **need for early communication on end-of-life medical issues to avoid misunderstanding or misrepresentation** (3). Despite the general importance of perceptions of end-of-life realities for potential advance care planning, little is known about the perceptions of common end-of-life situations and their accuracy among older adults in the general population. To fill this knowledge gap, we used nationally representative data on adults aged 58 and older in Switzerland to **assess their perceptions of important aspects of end-of-life health and healthcare along with their accuracy** in the Swiss context.

Method:

We use a nationally representative sample of adults aged 58 years and older who participated in wave 8 (2019/20) of the Swiss part of the Survey of Health, Ageing, and Retirement in Europe (4). The total number of respondents included was 1'217.

The questionnaire included 11 frequent end-of-life health and healthcare situations regarding cognitive impairment, medical treatment, and place of death. Respondents had to evaluate the frequency of occurrence of the 11 situations on a four-point scale: 1= very unlikely (0-25%), 2=rather unlikely (26-50%), 3= rather likely (51-75%), 4= very likely (76-100%). In addition, we also calculated a score regarding the accuracy of respondents' perceptions; the score adds one point for a right answer and zero; otherwise, the maximum possible value of the score is 11, and the minimum is 0. We did an Ordinary Least Squares (OLS) regression of the score on respondents' characteristics.

Results:

Older adults' perceptions of end-of-life medical situations in Switzerland were rather heterogeneous and often inaccurate. Study subjects overestimated the success of cardiopulmonary resuscitation, the utility of a fourth-line chemotherapy, of hospital admission for pneumonia for patients with advanced dementia and for artificial nutrition and hydration in the dying phase, while underestimating the effectiveness of pain management in this situation. Less than 28% of older adults correctly assessed the likelihood of dying in a nursing home, hospital or at home, respectively. Inaccurate views were more frequent in men (p < 0.01) and individuals with financial difficulties (p < 0.05), while adults aged 75+ (p < 0.01) and respondents from the German-speaking part of Switzerland (p < 0.01) had more accurate perceptions.

Figure 1: Percentage of respondents per categories of each end-of-life representations, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,217
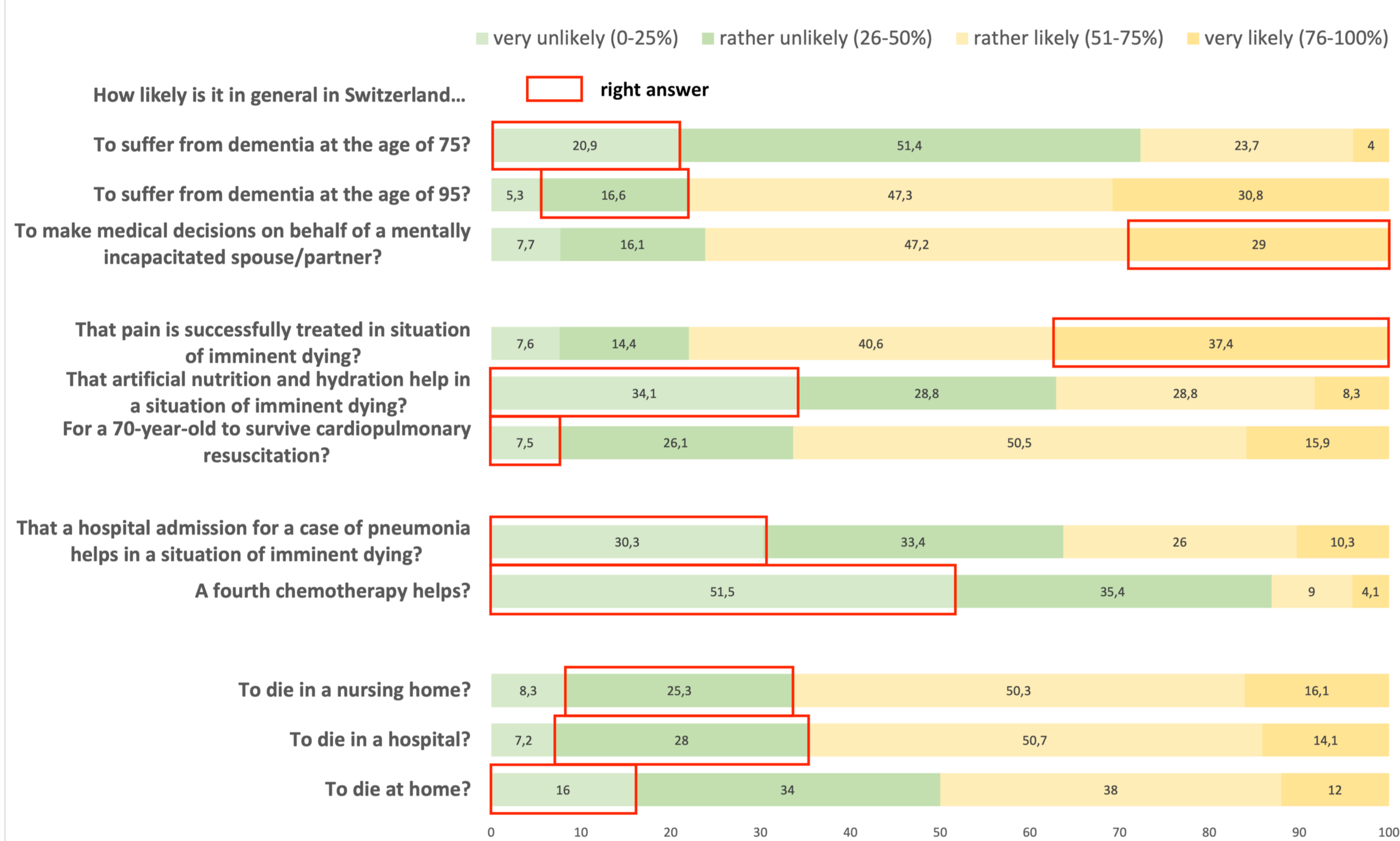
The figure shows respondents' perceptions per categories of probabilities of the 11 end-of-life health and healthcare situations. Information regarding the right answer categories on the 11 end-of-life medical situations questions are in Annexe 2.

Table 1: OLS regression of the score regarding the accuracy of each individual's perceptions on covariates, adults aged 58+, SHARE Switzerland, 2019/2020, N=1'217

	score
Gender (male)	
female	0.24**
	(0.09)
Age group (58-64 years)	
65-74 years	0.05
	(0.13)
75+ years	0.41**
	(0.14)
Partnership status (has a partner)	
no partner	0.09
	(0.12)
Linguistic regions (German)	
French	-0.35**
	(0.11)
Italian	-0.22
	(0.39)
Education (low)	
secondary	-0.11
	(0.14)
tertiary	0.15
	(0.17)
Make ends meet (easily)	
fairly easily	-0.11
	(0.11)
with difficulty	-0.34*
	(0.16)
Living area (urban)	
rural	0.04
	(0.10)
Self-rated health (bad health)	
good health	-0.00
	(0.14)
very good/excellent health	0.16
	(0.14)
Constant	2.95***
	(0.24)
Observations	1217

*Note, the score adds one point for a right answer and zero; otherwise, the maximum possible value of the score is 11, and the minimum is 0. Standard errors in parentheses have the following significance levels * p < 0.05, ** p < 0.01, *** p < 0.001.*

Conclusion:

The overall patterns of perceptions of many aspects of end-of-life situations of older adults in Switzerland seem largely consistent with current reality, even if their exact assessments are often rather inaccurate. Specifically, while perceptions of success of some medical treatments seemed largely in line with available data, perceptions of the prevalence of dementia among the oldest old or of the chances of success of out-of-hospital cardiopulmonary resuscitation in an older person are far from reality. What is more, perceptions often vary considerably across population groups, which highlights significant knowledge gaps regarding end-of-life health and healthcare realities in Switzerland in parts of the population. Indeed, women, individuals of older age groups, and the better off appeared to have more accurate perceptions of end-of-life situations. Nonetheless, our study reveals **significant misrepresentations of end-of-life realities among older adults in Switzerland** that may lead to unrealistic expectations regarding end-of-life care, result in disappointment of patients and families, as well as compromise the quality and reliability of advance care planning.

References:

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Published article:

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