



How can I choose?

Personal end-of-life health literacy: a key factor for advance care planning

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(x) I have no, real or perceived, direct or indirect conflicts of interest that relate to this presentation.

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The new context of dying



The new context of dying



Background (1)

The importance of end-of-life care decisions has increased over the recent decades mainly due to:

- the medical progress,
- the fear of overtreatment,
- the changes in the relationship between patients and healthcare providers, putting autonomy and self-determination at the center of each medical decision (1,2).

In addition, decision-making regarding the end of life is especially challenging (hypothetical scenarios, complex tradeoffs between quality and quantity of life, emotionally charged situations) (3,4).

Background (2)

As a result, individuals may have to make choices about situations they have little knowledge about (5,6).


Health literacy skills influence how people perceive their health difficulties, communicate with healthcare providers, and make medical decisions (7).

- End-of-life health literacy may influence individuals' knowledge, decision to engage in advance care planning, and the content of their advance care plans (8).

Research question

- What are the associations between individuals' end-of-life health literacy and their knowledge and behaviors toward advance care planning among older adults in Switzerland?

Study design



Survey of Health, Ageing and Retirement in Europe

2019

Self-administered questionnaire

Respondent ID: -

Name/Initials:

Interview date: //

IWER-ID:

Serial number:

SHARE population in Switzerland in 2019/2020:

⇒ Selection: 58+

⇒ Complete case analysis

⇒ Analytical sample: $n = 1,319$

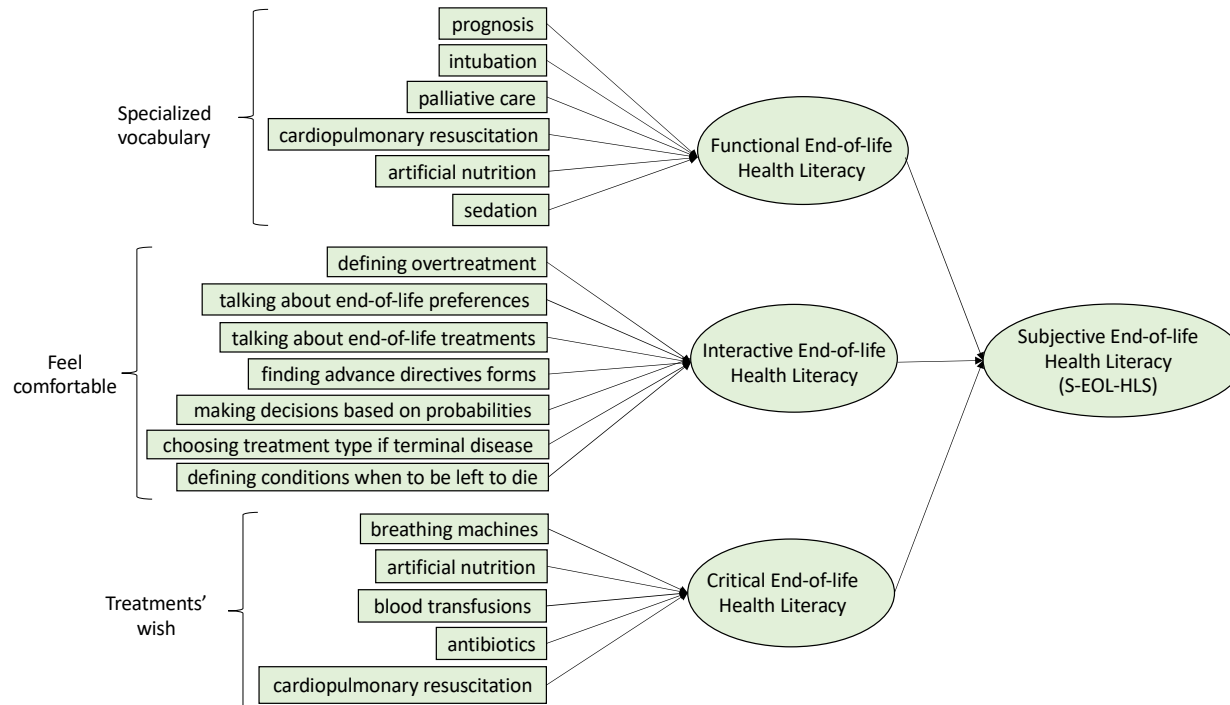
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End-of-Life health literacy scale

Appendix 1: the 3-factors model of the S-EOL-HLS



EOL health literacy score:

- 0 (very difficult/fairly difficult), 1 (very easy/fairly easy)
- The score initially ranges from 0 to 18 but is standardized and ranges from 0 to 3.9

Meier C, Vilpert S, Wiczorek M, Borrat-Besson C, Jox RJ, Maurer J. Development and validation of a subjective end-of-life health literacy scale. *PLOS ONE* 2023;18:e0292367.

End-of-life knowledge score

- **EOL knowledge score**

- Respondents had to evaluate the likelihood of 11 end-of-life medical situations
- The score initially ranges from 0 to 9 but is standardized and ranges from 0 to 5.1

30 (Question 30 continued)
In your opinion, how likely is it **in general in Switzerland...**

	very unlikely 0-25%	rather unlikely 26-50%	rather likely 51-75%	very likely 76-100%
30j) to suffer from dementia at the age of 95?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

- Meier C, Vilpert S, Borasio GD, Maurer J, Jox RJ. Perceptions and Knowledge Regarding Medical Situations at the End of Life among Older Adults in Switzerland. J Palliat Med. 2022 Jun 29.

End-of-life care planning

- **EOL discussion:**
 - Having discussed wishes for the end of life (0: No, 1:Yes)
- **Completion of advance directives:**
 - Having ADs (0: No, 1:Yes)
- **Appointed surrogate:**
 - Having appointed surrogate (0: No, 1:Yes)

Statistical analysis

- **Regressions:**
 - Multivariable OLS (End-of-life knowledge score) and probit model (binary variables of behaviors toward ACP)
 - Standards errors clustered at the household level
- **Controls:**
 - Sex, age groups, education levels, partnership status, subjective financial situation, Swiss linguistic regions, living area, and self-rated health

Results (1)

Table 1: Characteristics of the study population, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,319

	n	%
Gender		
Male	639	48.5
Female	680	51.5
Age groups		
58-64 years	352	26.7
65-74 years	579	43.9
75+ years	388	29.4
Education		
Low	192	14.6
Middle	848	64.3
High	279	21.1
Partnership status		
Has a partner	1,021	77.4
No partner	298	22.6
Make ends meet		
Easily	745	56.5
Fairly easily	416	31.5
With difficulty	158	12
Language		
German	960	72.8
French	316	24
Italian	43	3.2
Living area		
Urban	594	45
Rural	725	55
Self-rated health		
Poor/fair health	214	16.2
Good health	548	41.6
Very good/excellent health	557	42.2

Note, number of observations for the whole sample. AD = Advance Directives. EOL = End-Of-Life.

Results (2)

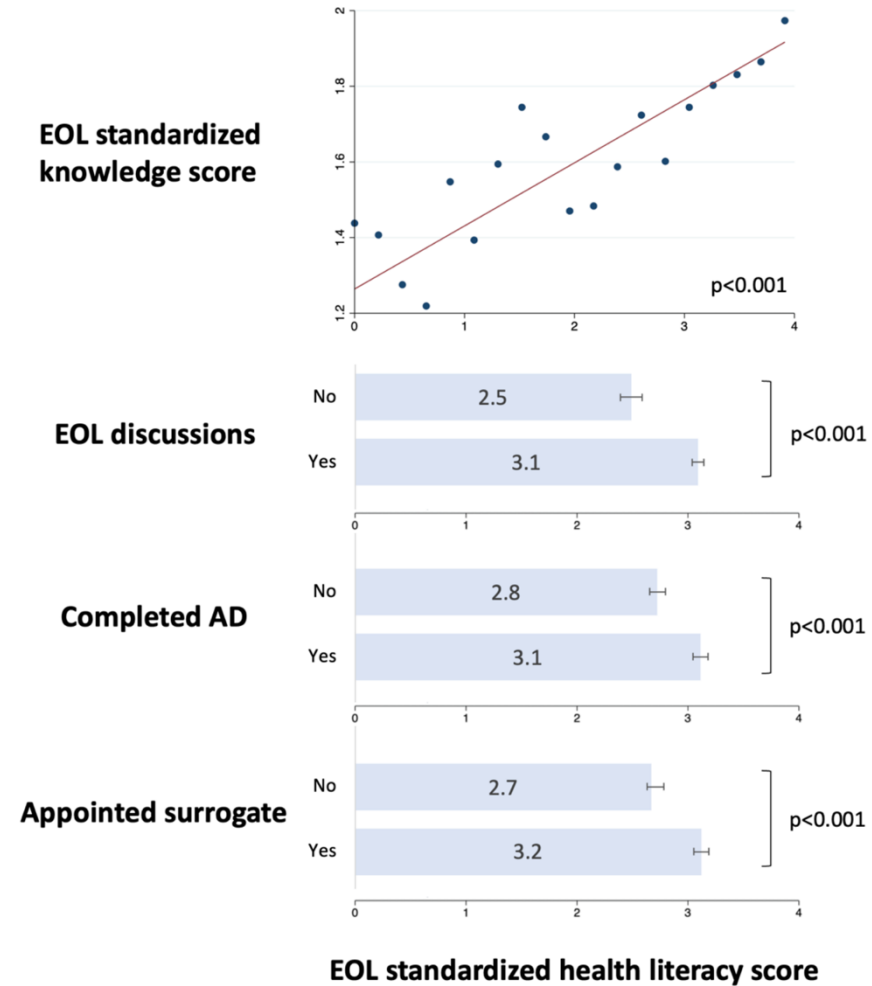
Table 1: Characteristics of the study population, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,319

	n	%
EOL discussions		
No	441	33.4
Yes	878	66.6
Completed AD		
No	759	57.5
Yes	560	42.5
Appointed surrogate		
No	733	55.6
Yes	586	44.4
Standardized EOL health literacy score	mean: 2.9 min: 0	std. dev: 1 max: 3.9
Standardized EOL knowledge score	mean: 1.7 min: 0	std. dev: 1 max: 5.1

Note, number of observations for the whole sample. AD = Advance Directives. EOL = End-Of-Life.

Results (3)

Figure 1: Average EOL health literacy standardized scores per EOL knowledge and behaviors toward ACP, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,319



Note, the first graph is a binned scatterplots of standardized end-of-life health literacy and knowledge scores, AD = Advance Directives. EOL = End-Of-Life. ACP = Advance Care Planning.

Results (4)

Table 2: Partial associations between EOL knowledge and behaviors toward ACP on the standardized EOL health literacy score, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,319

	EOL knowledge	EOL discussions	Completed AD	Appointed surrogate
Standardized EOL health literacy score	0.17*** (0.03)	0.14*** (0.01)	0.13*** (0.01)	0.12*** (0.01)
Observations	1,319	1,319	1,319	1,319

*The table shows average marginal effects and standard errors in parentheses. Statistical significance: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. AD = Advance Directives. EOL = End-Of-Life. ACP = Advance Care Planning. The first column shows the results from an ordinary least squares regression of the standardized EOL knowledge score on the standardized EOL health literacy score and the covariates. The next three columns present probit regressions models regressing each EOL health outcomes on the standardized EOL health literacy score and the covariates. The covariates include sex, age, education levels, partnership status, subjective financial situation, linguistic region, living area and self-rated health.*

Results (5)

Table 3: Partial associations between EOL knowledge and behaviors toward ACP on the three dimensions from the standardized EOL health literacy score, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,319

	EOL knowledge	EOL discussions	Completed AD	Appointed surrogate
Standardized functional EOL health literacy score	0.03 (0.03)	0.02 (0.01)	0.01 (0.02)	0.01 (0.02)
Standardized interactive EOL health literacy score	0.17*** (0.04)	0.12*** (0.01)	0.10*** (0.02)	0.08*** (0.02)
Standardized critical EOL health literacy score	0.00 (0.03)	0.02 (0.01)	0.04* (0.02)	0.06*** (0.02)
Observations	1,319	1,319	1,319	1,319

*The table shows average marginal effects and standard errors in parentheses. Statistical significance: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. AD = Advance Directives. EOL = End-Of-Life. ACP = Advance Care Planning. The first column shows the results from an ordinary least squares regression of the standardized EOL knowledge score on the three dimensions of the standardized EOL health literacy score and the covariates. The next three columns present probit regressions models regressing each EOL health outcomes on the three dimensions of standardized EOL health literacy score and the covariates. The covariates include sex, age, education levels, partnership status, subjective financial situation, linguistic region, living area and self-rated health.*

Conclusion

- Since autonomy and self-determination are at the center of each medical decision; it is necessary to support individuals in this process.
- Healthcare specialists already provide great support to help patients deal with their end-of-life.
- In contrast, little is known about how to assist the general older adult population. One key factor could be end-of-life health literacy.

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End-of-life health literacy, knowledge and behaviours towards advance care planning among older adults: cross-sectional evidence from Switzerland

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Thank you for your attention!

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