



Learning by Experience: Does caregiving for loved ones boost personal end-of-life health literacy?

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End-of-life care support



End-of-life care support



Background (1)

The **aging population** and the **medicalization** of aging have transformed end-of-life care, emphasizing the need for informed decision-making (1,2).

Enhancing **end-of-life health literacy** is vital for informed and empowered decision-making, as inadequate literacy is linked to:

- communication issues (3)
- confusion over treatment options (4)
- higher likelihood of receiving aggressive care (5)
- less engagement in advance care planning (6,7).

Background (2)

Older individuals in their final year face slow disease progression and functional decline, often needing hospitalization and extensive support from **informal caregivers** (8-10).


The reliance on caregivers for **practical, emotional, and decision-making support** underscores the importance of their awareness and understanding of treatment options (11-13).

- Despite the critical role of health literacy limited research exists on the determinants of end-of-life health literacy.

Research question

- What are the associations between **individuals' experiences with end-of-life care support** to loved ones and **end-of-life health literacy** among a population-based sample of 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: $n = 1,548$

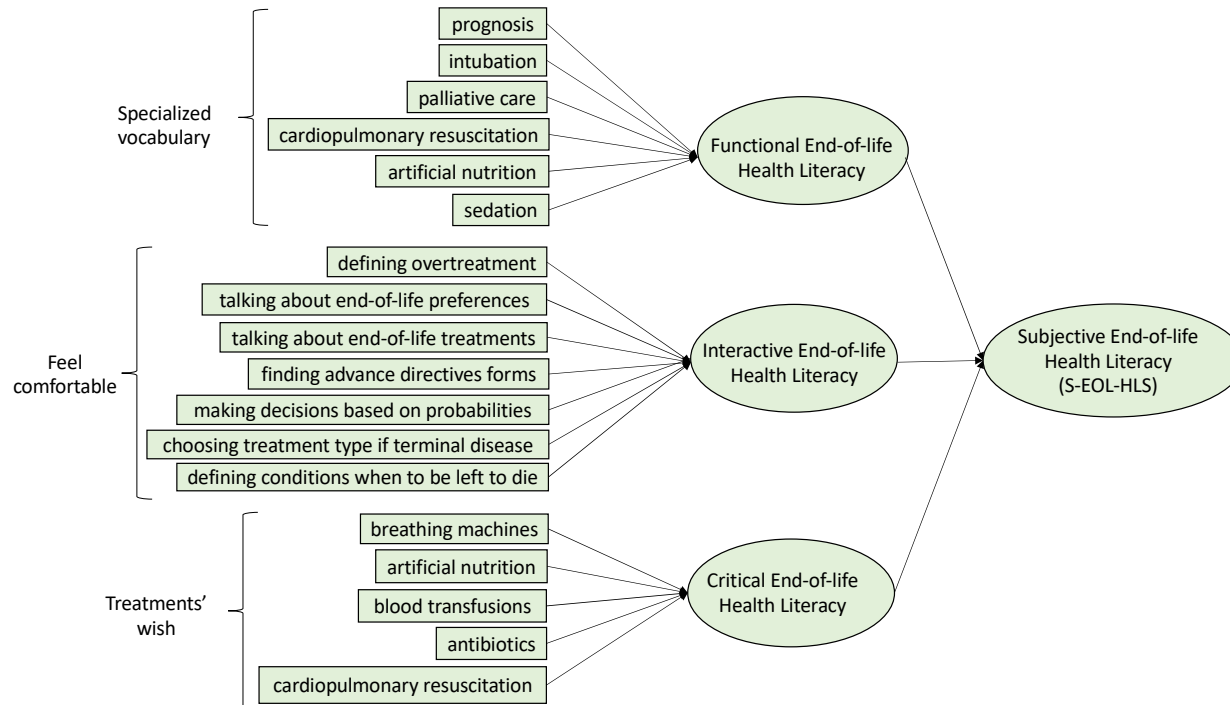
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End-of-Life health literacy scale

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.

Experience with end-of-life care support

- **Made medical decision :**
 - Have you ever made medical decisions for a person at the end of life who was close to you and who was no longer able to decide for him/herself? (0: No, 1:Yes)
- **Accompanied someone:**
 - Have you ever accompanied (being present, visiting, moral support) a relative or close friend at the end of life? (0: No, 1:Yes)
- **Cared for someone:**
 - Have you ever cared (personal care, giving medicine, feeding) for a relative or close friend at the end of life? (0: No, 1:Yes)

Statistical analysis

- **Regressions:**
 - Multivariable OLS (score) models
 - 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=1,548

	n	%
Gender		
Male	729	47.1
Female	819	52.9
Age groups		
58-64 years	383	24.7
65-74 years	655	42.3
75+ years	510	33.0
Education		
Low	267	17.2
Middle	978	63.2
High	303	19.6
Partnership status		
Has a partner	1,165	75.3
No partner	383	24.7
Make ends meet		
Easily	856	55.3
Fairly easily	492	31.8
With difficulty	200	12.9
Language		
German	1,104	71.3
French	387	25.0
Italian	57	3.7
Living area		
Urban	700	45.2
Rural	848	54.8
Self-rated health		
Poor/fair health	281	18.1
Good health	655	42.3
Very good/excellent health	612	39.5

Note, number of observations for the whole sample.

Results (2)

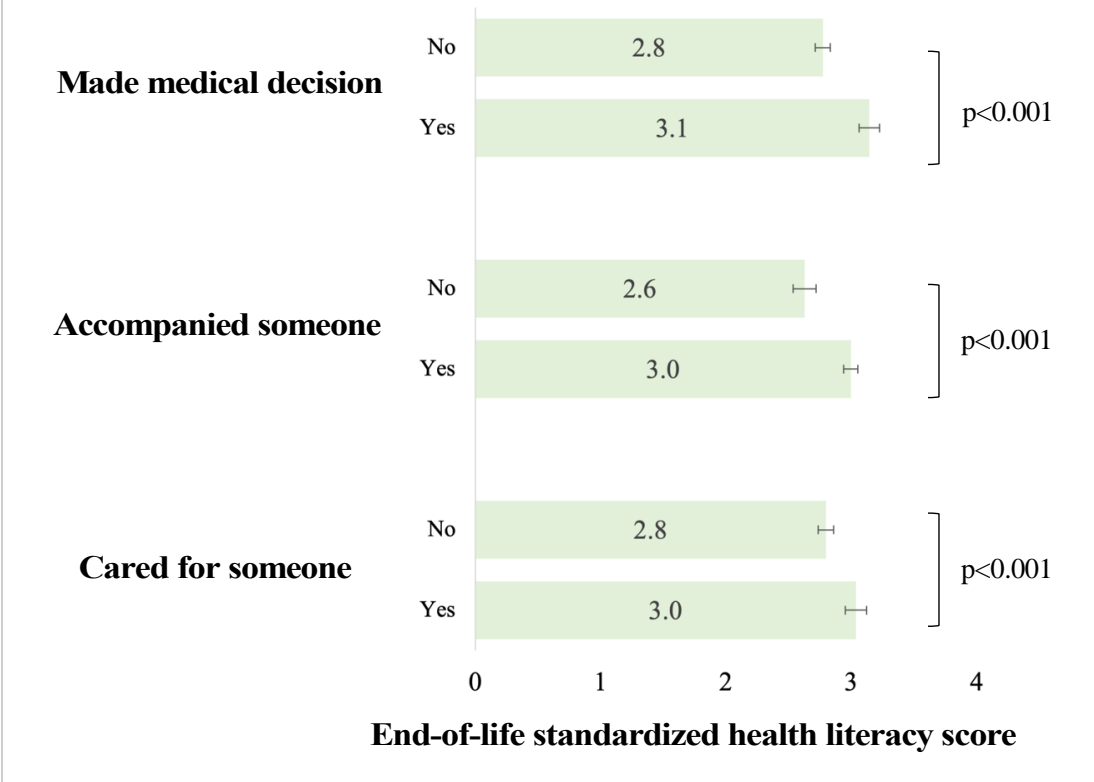
Table 1: Characteristics of the study population, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,548

	n	%
Made medical decision		
No	1,143	73.8
Yes	405	26.2
Accompanied someone		
No	531	34.3
Yes	1,017	65.7
Cared for someone		
No	1,077	69.6
Yes	471	30.4
End-of-life health literacy score standardized	mean: 2.9 min: 0	std. dev: 1 max: 3.9

Note, number of observations for the whole sample.

Results (3)

Figure 1: Average standardized scores of end-of-life health literacy by types of end-of-life care support, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,548



Results (4)

Table 2: Partial associations between standardized scores of end-of-life health literacy on the three types of end-of-life care support, adults aged 58+, SHARE Switzerland, 2019/2020, n=1,548

	End-of-life health literacy	End-of-life health literacy	End-of-life health literacy	End-of-life health literacy
Made medical decision	0.26*** (0.05)			0.18*** (0.05)
Accompanied someone		0.29*** (0.05)		0.21*** (0.06)
Cared for someone			0.23*** (0.05)	0.12* (0.06)
Observations	1,548	1,548	1,548	1,548

*The table shows average marginal effects and standard errors in parentheses. Statistical significance: * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. The columns show the results from ordinary least squares regressions of the standardized scores of end-of-life health literacy on the three types of end-of-life care support and the covariates. The covariates include sex, age, education levels, partnership status, subjective financial situation, linguistic region, living area and self-rated health.*

Conclusion

- Our findings suggest that **the provision of end-of-life support** to loved ones is associated with **higher end-of-life health literacy**.
- Thus, as caregivers gain experience caring for others, targeted interventions could leverage that knowledge and **encourage them to also think of engaging in end-of-life planning** for themselves.
- Also, when communicating to the general population regarding end-of-life issues, **using the testimony of caregivers could trigger individuals' interest** in improving their end-of-life health literacy skills.

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Thank you for your attention!

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