

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

Clément Meier ^{1,2,3}, Sarah Vilpert,^{2,3} Maud Wiecek,² Carmen Borrat-Besson,³ Ralf J Jox,^{4,5} Jürgen Maurer²

To cite: Meier C, Vilpert S, Wiecek M, *et al.* End-of-life health literacy, knowledge and behaviours towards advance care planning among older adults: cross-sectional evidence from Switzerland. *BMJ Public Health* 2024;**2**:e000600. doi:10.1136/bmjph-2023-000600

► Additional supplemental material is published online only. To view, please visit the journal online (<https://doi.org/10.1136/bmjph-2023-000600>).

Received 26 September 2023
Accepted 1 March 2024



© Author(s) (or their employer(s)) 2024. Re-use permitted under CC BY-NC. Published by BMJ.

¹University of Lausanne Faculty of Biology and Medicine, Lausanne, Switzerland

²University of Lausanne Faculty of Business and Economics, Lausanne, Switzerland

³FORS, Lausanne, Vaud, Switzerland

⁴Palliative and Supportive Care Service, Chair in Geriatric Palliative Care, Lausanne University Hospital, Lausanne, Switzerland

⁵Institute of Humanities in Medicine, University of Lausanne, Lausanne, Switzerland

Correspondence to
Clément Meier;
clement.meier@unil.ch

ABSTRACT

Introduction Population ageing, technological advancements and an increasing emphasis on patient empowerment imply that individuals are increasingly confronted with intricate end-of-life decisions. Personal end-of-life health literacy skills may help empower individuals to participate more actively in their own end-of-life decisions, including engagement in advance care planning (ACP). This study thus investigates the associations between individuals' end-of-life health literacy and their knowledge and behaviours toward ACP among a population-based sample of adults aged 58+ years in Switzerland.

Methods We used data from 1319 respondents from Wave 8 (2019/2020) of the Survey on Health, Ageing, and Retirement in Europe. The Subjective End-of-life Health Literacy Scale (S-EOL-HLS) served as the measurement tool. Respondents' end-of-life knowledge was assessed using test-based questions about 11 end-of-life medical situations. Behaviours toward ACP were measured by whether respondents have discussed their end-of-life wishes, completed advance directives (AD) and appointed a potential surrogate for medical decisions in case of incapacity. Associations were estimated using separate ordinary least square and probit regressions, controlling for social, health and regional characteristics.

Results Respondents with higher end-of-life health literacy tended to have better end-of-life knowledge and were more likely to have discussed their end-of-life wishes, to have completed AD and to have appointed a surrogate for medical decisions in case of incapacity. On regressing the outcomes on the three end-of-life health literacy dimensions, interactive health literacy positively correlated with end-of-life knowledge and the three behaviours toward ACP, while critical health literacy was only associated with having an AD and appointing a surrogate for medical decisions.

Conclusions Our findings suggest that end-of-life health literacy may play a significant role in individuals' level of end-of-life knowledge and their behaviour toward ACP. Thus, developing public health policies that aim at strengthening their end-of-life health literacy skills may increase individuals' engagement in the ACP process and make ACP more effective.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Individuals' health literacy significantly impacts their behaviours toward advance care planning (ACP), yet existing research relies on general health literacy measures; thus, this study employs the Subjective End-of-life Health Literacy Scale (S-EOL-HLS) to comprehensively assess the relationship between end-of-life health literacy and ACP behaviours in older Swiss adults.

WHAT THIS STUDY ADDS

⇒ This study reinforced that higher end-of-life health literacy is correlated with better end-of-life knowledge and positive behaviours toward ACP. Those with higher end-of-life health literacy are more likely to discuss end-of-life preferences, complete AD and appoint a medical surrogate. Among three end-of-life health literacy dimensions, the interactive dimension—focused on effective communication and engagement—stands out as the most influential.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The findings underscore the need for interventions that provide tailored information and support to older adults in engaging in ACP. Solutions such as specific consultations with healthcare professionals, a national day focusing on end-of-life discussions or the introduction of a 'Personal Healthcare Guide' can help improve individuals' end-of-life health literacy. Future research should explore the impacts of different demographics on end-of-life literacy and work on developing objective measures for a more comprehensive understanding. The results lay a foundation for strategies that prioritise the needs of older adults, facilitating a more dignified and respectful end-of-life process.

INTRODUCTION

Over recent decades, the need to make important end-of-life (EOL) healthcare decisions has increased drastically.¹ This growth can be attributed to medical advancements that

extend life, potential concerns about overtreatment and an evolving relationship between patients and healthcare providers, which now emphasises patient autonomy and self-determination in medical decisions.^{2,3} Furthermore, EOL decisions present their own set of challenges, often asking individuals to contemplate future hypothetical scenarios or confront current situations burdened with emotionally charged decisions. The complexity of EOL decisions arises from the acuity of the situation, the multitude of options available, uncertainties particularly concerning prognosis, a common lack of preparation and often impaired decisional capacity, whereby relevant scenarios frequently require individuals to weigh the trade-offs between quality and quantity of life.^{4,5} As a result, individuals may have to make challenging decisions about situations that are highly uncertain and about which they often have very little knowledge.^{6,7}

Advance care planning (ACP) is a proactive approach involving structured discussions between healthcare professionals, (potential) patients and often their families, anticipating possible health deterioration leading to decisional incapacity.⁸ Its primary objective is to prepare for communication and decision-making, thereby enhancing patient well-being throughout their healthcare journey and leading to improved EOL experiences as perceived by the patient.^{9–11} This process often culminates in the drafting of an advance directive (AD), that is, documented decisions that encapsulate patients' medical preferences, particularly regarding treatments they would have to accept or decline in situations where they may have become incapacitated, and information regarding the person they designated to make medical decisions for them in case of incapacity.¹² These processes and documents can play a pivotal role in protecting patient autonomy, ensuring that medical interventions resonate with their personal wishes, and offering guidance to families and healthcare practitioners in challenging decision-making situations.¹³ Despite the potential benefits of ACP, such as enhanced patient satisfaction, greater respect for patient autonomy and care more in line with patients' wishes,^{14–16} there remains a noticeable lack of awareness and engagement in ACP and AD use among the general population.^{17–19} This gap is especially pronounced among vulnerable older adults and those with limited health literacy.²⁰

Individuals' behaviours toward ACP often appear to be shaped by their health literacy, which has been shown to affect their understanding of health challenges, their communication with medical professionals and their ability to make informed medical decisions.^{21,22} Specifically, prior research showed that limited health literacy is associated with suboptimal self-care behaviour for diabetes,²³ poor health-related knowledge of chronic diseases,²⁴ communication gaps between patients and healthcare providers when discussing EOL care,²⁵ misunderstandings about EOL treatment options,²⁶ an increased probability of undergoing aggressive EOL care,²⁷ lesser engagement in ACP^{28,29} and fewer chances of having an AD.³⁰ Moreover, health literacy

has emerged as a pivotal factor in determining ACP engagement.^{31,32} While associations between health literacy and knowledge regarding ACP have been documented in existing literature,³³ much of the existing research has relied on rather general health literacy measures such as the Test of Functional Health Literacy in Adults.³⁴ These broad measures may often fail to capture important nuances related to EOL decisions, especially in emotionally charged situations of life and death, the heightened role of uncertainty and potential trade-offs between length and quality of life. Such decisions demand a deeper comprehension, given their sensitive nature. To the best of our knowledge, no studies are exploring the associations between specific EOL health literacy measures and EOL knowledge and behaviours toward ACP.

To fill this gap, the present study uses the recently validated Subjective End-of-life Health Literacy Scale (S-EOL-HLS)³⁵ to investigate the associations between individuals' EOL health literacy and their knowledge and behaviours toward ACP among a population-based sample of adults aged 58+ years in Switzerland. The new measure of EOL health literacy was the first instrument developed to assess the level of competencies individuals perceive in dealing with EOL care situations and decision-making. The tool was demonstrated to be a reliable and valid instrument for measuring older adults' self-perceived EOL health literacy.³⁵ In this study, we define EOL health literacy as the capacity to obtain, process and understand basic health information and services needed to make appropriate EOL decisions. In contrast, EOL knowledge refers to an individual's understanding of specific aspects of EOL care, such as palliative care options, legal aspects of ACP and medical interventions commonly used at the EOL. Another distinctive feature of this research is its use of the three dimensions within the S-EOL-HLS: functional, interactive and critical EOL health literacy. Designed to provide a multifaceted perspective on EOL health literacy, these dimensions allow our study to shed more light on the intricate associations between EOL health literacy and ACP, offering a comprehensive perspective absent in prior research on general health literacy and ACP.

MATERIALS AND METHODS

Study design and participants

We used cross-sectional data from the Wave 8 of the Survey on Health, Ageing, and Retirement in Europe (SHARE) that was collected between October 2019 and the beginning of March 2020.^{36,37} SHARE collects data every 2 years from targeted respondents and their partners aged 50 years and older in 28 European countries and Israel using Computer-Assisted Personal Interviewing. The internationally harmonised, questionnaire-based in-person interview collects information on individuals' health, socioeconomic status and social networks. In addition, each country can add a country-specific Paper-and-Pencil Self-Administered questionnaire. Our analyses include respondents from Switzerland who participated in the main questionnaire and the National Paper-and-Pencil questionnaire from Wave 8 on EOL issues.

Respondents consented to participate twice, when they agreed to schedule an interview and when they attended the in-person interview. SHARE samples are designed to be nationally representative of the target population of adults aged 50 years and older. However, as the Swiss sample has not been refreshed since 2011, we only include respondents aged 58 years and older in our analysis. In Switzerland, 2009 respondents participated in the main SHARE questionnaire; 94.4% also answered the National Paper-and-Pencil questionnaire (n=1896). After excluding respondents' partners aged 50–57 years and those with missing responses on variables used in the analysis, our final analytical sample includes 1319 respondents.

Outcome variables

EOL knowledge

The Swiss Paper-and-Pencil questionnaire integrated 11 items on the likelihood of important potential EOL medical situations that the respondents had to evaluate on a 4-point scale: 1=very unlikely (0–25%), 2=rather unlikely (26%–50%), 3=rather likely (51%–75%) and 4=very likely (76%–100%). EOL medical situations refer to issues like cognitive impairment, medical treatment and place of death (see online supplemental appendix 1). Following the approach of a previous study that used the same set of EOL knowledge questions,⁶ we defined the accuracy of perceptions of different EOL situations using dichotomised variables: 1 indicates a correct answer, and 0 indicates an incorrect answer. The correct category for the answer was determined using results from recently published research articles. For instance, in the first EOL medical situation, respondents were asked to rate the chances of suffering from dementia at the age of 75 years. Given that the prevalence estimate for dementia is lower than 5% for individuals aged 75 years or younger,³⁸ the correct category for the answer is 'very unlikely (0–25%)'. Further information can be found in online supplemental appendix 1. Then, the resulting initial EOL Knowledge Score that summed up all correct answers ranged from 0 to 9, as no respondents answered all questions correctly. Following the approach from Pelikan *et al*,³⁹ missing values were treated as 0, and the final EOL Knowledge Score only includes respondents with no more than two missing values on the items. In total, 259 respondents (15.1%) had more than two missing values on the 11 items. The score was then standardised by dividing it by its SD (1.78) and finally ranged from 0 to 5.1. This standardisation was done to normalise the distribution and make the score more interpretable in the context of our analysis.

Behaviours toward ACP

Respondents were asked whether they had ever discussed their wishes for the end of their life with someone (0=no, 1=yes), whether they had completed a written statement about their wishes and refusals for medical treatments and care (AD/living will) (0=no, 1=yes) and whether they had appointed someone in writing to make medical decisions for them should they not be able to make those

decisions for themselves (durable power of attorney, 0=no, 1=yes).

Exposure

Subjective End-of-Life Health Literacy Scale

The Swiss Paper-and-Pencil questionnaire included the items from the S-EOL-HLS,³⁵ a novel instrument designed to measure individuals' self-perceived competencies in managing EOL care situations and decision-making. The scale was previously developed and validated, demonstrating that the S-EOL-HLS is a reliable and valid tool for measuring EOL health literacy, and offers insights into individuals' readiness to engage in EOL planning and decision-making. In the validation paper, high internal consistency and reliability for the overall instrument were highlighted, with a Cronbach's alpha of 0.93. The validation paper also highlighted the potential of the S-EOL-HLS to identify individuals with limited EOL health literacy and guide interventions aimed at enhancing their understanding and engagement in EOL care planning.³⁵ The instrument consists of 18 items (see online supplemental appendix 2) divided into three dimensions (1) functional EOL health literacy, where respondents have to rate their level of understanding EOL medical terms; (2) interactive EOL health literacy, which assesses respondents' self-rated ease in defining treatment goals, in finding information on EOL planning options and in communicating about EOL issues; and (3) critical EOL health literacy, which asks respondents to indicate their self-rated competency in choosing medical treatments. Respondents evaluate each item on a 4-point Likert scale with answers ranging from 'very easy', 'fairly easy', 'fairly difficult', to 'very difficult'. The items are then dichotomised with a value of '0' for 'very difficult' and 'fairly difficult' and a value of '1' for the categories 'very easy' and 'fairly easy', allowing us to construct a score from 0 to 18. This means that a higher score indicates a greater level of EOL health literacy. Following the approach from Pelikan *et al*,³⁹ missing values were treated as 0, and the final EOL Health Literacy Score was then computed for respondents with no more than two missing item values. In total, 116 respondents (6.8%) had more than two missing values on the 18 items. The score was then standardised by dividing it by its SD (4.6), resulting in a range from 0 to 3.9. To deepen the analysis, three standardised EOL health literacy subscores were calculated based on the three dimensions of the scale: functional, interactive and critical EOL health literacy.

Covariates

Our statistical models include information on sex (male, female), age (58–64 years, 65–74 years, 75+ years), education levels (low=International Standard Classification of Education (ISCED) levels 0, 1, 2; middle=ISCED levels 3–4, high=ISCED levels 5–6⁴⁰), partnership status (has a partner, has no partner), Switzerland's linguistic regions (German, French or Italian), subjective financial difficulties (ability to make ends meet: easily, fairly easily and

with difficulty), living area (urban, rural) and self-rated health (poor/fair health, good health, very good/excellent health).

Statistical analysis

The characteristics of the study population were described using number counts and proportions. A binned scatterplot assessed the bivariate association between standardised EOL Health Literacy and EOL Knowledge Scores. Bivariate associations between average standardised EOL Health Literacy Score and behaviours toward EOL healthcare planning were computed with bar charts. The partial association between the standardised EOL Health Literacy Score and the standardised EOL Knowledge Score was assessed using ordinary least square regressions, while the respective associations between the standardised EOL Health Literacy Scores and the three behaviours toward ACP were explored using separate probit regression models. The same statistical modelling was used when considering the three dimensions of the End-of-Life Health Literacy Scale as exposures. Each regression model controlled for sex, age, education levels, partnership status, Switzerland's linguistic regions, subjective financial difficulties, living area and self-rated health. In addition, to account for potential unobserved dependencies between the target respondents and their partners, the error terms were clustered at the household level. All estimations used STATA/SE V.17.0 software (STATA Corporation) and results were reported as average marginal effects (AME) along with corresponding SEs clustered at the household level.

Patient and public involvement

Our research was conducted without the involvement of patients or the public in its design, execution, reporting, or dissemination strategies.

RESULTS

Selected characteristics of the study participants are displayed in [table 1](#). Of the 1319 participants, 680 (51.5%) were female, and the mean age was 70.6 years old (SD: 7.9). The age distribution was as follows: 352 participants (26.7%) were between 58 and 64 years, 579 (43.9%) were between 65 and 74 years and 388 (29.4%) were 75 years or older. In terms of education, 848 participants (64.3%) had a middle education level, 279 (21.1%) had a high education level and 192 (14.6%) had a low education level. Regarding partnership status, 1021 participants (77.4%) had a partner. Financially, 745 participants (56.5%) reported finding it 'easy' and 416 (31.5%) 'fairly easy' to make ends meet at the end of the month. Concerning the language region of Switzerland, 960 participants (72.8%) resided in the German-speaking parts, 316 (24%) in the French-speaking parts and 43 (3.2%) in the Italian-speaking parts. Geographically, 594 participants (45%) lived in urban settings and 725 (55%) in rural areas. For health assessment, 548 participants (41.6%) rated their health as good and 557 (42.2%) as

Table 1 Characteristics of the study population, adults aged 58+ years, SHARE Switzerland, 2019/2020, n=1319

	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	1021	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
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
Standardised EOL Health Literacy Score	Mean: 2.9 Min: 0	SD: 1 Max: 3.9
Standardised EOL Knowledge Score	Mean: 1.7 Min: 0	SD: 1 Max: 5.1
Note: number of observations for the whole sample. AD, advance directives; EOL, end-of-life.		

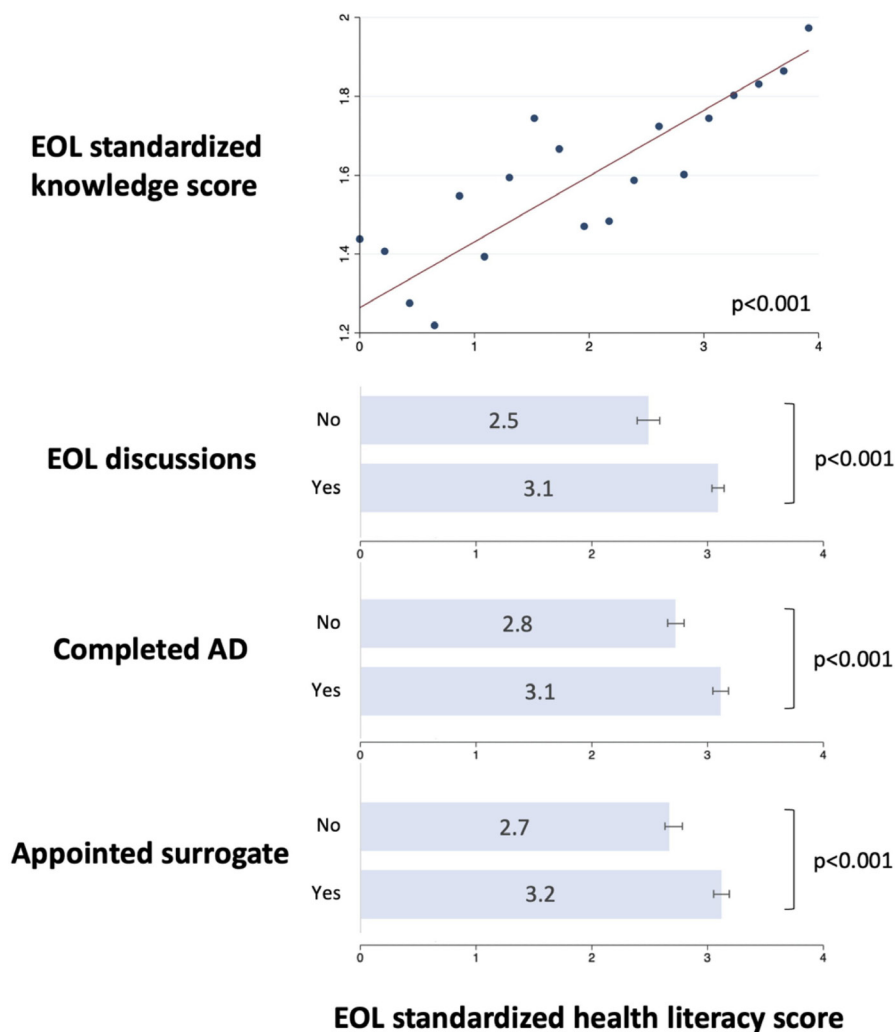


Figure 1 Average EOL Health Literacy Standardised Scores per EOL knowledge and behaviours toward ACP, adults aged 58+ years, SHARE Switzerland, 2019/2020, n=1319. Note, the first graph is a binned scatterplots of standardised EOL Health Literacy and Knowledge Scores. AD, advance directives; EOL, end-of-life; ACP, advance care planning.

very good or excellent. Concerning EOL healthcare planning, 878 participants (66.6%) had discussed their EOL wishes, 560 (42.5%) had completed AD and 586 (44.4%) had appointed a surrogate to make medical decisions.

The bivariate associations displayed in [figure 1](#) describe the relationship between the standardised EOL Health Literacy Score and both the standardised EOL Knowledge Score and behaviours toward ACP. The scatterplot graph demonstrates a positive association between EOL health literacy and knowledge; a higher standardised EOL Health Literacy Score is associated with a higher standardised EOL Knowledge Score. The next three bar charts show that respondents who had discussed their EOL wishes, completed an AD, or appointed a surrogate for medical decisions consistently exhibited higher standardised EOL Health Literacy Scores.

[Table 2](#) shows the partial associations between the standardised EOL Health Literacy Scores, the standardised EOL Knowledge Score and behaviours toward ACP. A one SD higher EOL Health Literacy Score is associated with an increase in the standardised EOL Knowledge

Score (AME: 0.17, $p < 0.001$), the likelihood of discussing EOL preferences (AME: 0.14, $p < 0.001$), the completion of AD (AME: 0.13, $p < 0.001$) and the appointment of a medical decision surrogate (AME: 0.12, $p < 0.001$). These findings have been adjusted for several confounders, including sex, age, education levels, partnership status, subjective financial situation, linguistic region, living area and self-assessed health.

The partial associations between the standardised EOL Knowledge Score, behaviours toward ACP and the three standardised scores of the distinct dimensions of EOL health literacy are presented in [table 3](#). The interactive dimension of EOL health literacy demonstrates the most consistent positive association with the exposure variables. An increase in the interactive EOL Health Literacy Score correlates with an increased standardised EOL Knowledge Score (AME: 0.17, $p < 0.001$), a higher likelihood of engaging in EOL discussions (AME: 0.12, $p < 0.001$), completion of AD (AME: 0.10, $p < 0.001$) and designation of a surrogate for medical decisions (AME: 0.08, $p < 0.001$). The critical dimension also exhibits

Table 2 Partial associations between EOL knowledge and behaviours toward ACP on the standardised EOL Health Literacy Score, adults aged 58+ years, SHARE Switzerland, 2019/2020, n=1319

	EOL knowledge	EOL discussions	Completed AD	Appointed surrogate
Standardised EOL Health Literacy Score	0.17*** (0.03)	0.14*** (0.01)	0.13*** (0.01)	0.12*** (0.01)
Observations	1319	1319	1319	1319

Average marginal effects and SEs are shown in parentheses. Statistical significance: *p<0.05, **p<0.01, ***p<0.001.

The first column shows the results from an ordinary least squares regression of the standardised EOL Knowledge Score on the standardised EOL Health Literacy Score and the covariates. The next three columns present probit regression models regressing each EOL health outcome on the standardised 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.

ACP, advance care planning; AD, advance directives; EOL, end-of-life.

associations, notably with the completion of AD (AME: 0.04, p<0.05) and the appointment of a surrogate (AME: 0.06, p<0.001). However, the associations related to the functional dimension are not statistically significant. All these associations have been adjusted for the same confounders as in [table 2](#).

DISCUSSION

Using data of 1319 adults aged 58 years and older from Switzerland, this study explored the relationships between EOL health literacy, knowledge and behaviours toward ACP. A positive correlation emerged, indicating that individuals with higher EOL Health Literacy Scores tend to possess better knowledge about EOL medical situations and are more proactive in planning for it. Particularly, the results highlight the association between increased EOL health literacy and the likelihood of discussing EOL preferences, completing AD and appointing a surrogate for medical decisions. Among the three dimensions of EOL health literacy assessed, the interactive dimension emerged as the most associated with the four outcomes variables. On the contrary, while the critical dimension also presented some notable associations, the functional dimension showed a clear tendency for better EOL knowledge and more positive behaviours toward ACP, but the corresponding associations did not turn out to be statistically significant. The findings from this study

reinforce and complement previous research that has demonstrated the importance of health literacy in influencing various behaviours toward ACP. In another study measuring death literacy, defined as individuals' skills and knowledge regarding the death system, the results showed that higher death literacy can be associated with better informed decisions regarding EOL and death care options.⁴¹ While the results go in the same direction, the death literacy index is primarily designed for group assessment and the items do not specifically address individuals' ability to navigate medical decisions at the EOL. Finally, what sets this research apart is its in-depth exploration of some aspects of the ACP process using a nuanced measure of EOL health literacy.

EOL knowledge and behaviours toward ACP

One significant obstacle to the wider adoption of AD and active engagement in ACP is a lack of knowledge to navigate the intricate landscape of EOL medical decisions.³³ However, so far, only a few studies have focused on the general population and their understanding of EOL healthcare options. Studies conducted in North America using knowledge assessment tests consistently indicate a significant knowledge gap concerning EOL care options among the general public.^{42–44} Another study found that while most older adults in China value healthcare transparency and autonomy, there is a significant lack

Table 3 Partial associations between EOL knowledge and behaviours toward ACP on the three dimensions from the standardised EOL Health Literacy Score, adults aged 58+ years, SHARE Switzerland, 2019/2020, n=1319

	EOL knowledge	EOL discussions	Completed AD	Appointed surrogate
Standardised functional EOL Health Literacy Score	0.03 (0.03)	0.02 (0.01)	0.01 (0.02)	0.01 (0.02)
Standardised interactive EOL Health Literacy Score	0.17*** (0.04)	0.12*** (0.01)	0.10*** (0.02)	0.08*** (0.02)
Standardised critical EOL Health Literacy Score	0.00 (0.03)	0.02 (0.01)	0.04* (0.02)	0.06*** (0.02)
Observations	1319	1319	1319	1319

Average marginal effects and SEs are shown in parentheses. Statistical significance: *p<0.05, **p<0.01, ***p<0.001.

The first column shows the results from an ordinary least squares regression of the standardised EOL Knowledge Score on the three dimensions of the standardised EOL Health Literacy Score and the covariates. The next three columns present probit regression models regressing each EOL health outcome on the three dimensions of standardised 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.

ACP, advance care planning; AD, advance directives; EOL, end-of-life.

of awareness and preference for ACP, potentially influenced by traditional values and education levels.⁴⁵ In addition, a population-based telephone survey in Hong Kong exploring behaviours and preferences of older adults regarding ACP revealed significant gaps between individuals' preferences to communicate and make their own EOL decisions and their awareness of ACP, with many also unfamiliar with AD.⁴⁶ Moreover, a study in Wales exploring public views on death and EOL care revealed the need to address societal taboos around death discussions, especially in light of the increased awareness brought about by the COVID-19 pandemic.⁴⁷ Finally, a study on older adults aged 55+ in Switzerland found notable misunderstandings about EOL healthcare and planning, potentially leading to suboptimal EOL decisions and limited patient participation.⁴⁸ Given the clear knowledge gaps highlighted in multiple studies about EOL decisions among older adults and considering that improved EOL healthcare knowledge enhances participation in ACP^{49–53} and the completion of AD,^{54,55} tackling this lack of awareness is essential. Providing individuals with appropriate EOL health literacy skills could increase their awareness of ACP, potentially improving their knowledge of and behaviours toward ACP.

EOL health literacy and its importance for ACP

Addressing knowledge gaps in EOL healthcare and related behaviours toward ACP requires focusing on empowering individuals to take control of their EOL decisions. As highlighted in a previous study analysing health literacy and EOL healthcare preferences, to support individuals effectively, it is essential to enhance their health literacy, ensuring they are well-informed and possess the necessary skills to make informed health-related decisions.⁵⁶ Two other studies supported those results, the first one showing that health literacy strongly influences knowledge, behaviours and decisions about hospice care among older adults⁵⁷ and the second one that health literacy significantly influences older adults' understanding of ACP more than their prior experience with ACP.⁵⁸ Although previous studies used general health literacy measures rather than one tailored specifically to EOL situations, they underscored the significance of health literacy skills in EOL healthcare decisions. With adequate EOL health literacy skills, individuals could improve their understanding of medical terms and the different types of EOL healthcare options, reduce their emotional barriers when communicating with healthcare providers and their loved ones, and thus facilitate healthcare that aligns with their preferences.²¹ Therefore, as highlighted by the results from our study, individuals' competencies for EOL decisions are crucial, as they positively correlate with EOL healthcare knowledge, discussions about EOL wishes, AD completion and the designation of a medical decision surrogate. Ultimately, enhancing EOL health literacy and increasing the adoption of ACP can foster a dignified and respectful EOL process while alleviating the decision-making burden

frequently shouldered by family members and healthcare providers.

EOL health literacy dimensions

This research identifies specific dimensions of EOL health literacy that are crucial for supporting patients, their loved ones and healthcare providers in their collective aim to align EOL healthcare with patients' values, preferences and goals. The distinct dimensions of functional, interactive and critical EOL health literacy are the first to provide an understanding of what composes the concept of EOL health literacy. The first dimension, functional EOL health literacy, measures individuals' comprehension of common EOL medical terms.³⁵ This dimension appeared to be the least influential, as its associations with EOL knowledge and behaviours towards ACP were not statistically significant. These non-significant results show that merely possessing the basic skills to understand EOL medical terms may be insufficient for individuals to have higher EOL knowledge and to engage in the ACP process. Although individuals might have the correct understanding of common EOL medical terms, higher skills are needed to engage in the ACP process. The second dimension, interactive EOL health literacy, evaluates respondents' self-assessed challenges in defining treatment goals, obtaining information on EOL healthcare planning options and discussing EOL matters.³⁵ Of all the dimensions, this one showed the most consistent associations with the outcomes of interest. Results indicated that higher scores in interactive EOL health literacy correlate with better knowledge of EOL, more discussions on the topic, higher completion rates of AD and more designation of a medical decision surrogate. These findings underscore the significance of the interactive dimension in EOL knowledge and behaviours toward ACP. It highlights the need to emphasise advanced cognitive and social skills, enabling individuals to engage in meaningful communication with healthcare providers, actively participate in ACP and gain a deeper comprehension of the dying process. In addition, it underscores that the more proactive aspects of ACP, such as seeking information and discussing EOL issues, can be challenging for some individuals. Therefore, providing them with the opportunity to initiate this process with social support could be beneficial in encouraging engagement in ACP. Lastly, the critical EOL health literacy dimension estimates respondents' difficulties in choosing EOL medical treatments.³⁵ Results from this dimension showed notable positive associations with both AD completion and surrogate appointment. These results from the critical dimension indicate that advanced cognitive and social skills, crucial for analysing and utilising information, are essential for individuals when translating the gathered information and informative discussions into making definitive decisions about EOL medical treatments. The results ultimately show that to complete AD and appoint a surrogate, both the interactive and the critical EOL health literacy dimensions

are essential. This highlights once again that individuals need particularly high skills to achieve the decision-making part.

Practical implications and future research

Existing research has shown that limited health literacy can lead to suboptimal participation and engagement in ACP.^{28 29} This study emphasises the pivotal role of EOL health literacy in improving knowledge about EOL medical situations and being more proactive in planning for it. As a result, it now raises the question of how to improve individuals' EOL health literacy to ensure they have the necessary skills for engaging in ACP. In addition, when examining the distinct dimensions of the scale, the results suggest that merely providing simplified information on EOL issues seems insufficient. Instead, creating new targeted interventions to support older adults in engaging in the ACP process and strengthening their skills is necessary. Such interventions could include offering consultations with health professionals to discuss potential decisions concerning EOL medical situations. For instance, in the Netherlands, research showed that inviting older adults to information sessions about EOL healthcare led by general practitioners can positively impact individuals' engagement in ACP.⁵⁹ The authors further explained that although this approach mainly resonates with older individuals already curious about the topic, it appears to be a straightforward way to encourage ACP.⁵⁹ It is also crucial to enlighten healthcare providers about the significance of assessing the health competency level of patients concerning EOL healthcare. This would enable them to tailor their communication, fostering better understanding between patients and healthcare providers. In a prospective study conducted in four palliative care units in Switzerland, the authors found that healthcare providers' behaviours might hinder patients from discussing potential future complications or completing AD, suggesting that the approach and perspectives of healthcare providers can significantly impact patient decisions regarding EOL healthcare.⁶⁰ Moreover, establishing another type of intervention for the public, such as a national day focusing on EOL issues, could serve as an excellent platform for widespread discussion, potentially equipping the general population with a deeper understanding of these intricate matters. Furthermore, when considering the significant impact that media coverage of personal ACP experiences has on health decisions,⁶¹ integrating such narratives into a national day could significantly enhance EOL health literacy among the general population. Finally, within the broader healthcare landscape, introducing a mandatory 'Personal Healthcare Guide' for older adults similar to vaccine booklets for children that details EOL healthcare options aligned with personal values, preferences and goals could not only bolster individual EOL planning skills but also encourage healthcare providers to initiate crucial EOL discussions, guide older adults in

maintaining these records and prompt the healthcare system to prioritise the needs of the ageing population.

Future studies might expand the scope of this study and investigate the differential impact of EOL health literacy across diverse demographic groups. Given the cultural, socioeconomic and educational differences, understanding how these groups vary in their EOL health literacy can inform targeted interventions. In addition, there is a need for the development and validation of objective measures for EOL health literacy, which could offer complementary insights to subjective assessments. Also, while our study emphasised three distinct dimensions of EOL health literacy, future research might explore other facets or different breakdowns of these dimensions in the context of EOL healthcare. Moreover, as the field of EOL healthcare evolves, it is important to constantly investigate significant factors such as EOL health literacy determinants in assuring a dignified and respectful EOL process for patients, their loved ones and healthcare providers. Finally, future research should prioritise designing and rigorously evaluating interventions to enhance EOL health literacy, ensuring that new strategies are both effective and evidence-based.

Limitations

Our research acknowledges several limitations. First, despite the extensive use and convenience of subjective measures like the S-EOL-HLS, they may be subject to potential reporting biases. Depending on their familiarity with EOL issues, participants might undervalue or overstate their actual skills. Second, the S-EOL-HLS items cover only a subset of the broad spectrum of EOL health literacy skills, which can raise questions about the data's comprehensiveness, potential bias and clinical relevance. Moreover, in measuring EOL knowledge, the use of both qualitative and quantitative labels for answer categories might have confused some participants. While some might have relied solely on one type of label when responding, others could have found the probability concepts challenging, even though such questions have been consistently used in the SHARE study. Additionally, while SHARE strives for an accurate representation of Switzerland's older population, potential attrition, a common challenge in longitudinal studies, especially among the oldest and most frail participants, could influence our results. Challenges around sample representation might also suffer from issues such as item non-response. However, the high response rate to the Swiss questionnaire and the consistent characteristics of those excluded from our sample offer some reassurance in our findings.

Finally, the cross-sectional nature of our study limits our ability to definitively establish causality and fully address the directionality of the relationship between EOL health literacy, EOL knowledge and behaviours toward ACP. To address this, further research employing a longitudinal design is required. Additionally, regarding potential residual confounding, we recognise that there may be

unmeasured variables that could influence EOL health literacy, EOL knowledge and ACP behaviours, such as cultural beliefs, personal values regarding death and dying, and previous experiences with EOL situations in a personal or familial context. Future studies should aim to identify and control for these potential confounders.

Conclusion

This study on 1319 older Swiss adults revealed a strong positive correlation between EOL health literacy, EOL knowledge and positive behaviours towards ACP. Individuals with higher EOL health literacy were more likely to discuss EOL preferences, complete AD and appoint a medical surrogate. The interactive dimension of EOL health literacy seemed to be the most influential, underscoring the importance of individuals' cognitive and social skills to communicate effectively with healthcare providers about care preferences, engage in ACP and develop a deeper understanding of the process of dying to help them make EOL decisions. Despite the importance of ACP, barriers such as limited awareness and knowledge gaps hinder its widespread adoption. Enhancing EOL health literacy can bridge these gaps, leading to more informed decisions that respect patient autonomy and reduce burdens on families and healthcare providers. The results also highlight the need for targeted interventions such as offering older adults specific ACP consultations with healthcare professionals, improving patient-healthcare provider communication, creating a national EOL day or introducing a 'Personal Healthcare Guide' to bolster EOL planning and prioritise the needs of older adults. Finally, future research should explore diverse demographic impacts on EOL literacy and develop objective measures for more comprehensive insights and improved EOL patient healthcare.

Acknowledgements We express our gratitude to the participants of the ACP-1 2023, the 8th International Conference on Advance Care Planning in Singapore, who provided feedback on the presentation of the preliminary results from this study. Their discerning insights and constructive critiques were invaluable in enhancing this paper.

Contributors CM, SV, MW and JM designed the study. CM conducted the analysis and drafted the article. All authors discussed the interpretation of findings and provided critical revision of the article for important intellectual content. CM acted as guarantor.

Funding This work was supported by the Swiss National Science Foundation (SNSF) for the project 'Healthy Ageing in the Face of Death: Preferences, Communication, Knowledge, and Behaviors Regarding End of Life and End-of-life Planning Among Older Adults in Switzerland' with grant number 10001C_188836. This paper uses data from SHARE Waves 8 (10.6103/SHARE.w8.800) see Börsch-Supan et al (2013) for methodological details.¹ The SHARE data collection has been funded by the European Commission, DG RTD through FP5 (QLK6-CT-2001-00360), FP6 (SHARE-I3: RII-CT-2006-062193, COMPARE: CIT5-CT-2005-028857, SHARELIFE: CIT4-CT-2006-028812), FP7 (SHARE-PREP: GA N°211909, SHARE-LEAP: GA N°227822, SHARE M4: GA N°261982, DASISH: GA N°283646) and Horizon 2020 (SHARE-DEV3: GA N°676536, SHARE-COHESION: GA N°870628, SERISS: GA N°654221, SSHOC: GA N°823782, SHARE-COVID19: GA N°101015924) and by DG Employment, Social Affairs & Inclusion through VS 2015/0195, VS 2016/0135, VS 2018/0285, VS 2019/0332, and VS 2020/0313. Additional funding from the German Ministry of Education and Research, the Max Planck Society for the Advancement of Science, the US National Institute on Aging (U01_AG09740-13S2, P01_AG005842, P01_AG08291, P30_AG12815, R21_AG025169, Y1-AG-4553-01, IAG_BSR06-11, OGH4_04-064,

HHSN271201300071C, RAG052527A) and from various national funding sources is gratefully acknowledged (see <https://share-eric.eu>).

Competing interests During the preparation of this work, the author(s) used OpenAI's ChatGPT and Grammarly in order to assist with the grammatical refinement of the paper. After using these tools/services, the author(s) reviewed and edited the content as needed and take(s) full responsibility for the content of the publication.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and our study obtained ethical approval number 66/14 from the ethics committee of the canton of Vaud, Switzerland, in March 2014. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. This article uses data from Borsch-Supan, A. (2022). Survey of Health, Ageing and Retirement in Europe (SHARE) Wave 8. Release version: 1.0.0. SHARE-ERIC. Data set. DOI: 10.6103/SHARE.w8.100. Study data already de-identified are available to the scientific community upon submitting a data requisition application to the SHARE study.

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iD

Clément Meier <http://orcid.org/0000-0002-3273-7993>

REFERENCES

- Cohen J. Serious illness, dying and grieving as public health issues. *Public Health* 2021;198:59–61. 10.1016/j.puhe.2021.06.016 Available: <https://doi.org/10.1016/j.puhe.2021.06.016>
- Etkind SN, Bone AE, Gomes B, et al. How many people will need palliative care in 2040? past trends, future projections and implications for services. *BMC Med* 2017;15:102. 10.1186/s12916-017-0860-2 Available: <https://doi.org/10.1186/s12916-017-0860-2>
- Bosshard G, Zellweger U, Bopp M, et al. Medical end-of-life practices in Switzerland: A comparison of 2001 and 2013. *JAMA Intern Med* 2016;176:555–6. 10.1001/jamainternmed.2015.7676 Available: <https://doi.org/10.1001/jamainternmed.2015.7676>
- van der Heide A, Deliens L, Faisst K, et al. End-of-life decision-making in six European countries: descriptive study. *Lancet* 2003;362:345–50. 10.1016/S0140-6736(03)14019-6 Available: [https://doi.org/10.1016/S0140-6736\(03\)14019-6](https://doi.org/10.1016/S0140-6736(03)14019-6)
- Becker C, Beck K, Vincent A, et al. Communication challenges in end-of-life decisions. *Swiss Med Wkly* 2020;150:Swiss Med Wkly. 2020;150:w20351. 10.4414/smw.2020.20351 Available: <https://doi.org/10.4414/smw.2020.20351>
- Meier C, Vilpert S, Borasio GD, et al. Perceptions and knowledge regarding medical situations at the end of life among older adults in Switzerland. *J Palliat Med* 2023;26:35–46. 10.1089/jpm.2022.0057 Available: <https://doi.org/10.1089/jpm.2022.0057>
- Patel P, Lyons L. Examining the knowledge, awareness, and perceptions of palliative care in the general public over time: A Scoping literature review. *Am J Hosp Palliat Care* 2020;37:481–7. 10.1177/1049909119885899 Available: <https://doi.org/10.1177/1049909119885899>

- 8 Sudore RL, Lum HD, You JJ, *et al.* Defining advance care planning for adults: A consensus definition from a Multidisciplinary Delphi panel. *J Pain Symptom Manage* 2017;53:821–32. 10.1016/j.jpainsymman.2016.12.331 Available: <https://doi.org/10.1016/j.jpainsymman.2016.12.331>
- 9 Rietjens JAC, Sudore RL, Connolly M, *et al.* Definition and recommendations for advance care planning: an international consensus supported by the European Association for palliative care. *The Lancet Oncology* 2017;18:e543–51. 10.1016/S1470-2045(17)30582-X Available: [https://doi.org/10.1016/S1470-2045\(17\)30582-X](https://doi.org/10.1016/S1470-2045(17)30582-X)
- 10 Borrat-Besson C, Vilpert S, Borasio GD, *et al.* “Views on a “good death”: end-of-life preferences and their association with socio-demographic characteristics in a representative sample of older adults in Switzerland”. *OMEGA (Westport)* 2022;85:409–28. 10.1177/0030222820945071 Available: <https://doi.org/10.1177/0030222820945071>
- 11 Krikorian A, Maldonado C, Pastrana T. Patient’s perspectives on the notion of a good death: A systematic review of the literature. *J Pain Symptom Manage* 2020;59:152–64. 10.1016/j.jpainsymman.2019.07.033 Available: <https://doi.org/10.1016/j.jpainsymman.2019.07.033>
- 12 Pautex S, Herrmann FR, Zulian GB. Role of advance directives in palliative care units: a prospective study. *Palliat Med* 2008;22:835–41. 10.1177/0269216308094336 Available: <https://doi.org/10.1177/0269216308094336>
- 13 van Wijmen MPS, Pasman HRW, Widdershoven GAM, *et al.* Motivations, aims and communication around advance directives: A mixed-methods study into the perspective of their owners and the influence of a current illness. *Patient Educ Couns* 2014;95:393–9. 10.1016/j.pec.2014.03.009 Available: <https://doi.org/10.1016/j.pec.2014.03.009>
- 14 Detering KM, Hancock AD, Reade MC, *et al.* The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010;340:c1345. 10.1136/bmj.c1345 Available: <https://doi.org/10.1136/bmj.c1345>
- 15 Silveira MJ, Kim SYH, Langa KM. Advance directives and outcomes of Surrogate decision making before death. *N Engl J Med* 2010;362:1211–8. 10.1056/NEJMsa0907901 Available: <https://doi.org/10.1056/NEJMsa0907901>
- 16 Arruda LM de, Abreu KPB, Santana LBC, *et al.* Variables that influence the medical decision regarding advance directives and their impact on end-of-life care. *Einstein (Sao Paulo)* 2020;18:eRW4852. 10.31744/einstein_journal/2020RW4852 Available: https://doi.org/10.31744/einstein_journal/2020RW4852
- 17 Rao JK, Anderson LA, Lin F-C, *et al.* Completion of advance directives among U.S. consumers. *Am J Prev Med* 2014;46:65–70. 10.1016/j.amepre.2013.09.008 Available: <https://doi.org/10.1016/j.amepre.2013.09.008>
- 18 Vilpert S, Borrat-Besson C, Maurer J, *et al.* Awareness, approval and completion of advance directives in older adults in Switzerland. *Swiss Med Wkly* 2018;148:Swiss Med Wkly. 2018;148:w14642. 10.4414/smw.2018.14642 Available: <https://doi.org/10.4414/smw.2018.14642>
- 19 Zimmermann M, Felder S, Streckeisen U, *et al.* *Das Lebensende in der Schweiz - Individuelle und gesellschaftliche Perspektiven*. Basel: Schwabe Verlag, 2019.
- 20 Sudore RL, Landefeld CS, Barnes DE, *et al.* An advance directive redesigned to meet the literacy level of most adults: a randomized trial. *Patient Educ Couns* 2007;69:165–95. 10.1016/j.pec.2007.08.015 Available: <https://doi.org/10.1016/j.pec.2007.08.015>
- 21 Ladin K, Buttafarro K, Hahn E, *et al.* End-of-life care? I’m not going to worry about that yet, health literacy gaps and end-of-life planning among elderly dialysis patients. *The Gerontologist*. *Gerontologist* 2018;58:290–9. 10.1093/geront/gnw267 Available: <https://doi.org/10.1093/geront/gnw267>
- 22 Murphy DJ, Burrows D, Santilli S, *et al.* The influence of the probability of survival on patients’ preferences regarding cardiopulmonary resuscitation. *N Engl J Med* 1994;330:545–9. 10.1056/NEJM199402243300807 Available: <https://doi.org/10.1056/NEJM199402243300807>
- 23 Tavakoly Sany SB, Esmaeily A, Lael-Monfared E, *et al.* Organizing framework to investigate associations between diabetes knowledge, health literacy, and self-care behaviors in patients with type 2 diabetes based on the extended parallel process model. *J Diabetes Metab Disord* 2020;19:1283–92. 10.1007/s40200-020-00642-w Available: <https://doi.org/10.1007/s40200-020-00642-w>
- 24 Gazmararian JA, Williams MV, Peel J, *et al.* Health literacy and knowledge of chronic disease. *Patient Educ Couns* 2003;51:267–75. 10.1016/s0738-3991(02)00239-2 Available: [https://doi.org/10.1016/s0738-3991\(02\)00239-2](https://doi.org/10.1016/s0738-3991(02)00239-2)
- 25 de Vries K, Banister E, Dening KH, *et al.* Advance care planning for older people: the influence of Ethnicity, religiosity, spirituality and health literacy. *Nurs Ethics* 2019;26:1946–54. 10.1177/0969733019833130 Available: <https://doi.org/10.1177/0969733019833130>
- 26 Melhado L, Bushy A. Exploring uncertainty in advance care planning in African Americans: does low health literacy influence decision making preference at end of life. *Am J Hosp Palliat Care* 2011;28:495–500. 10.1177/1049909110398005 Available: <https://doi.org/10.1177/1049909110398005>
- 27 Luo Q, Shi K, Hung P, *et al.* Associations between health literacy and end-of-life care intensity among Medicare beneficiaries. *Am J Hosp Palliat Care* 2021;38:626–33. 10.1177/1049909120988506 Available: <https://doi.org/10.1177/1049909120988506>
- 28 O Riordan J, Kane PM, Noble H, *et al.* n.d. Advance care planning and health literacy in older dialysis patients: qualitative interview study. *BMJ Support Palliat Care*:bmjspcare–2021 10.1136/bmjspcare-2021-003273 Available: <https://doi.org/10.1136/bmjspcare-2021-003273>
- 29 Volandes AE, Barry MJ, Chang Y, *et al.* Improving decision making at the end of life with Video images. *Med Decis Making* 2010;30:29–34. 10.1177/0272989X09341587 Available: <https://doi.org/10.1177/0272989X09341587>
- 30 Waite KR, Federman AD, McCarthy DM, *et al.* Literacy and race as risk factors for low rates of advance directives in older adults. *J American Geriatrics Society* 2013;61:403–6. 10.1111/jgs.12134 Available: <https://agsjournals.onlinelibrary.wiley.com/toc/15325415/61/3>
- 31 Skuiers L, Peinado S, Berkman N, *et al.* The health literacy skills framework. *J Health Commun* 2012;17:30–54. 10.1080/10810730.2012.713442 Available: <https://doi.org/10.1080/10810730.2012.713442>
- 32 Paasche-Orlow MK, Wolf MS. The causal pathways linking health literacy to health outcomes. *Am J Health Behav* 2007;31:19–26. 10.5993/AJHB.31.s1.4 Available: <https://doi.org/10.5555/ajhb.2007.31.supp.S19>
- 33 Kermel-Schiffman I, Werner P. Knowledge regarding advance care planning: A systematic review. *Arch Gerontol Geriatr* 2017;73:133–42. 10.1016/j.archger.2017.07.012 Available: <https://doi.org/10.1016/j.archger.2017.07.012>
- 34 Parker RM, Baker DW, Williams MV, *et al.* The test of functional health literacy in adults: a new instrument for measuring patients’ literacy skills. *J Gen Intern Med* 1995;10:537–41. 10.1007/BF02640361 Available: <https://doi.org/10.1007/BF02640361>
- 35 Meier C, Vilpert S, Wiecezorek M, *et al.* Development and validation of a subjective end-of-life health literacy scale. *PLOS ONE* 2023;18:e0292367. 10.1371/journal.pone.0292367 Available: <https://doi.org/10.1371/journal.pone.0292367>
- 36 Börsch-Supan A. The Survey of Health, Ageing and Retirement in Europe (SHARE): Release Guides 8.0.0 2022, Available: <https://doi.org/10.6103/SHARE.w8.800>
- 37 Bergmann M, Börsch-Supan A. *SHARE Wave 8 Methodology: Collecting Cross-National Survey Data in Times of COVID-19*. Munich MEA Max Planck Inst Soc Law Soc Policy, 2021.
- 38 OFSP BAS. *ALZ Alzheimer Schweiz: Demenz in der Schweiz 2020: Zahlen und Fakten*. 2020.
- 39 Pelikan J, Ganahl K, Van den S, *et al.* Measuring health literacy in Europe: introducing the European health literacy survey questionnaire (HLS-EU-Q). 2019.
- 40 Hoffmeyer-Zlotnik JHP, Wolf C. International standard classification of education, ISCED 1997. Adv. cross-Natl. COMP. Eur. work. book Demogr. socio-ECON. *Adv Cross-Natl Comp Eur Work Book Demogr Socio-Econ Var* 2003:195–220.
- 41 Noonan K, Horsfall D, Leonard R, *et al.* Developing death literacy. *Progress in Palliative Care* 2016;24:31–5. 10.1080/09699260.2015.1103498 Available: <https://doi.org/10.1080/09699260.2015.1103498>
- 42 Jody M, Jackson RN, Sharon J, *et al.* Knowledge, attitudes, and preferences regarding advance directives among patients of a managed care organization. 2009;15.
- 43 Kopp SW. The influence of death attitudes and knowledge of end of life options on attitudes toward physician-assisted suicide. *OMEGA (Westport)* 2008;58:299–311. 10.2190/om.58.4.c Available: <https://doi.org/10.2190/OM.58.4.c>
- 44 Silveira MJ, DiPiero A, Gerrity MS, *et al.* Patients’ knowledge of options at the end of life: ignorance in the face of death. *JAMA* 2000;284:2483–8. 10.1001/jama.284.19.2483 Available: <https://doi.org/10.1001/jama.284.19.2483>
- 45 Zhang N, Ning X, Zhu M, *et al.* Attitudes towards advance care planning and Healthcare autonomy among community-dwelling older adults in Beijing, China. *Biomed Res Int* 2015;2015:453932.

- 10.1155/2015/453932 Available: <https://doi.org/10.1155/2015/453932>
- 46 Chung R-N, Wong E-Y, Kiang N, *et al.* Knowledge, attitudes, and preferences of advance decisions, end-of-life care, and place of care and death in Hong Kong. A population-based telephone survey of 1067 adults. *J Am Med Dir Assoc* 2017;18:S1525-8610(16)30670-3. 10.1016/j.jamda.2016.12.066 Available: <https://doi.org/10.1016/j.jamda.2016.12.066>
- 47 Islam I, Nelson A, Longo M, *et al.* Before the 2020 pandemic: an observational study exploring public knowledge, attitudes, plans, and preferences towards death and end of life care in Wales. *BMC Palliat Care* 2021;20:116. 10.1186/s12904-021-00806-2 Available: <https://doi.org/10.1186/s12904-021-00806-2>
- 48 Vilpert S, Borasio GD, Maurer J. Knowledge gaps in end-of-life care and planning options among older adults in Switzerland. *Int J Public Health* 2022;67. 10.3389/ijph.2022.1604676 Available: <https://doi.org/10.3389/ijph.2022.1604676>
- 49 Fried TR, Redding CA, Robbins ML, *et al.* Stages of change for the component behaviors of advance care planning. *J American Geriatrics Society* 2010;58:2329-36. 10.1111/j.1532-5415.2010.03184.x Available: <https://agsjournals.onlinelibrary.wiley.com/toc/15325415/58/12>
- 50 Sudore RL, Knight SJ, McMahan RD, *et al.* A novel Website to prepare diverse older adults for decision making and advance care planning: A pilot study. *J Pain Symptom Manage* 2014;47:674-86. 10.1016/j.jpainsymman.2013.05.023 Available: <https://doi.org/10.1016/j.jpainsymman.2013.05.023>
- 51 Zhang X, Jeong S-S, Chan S. Advance care planning for older people in Mainland China: an integrative literature review. *Int J Older People Nurs* 2021;16:e12409. 10.1111/opn.12409 Available: <https://doi.org/10.1111/opn.12409>
- 52 Yorke J, Yobo-Addo E, Singh K, *et al.* Baseline knowledge attitudes satisfaction and aspirations with advance care planning: A cross-sectional study. *Am J Hosp Palliat Care* 2022;39:448-55. 10.1177/10499091211030447 Available: <https://doi.org/10.1177/10499091211030447>
- 53 Schreiber-Baum HC, Xenakis LE, Chen EK, *et al.* A qualitative inquiry on palliative and end-of-life care policy reform. *J Palliat Med* 2016;19:400-7. 10.1089/jpm.2015.0296 Available: <https://doi.org/10.1089/jpm.2015.0296>
- 54 Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *Gerontologist* 2005;45:634-41. 10.1093/geront/45.5.634 Available: <https://doi.org/10.1093/geront/45.5.634>
- 55 Fischer SM, Sauaia A, Min S-J, *et al.* Advance directive discussions: lost in translation or lost opportunities *J Palliat Med* 2012;15:86-92. 10.1089/jpm.2011.0328 Available: <https://doi.org/10.1089/jpm.2011.0328>
- 56 Volandes AE, Paasche-Orlow M, Gillick MR, *et al.* Health literacy not race predicts end-of-life care preferences. *J Palliat Med* 2008;11:754-62. 10.1089/jpm.2007.0224 Available: <https://doi.org/10.1089/jpm.2007.0224>
- 57 Huang H-Y, Kuo K-M, Lu I-C, *et al.* The impact of health literacy on knowledge, attitude and decision towards Hospice care among community-dwelling seniors. *Health Soc Care Community* 2019;27:e724-33. 10.1111/hsc.12791 Available: <https://doi.org/10.1111/hsc.12791>
- 58 Nouri SS, Barnes DE, Volow AM, *et al.* Health literacy matters more than experience for advance care planning knowledge among older adults. *J Am Geriatr Soc* 2019;67:2151-6. 10.1111/jgs.16129 Available: <https://doi.org/10.1111/jgs.16129>
- 59 van der Plas AGM, Pasman HRW, Kox RMK, *et al.* Information meetings on end-of-life care for older people by the general practitioner to stimulate advance care planning: a pre-post evaluation study. *BMC Fam Pract* 2021;22:109. 10.1186/s12875-021-01463-3 Available: <https://doi.org/10.1186/s12875-021-01463-3>
- 60 Pautex S, Gamondi C, Philippin Y, *et al.* Advance directives and end-of-life decisions in Switzerland: role of patients, relatives and health professionals. *BMJ Support Palliat Care* 2018;8:475-84. 10.1136/bmjspcare-2014-000730 Available: <https://doi.org/10.1136/bmjspcare-2014-000730>
- 61 Sudore RL, Landefeld CS, Pantilat SZ, *et al.* Reach and impact of a mass media event among vulnerable patients: the Terri Schiavo story. *J Gen Intern Med* 2008;23:1854-7. 10.1007/s11606-008-0733-7 Available: <https://doi.org/10.1007/s11606-008-0733-7>