

End-of-life preferences among different forms of engagement in advance care planning

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Background

Advance care planning (ACP) is the process of helping adults understand and share their personal values, life goals, and preferences for medical care, anticipating future decisional incapacity and documenting their preferences in advance directives (AD).

Previous population-based studies have shown that many end-of-life (EOL) aspects pertaining to medical, psychosocial, burden and control dimensions were considered important for most Swiss residents aged 55+, with significant variations across sociodemographic groups (Borrat-Besson et al., 2020, 2022).

Aim

To examine the association between engagement in advanced care planning (ACP) and the importance attached to different EOL aspects.

Method

Data: Data from respondents of wave 6 (2015) of the Survey of Health, Ageing and Retirement in Europe (SHARE) in Switzerland who also completed a paper-and-pencil questionnaire on EOL issues administered after their SHARE face-to-face interview.

The final analytical sample included 2063 individuals aged 55+ living in Switzerland.

Dependent Variables: Respondents assessed the importance of 23 items related to various aspects of the EOL on a 4-point Likert scale (11 representative of each of the four dimensions are presented here). The answers were dummy coded (0='not important' or 'not so important' and 1='important' or 'very important').

Independent Variable: Respondents were asked whether they discussed their EOL preferences (0='no' and 1='yes') and had an AD (0='no' and 1='yes'). Engagement in ACP was derived from these two variables.

Statistical Analysis: Associations between the dummy coded variables assessing the importance attached to the different EOL aspects and engagement in ACP were examined using multivariable logistic regression models, controlling for sociodemographic, regional and health covariates.

Key findings

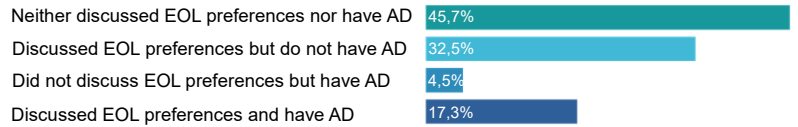
Most participants considered many different EOL aspects important or very important, with significant variations among participants depending on their engagement in ACP for some EOL aspects.

Specifically:

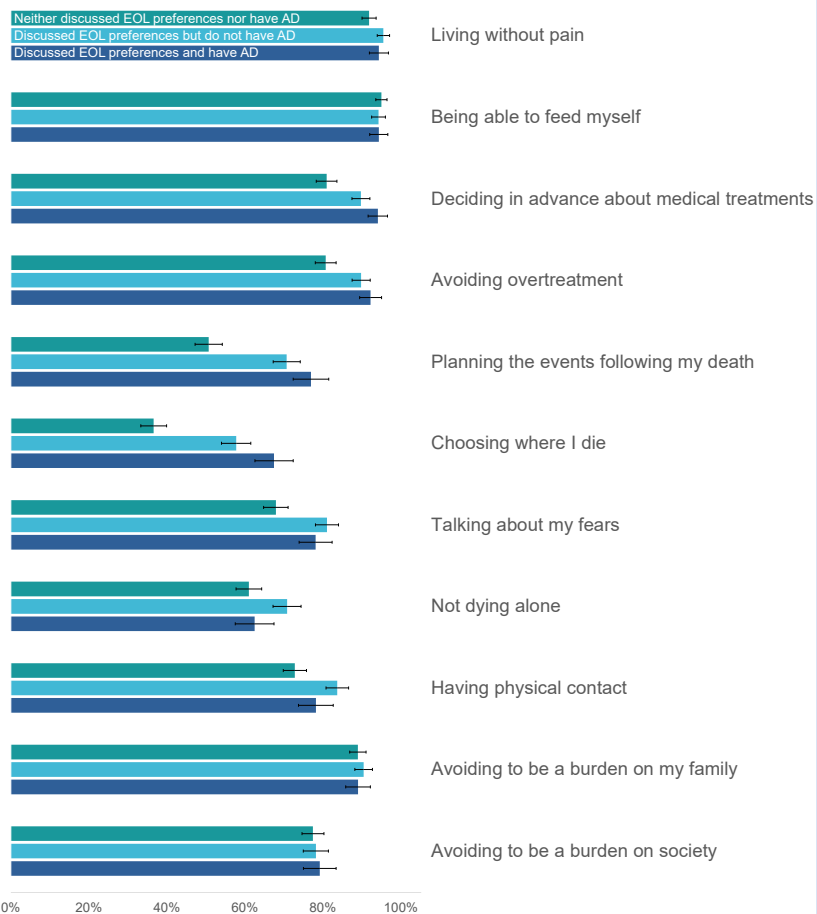
- There was no significant differences in the importance attached to the medical aspects (e.g., living without pain, being able to feed myself) in relation to engagement in ACP.
- There was also no significant differences in the importance attached to avoid to be a burden on family and on society in relation to engagement in ACP.
- Compared with participants who had neither discussed their EOL preferences nor written ADs, those who had conducted such discussion, whether or not accompanied by the writing of ADs, were significantly more likely to find it important to prepare for the EOL (e.g., plan the event following death), decide on related aspects (e.g., decide in advance about treatment, choose the place of death) and avoid overtreatment.
- Participants who discussed their EOL preferences without making ADs were significantly more likely to find psychosocial aspects (e.g., talking about fears, not dying alone, having physical contact) important compared to the other groups.

Results

Weighted distribution of engagement in ACP ($N_{\text{total}} = 2063$)



Predicted percentage* of individuals, broken by engagement levels in ACP**, rating EOL aspects important or very important with 95% confidence intervals



*Predicted percentages were determined using multivariable logistic regression models with age, education, linguistic region, partnership status, children, living area, financial situation, frequency of prayer, subjective health and depression as covariates.

**The predicted margins for the category «Did not discuss EOL preferences but have AD» are not presented due to the limited sample size, resulting in large confidence intervals.

Discussion

Our results show that individuals who discuss their EOL preferences without writing ADs find just as important to prepare for and plan their EOL as those who do have ADs. However, psychosocial aspects seem to be of particular importance to them.

These findings confirm the importance of a comprehensive, holistic, and multidisciplinary approach to the EOL, as practiced in palliative care and as conceived in ACP.

Our results also suggest that better highlighting the non-medical aspects included in ACP when promoting them, and encouraging the preparation of ACP outside the medical setting as well, could motivate a greater number of individuals to actively prepare for their EOL.