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Participating in decision-making at the end of life: The self-reported ability of people with cancer across 11 countries

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ABSTRACT

Objectives: Uncertainty among healthcare providers about patients' ability to make care decisions is a barrier to shared decision-making. We aimed to assess the self-reported decision-making ability of patients with cancer at the end of life.

Methods: Data from 11 countries of adults with a limited life expectancy and cancer as the primary diagnosis were used. Participants completed a questionnaire, including one item on decision-making ability and two on decision-making preferences. Correlations between self-reported ability and preferences were tested using Kendall's tau. Associations between decision-making ability and patient characteristics were determined using mixed-effects ordinal regression models.

Results: The sample (n = 1076, 53 % identified as men) had a mean age of 69 years (SD: 11.5). Among them, 80 % reported being able to make decisions about their life and care *most of the time*, 14 % *some of the time*, 5 % *only a little of the time,* and 2 % *never*. Regarding preferences, 95 % preferred to be involved in decision-making and 44 % preferred the doctors to make the decisions. These preferences were weakly correlated with decision-making ability (Kendall's tau: 0.13 and −0.11, respectively). Feeling able to make decisions was less likely for those institutionalized (versus living with relatives, OR: 0.26, 95 % CI: 0.12;0.55), those with tertiary education (versus primary/no education, OR: 0.43, 95 % CI: 0.22;0.85) and those without clear understanding of their health (versus those with understanding, OR: 0.29, 95 % CI: 0.16;0.52).

Conclusions: Although most patients felt able to make decisions about their care, two out of every ten did not. About five out of ten preferred their doctors to make decisions.

Practice implications: As almost all patients want to be involved in decisions, we suggest that providers discuss with patients how decisions will be made. This may enable providers to identify patients' needs and adapt the decision-making process to their abilities and preferences.

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1. Introduction

Decision-making about care at the end of life is complex due to unpredictable disease courses, complex care requirements, and communication challenges between patients and healthcare providers [1–4]. Misalignment between patients' preferred care and the care actually received can lead to reduced quality of life [5–8]. In cancer care, challenges are particularly pronounced as the disease may reach a stage where cure is no longer possible and treatment shifts from pursuing survival to maintaining quality of life [1]. In this phase, timely conversations with patients about their treatment goals and options are needed.

To support patients and healthcare providers in making care decisions based on evidence, clinical expertise, and patient values, shared decision-making (SDM) has become a recognized approach [9]. Barriers to SDM include healthcare providers' uncertainty about implementing it effectively and their reluctance to engage when they believe that SDM could lead to decisions worsening the patient's prognosis, often due to the severity or complexity of the disease [10]. Moreover, uncertainty remains about patients' ability to engage in decisions about their care. For example, two systematic reviews on decision-making during palliative care highlight that while many patients with cancer express a willingness to participate in treatment decisions, the emotional burden, stress, and urgency of care situations can hinder their ability to do so [11,12]. Consequently, SDM does not always occur in clinical practice, despite its recognized importance.

To gain better understanding of decision-making ability near the end of life, we investigated whether patients with cancer at the end of life considered themselves able to make decisions about their life and care, and whether these abilities are related to their decision-making preferences and sociodemographic factors.

2. Methods

2.1. Study design and setting

This study used baseline data from the iLIVE cohort study, which has been described in detail by Yildiz et al. [13]. It was conducted in 11 countries: Argentina, Germany, Iceland, the Netherlands, New Zealand, Norway, Slovenia, Sweden, Switzerland, Spain, and the United Kingdom.

2.2. Study population

Physicians screened patients with a limited life expectancy for eligibility, using a modified version of the Gold Standards Framework Proactive Identification Guidance (GSF-PIG) [14]. Additional inclusion criteria included being at least 18 years old, being aware of the unlikelihood of recovery, and being able to provide informed consent. This paper specifically focused on patients whose primary diagnosis was cancer.

2.3. Measures

2.3.1. Questionnaire topics

Patients completed a questionnaire on their experiences, concerns, expectations, and preferences with respect to their care. We used items on decision-making ability and preferences. Ability was assessed with one item from the seven-item ICECAP Supportive Care Measure (ICECAP-SCM): '*I am able to make decisions that I need to make about life and care*', rated from '*Most of the time*' to '*Never*' [15]. Preferences were measured with two items from the 27-item Attitudes of Older People to End-of-Life Issues tool (AEOLI): '*I want to be involved in decision-making about the care I receive*' and '*I prefer the doctor to make all the decisions about my care*', rated from '*Strongly agree*' to '*Strongly disagree*' [16].

2.3.2. Sociodemographic and clinical characteristics

Patients provided information about year of birth, gender, living situation, religious or philosophical beliefs, education, socio-economic status and health status (EuroQol 5 Dimension questionnaire and EuroQol visual analog scale [17]). Physicians supplied information on patients' primary diagnosis, functional status (Australian version of the Karnofsky Performance Status [18]) and survival status.

2.4. Statistical analyses

Correlations between decision-making ability and preferences were tested using Kendall's tau correlation test. Univariable and multivariable relationships between decision-making ability and patients' background characteristics were examined using ordinal cumulative linked (mixed) models. Multivariable analysis included a random intercept for country, computing median odd ratios ((M)ORs). To account for missing data in the regression analyses, multiple imputation of the independent variables was performed using 20 imputed datasets. All analyses were conducted in R studio version 4.3.2.

2.5. Ethics

The study was approved by appropriate ethical authorities in all participating countries. Participants provided informed consent. The study is registered in ClinicalTrials.gov (NCT04271085).

3. Results

3.1. Descriptive statistics

Of the 1423 patients participating in the iLIVE cohort study, 1076 (75.5 %) had cancer. Patients with cancer were on average 69 years old (SD: 11.5); 569 (52.9 %) identified as men and 507 (47.1 %) as women, see Table 1. Table 2 provides an overview of patients' (self-reported) decision-making ability and preferences: 790 (79.7 %) patients reported to be able to make necessary decisions about their life and care *most of the time*, 134 (13.6 %) had that ability *some of the time*, 47 (4.7 %) *only a little of the time* and 20 (2 %) *never*. Moreover, 904 (94.9 %) patients wanted to be involved in making decisions about their care and 409 (44.0 %) preferred their doctor to make all decisions about their care.

3.2. Correlation between decision-making ability and preferences

Figs. 1 and 2 show a weak correlation between patients' decision-making ability and their preference to be involved in decision-making (Kendall's correlation tau: 0.13, p-value: <0.0001), and for their doctor making the decisions (Kendall's correlation tau: −0.11, p-value: <0.001), respectively.

3.3. Regression analyses

Table 3 displays the associations between patients' decision-making ability and their characteristics. Multivariable analysis showed that those living in an institution were less likely to feel able to make decisions about their life and care, compared to those living with relatives (OR: 0.26, 95 % CI: 0.12–0.55). Individuals with tertiary education were less likely to feel able to make these decisions compared to those with primary or no education (OR: 0.43, 95 % CI: 0.22–0.85). Those who

Table 1
Characteristics of participants (N = 1076).

Variable, category	
Age at inclusion (in years)	
Mean (SD)	69.4 (11.5)
Range (min-max)	25–96
Missing	*0*
Gender	**n (%)**
Man	569 (52.9)
Woman	507 (47.1)
Living situation	**n (%)**
Alone	270 (30.0)
With relatives	575 (64.0)
In an institution	39 (4.3)
Other	15 (1.7)
Missing	*177*
Country	**n (%)**
Argentina	153 (14.2)
Switzerland	87 (8.1)
Germany	80 (7.4)
Spain	139 (12.9)
UK	84 (7.8)
Iceland	98 (9.1)
Netherlands	134 (12.5)
Norway	128 (11.9)
New Zealand	35 (3.3)
Sweden	53 (4.9)
Slovenia	85 (7.9)
Religion	**n (%)**
Yes	450 (51.6)
No	388 (44.5)
Prefer not to answer	34 (3.9)
Missing	*204*
Educational level	**n (%)**
None or primary	117 (13.2)
Secondary	286 (32.3)
Tertiary	214 (24.2)
University	266 (30.1)
Other	2 (0.2)
Missing	*191*
Socio-economic situation	**n (%)**
Retired	590 (66.4)
Disability pension or long-term sick leave	153 (17.2)
Part-time or full-time paid employment or self-employed	80 (9.0)
Unemployed (no paid job)	41 (4.6)
Other	25 (2.8)
Missing	*187*
I have a clear understanding of my health condition	**n (%)**
(Strongly) agree	851 (88.5)
Neither	51 (5.4)
(Strongly) disagree	59 (6.1)
Missing	*115*
Health status, EQ-VAS score	
Mean (SD)	49 (24)
Range (min-max)	0–100
Missing	*78*
Functional status, Karnofsky Performance Status	**n (%)**
Unable to care for self - disease may be progressing rapidly. (0−40)	225 (21.2)
Unable to work - varying amount of assistance needed. (50−70)	618 (58.3)
Able to carry on normal activity and to work - no special care needed. (80−100)	217 (20.5)
Missing	*16*
Survival status	**n (%)**
Died within 1 month after study inclusion	306 (30.6)
Died month 2–6	228 (22.8)
Died, date unknown	142 (14.2)
Survived beyond month 6	257 (25.6)
Survived month 1 but further survival status unknown	68 (6.8)
Missing	*75*

reported not understanding their health condition were less likely to feel able to make decisions compared to those who reported understanding their health condition (OR: 0.29, 95 % CI: 0.16–0.52). We found moderate between-country differences for patients reporting to be able to make these decisions (MOR: 1.99, SD: 0.72).

4. Discussion and conclusion

4.1. Discussion

We found that the majority of patients with cancer at the end of life considered themselves able to make decisions about their life and care. While self-efficacy in decision-making has been studied among people with cancer [19,20], proportions of patients considering themselves able to make decisions were not yet reported. We also found that decision-making ability and preferences are largely independent in the last phase of life. Similar results have been observed among people with earlier stages of cancer, where self-efficacy in decision-making was comparable among those who preferred to make decisions themselves compared to those who did not [19].

While preferences were not associated with decision-making ability, our findings suggest that, at the end of life, decision-making ability is suboptimal in patients living in institutions or with limited understanding of their health. This observation aligns with a review on SDM in cancer care, which identified limited health literacy as a barrier to participating in decision-making and emphasized the role of organizational factors [12]. However, systematic reviews report that support of healthcare providers improves patients' decision-making ability regardless of these barriers [21,22]. Unexpectedly, we found that patients with tertiary education were less likely to feel able to make decisions compared to those with primary education or no education, contradicting literature that notes education as supportive for involvement in decision-making [23]. Our findings suggest that education may not be a facilitator of decision-making ability in end-of-life contexts. However, we could not ascertain why this association emerged.

This study's strengths include its large, international sample and structured assessment of participants' eligibility by physicians, using the modified GSF-PIG to assess life expectancy. However, there are limitations to consider. First, we used a single-item measure of decision-making ability, which limits reliability and validity as it does not capture the multidimensional nature of the decision-making process. Second, items on decision-making abilities and preferences were closed questions, further limiting understanding of what the patients' actual abilities were and why patients feel (un)able to decide. Last, the number and type of study sites varied per country, which led us to refrain from conducting country-specific analyses.

4.2. Conclusion

Although the majority of patients with cancer at the end of life considered themselves able to make decisions about their life and care, still two out of every ten patients did not. About five out of ten preferred doctors to make decisions. This highlights the need for healthcare providers to engage patients in conversations to discuss how decisions will be made.

4.3. Practice implications

As most patients wanted to be involved in decisions, we suggest that healthcare providers initiate early conversations to explore patients' needs and preferences regarding decision-making. Quality of care may improve when these aspects are openly discussed [24]. If a patient feels unable to make decisions, this should be addressed, and the decision-making process should be adapted to their abilities. Conversely, patients capable of making decisions may still prefer not to do so. By clarifying how decisions will be made, providers can help reduce decisional burden and align care with individual values [25]. This approach is especially important in end-of-life care, where decisions are often complex and emotionally charged [21].

Table 2
Self-reported decision-making ability and preferences of people with cancer at the end of life.

Variable, category	**n (%)**
I am able to make decisions that I need to make about my life and care	
Most of the time	790 (79.7)
Some of the time	134 (13.6)
Only a little of the time	47 (4.7)
Never	20 (2.0)
Missing	*85*
I want to be involved in decision-making about the care I receive	
(Strongly) agree	904 (94.9)
Neither	25 (2.6)
(Strongly) disagree	24 (2.5)
Missing	*123*
I prefer the doctors to make all the decisions about my care	
(Strongly) agree	409 (44.0)
Neither	127 (13.7)
(Strongly) disagree	394 (42.3)
Missing	*146*

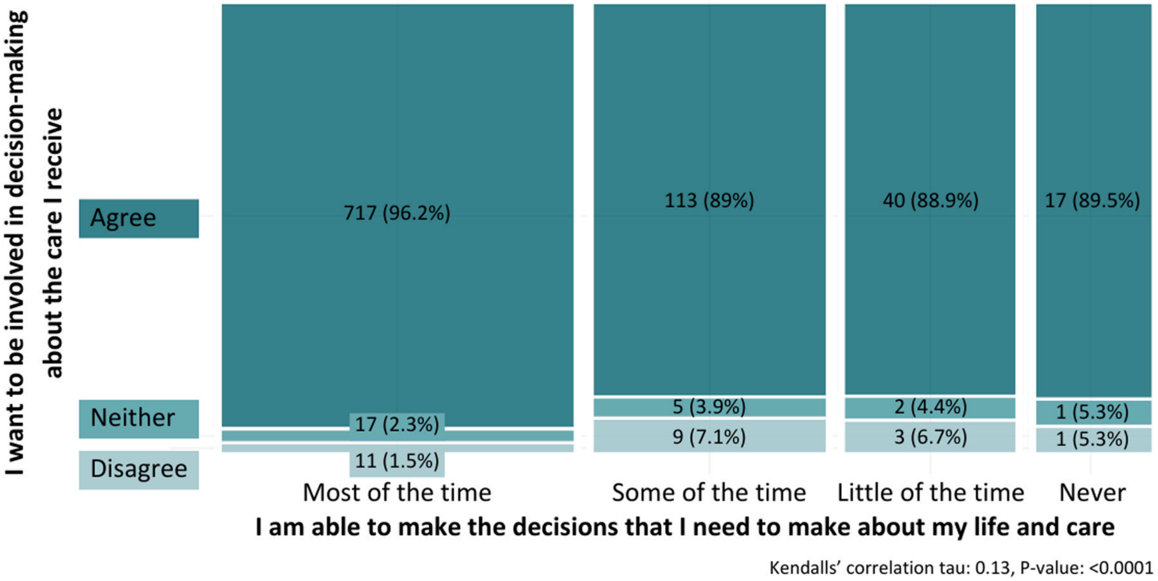

Fig. 1. The correlation between self-reported ability to make decisions about life and care among people with cancer at the end of life and their preference for wanting to be involved in decision-making about the care they receive. The percentages within each vertical bar sum up to 100 %.

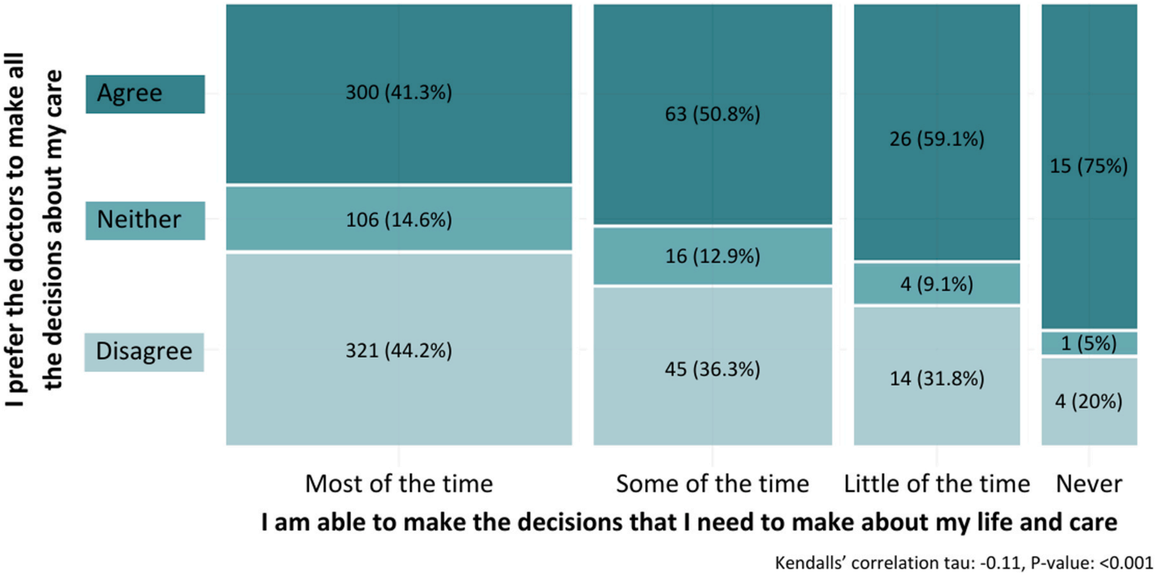

Fig. 2. The correlation between self-reported ability to make decisions about life and care among people with cancer at the end of life and their preference for doctors to make decisions about their care. The percentages within each vertical bar sum up to 100 %.

Table 3
Ordinal univariable regression and multivariable regression, including a random intercept for country, of decision-making ability of patients with cancer at the end of life. The reference categories are in italics and between brackets.

Variable and (*reference*) category	**More likely to be able to make decisions that they need to make about their life and care**					
	Univariable			Multivariable		
	OR	95 % CI	Sig.	OR	95 % CI	Sig.
Age per 10-year increase	0.98	0.86;1.12	0.81	1.03	0.83;1.27	0.82
Gender						
(Man)	1			1		
Woman	1.26	0.93;1.72	0.14	1.28	0.90;1.83	0.17
Living situation						
(With relatives)	1			1		
Alone	0.81	0.57;1.17	0.26	0.84	0.56;1.27	0.40
In an institution	0.23	0.12;0.44	<0.0001	0.26	0.12;0.55	<0.001
Religion						
(Yes)	1			1		
No	1.05	0.76;1.45	0.77	1.05	0.73;1.50	0.81
Educational level						
(None or primary)	1			1		
Secondary	0.68	0.38;1.21	0.19	0.61	0.31;1.18	0.14
Tertiary	0.42	0.24;0.75	0.004	0.43	0.22;0.85	0.01
University	0.67	0.38;1.19	0.17	0.64	0.33;1.24	0.18
Socio-economic situation						
(Retired)	1			1		
Disability pension or long-term illness	0.91	0.61;1.37	0.66	0.99	0.55;1.76	0.97
Employed	1.36	0.73;2.52	0.33	1.73	0.79;3.79	0.17
Unemployed or homemaker	1.12	0.55;2.25	0.76	0.64	0.27;1.48	0.29
I have a clear understanding of my health condition						
(Agree)	1			1		
Neither	0.68	0.34;1.36	0.28	0.53	0.26;1.11	0.09
Disagree	0.31	0.18;0.53	<0.0001	0.29	0.16;0.52	<0.0001
Health status, EQ-VAS score	1.01	1.00;1.01	0.03	1.00	1.00;1.01	0.40
Functional status, Karnofsky Performance Status						
(Unable to care for self)	1			1		
Unable to work	1.61	1.11;2.33	0.01	1.21	0.78;1.89	0.40
Able to carry on normal activity and to work	1.70	1.06;2.72	0.03	1.36	0.73;2.51	0.33
Survival status						
(Died within 1 month)	1			1		
Died month 2–6	0.82	0.54;1.23	0.33	0.86	0.51;1.45	0.58
Survived beyond month 6	1.41	0.92;2.17	0.11	1.35	0.78;2.32	0.29
Country				**Random effect**, MOR (SD): 1.99 (0.72)		
(UK)	1					
Argentina	1.05	0.57;1.95	0.87			
Switzerland	1.77	0.83;3.79	0.14			
Germany	1.72	0.76;3.90	0.19			
Spain	3.36	1.57;7.20	0.002			
Iceland	2.40	1.04;5.50	0.04			
Netherlands	1.50	0.75;2.98	0.25			
Norway	0.90	0.48;1.71	0.76			
New Zealand	2.76	0.87;8.73	0.09			
Sweden	2.45	0.91;6.58	0.08			
Slovenia	0.40	0.20;0.79	0.008			

Abbreviations: CI, confidence interval; MOR, median odds ratio; OR, odds ratio; SD, standard deviation.

CRediT authorship contribution statement

Judith AC Rietjens: Writing – review & editing, Methodology, Conceptualization. **Pilar Barnestein-Fonseca:** Writing – review & editing. **Dröfn Birgisdóttir:** Writing – review & editing. **Melanie Joshi:** Writing – review & editing. **Vilma A Tripodoro:** Writing – review & editing. **Stephen Mason:** Writing – review & editing. **Agnes van der Heide:** Writing – review & editing, Project administration, Methodology, Funding acquisition. **Yassin Engelberts:** Writing – review & editing, Writing – original draft, Visualization, Methodology, Formal analysis, Conceptualization. **Dagny Faksvåg Haugen:** Writing – review & editing. **Antoine Elyn:** Writing – review & editing. **Laura A Hartman:** Writing – review & editing. **Claudia Fischer:** Writing – review & editing. **Ida J Korfage:** Writing – review & editing, Supervision, Project administration, Methodology, Conceptualization.

Ethics approvals

The study has been conducted in accordance with national and international regulations and guidelines, including the Declaration of Helsinki, and the International Conference on Harmonisation (ICH) guidance on Good Clinical Practice (GCP). The study has been approved by ethics committees and institutional review boards in all participating countries. The following ethics committees have approved the study:

- Regional Committee for Medical and Health Research Ethics South East D (35035), Norway.
- Komisija Republike Slovenije za Medicinsko etiko (0120–129/2020/3), Slovenia.
- Health Research Authority (HRA) and Health and Care Research Wales (HCRW) (272927), UK.
- Comité de Ética de la Investigación Provincial de Málaga, Hospital Regional Universitario de Malaga, Spain.

- Swedish Ethical Review Authority (2020–01956), Lund University, Sweden.
- The National Bioethics Committee (VSN-20–129), Iceland.
- Ethics Commission of Cologne University, Faculty of Medicine (19–1456_1).
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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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