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Preferences for discussing life expectancy: A cross-sectional survey among geriatric outpatients in Denmark

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Introduction

A discussion of life expectancy allows patients to make choices that fit with their health context.[1,2] Our recently published systematic review on patient preferences for discussing life expectancy found that, in 24 out of 31 of the included studies, the majority of patients (≥50%) reported a positive attitude towards discussing life expectancy.[3] Previous studies have focused mostly on patients with cancer,[3] while few have focused on older adults with frailty.[3] We examined Danish geriatric outpatients' preferences for discussing life expectancy with a physician.

Methods

We conducted our survey in the geriatric outpatient clinic at Odense University Hospital, Denmark, from September to November 2020. Patients were excluded if their visit concerned a dementia assessment, if they did not speak Danish, or if the nurses deemed them of low cognitive ability.

We developed a survey based on previous literature[3] and with input from Danish experts on the topic. We piloted the survey among four patients, using cognitive interviews, and revised it into a final version. The survey had two sections, one exploring patient characteristics and one exploring patient preferences for discussing life expectancy. One author (EB) interviewed patients in a private room in the geriatric outpatient clinic. Patients were given as much time as needed to provide their answers. The interviews lasted on average 20 minutes. The outcome of interest was patients' willingness to discuss life expectancy with a physician, defined as: *not willing at all, to a low degree, to a medium degree,* or *to a high degree.* We reported results using descriptive statistics.

The study was registered in the Region of Southern Denmark's repository (approval 20/35470). The Regional Committees on Health Research Ethics waived registration due to the study design (case number 20202000-146).

Results

Ninety-three patients were invited to participate in the study of which 70 completed the survey (response rate: 75%) (**Table 1**).

The most prominent degree of willingness to discuss life expectancy was *to a high degree* (51%, n=36) followed by *to a medium degree* (26%, n=18), *to a low degree* (11%, n=8), and *not willing at all* (11%, n=8) (**Table 2**). Most patients (87%, n=61) had not previously been offered a discussion about their estimated life expectancy by a physician. However, 81% (n=57) of patients deemed it appropriate for a physician to initiate such a discussion as long as the patients had the opportunity to decline the offer (**Table 2**). Over half (63%, n=44) of patients had little or no trust in their physician's ability to predict life expectancy correctly. This was a prominent reason for not wanting to discuss life expectancy (75%, n=12) among those unwilling to discuss (**Table 2**).

Discussion

Most patients in our study reported having not been previously offered a discussion about life expectancy by a physician. However, four out of five patients deemed it appropriate for a physician to offer the discussion. This is consistent with previous studies among similar patient groups.[4–6] However, a survey conducted among 878 older persons, using an online hypothetical patient scenario,[6] found that most people unwilling to discuss their life expectancy did also not find it appropriate for a patient to even be offered a discussion on the topic. This may suggest that patients' preferences are affected by the context in which the topic is posed.

Our study population might have been in a different mindset compared to people considering a hypothetical patient scenario, as we approached patients directly following their clinic appointment and phrased the question directly about them. Given that our setting is closer to where such a discussion might normally take place during a real-life consultation, it is likely more reflective of preferences and attitudes in clinical practice.

Our survey was susceptible to recall bias and social desirability bias, possibly leading to an overrepresentation of positive preferences and underestimation of previous discussions. Further, our results may not be representative of patients of other nationalities or different healthcare settings.

Our findings suggest that physicians should generally offer to discuss life expectancy with most geriatric outpatients without fear of patients' reactions as long as the patients have the option to

decline the offer. However, this needs to be confirmed in other care contexts for older people living with frailty.

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Software

Study data were collected and managed using REDCap electronic data capture tools hosted at University of Southern Denmark. REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources. (Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research Electronic Data Capture (REDCap) - A metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009;42(2):377-381. doi:10.1016/j.jbi.2008.08.010, Harris PA, Taylor R, Minor BL, et al. The REDCap consortium: Building an international community of software platform partners. *J Biomed Inform*. 2019;95:103208. doi:10.1016/j.jbi.2019.103208)

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Declarations of conflicts of interest

All authors have submitted a disclosure of potential conflicts of interest form and declare that they have no conflict of interest.

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Table 1. *Patient characteristics for the study population and stratified for patients who wanted to discuss life expectancy and patients who did not want to discuss life expectancy.**

	Study population (n=70)†	Wanted to discuss life expectancy (n=54)†	Did not want to discuss life expectancy (n=16)†
Age, median (IQR)	82 (76-86)	81 (75-86)	82 (81-86)
Female, n (%)	45 (64)	34 (63)	11 (69)
Number of regular medications, n (%)			
0-4	12 (17)	7 (13)	5 (31)
5-9	29 (41)	25 (46)	4 (25)
≥10	29 (41)	22 (41)	7 (44)
Comorbidity, n (%)			
Hypertension	33 (47)	26 (48)	7 (44)
Osteoporosis	25 (36)	22 (41)	3 (19)
Atrial fibrillation	17 (24)	12 (22)	5 (31)
Cardiovascular disease	16 (23)	12 (22)	4 (25)
Mental and behavioral disorder	14 (20)	13 (24)	1 (6)
Musculoskeletal disorders	13 (19)	11 (20)	2 (13)
Cerebrovascular disease	10 (14)	10 (19)	-
Thyroid disease	9 (13)	9 (17)	-
Type 2 diabetes	9 (13)	5 (9)	4 (25)
Chronic obstructive pulmonary disease	9 (13)	6 (11)	3 (19)
Digestives disease	9 (13)	7 (13)	2 (13)
Educational level, n (%)			
Primary school	18 (26)	10 (19)	8 (50)
High school	28 (40)	24 (44)	4 (25)
Business school	9 (13)	7 (13)	2 (13)
Bachelor	12 (17)	11 (20)	1 (6)
Master	3 (4)	2 (4)	1 (6)
Marital status, n (%)			
Married	21 (30)	16 (30)	5 (31)
Widowed	32 (46)	24 (44)	8 (50)
Single	13 (19)	11 (20)	2 (13)
Other‡	4 (6)	3 (6)	1 (6)
Living relative(s), n (%)			
Yes	66 (94)	50 (93)	16 (100)
No	4 (6)	4 (7)	-
Had a relative present during survey, n (%)			
Yes	17 (24)	12 (22)	5 (31)
No	56 (80)	42 (78)	11 (69)
Self-rated importance of religion, n (%)			
Not disclosed	1 (1)	1 (2)	-
Not religious	19 (27)	15 (28)	4 (25)
Low	11 (16)	8 (15)	3 (19)
Medium	31 (44)	22 (41)	9 (56)
High	8 (11)	8 (15)	-
Living situation, n (%)			
Private home with relatives, no home care	15 (21)	11 (20)	4 (25)
Private home with relatives, with home care	5 (7)	3 (6)	2 (13)
Private home alone, no home care	17 (24)	13 (24)	4 (25)
Private home alone, with home care	31 (44)	25 (46)	6 (38)
Nursing home	2 (3)	2 (4)	-

*This table comprises the full first section of the survey.
†Does not add up to 100% due to decimal round up.
‡Other includes domestic partners and significant others

Table 2. *Patients' willingness to discuss life expectancy with a physician as well as reasons for wanting/not wanting to discuss life expectancy with a physician for the study population and stratified for patients who wanted to discuss life expectancy (willing to a medium degree or to a high degree) and patients who did not want to discuss life expectancy (willing to a low degree or not willing at all).* Patients indicating a positive preference towards discussing life expectancy were asked to disagree/agree to statements about wanting to discuss life expectancy, while patients indicating a negative preference were asked statements about not wanting to discuss. Both groups had the option to give other reasons.†*

	Study population (n=70)‡	Wanted to discuss life expectancy (n=54)‡	Did not want to discuss life expectancy (n=16)‡
To which degree would you be willing to discuss life expectancy with your physician? n (%)			
Not willing	8 (11)	-	8 (50)
Low degree	8 (11)	-	8 (50)
Medium degree	18 (26)	18 (33)	-
High degree	36 (51)	36 (67)	-
Previously discussed life expectancy with healthcare professional, n (%)			
Yes, for myself	2 (3)	2 (4)	-
Yes, for a relative	6 (9)	4 (7)	2 (13)
No, never offered	61 (87)	47 (87)	14 (88)
No, rejected an offer	1 (1)	1 (2)	-
Level of trust that physician can predict life expectancy correctly, n (%)			
Don't know	9 (13)	7 (13)	2 (13)
None	23 (33)	16 (30)	7 (44)
Low	21 (30)	19 (35)	3 (19)
Medium	11 (16)	8 (15)	3 (19)
High	5 (7)	4 (7)	1 (6)
Is it acceptable for the physician to initiate a discussion about life expectancy? n (%)			
Yes, as long as I can say no	57 (81)	45 (83)	12 (75)
Yes, the physician should always initiate if they deemed it medically relevant, even if I do not want to discuss my life expectancy	8 (11)	7 (13)	1 (6)
No, it is not appropriate	5 (7)	2 (4)	3 (19)
Is it the physician's choice whether relatives are present during life expectancy discussion? n (%)			
Yes	10 (14)	8 (15)	2 (13)
No	60 (86)	46 (85)	14 (88)
How would you prefer a health decision were made, if it depended on your estimated life expectancy? n (%)			
The physician should decide	9 (13)	7 (13)	2 (13)
I should decide	18 (26)	14 (26)	4 (25)
The physician and I should decide together	43 (61)	33 (61)	10 (63)
Reasons for wanting to discuss life expectancy among those wanting to discuss, n (%)		**Agree**	
To ensure the best personal treatment plan	-	48 (89)	-
To get information about what the future might hold	-	30 (56)	-
To make me feel less scared	-	42 (78)	-
To make my relatives feel less scared	-	37(69)	-
A good and trusting relationship with physician†	-	17 (31)	-

Belief that the physician will only bring it up if the discussion is relevant†	-	6 (11)	-
Reasons for not wanting to discuss life expectancy among those not wanting to discuss, n (%)			**Agree**
It is an uncomfortable topic to discuss	-	-	9 (56)
Death is part of god's plan/fate	-	-	6 (38)
Physicians cannot predict life expectancy correctly	-	-	12 (75)
I do not want to know when I might die	-	-	15 (94)
It would make me feel scared	-	-	6 (38)
It would make my relatives feel scared	-	-	3 (19)
Belief that life expectancy is too personal an issue to discuss with a physician†	-	-	2 (13)

*This table comprises the full first section of the survey.
†Other reasons mentioned by patients than those listed in the survey.
‡Does not add up to 100% due to decimal round up.