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BRIEF REPORT

What factors are associated with advance care planning in community-dwelling older people? Data from TILDA

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Key summary points

Aim To analyse advance care planning in a large population-representative cohort of older people.

Findings While overall 1 in 4 had discussed their future care wishes, only 10% of these had an advance care plan documented in writing and only 2% had discussed with a healthcare profesisonal.

Message Further work is required to educate the public and helathcare professionals regarding treatment choices at end-of-life.

Abstract

Purpose To assess advance care planning (ACP) in a large population-representative sample of older people.

Methods At Wave 4 of the Irish Longitudinal Study on Ageing, participants were asked: Have you made your wishes/preferences known about the kind of care that you would like to receive in the event of serious illness?

Results One quarter (1153/4831) had discussed ACP. Of those, 90% had discussed with family/friends, 10% documented ACP in writing, while 2% had discussed with a healthcare professional. Age ≥ 80 years [OR 1.63 (1.31–2.02)], female sex [OR 1.58 (1.37–1.83)], higher educational attainment [OR 1.42 (1.18–1.71)], poorer self-rated health [OR 1.67 (1.06–2.62)] and lower levels of religiosity [OR 1.50 (1.02–2.19)] were independently associated with ACP.

Conclusion Only one in four older people had discussed ACP informally, while less than 3% have ACP documented in writing. Further work is required to educate the public and healthcare professionals regarding treatment choices at end-of-life.

Keywords Advance care planning · Palliative care · End of life · Older

Introduction

Advance care planning (ACP) is the process, whereby people communicate their wishes and preferences for future healthcare with family, colleagues, carers, or healthcare professionals, while they are still able to do so [1]. This can help inform care if an individual subsequently loses the ability to make their own, informed decisions [2].

In this context, there is evidence that ACP improves communication and documentation of care preferences at end-of-life, as well as the likelihood of dying in one's preferred place [3, 4]. Despite this, the proportion of older people who engage in ACP is generally considered low despite over 70% of community-dwelling older people reporting that they would be interested in engaging with ACP [5].

Studies have suggested potential barriers to ACP at the level of the patient (beliefs, difficulty understanding limitations/complications of available treatments), healthcare professional (time constraints, lack of training) and system (transfers of care, infrastructure to communicate preferences), while enabling factors include integration of ACP into policy, creating capacity for clinicians and greater public engagement [6, 7].

The aim of this study, therefore, is to enhance our understanding of ACP engagement amongst older people by examining the proportion who discuss and document ACP in

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a large population-representative sample of older people and to establish what factors are associated with ACP, including contact with healthcare professionals and self-rated health.

Methods

Study design

This study ascertains the prevalence of ACP discussion and documentation, as well as factors associated with ACP, in a population-representative sample of community-dwelling older people from the Irish Longitudinal Study on Ageing (TILDA).

The TILDA study design has been outlined previously [8]. This study uses data from Wave 4 collected in 2016. Participants were included if they were aged ≥ 60 years at Wave 4 and underwent assessment regarding an ACP.

Advance care plan

At Wave 4, participants were asked: Have you made your wishes/preferences known about the kind of care that you would like to receive in the event of serious illness?

If yes, they were then asked if this had been documented informally (family/carers or medical professionals) or formally (by written advanced care plan).

Covariates

Covariates were chosen a priori based on their hypothesised association with engagement in ACP amongst older people. Educational attainment and marital status and number of hospital and general practitioner visits were obtained by self-report. Activities of daily living (ADL) Impairment was defined as having one or more impairment in instrumental ADLs, including cleaning, and maintaining the house, managing money, moving within the community, and preparing meals. Self-report was also elicited for self-rated health (rated as excellent, very good, good, fair, or poor) and religiosity (rated as very important, somewhat important, not too important, or not at all important).

Participants were also asked: 'In the last month, have you felt that you would rather be dead? And those who answered affirmatively were defined as having 'Wish to Die' [9]. This variable was included as it has been shown within the TILDA cohort to be longitudinally associated with early mortality and thus assessment of the link with advance care planning was of interest [9].

Statistical analysis

Data were analysed using Stata (Statacorp).

Baseline characteristics of the study sample were presented descriptively by ACP status. Proportions (rounded to two decimal places) were presented for binary variables.

Logistic regression models reporting odds ratios with 95% confidence intervals were used to analyse the association with covariates of interest with ACP status. Covariates were chosen a prior based on their likelihood of association with ACP.

Ethics

The TILDA study was approved by the Faculty of Health Sciences Research Ethics Committee at Trinity College Dublin and all participants gave informed written consent. All experimental procedures adhered to the Declaration of Helsinki.

Results

One quarter of the study sample (1153/4831) had discussed ACP. Of those who discussed ACP, 90% (1028/1153) had discussed it with a family or friend, 10% (119/1153) had their wishes documented in writing, while 2% (27/1153) had discussed ACP with a healthcare professional.

Over one-third (34%, 246/723) of participants aged ≥ 80 years had discussed ACP, with 5% (40/723) having an ACP documented in writing.

Table 1 demonstrates the differences in baseline characteristics between participants who discussed ACP compared to those who had not. Those who had discussed ACP were older, more likely to be female, widowed and have tertiary level educational attainment.

Participants who had discussed ACP had a higher mean number of visits to their general practitioner [4.23 (95% CI 3.88–4.01) visits vs. 3.88 (95% CI 3.72–4.04); $t = -2.25$; $p = 0.0245$] and to the emergency department [0.29 (95% CI 0.25–0.34) vs. 0.23 (0.20–0.25): $t = -2.58$; $p = 0.0098$] within the last 12 months when compared to those who had not discussed ACP, but there was no significant difference in terms of outpatient hospital visits between groups [1.57 (95% CI 1.27–1.87) vs. 1.42 (95% CI 1.30–1.54); $t = -1.10$; $p = 0.2706$].

As shown in Table 2, age ≥ 80 years [OR 1.63 (1.31–2.02)], female sex [OR 1.58 (1.37–1.83)], higher educational attainment [OR 1.42 (1.18–1.71)], poorer self-rated health [OR 1.67 (1.06–2.62)] and lower levels of religiosity [OR 1.50 (1.02–2.19)] were independently associated with ACP discussion in fully adjusted logistic regression models.

Table 1 Baseline characteristics by advance care planning discussion

	ACP ($n=1153$)	No ACP ($n=3228$)
Mean age (years), 95% CI	72.00 (71.50–72.47)	70.63 (70.37–70.90)
Age breakdown (prop. with 95% CI)		
60–69 years	0.45 (0.42–0.48)	0.50 (0.49–0.52)
70–79 years	0.34 (0.31–0.36)	0.35 (0.33–0.36)
≥ 80 years	0.21 (0.19–0.24)	0.15 (0.14–0.16)
Female sex (prop. with 95% CI)	0.64 (0.61–0.67)	0.52 (0.50–0.54)
Marital status		
Married	0.63 (0.60–0.66)	0.68 (0.66–0.69)
Never married	0.07 (0.06–0.09)	0.09 (0.08–0.10)
Separated/divorced	0.06 (0.05–0.08)	0.06 (0.06–0.07)
Widowed	0.23 (0.21–0.26)	0.17 (0.16–0.18)
Educational attainment (prop. with 95% CI)		
Primary/none	0.26 (0.24–0.29)	0.29 (0.28–0.31)
Secondary	0.37 (0.34–0.40)	0.40 (0.38–0.42)
Tertiary/higher	0.37 (0.34–0.39)	0.31 (0.29–0.32)
ADL impairment (prop. with 95% CI)[a]	0.10 (0.08–0.11)	0.07 (0.06–0.08)
Self-rated health (prop. with 95% CI)		
Excellent	0.11 (0.10–0.13)	0.13 (0.12–0.14)
Very good	0.36 (0.34–0.39)	0.33 (0.31–0.35)
Good	0.35 (0.32–0.38)	0.37 (0.36–0.39)
Fair	0.14 (0.12–0.17)	0.15 (0.13–0.16)
Poor	0.04 (0.03–0.05)	0.02 (0.02–0.03)
Religiosity (prop. with 95% CI)		
Very important	0.53 (0.51–0.56)	0.51 (0.49–0.52)
Somewhat important	0.29 (0.27–0.32)	0.31 (0.29–0.32)
Not too important	0.13 (0.11–0.15)	0.16 (0.14–0.17)
Not at all important	0.04 (0.03–0.05)	0.03 (0.02–0.04)
'Wish to Die' (prop. with 95% CI)[b]	0.03 (0.02–0.04)	0.02 (0.02–0.03)

ACP advanced care planning, *CI* confidence interval, *Prop*. proportion, *ADL* activities of daily living

[a]Activities of daily living (ADL) impairment was defined as having one or more impairment in instrumental ADLs, including cleaning, and maintaining the house, managing money, moving within the community and preparing meals

[b]Participants were also asked: 'In the last month, have you felt that you would rather be dead? And those who answered affirmatively were defined as having 'Wish to Die'

Discussion

This study examines levels of engagement with ACP in a population-representative sample of community-dwelling older people.

We found that one in four older people have engaged in ACP by discussing the subject informally, including 1 in 3 of those aged ≥ 80 years. However, only 1 in 10 of those have their wishes formally documented in writing, including only 1 in 20 aged ≥ 80 years. Furthermore, less than 1% (27/4354) of the study sample had discussed ACP with a healthcare professional, and this mismatch between willingness to discuss ACP informally but not with a healthcare professional is an important, new finding in a population-representative sample.

Prior studies have demonstrated similarly low levels of engagement with ACP in smaller cohorts of older people presenting to the emergency department [10], admitted to hospital [11] and undergoing complex surgery [12] but there is limited work to date on large, population-representative samples, such as the TILDA cohort.

We further found that older age, female sex, higher educational attainment, poor self-reported health, and lower levels of religiosity were independently associated a higher likelihood of ACP. While most of these factors have already demonstrated an association with ACP in smaller cohorts [13, 14], the link with religiosity is less consistent, as higher levels of religious beliefs and attendance across different religions have previously been linked with higher engagement in ACP [15, 16]. Over 90% of participants in this study reported their religion as Roman Catholic, however, and this homogeneity in terms of religious beliefs and cultures may have influenced these findings. In addition, Irish people may be more uncomfortable with and less informed about the processes of dying and death [17].

Table 2 Logistic regression model with advance care planning discussion as dependent variable

	Odds ratio (95% CI)	*Z*	*P* value
Age category (Ref: 60–69 years)			
70–79 years	1.13 (0.96–1.33)	1.48	0.140
≥ 80 years	1.63 (1.31–2.02)	4.46	< 0.001
Female sex	1.58 (1.37–1.83)	6.16	< 0.001
Marital status (ref: married)			
Never married	0.80 (0.61–1.04)	− 1.66	0.096
Separated/divorced	1.01 (0.76–1.35)	0.09	0.929
Widowed	1.18 (0.98–1.42)	1.70	0.088
Educational attainment (ref: primary)			
Secondary	1.09 (0.91–1.30)	0.93	0.352
25 Tertiary/higher	1.42 (1.18–1.71)	3.78	< 0.001
ADL impairment[a]	1.18 (0.91–1.54)	1.23	0.219
Self-rated health (ref: excellent)			
Very good	1.24 (0.98–1.56)	1.80	0.072
Good	1.06 (0.84–1.34)	0.48	0.629
Fair	1.03 (0.78–1.37)	0.24	0.810
Poor	1.67 (1.06–2.62)	2.23	0.026
Religiosity (ref: very important)			
Somewhat important	1.04 (0.88–1.22)	0.47	0.638
Not too important	0.98 (0.79–1.21)	− 0.17	0.869
Not at all important	1.50 (1.02–2.19)	2.11	0.035
'Wish to Die'[b]	0.99 (0.98–1.01)	− 0.97	0.331

CI confidence interval, *ADL* activities of daily living

[a]Activities of daily living (ADL) impairment was defined as having one or more impairment in instrumental ADLs, including cleaning, and maintaining the house, managing money, moving within the community and preparing meals

[b]Participants were also asked: 'In the last month, have you felt that you would rather be dead? And those who answered affirmatively were defined as having 'Wish to Die'

Perhaps surprisingly reporting a wish to die was not associated with ACP engagement. Numbers reporting wish to die were relatively low, however ($n = 104$, 2% of study sample). Furthermore, we have shown previously that a wish to die may not represent a fixed position, with less than 30% continuing to report this wish when reassessed after 2 years and, therefore, may not translate into firm beliefs around treatment at end-of-life [9].

Our findings regarding ACP discussions with healthcare professionals is important, with less than 2% of participants aged ≥ 80 years (11/723) engaging in ACP with a doctor or other healthcare professional, despite on average making 4 general practitioner and 1 hospital out-patient visits in the preceding 12 months. Indeed, almost 90% of those who had engaged in ACP had done so only in the context of family discussions rather than via written documentation (10% of those with ACP) or via discussion with a healthcare professional (2% of those with ACP). Lack of education and insufficient time have been cited by healthcare professionals as the primary barriers to discussing ACP with patients [18]. Discussing and assessing patient's concerns, wishes and expectations regarding care and decisions at the end of life with due regard for action when the person is unable to communicate or lacks mental capacity has been identified as a palliative care core competency for geriatricians by the EUGMS [19].

It must also be noted, however, that ACP is complex, and many older adults may not be open to it. It can also be challenging to ask patients to articulate their wishes around hypothetical future scenarios, and that opinions and wishes can change over time, particularly in the context of end-of-life care, where treatment choices can be unpredictable, fluid and influenced by emotion [20].

In conclusion, only one in four of this population-representative sample of older people had discussed ACP informally, while less than 3% have ACP documented in writing. Many older people may not wish to engage in ACP, but for those who do, healthcare professionals should be attuned to this unmet need by openly discussing future wishes, treatment choices and goals with them. Given that three in four do not engage in ACP, however, alternative approaches may need to be considered, including advance appointment of a trusted health care proxy or decision-maker.

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Declarations

Conflict of interest The author declares that they have no conflict of interest.

Ethical approval The TILDA study was approved by the Faculty of Health Sciences Research Ethics Committee at Trinity College Dublin and all experimental procedures adhered to the Declaration of Helsinki.

Informed consent All participants gave informed written consent.

Availability of data and materials Not applicable.

Code availability Not applicable.

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