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What factors are associated with having an advance directive among older adults new to long-term care services?

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Abstract

Objectives—To explore differences in having an advance directive among older adults newly transitioned to long-term services and support settings (LTSS; i.e., nursing homes, NH; assisted living facilities, ALF; home and community-based services, H&CBS).

Design—Cross sectional survey.

Setting—LTSS in New York and Pennsylvania.

Participants—Four-hundred and seventy older adults who recently started receiving LTSS. Included in this analyses, N=442 (ALF: n=153; NH: n=145; H&CBS: n=144).

Measurements—Interviews consisted of questions about advance directives (Living will and Health Care Power of Attorney-HCPOA), significant health changes in the six month prior to the start of long-term care support services, Mini-Mental State Examination, and basic demographics.

Results—Sixty-one percent (270/442) of older adults receiving LTSS reported having either a living will and/or a HCPOA. ALF residents reported having an advance directive more frequently than NH residents and older adults receiving LTSS in their own home (living will: $X^2[2] = 120.9$; $P < .001$; HCPOA: $X^2[2] = 69.1$; $P < .001$). In multivariate logistic regression models, receiving LTSS at an ALF (OR = 5.01; $P < .001$), being white (OR = 2.87; $P < .001$), having greater than 12 years of education (OR = 2.50; $P < .001$) and experiencing a significant health change in last 6-months (OR = 1.97; $P = .007$) were predictive of having a living will. Receiving LTSS at an ALF (OR = 4.16; $P < .001$), having greater than 12 years of education (OR = 1.74, $P = 0.022$), and having had a significant change in health in the last six months (OR = 1.61; $P = .037$) were predictive in having a HCPOA in this population of LTSS recipients.

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Conclusions—These data provide insight into advance directives and older adults new to LTSS. Future research is needed to better understand the barriers to completing advance directives before and during enrollment in LTSS as well to assess advance directive completion changes over time for this population of older adults.

Keywords

nursing home; assisted living; advanced care planning; PACE

INTRODUCTION

In the U.S., approximately 10 million people residing in the community or in institutional settings report the need for long-term services and support (LTSS).¹ Approximately 50% of this population is age 65 and older.¹ Presently about 14% of the U.S. population is age 85 and older, and it is expected to grow to more than 21% by 2050² thus increasing the need for LTSS. With advances in medicine and improvements in the management of chronic diseases this population of older adults will live longer but with increased complexity of care needs.³ As this population grows and the need for LTSS increases so does the need for understanding advance care planning within this population.

A critical first step is to better understand which older adults new to LTSS already have advance directives and what differences exist among older adults new to LTSS. Advance directives, specifically living wills and health care power of attorney (HCPOA), have received widespread attention since the Patient Self-Determination Act (PSDA, Public Law No. 101-508) was enacted in 1991. Advance directives allow an individual the opportunity to document their preferences for potentially life-saving medical treatment in the event he or she is unable to communicate. For older adults with multiple chronic illnesses advance care planning, having health care preference discussions⁴ and, specifically, putting preferences in writing, is critical so that health care providers⁵ and family members⁶, who are often called upon to make decisions for their relatives, have some understanding of how to make decisions that best match the patients' preferences.

Among all older adults, the estimates of those with advance directives (i.e., living wills or HCPOA) varies from 4% to 97%⁷⁻¹⁰ depending on the sample of older adults and where those older adults reside. For example, the prevalence of advance directives among older adults living at home and receiving community based services (H&CBS), ranges from 1.5% to 20%.⁷ Among nursing home (NH) residents, the estimates of those with advance directives are higher, ranging from 18% to 70%, depending on whether the data are self report or administrative (e.g., Minimum Data Set).⁸⁻¹⁰ Limited data exists on the number of older adults with advance directives living in assisted living facilities (ALFs). The findings from one survey of ALFs reported 48%-69% of deceased ALF residents had an advance directive while family members reported much higher estimates (91%-97%).¹¹ There are no studies that have estimated the prevalence of advance directives in ALFs based on residents self report.

Although there is a growing body of literature that has estimated the prevalence of advance directives among older adults living in NHs and at home, little is known about advance directives when older adults first transition into LTSS or the factors associated with having an advance directive for this population. No studies to date have compared older adults new to these three types of LTSS (e.g., NH, ALF, and H&CBS) or compared the factors associated with having an advance directive among all three groups. The aim of this study was to determine the factors associated with having an advance directive among groups of older adults newly transitioned to receiving LTSS.

METHODS

Design

This study is part of a larger longitudinal study investigating Health Related Quality of Life (HRQoL) in older adults new to LTSS.¹ Data for this study come from the baseline interviews with new LTSS recipients.

Sample

The study was conducted in the Philadelphia (PA) and New York City (NY) metropolitan service areas. To be eligible, subjects were within 60 days of moving to a NH, ALF, or the start of receiving H&CBS, age 60 or older, could communicate in either English or Spanish, and had a Mini Mental State Examination (MMSE) score of 12 or greater. Each study site had staff that systematically identified all potential subjects who were new to their location (NH, ALF) or service (H&CBS) and referred the list of new LTSS members to a HRQoL study team member. A total of 1311 (909 in PA and 402 in NY) older adults were referred by partnering agencies and approached to participate between March 2007 and July 2010.

A HRQoL study team member would approach the elder in person, explain the study and perform the MMSE. Older adults who scored ≥ 23 on the MMSE were considered capable to provide written informed consent and eligible to enroll without proxy consent. For older adults who scored between 22-12 on the MMSE, assent to participate was obtained from the LTSS recipient and a legally authorized representative for the recipient was contacted, the study was explained and written consent obtained for the LTSS recipient to participate. Four-hundred and eighty older adults did not meet eligibility criteria primarily due to scoring < 12 on the MMSE and prior use of LTSS. Among those eligible to enroll ($n=831$), 308 (37.1%) declined to participate (reasons: lack of interest in research and did not want to spend time participating) and 48 did not have a legally authorized representative to co-sign or willing to co-sign the informed consent and were not enrolled. Five individuals in the NY sample were dropped post enrollment for administrative reasons. A final sample of 470 were enrolled into the HRQoL study (ALF: $n=156$; NH: $n=158$; H&CBS: $n=156$).

Measures

Baseline interview data presented here is based on questions about advance directives, cognition, significant health changes in the six month prior to receiving LTSS, and demographics.

Advance Directives—LTSS recipients were asked if they had an advance directive (e.g., living will and health care power of attorney) at the time of the interview. A definition of the document was provided for each document type. Living will was defined as a legal document that allows a person to state the kind of health care they do or do not want under certain circumstances if they are unable to make the decision for themselves. LTSS recipients were also asked if they had a health care power of attorney (HCPOA) (yes/no/unsure) the definition included phrasing that allowed for other legal documents that identify someone to make health care decisions also known as a “health care proxy”. For both variables, if the answer was “unsure” we collapsed this small group into the “no” category for analyses.

Cognitive Status—Mini Mental State Examination (MMSE)¹², is a widely used tool that measures orientation to time and place, recall ability, short-term memory and arithmetic

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ability in elderly patients. In general, scores >23 indicate intact cognition, 20-23 mild cognitive impairment, 19-12 moderate cognitive impairment and <12 severe cognitive impairment.¹²

Functional Status—Katz Index of Activities of Daily Living¹³ (ADL) measures individuals' abilities to perform activities of daily living. The index was self-rated or used with LTSS staff if the older adult scored <23 on the MMSE. This six-item instrument assesses independence or dependence in the activities of bathing, dressing, toileting, transferring, continence, and feeding. Scores range from 0-6 with higher scores indicating better functional status. Inter-rater reliability of 0.95 and correct classification of 96% of people has been reported using the instrument.¹⁴

Significant changes in health—Older adults were asked if they had any significant health status changes in the last six months (yes/no). Significance was left to the interpretation of the elder in this self-reported item.

Demographic characteristics—Basic demographic information included race (white/other), gender (male/female), age (continuous), education (continuous), marital status (dichotomous married/not married), and income (ordinal). Finally older adults were classified by the type of LTSS they were receiving (categorical: home & community based services=1, nursing home=2, assisted living=3).

Analyses

Descriptive statistics are presented. Standard parametric tests were used to make comparisons to describe the sample (e.g., chi squares, Oneway ANOVA). Finally, univariate and multivariate logistic regression were used to describe the relationship between older adult characteristics and advance directives among this population newly transitioned to LTSS. Only variables significant at $P = .25$ were included in the final model. The variable for living will was not included when modeling HCPOA and vice versa.

Ethics

This study was reviewed and approved by the site Institutional Review Boards at the University of Pennsylvania and the Visiting Nurse Service of New York.

RESULTS

Of the 470 enrolled older adults, 28 interviews had incomplete data in one or more independent variables and were excluded from these analyses. A final sample of 442 older adults newly enrolled in LTSS with complete data at the baseline interview are presented (ALF: n=153; NH: n=145; H&CBS: n=144). See Table 1.

On average older adults were 81.0 years old (range: 60-98), female (71.0%), white (52.0%), had twelve or fewer years of education (59.7%), some cognitive impairment (MMSE; mean: 24) and moderate deficits in basic activities of daily living (mean: 4.3 ± 1.9 , range: 0-6). See Table 1. Thirty-nine percent of older adults had a significant health change in the six months before the start of LTSS. When adjusted by the type of LTC service, ALF residents were significantly older (mean: 87 years) than NH residents (mean: 77 years) or older adults receiving H&CBS (mean: 79 years) (Oneway ANOVA: $\chi^2[2] = 24.8, P < .001$). A significant number of male older adults resided in NHs (42.8%) than in ALFs (16.3%) or in their own home (28.5%) ($\chi^2[2] = 25.3, P < .001$). ALF residents were more likely to be white (93.5%) in comparison to NH residents (32.4%) and older adults receiving H&CBS (27.8%; $\chi^2[2] = 161.5, P < .001$). ALF residents (66.7%) were more likely to have >12 years

of education in comparison to NH residents (34.5%) and older adults receiving H&CBS (18.1%; $\chi^2[2] = 75.9, P < .001$). NH residents (mean: 22) had lower MMSE scores than older adults receiving H&CBS (mean: 24) or ALF residents (mean: 25) (Oneway ANOVA: $\chi^2[2] = 25.1, P < 0.001$). Finally, NH residents (mean: 3.5) had significantly more deficits in function (ADLs) than older adults receiving H&CBS (mean: 4.5) or ALF residents (mean: 5.0) (Oneway ANOVA: $\chi^2[2] = 29.2, P < 0.001$).

Do older adults have advance directives when they start receiving LTSS?

Sixty-one percent of older adults receiving LTSS reported having an advance directive (either a living will, HCPOA, or both). The majority of ALF residents reported having an advance directive when they were interviewed (ALF: have a living will: 84.3%; have a HCPOA: 79.7%) in comparison to less than half of NH residents (NH: have a living will: 39.1%; HCPOA: 40.7%) or older adults receiving H&CBS (H&CBS: have a living will: 22.9%; HCPOA: 36.1%) (living will: $\chi^2[2] = 120.9, P < .001$; HCPOA: $\chi^2[2] = 69.1, P < .001$). Forty-one percent of older adults receiving LTSS had both types of advance directives, most commonly in the ALF group (112/153, 73.2%). Thirty-nine percent of older adults had neither type of document, with the H&CBS group having the greatest percentage of individuals that had neither document (92/144, 63.9%).

What factors are associated with having an advance directive among LTSS recipients?

Univariate analyses identified several factors significant with older adults reporting having a living will. First, the type of LTSS was significant, with the odds of an older adult having a living will being 18.08 times higher if the older adult was receiving LTSS in an ALF than at home (95% Confidence Interval [95% CI]: 10.08-32.40, $P \leq .001$). The odds of having a living will were 2.18 times greater for older adults receiving LTSS in a NH than at home (95% CI: 1.31-3.64, $P = .003$). For age, the odds of having a living will increased by a factor of 1.06 for each 1-year increase in the age of the LTSS recipient (95% CI: 1.03-1.08, $P \leq .001$). Older adults with greater than 12 years of education had an odds of having a living will 5.33 times higher than older adults with ≤ 12 years of education (95% CI: 3.51-8.09, $P \leq .001$). For each 1-point increase in MMSE score, the odds of having a living will increased by a factor of 1.07 (95% CI: 1.03-1.12, $P = .002$). Being white increased the odds of having a living will by 7.43 in comparison to non-white older adults new to LTSS (95% CI: 4.87-11.32, $P \leq .001$). Older adults receiving LTSS who reported having a significant change in health status in the past six months had an odds of having a living will 2.14 times higher than older adults who did not report a significant change in the past six months (95% CI: 1.45-3.17, $P \leq .001$). Functional status (OR=1.09, 95% CI: 0.99-1.21, $P = .087$) although not significant at the 0.05, was significant at the $P \leq .25$ level for reporting having a living will and was included in the building of the final model. Gender was not significant in univariate analyses for having a living will.

Univariate analyses for HCPOA revealed that the type of LTSS increased the odds of having a HCPOA but only for those older adults in ALFs as compared to older adults receiving services at home (H&CBS: reference group; ALF: OR=6.96, 95% CI: 4.14-11.72, $P \leq .001$; ALF: OR=1.21, 95% CI: 0.76-1.95, $P = .424$). For age, each 1-year increase in the age of the LTSS recipient increased the odds of having a HCPOA by a factor of 1.05 (95% CI: 1.03-1.08, $P \leq .001$). Among LTSS recipients with greater than ≤ 12 years of education the odds of having a HCPOA was 3.13 times higher than those LTSS recipients with ≤ 12 years of education (95% CI: 2.10-4.68, $P \leq .001$). Being white increased the odds of having a HCPOA by 3.41 in comparison to non-white older adults new to LTSS (95% CI: 2.31-5.04, $P \leq .001$). Among LTSS recipients who reported a significant change in health status in the past six months, the odds of having a HCPOA was 1.74 times higher than recipients who did not report a significant change in health in the past six months (95% CI: 1.18-2.56, $P = .$

005). For each 1-point increase in MMSE score the odds of having a HCPOA increase by a factor of 1.05 (95% CI: 1.01-1.10, $P = .022$). Being male (OR=1.17, 95% CI: 0.77-1.77, $P = .46$) and functional status (OR=1.09, 95% CI: 0.99-1.21, $P = .08$) although not significant at the 0.05, were significant at the $P \leq .25$ level for reporting having a HCPOA and were included in the building of the final model.

In univariate analyses, the odds of having either type of written advance directive were 17.56 times greater for ALF residents (95% CI: 9.20-33.52; $P \leq .001$) and 2.12 times greater for NH residents (95% CI: 1.32-3.39; $P = .002$) in comparison to older adults receiving LTSS in their own home (H&CBS= reference group). The odds of having either written advance directive increased by a factor of 1.05 for each 1-year increase in the age of the LTSS recipient (95% CI: 1.03-1.08, $P < .001$). Among LTSS recipients with greater than 12 years of education, the odds of having either written advance directive was 4.41 times higher than those LTSS recipients with ≤ 12 years of education (95% CI: 2.83-6.85, $P \leq .001$). Among white LTSS recipients, the odds of having a written advance directive were 4.46 times greater than non-white LTSS recipients (95% CI: 2.96-6.74, $P < .001$) and reporting a significant change in health in the past six months increased the odds of having any form of written advance directive by a factor 1.85 (95% CI: 1.23-2.77, $P = .003$).

Final models were constructed to predict having a living will, a HCPOA or either advance directive. See Table 2. Factors associated with having a living will in the multivariate logistic regression model were living in an ALF (OR=7.48, 95% CI: 3.71-15.04, $P < .001$), greater than 12 years of education (OR=2.50, 95% CI: 1.51-4.16, $P < .001$), being white (OR=2.87, 95% CI: 1.65-4.99, $P < .001$) and having had a significant change in their health in the last six months (OR=1.97, 95% CI: 1.20-3.24, $P = .007$). In multivariate logistic regression for HCPOA, only living in an ALF (OR=4.10, 95% CI: 2.15-7.80, $P < .001$), greater than 12 years of education (OR=1.74, 95% CI: 1.08-2.78, $P = .022$), and having had a significant change in health in the last six months (OR=1.61, 95% CI: 1.03-2.51, $P = .037$) were significant factors in having a HCPOA in this population of new LTSS recipients. In multivariate logistic regression for having any advance directive, living in an ALF (OR=5.25, 95% CI: 2.49-11.05, $P < .001$) or a NH (OR=1.75, 95% CI: 4.39-19.31, $P = .024$) and greater than 12 years of education (OR=2.22, 95% CI: 1.34-3.66, $P = .002$) were significant factors in having any type of advance directive in this population of new LTSS recipients.

DISCUSSION

The aim of this study was to determine the factors associated with having an advance directive among groups of older adults new to long-term services and supports. Although 61.1% (270/442) of older adults receiving LTSS reported having either a living will, a durable power of attorney for health care or both, the majority of these older adults live in ALFs (139/153, 90.8%). This study highlights that some older adults new to LTSS do have advance directives, but there are significant differences with respect to education, race, type of LTSS and health status changes in the past six months associated with having an advance directive. These data shed light on three important insights into predictors of having an advance directive among older adults new to long term support services.

First, older adults receiving LTSS in their own homes are less likely at the start of LTSSs to have any written advance directives in comparison to older adults receiving LTSS in a NH or ALF. This may be due in part to NH and ALF residents may be seeing health care providers more frequently in the setting in which they reside in comparison to older adults who receive LTSS at home. Findings from this study reveal that older adults living in ALFs are putting together advance directives in significantly greater percentages than their peers

in NHs or H&CBS. It is possible that the ALF group plans over an extended period of time before transitioning to the ALF setting than those individuals who receive LTSS in NHs or in their own home. In addition, this population was significantly older than the NH and H&CBS groups but age was not significant in multivariate models. Findings from intervention studies with older adults in the primary care setting indicate that older age was associated with greater advance directive completion.^{15, 16} However, once age was controlled for in the multivariate model it was no longer a significant predictor of having an advance directive at the start of LTSS for this population. Overall, the report of having an advance directive was higher than previously reported percentages for these populations. One potential reason for this higher percentage may be that LTSS organizations are requiring advance directives as part of the admission to an ALF or NH or as part of the H&CBS enrollment. Another reason may be that these older adults report having put documents together but have not provided copies to the LTSS provider as has been found in other research.¹¹ This was unknown for these sites and population and a limitation of the study. Finally, further investigation into similarities and differences between LTSS recipients advance directive completion in other areas of the U.S. as well as the characteristics of those LTSS is needed.

Second, older adults experiencing a significant health change in last 6-months was predictive of having either a living will or a HCPOA after controlling for other independent variables. This could indicate that many of these older adults are experiencing health status changes, which may have precipitated their transition to receiving LTSS, and could have been the catalyst in the completion of an advance directive.¹⁷ It is possible that the discussions with health care professionals, either during or after a hospital stay or during a primary care visit, could be influencing the completion of advance directives for this population. Alternatively, it may be that the population completing an advance directive has multiple health problems and planning has been part of the health care and life process. Since we do not know at what point in time the advance directive was created, only that they report having an advance directive, future research into this relationship is needed.

Third, after controlling for demographics, several patient characteristics were predictive of having an advance directive. Education was significant regardless of type of advance directive and race was significant for having a living will. This finding is similar to other research on living will completion, which shows that white older adults are more likely to complete a living will^{10, 18} and older adults with less than a high school education are less likely to complete a living will.¹⁹ The finding that location of LTSS (NH, ALF or H&CBS) and education were the only significant predictors of having any type of advance directive would appear to indicate that a communal setting (i.e., ALF or NH) and having greater than 12 years of education are predictive of having an advance directive at the start of LTSS. This population of older adults receiving LTSS at home may put together these documents over time as they begin to receive services. Future longitudinal research to assess the natural trajectory of changes in advance directive completion over time for H&CBS recipients is needed. Regardless of previous findings on advance directive completion, these are the first data, to our knowledge, to compare having an advance directive in multiple LTSS populations at the start of receiving services.

Finally, an additional limitation for this study is the inclusion of older adults with “moderate” cognitive impairment as is defined by MMSE cut points (MMSE: 12-19). Because we included older adults with moderate cognitive impairment, it is possible that their recall in having a living will or HCPOA was inaccurate. Unfortunately, we were unable to verify their self-report data with the actual copy of the advance directive to confirm or negate the information. Analyses were run with only those subjects with MMSE scores >20 (mild cognitive impairment to normal cognition) in the multivariate logistic regression

models and the results were the same. Therefore, we feel confident in our results with this broader population. In addition, LTSS recipients with normal cognition and many with mild impairment can still fully contribute to discussions about health care preferences thus leaving time for conversations to occur and documentation to be put into place. LTC providers (physicians, nurses, social workers, etc.) play a critical role in eliciting and discussing the health care preferences of these older adults and revisiting these discussions with LTSS recipients and their family members, as needed.

CONCLUSION

These data provide insight into advance directives and older adults new to LTSS and further highlight that non-white older adults with a high school education or less are less likely to have a living will at the start of LTSS. Recent research supports the continued use of advance directives²⁰ as a way to either document health care preferences (i.e., living will) or convey health care preferences to a proxy decision maker (i.e., HCPOA) and can help providers guide care at the end of life. Education of older adults receiving LTSS, proxy decision makers, and LTC service providers on advance directive types and usefulness before the older adult can no longer participate in the preference discussion is key. This will help LTSS recipients and proxy decision makers, most often family caregivers, make end of life decisions based on what the patient would have wanted.

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Table 1
Demographics and Characteristics of Long-Term Services and Support Recipients (N=442)

	ALL N=442	Assisted Living Facility n=153	Nursing Home n=145	Home & Community Based Services n=144
	Mean±sd (range)	Mean±sd (range)	Mean±sd (range)	Mean±sd (range)
Age (years)	81.0±8.8 (60-98)	86.3±6.0 (62-98)	76.7 ±9.1 (60-97)	79.1±7.7 (63-97)
Mini Mental State Examination Score (MMSE)	24.1±4.2 (12-30)	25.4±3.8 (13-30)	22.3±4.9 (12-30)	24.7±3.2 (14-30)
Functional Status (Katz)	4.3±1.9 (0-6)	5.0±1.4 (0-6)	3.5±2.1 (0-6)	4.5±1.7 (0-6)
	N (%)	N (%)	N (%)	N (%)
Male	128 (29.0%)	25 (16.3%)	62 (42.8%)	41 (28.5%)
Education, (> 12 years)	178 (40.3%)	102 (66.7%)	50 (34.5%)	26 (18.1%)
White	230 (52.0%)	143 (93.5%)	47 (32.4%)	40 (27.8%)
Significant change in health in last 6 months	172 (38.9%)	68 (44.4%)	69 (47.6%)	35 (24.3%)

NOTE: See methods section for inclusion and exclusion criteria. Subjects had to score 12 or higher on the Mini Mental State Examination to enroll.

Table 2
What factors are associated with having an advance directive? Multivariate Logistic Regression

	Multivariate			
	Living Will	HCPOA	Advance Directive (Any vs. None)	
	OR (95% CI)	OR (95% CI)	OR (95% CI)	
LTSS				
Home & Community Based Services	<i>ref group</i>	<i>ref group</i>	<i>ref group</i>	
Assisted Living Facilities	7.48 (3.72-15.04) ***	4.10 (2.15-7.80) ***	9.20 (4.39-19.31) ***	
Nursing Homes	1.49 (0.82-2.71)	0.98 (0.57-1.69)	1.75 (1.08-2.85) *	
Age (years)	0.99 (0.96-1.02)	1.00 (0.98-1.04)	1.00 (0.97-1.03)	
Mini Mental State Examination Score	0.99 (0.93-1.05)	1.00 (0.94-1.06)		
Education (> 12yrs)	2.50 (1.51-4.16) ***	1.74 (1.08-2.79) *	2.21 (1.34-3.66) **	
White	2.86 (1.65-4.99) ***	1.29 (0.77-2.17)	1.53 (0.92-2.56)	
Significant change in health in last 6 months	1.97 (1.20-3.24) **	1.61 (1.03-2.51) *	1.48 (0.93-2.35)	
Functional Status (Katz)	0.95 (0.83-1.08)	0.99 (0.88-1.11)		

* $P < .05$

** $P < .01$

*** $P < .001$

LTSS = Long-Term Services and Supports; HCPOA = Health Care Power of Attorney