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Agreement between Older Persons and their Surrogate Decision Makers Regarding Participation in Advance Care Planning

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Abstract

Objectives—To examine agreement between older persons and their surrogates regarding participation in advance care planning (ACP).

Design—Observational cohort study.

Setting—Community

Participants—Persons age 65 and the individual they identified as most likely to make treatment decisions on their behalf.

Measurements—Older persons were asked about participation in four activities: 1. Completion of living will; 2. Completion of health care proxy; 3. Communication regarding views about life-sustaining treatment; 4. Communication regarding views about quality versus quantity of life. Surrogates were asked whether they believed the older person had completed these activities.

Results—Of 216 pairs, 81% agreed about whether a living will had been completed [$k = .61$, 95% confidence interval (CI) .51, .72]. Only 68% of pairs agreed about whether a health care proxy had been completed ($k = .39$, 95% CI .29, .50), 64% agreed about whether they had communicated regarding life-sustaining treatment ($k = .22$, 95% CI .09, .35), and 62% agreed about whether they had communicated regarding quality versus quantity of life ($k = .23$, 95% CI .11, .35).

Conclusions—While agreement between older persons and their surrogates regarding living will completion was good, agreement about participation in other aspects of ACP was fair to poor. Additional study is necessary to determine who is providing the most accurate report of objective

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Author Contributions:

Study concept and design: TRF, CAR, MLR Acquisition of subjects and data: TRF, JRO, LI Analysis and interpretation of data: TRF, CAR, MLR, JRO, LI Preparation of manuscript: TRF Editing of manuscript: CAR, MLR, JRO, LI

Conflict of Interest Checklist:

ACP components and whether agreement regarding participation in ACP is associated with greater shared understanding of patients' preferences.

Keywords

advance care planning; surrogate decision making; communication

INTRODUCTION

Advance care planning (ACP) is the process by which individuals can specify the care they wish to receive if they become incapable of participating in treatment decision making. Traditional forms of advance care planning, such as the completion of living wills and health care proxies, are being supplemented by the promotion of communication between patients and their loved ones or surrogate decision makers and between patients and physicians.¹⁻³ Because ACP is frequently investigated as an important component of end-of-life care, surrogates may be interviewed after the death of a patient and asked to report on not only their own but also on patients' participation in different components of ACP.⁴ The use of surrogates to provide this information assumes that they are knowledgeable informants about their loved one's participation in ACP. However, there is indirect evidence to suggest that surrogates may not have accurate information, particularly for the communication components of ACP. Studies have demonstrated that, despite patients' beliefs that their loved ones understand their wishes regarding end-of-life care, surrogate-patient agreement regarding patients' specific treatment preferences and goals of care is poor.⁵ In addition, one study of older persons with advanced illness and their caregivers demonstrated frequent disagreement regarding desire for and difficulty of communication about the patient's illness.⁶ These data suggest that patients and their surrogates may not be in agreement about whether ACP has been completed.

The purpose of the study was to examine agreement between the reports of older persons and their surrogates regarding older persons' participation in ACP, considered as a group of behaviors including communication regarding treatment preferences and goals, and completion of advance directive documents.

METHODS

Participants

Participants consisted of two groups: older persons and their surrogates. The older persons were age 65 years and older recruited from two primary care practices and one senior center. These sites were purposefully selected in order to provide access to a group of older persons with diversity in race, socioeconomic status, and health status. In the primary care practices, letters were sent to sequential persons age 65 who were screened by their physician as not having a diagnosis of dementia. Persons who agreed (92% and 88% in the two practices) underwent a telephone screen to determine exclusion criteria, which included: non-English speaker (7% and 2%), hearing loss precluding participation in interview (7% and 1%), nursing home resident (0% and 1%), acute episode of illness (8% and 4%), and cognitive impairment, defined as <2/3 recall on a test of short-term memory (7% and <1%). Among

eligible participants, 83% and 80% completed interviews. In the senior center, volunteers were solicited for participation. Everyone who volunteered at the senior center was eligible for participation and completed interviews (100%).

These participants were asked to provide contact information for the person who would be most likely to make treatment decisions on their behalf if they were unable to participate in decision making. Among the 304 older persons, 227 (75%) provided the name and contact information of their surrogate. Among these 227, 1 had died prior to contact, 9 refused participation, and 1 agreed to a partial interview, resulting in 216 surrogate participants, a 95% participation rate among those for whom we received contact information and a 71% overall participation rate. Only older persons whose surrogate participated in the study are included in the current analyses.

Data collection

All procedures and surveys were approved by the Human Investigations Committee of the Yale University School of Medicine. Interviews were conducted by trained interviewers with older persons in person and with surrogates by telephone. Descriptive variables for the older persons included measures of sociodemographic status (age, ethnicity, race, education, household composition) and health status (self-rated health; chronic conditions; instrumental activities of daily living⁷). Descriptive variables for the surrogates included ethnicity, race, gender, relationship to the older person, and frequency of contact with the older person, either in person or by telephone.

Older persons were asked about whether they had participated in each of four activities, proposed to represent the discrete behavioral components of ACP:⁸ a) completion of a living will, described as: “A living will is not the same as a regular will. This is a piece of paper that generally includes a statement saying that if a person's condition is thought to be terminal or if the person is permanently unconscious, then the person should not be kept alive through life support systems;” b) completion of a health care proxy, described as: “Naming a health care proxy means that you have decided on the person that you want to make medical decisions for you when you are unable. It also includes filling out a form stating that this person is your choice for a health care proxy;” c) communication between individual and loved ones regarding individuals’ views about the use of life-sustaining treatment; d) communication between patient and loved ones regarding individuals’ views about quality versus quantity of life. The latter two were designed to assess whether older persons had undergone a process of clarifying and discussing their goals of care. The challenge to such an assessment is that this is a complex task, ideally encompassing patients’ values as they relate to the acceptability of diminishing states of health, the trade-offs between the benefits and burdens of interventions, and the likelihood of different health outcomes. Because preliminary work suggested that many older persons may not be familiar with one or more of these concepts, we simplified the notion of clarification of goals to include the most fundamental concepts likely to be familiar to a diverse group of older persons.

Surrogates were asked corresponding questions about whether they believed the older person had completed these ACP activities.

Analysis

Frequencies, proportions, and means (standard deviations) were used to characterize the study participants. Agreement between older persons and surrogates regarding the older person's participation in ACP was examined in 2×2 tables and characterized using both percent agreement and the kappa coefficient, which takes into account agreement that occurs by chance alone.

RESULTS

The older persons had a mean (SD) age of 74 (7.0) years, 71% were female, 27% were non-white, and 38% lived alone (Table 1). They had a mean (SD) of 3.9 (2.1) chronic diseases, 20% had 1 or more IADL disabilities, and 20% rated their health as fair or poor. The majority of their surrogates were either children (42%) or spouses (41%), and 77% of surrogates reported speaking with the older person on a daily basis.

Of the older person - surrogate pairs, 81% agreed about whether or not a living will had been completed [$k = .61$, 95% confidence interval (CI) $.51, .72$] (Table 2). Agreement was substantially lower for the remaining ACP activities. Only 68% of pairs agreed about whether a health care proxy had been completed ($k = .39$, 95% CI $.29, .50$), 64% agreed about whether they had communicated regarding the older person's' views on the use of life-sustaining treatment ($k = .22$, 95% CI $.09, .35$), and 62% agreed about whether they had communicated regarding the older person's views on quality versus quantity of life ($k = .23$, 95% CI $.11, .35$). For each of the behaviors, when disagreement occurred, there were a larger proportion of pairs in which surrogates reported the activity had been completed when the older person reported that it had not than pairs in which the opposite pattern of reporting occurred. For example, regarding communication about quality versus quantity of life, in 75% of the disagreeing pairs, the surrogate reported that the communication had occurred while the patient reported it had not.

DISCUSSION

In this study of community-living older persons and the individuals these persons identified as their preferred surrogate decision makers, agreement was good regarding their reports of whether the person had completed a living will. However, agreement was only fair to poor regarding their reports of whether the person had engaged in a variety of other ACP activities that, by their very nature, should involve both the patient and surrogate. Whereas 81% agreed about whether the person had completed a living will, only 62-68% agreed about whether the person had completed a health care proxy or whether they had communicated regarding the older persons' attitudes toward life-sustaining treatment and toward quality versus quantity of life.

The poor concordance demonstrated in the current study for the majority of ACP activities mirrors the findings of similarly poor concordance between patient and caregiver reports for various aspects of care among persons with advanced illness, including patients' symptoms, caregiving needs, and fears concerning the future.⁹ The poor concordance is also consistent with the multiple studies performed among many different patient populations

demonstrating poor patient-surrogate agreement regarding patients' end-of-life treatment preferences.^{5, 10, 11} The direction of the disagreement, with surrogates more frequently reporting completion of ACP activities while patients reported lack of completion, is unexpected given previous findings regarding patient-caregiver communication and patient and surrogate attitudes toward surrogate decision making. While older persons trust their loved ones to make surrogate healthcare decisions on their behalf,¹² surrogate decision makers cite lack of knowledge regarding patients' preferences as a cause of stress.¹³ In addition, among patients with advanced illness and their caregivers, a greater proportion of caregivers than patients cite a desire for more communication and find communication difficult when they disagree.⁶ Based on these prior findings, it might have been expected that the older persons in the current study would be more likely to report communication regarding their end-of-life preferences than their surrogates. Instead, we found that, when surrogates and patients disagreed, surrogates were more likely to report that communication had occurred. Nonetheless

Although agreement about completion of living wills was higher than agreement about communication regarding patients' preferences, there was nonetheless a substantial proportion of pairs who did not agree about whether a living will had been completed. This disagreement is particularly striking given that the completion of advance directive documents is an objective behavior, as compared to perceptions of communication, which are more subjective. The finding that both older persons and surrogates reported completion when the other did not raises the question of who is the more accurate informant. While it is plausible that surrogates may be unaware that they have been formally appointed as proxy decision makers, the reasons for why older persons would be unaware that they had assigned a health care proxy are less clear. The exclusion of participants with cognitive impairment as identified using a test of short-term memory makes it less likely that they simply did not remember completing the form. It is possible that both older persons and surrogates may have had poor knowledge of health care proxies¹⁴ and thus confused completion of proxy or durable power of attorney for health care forms with completion of standard power of attorney forms. Because it is possible to confirm whether a health care proxy has been completed, further research in which patient and surrogate reports are supplemented by review of the documents they have filled out will enable researchers to answer the question of who is the more accurate informant.

Regardless of who is more accurate in reporting completion of advance directive documents, the high prevalence of disagreement regarding communication implies that surrogates may not be satisfactory informants of whether the care that patients received at the end of life was consistent with their preferences, as they are frequently called upon to do.^{4, 15} The results of this study have implications not only for the accuracy of surrogate reports but also for the experience of surrogate decision making. The perception that surrogates have engaged in communication regarding the older person's preferences when the older person disagrees can result in either decreasing or increasing the burdens associated with surrogate decision making. On the one hand, believing that they have discussed preferences can decrease surrogates' burden by increasing confidence that they are making decisions based on patients' desires.^{13, 16, 17} On the other hand, if mistaken beliefs about communication are associated with mistaken beliefs about preferences, surrogates' misapprehensions about

patients' preferences can increase their burden if, for example, they are unable to carry out preferences they mistakenly believe the patient to have held.¹⁸ The meaning of the disagreement for the actual decisions that are made is also complex. Surrogates who mistakenly believe they have heard from their loved ones about their preferences may make decisions that are not consistent with actual wishes. However, many patients may want their surrogates to have leeway to override their stated preferences.^{19, 20} Ultimately, because this study did not include an assessment of patients' treatment preferences, we cannot draw any conclusions about whether agreement regarding participation in ACP is associated with agreement regarding patients' preferences. It is possible that, despite a lack of agreement regarding the process, patients and surrogates can achieve one of the primary objectives of ACP; namely, surrogates' understanding of patients' wishes.

Nonetheless, the lack of consensus regarding whether communication occurred is problematic in and of itself, independent of its implications for surrogate decision making. Patients with advanced illness and their surrogates identify strengthening relationships²¹ and having someone to listen²² as key components in the quality of their care. Disagreement about ACP communication suggests that these objectives are not being achieved sufficiently. Ensuring that both patients and surrogates feel they have been heard by addressing the barriers to communication must therefore be explicitly addressed in the process of ACP. Recent study has shown that these barriers are amenable to appropriate intervention.²³

We elected to include older persons regardless of their health status in order to increase the generalizability of the study results. However, if, with advancing illness, communication between patients and surrogates improves, then these results may not reflect the status of agreement at the time of a patient's final illness and death.^{4, 24} In addition, participation in ACP is a complex process, and the four specific activities assessed in this study may not have captured the full spectrum of advance planning.

Ideally, ACP is a process by which patients and their loved ones can ensure that they have discussed the care that patients will receive if they can no longer participate in medical decision making. The poor agreement between older persons and their surrogate decision makers regarding participation in different aspects of ACP highlights the need to determine who is providing the most accurate report of whether objective components of ACP have been completed. It also supports the need for additional research to determine whether agreement regarding participation in ACP is associated with greater shared understanding of patients' preferences.

Elements of Financial/Personal Conflicts	TRF		CAR		MLR		JRO		LI	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Employment or Affiliation		x		x		x		x		x
Grants/Funds		x		x		x		X		X
Honoraria		X		X		X		X		X

Elements of Financial/Personal Conflicts	TRF		CAR		MLR		JRO		LI	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Speaker Forum		X		X		X		X		X
Consultant		X		X		X		X		X
Stocks		X		X		X		X		X
Royalties		X		X		X		X		X
Expert Testimony		X		X		X		X		X
Board Member		X		X		X		X		X
Patents		X		X		X		X		X
Personal Relationship		X		X		X		X		X

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TABLE 1

Description of N=218 older persons and their surrogates

Characteristic	Value
<u>Older persons</u>	
Age, mean years (SD)	74 (7.0)
Female, %	71
Non-Hispanic ethnicity, %	<1
Race, %	
<u>White</u>	<u>72</u>
<u>Black</u>	<u>24</u>
<u>Other</u>	<u>4</u>
Greater than high school education, %	64
Married, %	52
Lives alone, %	38
Chronic diseases, mean number (SD)	3.9 (2.1)
1 IADL disability, %	20
Self-rated health fair/poor, %	20
<u>Surrogates</u>	
Female, %	68
Non-Hispanic ethnicity, %	<1
Race, %	
<u>White</u>	<u>69</u>
<u>Black</u>	<u>26</u>
<u>Other</u>	<u>5</u>
Relationship to older person, %	
Child	42
<u>Spouse</u>	<u>40</u>
<u>Significant other</u>	<u>1</u>
Other relative	12
Other	5
Frequency of contact, %	
Daily	77
Weekly	19
Less than weekly	4

TABLE 2
 Agreement between older persons/surrogate pairs regarding older persons' participation in ACP activities

ACP activity	Agreement: activity completed	Agreement: activity not completed	Older person reports completion	Surrogate reports completion	Kappa (95% Confidence interval)
Living will	97 (45)	78 (36)	14 (6)	28 (13)	.61 (.51, .72)
Health care proxy	64 (30)	82 (38)	8 (4)	61 (28)	.39 (.29, .50)
Communication about life-sustaining treatment	103 (47)	37 (17)	31 (14)	47 (22)	.22 (.09, .35)
Communication about quality versus quantity of life	86 (40)	47 (22)	21 (10)	62 (29)	.23 (.11, .35)