

HEALTH CARE REFORM

Failure to Engage Hospitalized Elderly Patients and Their Families in Advance Care Planning

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Importance: Advance care planning can improve patient-centered care and potentially reduce intensification of care at the end of life.

Objectives: To inquire about patients' advance care planning activities before hospitalization and preferences for care from the perspectives of patients and family members, as well as to measure real-time concordance between expressed preferences for care and documentation of those preferences in the medical record.

Design: Prospective study.

Setting: Twelve acute care hospitals in Canada.

Participants: Elderly patients who were at high risk of dying in the next 6 months and their family members.

Main Outcome Measures: Responses to an in-person administered questionnaire and concordance of expressed preferences and orders of care documented in the medical record.

Results: Of 513 patients and 366 family members approached, 278 patients (54.2%) and 225 family mem-

bers (61.5%) consented to participate. The mean ages of patients and family members were 80.0 and 60.8 years, respectively. Before hospitalization, most patients (76.3%) had thought about end-of-life (EOL) care, and only 11.9% preferred life-prolonging care; 47.9% of patients had completed an advance care plan, and 73.3% had formally named a surrogate decision maker for health care. Of patients who had discussed their wishes, only 30.3% had done so with the family physician and 55.3% with any member of the health care team. Agreement between patients' expressed preferences for EOL care and documentation in the medical record was 30.2%. Family members' perspectives were similar to those of patients.

Conclusions and Relevance: Many elderly patients at high risk of dying and their family members have expressed preferences for medical treatments at the EOL. However, communication with health care professionals and documentation of these preferences remains inadequate. Efforts to reduce this significant medical error of omission are warranted.

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THERE EXISTS A PROFOUND paradox in modern medicine at the end of life (EOL). Although most elderly patients prefer only comfort measures at the EOL, life-sustaining technologies are increasingly being used in the final stages of life. For example, most persons prefer to be cared for and die at home,¹⁻³ but in the Western world, the dying experience usually occurs in the hospital, and one-fifth of hospital deaths occur in an intensive care unit.⁴⁻⁶ Most older patients value quality of life over the unnecessary prolongation of life through the use of technology.⁷⁻¹⁰ However, life support measures are often provided to patients during the final

months of life, even when the patient or family prefers comfort care.¹¹

See Invited Commentary at end of article

Advance care planning (ACP) is an ongoing process of reflection and communication in which a person who has decision-making capacity makes decisions regarding future health and/or personal care in the event that he or she becomes incapable of consenting to or refusing treatment or other care.¹² This process ideally involves discussions with health care providers, family members, and close friends regarding one's values and the health states

one would find acceptable or unacceptable and establishing how much leeway the surrogate is given to make future “in the moment” decisions about one’s care at the EOL.¹³ The ACP process may result in a verbal or written advance care plan, which may include instructions about medical treatments wanted or not wanted at the EOL, as well as the values that guide these significant decisions (ie, an advance directive). It may also result in someone being nominated as a surrogate decision maker to make decisions for the person if they become incapable. The process encourages dialogue between patients; their family, friends, and surrogate decision makers; and the health care team.

Although there may be limitations to the validity and clinical utility of documented advance directives,¹⁴ the conversations surrounding the ACP process are essential to providing patient-centered care. Moreover, ACP practices are associated with better quality of life for patients during the terminal phase of life, better outcomes for family caregivers, and less resource-intensive care at the EOL.¹⁵⁻²⁰ Accordingly, many practitioners around the world have begun to embed ACP into health care.²¹ A recent multi-institution evaluation of EOL care from the perspective of patients who had advanced illness showed that there are opportunities to improve timely provision of information about the patient’s condition and discussions with the physician regarding final location of care and use of technology at the EOL.²²

To our knowledge, there has been no rigorous audit or evaluation of ACP from the patient or family perspective using validated questionnaires that assess the frequency of engagement in key ACP activities. Based on the Knowledge-to-Action model for knowledge translation,²³ the next steps for implementing strategies to improve ACP should include identification of gaps between knowledge and current practice in the local context. Thus, the primary purpose of this study was to determine, from the perspectives of acutely ill patients and their family members, the prevalence of ACP and its components before the index hospitalization and the concordance between patients’ expressed preferences and prescribed levels of care as documented in the medical record. In addition, we assessed patients’ and family members’ overall satisfaction with EOL communication and decision making during the last 4 weeks.

METHODS

Between September 1, 2011, and March 15, 2012, we conducted a multicenter, prospective, study in 12 acute care hospitals in Canada. We administered a questionnaire during face-to-face interviews with patients and family members to assess the quantity and quality of ACP. We included a convenience sample of large hospitals in British Columbia, Alberta, Ontario, and Quebec. Hospitalized patients were enrolled if they had advanced pulmonary, cardiac, or liver disease or metastatic cancer (see eAppendix for details; <http://www.jamainternalmed.com>) or if they were aged 80 years or older and admitted to the hospital from the community for an acute medical or surgical condition. If none of these criteria were met, any patient whose death within the next 6 months would not surprise any member of his or her care team was also in-

cluded.²⁴ These criteria define a patient population at high risk of dying during the subsequent 6 months.^{9,11} To provide a representative sample of each site’s performance, we planned to enroll 30 patients and 30 family members per site.

Potentially eligible patients were identified by screening hospital records or by a referral from a member of the patient’s health care team. When research personnel were available, we approached consecutive eligible patients and their family members from participating hospital units for their consent to participate. Patients unable to communicate for cognitive reasons and non-English- and non-French-speaking individuals (assessed subjectively by staff) were excluded, but if family members were available, they were approached independent of the patient. Otherwise, enrolled study patients were asked to identify an adult family member who knew them best (inclusive of partners, significant others, and/or close friends) and who had visited the patient at least once during the current hospitalization. These same criteria applied to family members of eligible but nonparticipating patients. We timed our initial approach to be 48 to 120 hours after admission of the patient to allow for abatement of symptoms present at admission so that the patient and family could participate in an interview.

After obtaining written informed consent, the research assistant conducted separate face-to-face interviews with patients and family members. The details of questionnaire development and validation are described elsewhere.²⁵ Questions addressed their engagement in ACP both before and during the current hospitalization. We assessed the extent to which patients had completed elements of ACP, including thinking about the kinds of life-sustaining treatments they would or would not want, what their current preferences were, whether they had shared these preferences with anyone (and if so, with whom), and whether a physician had discussed their prognosis with them. We also sought to determine whether the patients believed that they had formally documented these wishes in a written advance care plan or directive, whether they had formally documented their choice of surrogate decision maker, and whether they had been asked about these *prior* discussions or written documents on admission to the hospital. We asked family members about their wishes for the patient, not a proxy assessment of the patient’s wishes. To measure the quality of these decisions made near or at the EOL, we used a validated instrument to assess satisfaction with EOL communication and decision making, the Canadian Health Care Evaluation Project (CANHELP) Questionnaire.²⁶ We administered questions related to the domains that were relevant to communication and decision making (relationship with physicians, communication, decision making, and role of family). This questionnaire asked about level of satisfaction with specific aspects of care during the last 4 weeks (regardless of location of care). Demographic characteristics of the patients and family members (detailed in the eAppendix) were determined from direct interview of the patient and/or family or abstraction from the medical record.

Immediately after completion of the interview, the study nurse reviewed the medical record to determine whether there were any prescribed orders to withhold, limit, or withdraw life-sustaining therapies, the presence or absence of a standardized way to identify and store ACP documents, and any other documentation in the medical record of a discussion between health care providers and the patient and family regarding these issues. The documented treatment goals were abstracted in the same way they were elicited from the patient or family. When patients or families preferred “mixed” levels of care, this was considered concordant provided there was a mix of aggressive and comfort measures in the record.

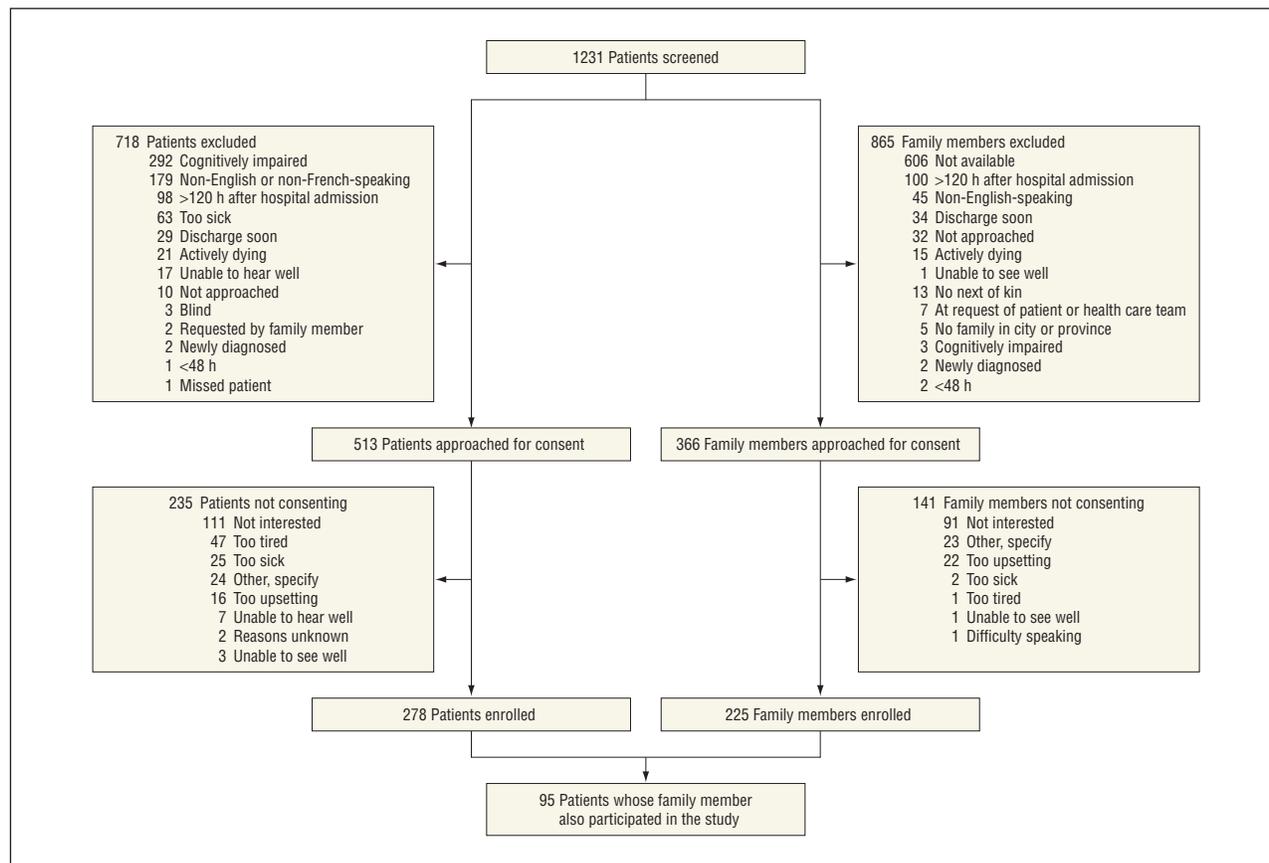


Figure 1. Flow diagram of patients and families involved in this study.

STATISTICAL ANALYSIS

The overall prevalence of key components of ACP is reported for patients and family members as percentages of respondents and 95% CIs. The confidence limits were calculated by the Wald approach, using standard errors estimated by Taylor series linearization to account for the design effect of having the hospitals as the primary sampling unit. These estimates were calculated by the SURVEYFREQ procedure of SAS software (version 9.3; SAS Institute, Inc).²⁷ Crude agreement between stated preferences and prescribed levels of care was calculated as the percentage of patients whose stated preference matched their documented orders in their record. Patients who had missing preference data or missing documented orders were excluded from this analysis. For the CANHELP questionnaire, response options were as follows: 1, not at all satisfied; 2, not very satisfied; 3, somewhat satisfied; 4, very satisfied; and 5, completely satisfied. The “overall” satisfaction score is the unweighted average for all answered questions. The domain scores are the average of nonmissing questions specific to each domain. All scores were rescaled to range between 0 (worst possible value) and 100 (best possible value).

This study was approved by the research ethics board of each participating institution.

RESULTS

We approached 513 eligible patients and 366 potentially eligible family members during the study period; 278 patients and 225 family members consented, yielding an enrollment rate of 54.2% and 61.5%, respectively

(**Figure 1**). For 95 of the 225 participating family members (42.2%), the corresponding patient participated as well. For 130 family members (57.8%), the patient did not participate, usually because he or she was too ill. On average, interviews occurred 3 days (interquartile range, 2.0-4.0 days) after admission. The mean age of the patients was 80 years, and 37.1% lived alone (**Table 1**). The mean age of the family members was 60.8 years; most were children of the patient (56.3%) (**Table 2**). Most patients and family members were white and spoke either English or French. There were significant differences in baseline demographics between participating and nonparticipating patients (Table 1).

Before hospitalization, most of the participating patients and family members (76.3% and 81.7%, respectively) had thought about future care for themselves or their loved one. Of those who had, 88.7% of patients and 88.1% of family members had discussed these wishes with someone (**Table 3**). Most of these discussions were with another family member. Only 17.0% of patients and 18.2% of family members had discussed their preferences with a specialist physician, and only 30.3% of patients and 22.6% of family members had discussed their preferences with a family physician (Table 3). Of those patients and family members who responded that they had discussed these wishes for care with someone before hospitalization, 55.3% of patients and 62.7% of family members said that they had discussed them with at least 1 member of the

Table 1. Patient Demographics^a

Demographic Characteristic	278 Participants	130 Nonparticipants	P Value ^b
Age, mean (SD) [range], y	80.0 (9.3) [55.0-99.0]	84.1 (8.7) [57.0-103.0]	<.001
Sex			
Male	131 (47.1)	51 (39.2)	.12
Female	147 (52.9)	78 (60.0)	
Charlson comorbidity index, mean (SD) [range] ^c	2.3 (2.8) [0.0-12.0]	NA	
Marital status			
Married or living as married	99 (35.6)	60 (46.2)	.02
Widowed	124 (44.6)	57 (43.8)	
Never married	18 (6.5)	1 (0.8)	
Divorced or separated; not remarried	37 (13.3)	12 (9.2)	
Residence in last month (if in the hospital, then month before hospitalization)			
Home (or other private dwelling) alone	103 (37.1)	30 (23.1)	.003
Home (or other private dwelling) with spouse or significant other	89 (32.0)	41 (31.5)	
Home (or other private dwelling) with children or other family members	34 (12.2)	24 (18.5)	
Retirement residence	36 (12.9)	14 (10.8)	
Long-term care or nursing home	14 (5.0)	20 (15.4)	
Rehabilitation facility	1 (0.4)	0	
Other (specify)	1 (0.4)	1 (0.8)	
Location of last residence noted above			
Rural	32 (11.6)	8 (6.2)	.11
Urban	244 (87.8)	120 (92.3)	
Missing	1 (0.4)	2 (1.5)	
Health literacy (REALM-R) score, mean (SD) [range] ^d	7.3 (1.6) [0.0-8.0]	NA	
Education (highest level achieved)			
Elementary school or less	39 (14.0)	33 (25.4)	.006
Some high school	70 (25.2)	28 (21.5)	
High school graduate	58 (20.9)	30 (23.1)	
Some college (including CEGEP) or trade school	31 (11.2)	6 (4.6)	
College diploma (including DEC) or trade school	27 (9.7)	11 (8.5)	
Some university	12 (4.3)	4 (3.1)	
University degree	24 (8.6)	11 (8.5)	
Postgraduate degree	17 (6.1)	3 (2.3)	
Declined to respond	0	2 (1.5)	
Identification with formal religious group or practice			
None	82 (29.5)	35 (26.9)	.09
Protestant (Anglican, Baptist, or United Methodist)	105 (37.8)	34 (26.2)	
Catholic	63 (22.7)	37 (28.5)	
Jewish	4 (1.4)	2 (1.5)	
Muslim	1 (0.4)	1 (0.8)	
Sikh	1 (0.4)	2 (1.5)	
Other (specify)	22 (7.9)	19 (14.6)	
Race and language			
White	263 (94.6)	103 (79.2)	<.001
White; speaking a language other than English or French on a daily basis	48 (17.3)	38 (29.2)	.006
Nonwhite; speaking a language other than English or French on a daily basis	9/278 (3.2)	24/130 (18.5)	<.001
Patient's current fitness or frailty			
Very fit (category 1)	16 (5.8)	3 (2.3)	<.001
Well (category 2)	33 (11.9)	5 (3.8)	
Managing well (category 3)	54 (19.4)	16 (12.3)	
Vulnerable (category 4)	79 (28.4)	27 (20.8)	
Mildly frail (category 5)	52 (18.7)	26 (20.0)	
Moderately frail (category 6)	35 (12.6)	29 (22.3)	
Severely frail (category 7)	7 (2.5)	18 (13.8)	
Very severely frail (category 8)	2 (0.7)	6 (4.6)	
Inclusion criteria			
Age ≥55 y or with chronic obstructive lung disease, congestive heart failure, cirrhosis, cancer, and/or end-stage dementia	113 (40.6)	33 (25.4)	.003
Age ≥80 y and admitted to hospital from community for acute medical or surgical condition	165 (59.4)	97 (74.6)	
Care team assessment ^e	0	0	
Diagnosis			
Chronic obstructive lung disease	39 (14.0)	5 (3.8)	.002
Congestive heart failure	27 (9.7)	10 (7.7)	.51
Cirrhosis	3 (1.1)	0	.24
Cancer	54 (19.4)	18 (13.8)	.17
End-stage dementia	0	3 (2.3)	.01
Hospital length of stay, mean (SD) [range], d	14.5 (28.0) [2.0-377.0]	18.5 (39.0) [2.0-386.0]	.35
Death in hospital	9 (3.2)	14 (10.8)	.002

Abbreviations: CEGEP, Collège d'enseignement général et professionnel; DEC, diplôme d'études collégiales; NA, not applicable; REALM-R, rapid estimate of adult literacy in medicine-revised.

^aData are given as number (percentage) of patients unless otherwise indicated. Values may not sum to total owing to missing data.

^bBoldface P values indicate significant differences ($P < .05$).

^cHigher scores reflect more comorbid conditions.

^dThose with a REALM-R score of ≤6 (of a total of 8) should be considered at risk for poor health literacy (see eAppendix).

^eAny patient whose death within the next 6 months would not surprise any member of his or her care team was also included.

Table 2. Family Member Demographics^a

Demographic Characteristic	Findings in 225 Family Members
Age, mean (SD) [range], y	60.8 (13.7) [20.0-92.0]
Sex	
Male	54 (24.1)
Female	170 (75.9)
Relationship to patient	
Spouse or partner	77 (34.4)
Parent	3 (1.3)
Parent-in-law	3 (1.3)
Daughter or son	126 (56.3)
Sister or brother	2 (0.9)
Other (specify)	13 (5.8)
Education (highest level achieved)	
Elementary school or less	7 (3.1)
Some high school	26 (11.6)
High school graduate	41 (18.3)
Some college (including CEGEP) or trade school	29 (12.9)
College diploma (including DEC) or trade school	41 (18.3)
Some university	12 (5.4)
University degree	47 (21.0)
Postgraduate degree	19 (8.5)
Declined to respond	2 (0.9)
Health literacy (REALM-R) score, mean (SD) [range] ^b	7.8 (0.9) [1.0-8.0]
Identification with formal religious group or practice	
None	68 (30.4)
Protestant (Anglican, Baptist, United Methodist)	60 (26.8)
Catholic	65 (29.0)
Jewish	4 (1.8)
Muslim	1 (0.4)
Sikh	2 (0.9)
Other (specify)	22 (9.8)
Declined to respond	2 (0.9)
Respondent is the surrogate decision maker (n = 224)	191 (85.3)
Race and language	
White (n = 221)	191 (86.4)
White; speaking a language other than English or French on a daily basis (n = 221)	47 (21.3)
Nonwhite; speaking a language other than English or French on a daily basis (n = 221)	21 (9.5)
Patient is a study participant (n = 224)	95 (42.4)
Reason for patient nonparticipation ^c	
Too tired, sick, or weak	64 (44.4)
Emotionally overwhelmed or stressed	10 (6.9)
Hearing or speech problems	13 (9.0)
Literacy, reading, or language difficulties	28 (19.4)
Refusal to participate	10 (6.9)
Cognitive impairment	19 (13.2)

Abbreviations: CEGEP, Collège d'enseignement général et professionnel; DEC, diplôme d'études collégiales; REALM-R, rapid estimate of adult literacy in medicine—revised.

^aData are given as number (percentage) of family members unless otherwise indicated. Values may not sum to total owing to missing data.

^bThose with a REALM-R score of ≤ 6 (of a total of 8) should be considered at risk for poor health literacy (see eAppendix).

^cn=130 patients, but there can be more than 1 response for a given patient, or a patient can have more than 1 reason to be excluded.

health care team that was caring for the patient during the index hospitalization (physician, nurse, social worker, or spiritual care worker). Before hospitalization, only 20.1% of patients and 33.2% of family members reported participating in a discussion about the patient's prognosis with a physician.

Of participating patients, 47.9% reported having completed a written advance care plan, and 73.3% had been through a formally documented process of naming a surrogate decision maker (Table 3). When family members were asked, 52.2% reported the patient had an advance care plan, and 72.1% reported that the patient had nominated a surrogate decision maker. On admission to the

hospital, only 24.8% of patients and 31.7% of family members reported that they had been asked about these prior discussions or written documents.

Most patients preferred comfort care (30.6%) or a mix of comfort and full medical care that does not include resuscitation (30.6%), whereas only 11.9% preferred life-prolonging medical care, including resuscitation, in the event of a deterioration in their health (Table 3). Similarly, family members more commonly preferred comfort care for the patient (34.8%) or a mix of comfort and full medical care that does not include resuscitation (27.7%); only 14.7% preferred aggressive medical care, including resuscitation (Table 3).

Table 3. Prevalence of Key Components of Advance Care Planning

Questions About Advanced Care Planning Before Hospitalization	% (95% CI) ^a	
	278 Patients	224 Family Members
Have you ever considered or thought about what kinds of life-sustaining treatments you would want, or not want, for yourself (or for your loved one) in the event your (their) physical health deteriorated?	76.3 (68.1-84.4)	81.7 (76.7-86.6)
As it relates to your overall plan of care, if the situation were to arise in which there was a deterioration of your (or your loved one's) health, which option, at this point in time, would you prefer for your/their care?		
Unsure	7.9 (2.9-12.9)	7.6 (2.5-12.7)
Aggressive use of heroic measures and artificial life-sustaining treatments, including CPR, to keep me/my loved one alive at all costs	11.9 (5.2-18.5)	14.7 (8.1-21.4)
Full medical care, but in the event my/my loved one's heart or breathing stops, no CPR	18.3 (13.5-23.2)	15.2 (9.9-20.5)
Physicians will be focused on my/my loved one's comfort by alleviating suffering and not on keeping me/my loved one alive by artificial means or heroic measures, such as trying to prolong my/my loved one's life with CPR and other life-sustaining technologies	30.6 (22.3-38.8)	34.8 (29.0-40.6)
A mix of above (eg, try to fix problems but if not getting better, switch to focusing only on my/my loved one's comfort, even if it hastens death)	30.6 (19.4-41.8)	27.7 (20.3-35.0)
Declined to respond	0.7 (0.0-2.2)	...
If yes, ^b did you discuss these wishes with anyone? ^c	88.7 (83.6-93.8)	88.1 (81.5-94.4)
Physician		
Family	30.3 (26.1-34.5)	22.6 (13.5-31.7)
Specialist	17.0 (6.7-27.3)	18.2 (9.7-26.8)
Other	17.0 (3.0-31.0)	23.3 (8.8-37.7)
Nurse	8.0 (1.8-14.1)	10.1 (5.2-14.9)
Social worker	5.3 (0.7-9.9)	5.7 (1.5-9.8)
Spiritual care provider	6.4 (0.8-12.0)	1.9 (0.0-4.9)
Family member(s)	92.0 (86.9-97.1)	83.0 (73.1-93.0)
Surrogate decision maker	56.4 (33.3-79.5)	...
Other family	...	74.2 (65.9-82.5)
Lawyer	29.8 (13.5-46.1)	27.0 (11.6-42.4)
Other	2.1 (0.0-4.9)	6.9 (0.4-13.4)
Prior to hospitalization, did the physician ever talk to you about a poor prognosis or indicated in some way that you/your loved one had a limited time left to live?	20.1 (13.4-26.9)	33.2 (24.1-42.0)
Do you/does your loved one have an advance directive or living will or some other written document describing the medical treatments you/they would want (or not want) in the event you/they are unable to communicate for yourself/themselves as a result of a life-threatening health problem?	47.9 (35.3-60.6)	52.2 (39.6-64.7)
Have you/your loved one formally designated someone, in writing, whom you/they trust to represent your/their wishes concerning medical treatment decisions in the event you/they are not able to do so?	73.3 (69.4-77.1)	72.1 (62.1-82.0)
On admission to the hospital, were you/your loved one asked whether you/they had prior discussions or written documents about the use of life-sustaining treatments?	24.8 (16.9-32.7)	31.7 (19.6-43.8)

Abbreviation: CPR, cardiopulmonary resuscitation.

^aWhere not otherwise specified, percentages representing proportion responding yes. Values may not sum to total owing to missing data.

^bOf the 212 patients and 183 family members who responded yes to the prior question.

^cOf the 188 patients and 159 family members who responded to this question.

Of the 276 patients who had expressed a preference for care, 77 (27.9%) did not have a written order in the record stating the goal of care. Of these, only 12 (15.6%) preferred aggressive medical management, including resuscitation. Of the 224 family members who had expressed a preference of care for the patient, 71 patients (31.7%) did not have a written order in the record stating the goal of care. Of these, 12 (16.9%) preferred aggressive management, including resuscitation. For the 199 patients and 153 family members who had expressed a preference for care and for whom a written goals-of-care order was present in the patient's record, crude agreement between patients' and family members' expressed preferences and the documented goals-of-care order in

the medical record was 30.2% and 31.4%, respectively (see eTables 1 and 2). The area of greatest discordance was that 28.1% of patients (56 of 199) preferred comfort measures only, but this preference was documented in only 4.5% (9 of 199) of stated goals (**Figure 2A**). Among family members, 34.6% (53 of 153) preferred that the patient receive comfort measures only, but this was documented in only 17.0% (26 of 153) (**Figure 2B**).

The mean (SD) satisfaction score from the CANHELP surveys for patients was 69.1 (17.0) (**eFigure 1**) and for family members it was 61.0 (20.6) (**eFigure 2**). The lowest levels of satisfaction for patients related to discussion about future location of EOL care and what to expect at the end stages of illness. For family members, the

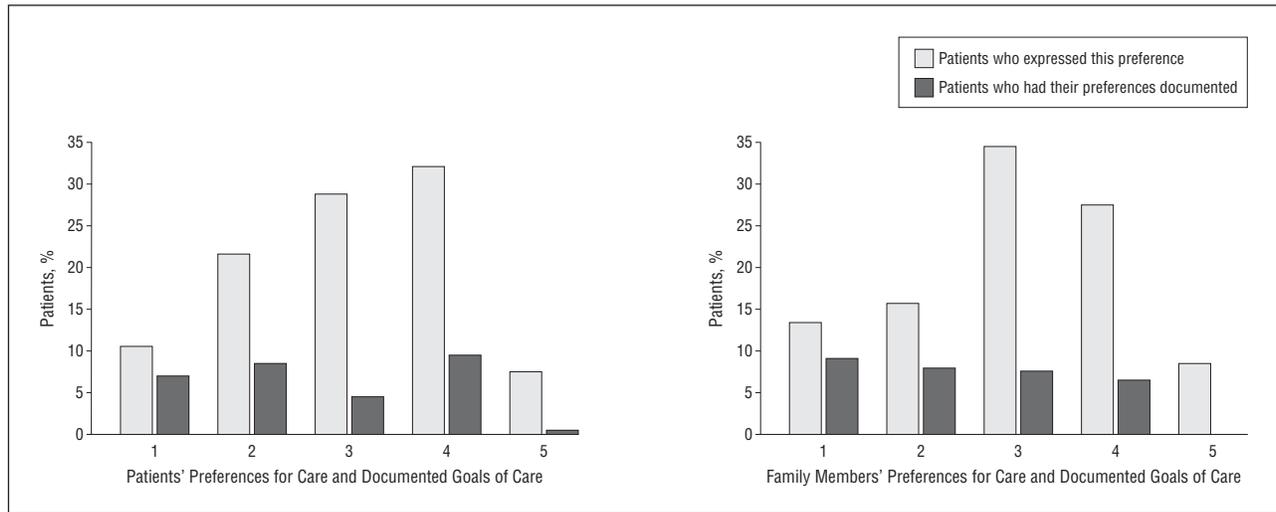


Figure 2. Relationship between expressed preferences for use (or nonuse) of life-sustaining treatments and documented goals of care in the medical record. A, Patients' preferences for care and documented goals of care. Two patients with missing preference data and 77 with missing documentation were excluded; 199 of 278 enrolled patients (71.6%) were included in the analysis. The preferences were described and categorized as follows: (1) aggressive use of heroic measures and artificial life-sustaining treatments, including CPR (cardiopulmonary resuscitation), to keep me alive at all costs; (2) full medical care, but in the event my heart or breathing stops, no CPR; (3) physicians will be focused on my comfort by alleviating suffering and not on keeping me alive by artificial means or heroic measures, such as trying to prolong my life with CPR and other life-sustaining technologies; (4) a mix of the above options (eg, try to fix problems, but if I am not getting better, switch to focusing only on my comfort, even if it hastens death); (5) unsure; and (6) other. B, Family members' preferences for patient care and documented goals of care, with categories as listed for panel A. One family member with missing data and 71 with missing documentation were excluded; 153 of 225 enrolled family members (68.0%) were included in this analysis.

lowest levels of satisfaction related to discussions about the future location of EOL care and the use of life-sustaining technologies.

COMMENT

In this multicenter audit of ACP practices in 12 hospitals in Canada, we used a validated questionnaire to interview patients and families shortly after hospital admission to determine their engagement in key ACP process steps and preferences for EOL care. We then determined whether their preferences were accurately documented in the medical record. We found that the majority of patients and family members had considered and discussed the use or nonuse of life-sustaining technologies near the EOL and could clearly express their preferences for EOL care. However, there was very little effective communication about ACP between the patient or family and members of the health care team before hospitalization. Moreover, less than one-third of patients and families reported that they had been asked about their advance care plans on admission to the hospital. Of patients and families who reported a preference for the use of life-sustaining treatments, nearly 30% did not have any documentation of a preference in the medical record. When preferences were documented, in more than two-thirds of cases the documented preferences were discordant with the patient's or family's expressed preferences. This level of discordance is remarkable given that documentation of preferences and the reports of patients and families occurred at nearly the same time.

Our results show high levels of patient and family engagement in core ACP activities, consistent with findings of other published studies.²⁸ The situation is markedly improved from 20 years ago when a survey of

outpatients attending a general medical clinic found that very few patients had thought about EOL treatment preferences or communicated them to even a family member, and none had written down their plans.²⁹ However, there is still room for improvement. Barriers to engaging in ACP are emerging from qualitative studies and include personal barriers to discussing ACP, such as a fear of "tempting fate," a perception that the health care professional did not have time for the conversation, and fear of upsetting the patient.³⁰⁻³³ Reducing these barriers and encouraging patients and their family members to reflect on their preferences, communicate them, and record them in appropriate documents should be a high priority for health care systems. Resources to assist with this effort can be found on several websites.³⁴⁻³⁸

Our results show that even when patients and families have thought about and expressed preferences for EOL care before hospitalization, members of the health care team that is caring for the patient during the index hospitalization are not discussing them with the patient or family members and these preferences are not documented in the medical record. Most commonly, patients and family members preferred less aggressive care than what was prescribed. In most settings, this may partially be due to the policy that "for resuscitation" or full code is the default position so that, in the absence of conversations early in the hospital stay, patients are prescribed treatments incongruent with their preferences. Aggressive treatment at the EOL has been shown to result in poorer quality of life for patients and family members, poorer quality of death, negative long-term consequences for the family, and wasted health care resources.^{17,20} Efforts to provide more patient-centered EOL care that is consistent with patients' preferences need urgent attention. Asking patients and family members

about existing documents or past conversations seems like a simple starting point. Finally, documentation forms and strategies, such as Physician Orders for Life-Sustaining Treatment (or similar), may help improve the clarity of documented goals of care³⁹ and may facilitate the communication of preferences across time and locations of care.

Despite the presence of advance directive legislation in most provinces in Canada,⁴⁰ our findings suggest that there are large gaps in communication, decision making, and documentation if our goal is truly to achieve patient-centered care. Patients' ratings of satisfaction with EOL care offer some suggestions for prioritizing our quality improvement efforts. Patients and families were least satisfied with the discussions they had with physicians and other members of the health care team regarding what to expect at the EOL, the location of terminal care, and the use of life-sustaining measures.

Although communication with physicians in the hospital about patient or family preferences occurred in only one-third of cases, communication with other health care professionals was strikingly low; less than 10% of patients and family members communicated their preferences for use of life-sustaining measures to nurses, social workers, and spiritual care workers (Table 3). Given that the largest unmet needs of this population are emotional, psychological, spiritual, and informational,²¹ expanding the time, availability, and engagement of allied health care professionals may be more effective and efficient than relying on conventional physician-led initiatives. Others have shown that trained nonphysician facilitators in collaboration with treating physicians can help significantly in engaging patients and families in ACP.³⁸ Moving these conversations from the acute care sector to community settings or primary care also seems sensible. However, these conversations do not commonly occur with family physicians either (Table 3). If systems are not put in place to ensure the communication of previously stated preferences across the health care system, increasing primary care sector involvement in ACP may not be effective. Understanding the perspectives of health care professionals on ACP is clearly important in closing the communication gaps and is the subject of another multicenter study by our group (the DECIDE Study).⁴¹

To our knowledge, our study is the first large-scale evaluation of ACP from a patient and family perspective in the acute care setting. Previously published audits of ACP practice have relied on abstractions from medical record.^{9,42} The strengths of this study include the use of validated instruments to elicit patient and family member perspectives, including satisfaction with EOL care in a large, clinically heterogeneous, multicenter sample and real-time, prospective measurement of concordance between patient preferences and prescriptions about level of care at the EOL, which increases the value and generalizability of our findings. The limitation of this work is that our sample is largely a white, English-speaking population sampled at a single time point in the hospital. We do not address communications, clarifications of goals of care, and actual care that may have been provided later in the hospital stay. Recruiting patients 48 to 120 hours after hospital admission may have resulted in a select sample by excluding patients who had died or

been discharged before that time period. Furthermore, our data may not be generalizable to a broader community-dwelling elderly patient population because we sampled a select population of persons who were admitted to the hospital.

CONCLUSIONS

Our study of patients at high risk for dying and their family members has identified several gaps in communication and documentation in the care of these sick, elderly patients. For the most part, these patients and their family members have considered their wishes for medical treatments at the EOL, but there has been very little communication with health care professionals (either before or during hospitalization) and inadequate documentation of these wishes. As a consequence, there is a disconnect between patients' and family members' wishes for less aggressive medical management at the EOL and documentation in the patient record. More concerted efforts from all health care professionals and decision makers are warranted to narrow these gaps and improve EOL care. Investing in ACP is perhaps the single most important thing we can do as a society and as stewards of our health care system to improve the quality of care from the perspectives of patients and family members and to reduce health care costs at the EOL.

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INVITED COMMENTARY

Disregard of Patients' Preferences Is a Medical Error

To physicians, what is encompassed by the term *medical error* may seem self-evident. It is the surgery performed on the wrong limb, the medication given to the wrong patient, or the medical test that falls through the cracks. Medical errors involve acts of omission as well as commission. During the past decade, we have attempted to systematically address diagnostic, treatment, and equipment-related errors and improve patient safety in medicine. Public awareness of the health care system's efforts to improve patient safety has been raised through the groundbreaking Institute of Medicine report calling for system-level change,¹ a physician-authored *New York Times* bestseller on patient safeguards through checklists,² and a privately instigated campaign to save 100 000 lives by reducing medical errors across 3000 American hospitals.³ However, do we, as clinicians, recognize the full scope of what may constitute medical errors in practice?

Despite our recognition and understanding of the importance of patient safety for surgical treatment, procedures, and medications, the health care system has appeared to ignore a central safety issue that involves life-or-death decisions: the code status discussion and order during hospital admission for patients with serious or terminal illness. In this issue, Heyland and colleagues⁴ offer strong evidence for why we should view knowledge and documentation of patients' preferences for medical treatment through the lens of patient safety. The authors present a multi-site research study across 12 Canadian hospitals involving 278 patients and 255 family members. Patients either were aged 80 years or older or had a high risk of dying within the next 6 months; all patients were hospitalized for serious illness. Through validated survey measurements, Heyland et al found that more than 76% of patients had thought about their wishes for medical care, and nearly half reported completing a written advance directive or proxy docu-

ment before hospitalization. However, less than one-third of patients had spoken to their outpatient family physician about their preferences before hospitalization, and only one-fourth recalled being asked about their preferences or advanced directives during the current admission. As a result of this breakdown in communication, more than two-thirds of patients' preferences were either not documented at all or documented incorrectly in the medical record. In other words, close to 70% of the physician orders concerning intensity of treatment (such as cardiopulmonary resuscitation and intubation) were discordant with current patient wishes. In any other area of medicine, this would be viewed as an egregious "failure of communication" error.³

Despite evidence of a lapse in patient safety, there is some good news. The findings reported by Heyland et al⁴ demonstrate that engagement in advance care planning has increased dramatically during the 2 decades since the SUPPORT study.⁵ A shift in attitudes about advance care planning in the community seems to have occurred, possibly through public health campaigns and the media.⁶ Advance care planning involves many separate behaviors, such as identifying and asking someone to be a surrogate decision maker, identifying individual goals, communicating those goals, and preparing for medical decision making.⁷ Deciding about specific treatment preferences, such as cardiopulmonary resuscitation and code status, is one aspect of the advance care planning process that may directly affect the care received in the hospital. Because patients change their minds during the trajectory of their illness, advance care planning has also begun to be thought of as a process rather than a one-time event.^{7,8} Major strengths of the current study include its implicit recognition of this fact and the authors' demonstrated ability to ask questions about real-time end-of-life treatment preferences. The authors did not rely solely on old advance directive forms from prior