

Effectiveness of Care Coordination and Health Counseling in Advancing Illness

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Systematic reviews about care coordination report beneficial quality outcomes of programs that coordinate care for individuals with chronic illnesses such as heart disease and diabetes mellitus.^{1,2} This literature suggests that the effectiveness of coordination programs is most likely when such programs appropriately match the problems they are designed to address. The need for improved coordination of health services is well documented. This need will increase given the probability of fewer primary care providers, larger volume of patients with more needs, and a lack of reimbursement for coordination activities. Also, increased longevity will lead to more clinically complex patients needing coordination.³ Furthermore, care coordination by physician-led teams is recognized as a promising means to reform health system inefficiencies.⁴

However, there has been less focus on coordination programs for populations with advanced illness.^{5,6} The literature has sparse evidence of benefit from specialized programs for patients with advanced disease.⁷ Therefore, we evaluated a health counseling and care coordination program matched to the needs of populations with advanced illness and delivered in cooperation with referring physicians.

METHODS

Participants

The sample was drawn from the Kaiser Permanente health system. Participants had advanced stages of cancer, congestive heart failure, end-stage pulmonary disease, or end-stage renal disease. For cancer, we included individuals with solid-tumor cancers with metastasis. For congestive heart failure, we included (1) individuals who had an ejection fraction of 30% or lower and persistent New York Heart Association (NYHA) functional class III or IV symptoms and were not a heart transplant candidate, (2) individuals who had severe aortic stenosis or severe mitral regurgitation and persistent NYHA functional class III or IV symptoms and were not a heart transplant candidate, or (3) individuals who had persistent NYHA functional class III or IV symptoms. We defined end-stage pulmonary disease as (1) severe chronic lung disease with progression to end stage (ie, disabling dyspnea at rest or during minimal exertion, poor or no response to bronchodilators, or decreased functional capacity) or (2) hypoxemia or hypercapnia on room

Objective: To evaluate the Advanced Illness Coordinated Care Program (hereafter AICCP) for effects on health delivery among patients and caregivers, quality of life, advance planning, and health service utilization.

Study Design: Prospective trial involving 532 patients and 185 caregivers. AICCP consisted of care coordination, health counseling, and education delivered in cooperation with physicians.

Methods: Patients with advanced disease and their caregivers were assigned to AICCP or usual care (UC). Data sources included self-report, medical record review, and health plan databases. Statistical analyses used *t* test, χ^2 test, regression analysis, and analysis of variance.

Results: Compared with those in UC, AICCP participants had improved communication and care concerning symptoms ($P = .02$), support in understanding and coping with their illness ($P = .01$), advance planning ($P < .001$), support in managing family decision making ($P = .002$), and help in accessing spiritual support ($P < .001$). AICCP caregivers received more attention for emotional and spiritual needs ($P = .02$). AICCP participants were 2.23 times more likely to formulate an advance directive ($P < .001$) (5.5 months sooner [$P < .001$]) and were 1.26 times more likely to agree to a do-not-resuscitate or do-not-intubate order ($P = .04$). AICCP participants had on average 1.89 fewer inpatient admissions ($P = .045$). There was no difference in 1-year survival ($P = .80$).

Conclusions: AICCP improved communication and care delivery, advance planning, and do-not-resuscitate or do-not-intubate orders in a population at risk to use them. AICCP had fewer admissions. Coordination and health counseling seem matched for those coping with advancing illness.

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Take-Away Points

An Advanced Illness Coordinated Care Program (hereafter AICCP) that included health counseling was developed for patients with advanced illness (congestive heart failure, end-stage pulmonary disease, end-stage renal disease, and cancer) in 3 settings of a multistate health plan.

- AICCP resulted in improved communication about discomfort, support for decision making and problem resolution, and attention to caregiver needs.
- AICCP also resulted in increased formulation of advance directives (5.5 months sooner), more agreement to do-not-resuscitate or do-not-intubate orders, and fewer inpatient admissions, with no difference in survival.
- Specialized programming matched to the needs of patients coping with advanced disease improved health delivery and reduced admissions.

counseling, (2) education, and (3) care coordination.

AICCP was delivered by social workers and a health educator with 16 hours of initial training and with 20 hours of follow-up. AICCP meetings were face to face, lasting a mean of 59.0 (SD = 22.1) minutes, including brief follow-up telephone contacts. The mean number of sessions was 4.9 (SD = 2.1) (range,

air (ie, partial pressure of oxygen <56 mm Hg by arterial blood gases or arterial saturation <88% or partial pressure of carbon dioxide ≥51 mm Hg by arterial blood gases) or continuous oxygen. Finally, we included individuals on dialysis or individuals with a recommendation that dialysis should begin within 3 months who also had 1 or more hospitalizations or emergency department visits for complications of end-stage renal disease within the past year.

We excluded patients who (1) resided in intensive care or skilled nursing settings, (2) were enrolled in an end-of-life service, (3) did not speak English, or (4) were cognitively impaired.⁸ Once participants completed informed consents, they were asked to identify a surrogate who had knowledge of their health needs and services. Because most surrogates were spouses who helped patients, we describe them as caregivers to capture the larger role that they usually had in patients' lives. A total of 185 caregivers completed interviews (Table 1).

Although the study was initiated at 4 sites, 1 site withdrew from participation because they needed to shift study personnel to usual care (UC) service delivery. Resources to complete recruitment from this site were unavailable. We analyzed results with and without these participants.

Study Protocol

The study was approved by institutional review boards at Kaiser Permanente and the University at Albany–State University of New York. Recruiters blinded to group assignment enrolled 532 patients. We assigned participants to the Advanced Illness Coordinated Care Program (hereafter AICCP) (n = 267) or to UC (n = 265).⁹ Four hundred three participants (198 in AICCP and 205 in UC) completed the baseline and posttest questionnaires. Of 129 participants who did not complete posttests, 88 died before the posttest, and 41 did not agree to complete the posttest.

Intervention

AICCP is designed to help patients and families optimally manage living with advancing illness. The 6-session model has the following 3 components: (1) nondirective health

0-10 [mode, 6]), with 81.9% of patients completing 3 to 7 sessions. On average, caregivers attended 50% of sessions based on patient preference, caregiver availability, and need.

The topics covered across sessions were structured in a biopsychosocial 3-domain format, including the following: (1) health-related topics included but were not limited to understanding illness, treatment expectations, emerging symptoms, adherence to treatment recommendations, communication with health professionals, and advance planning; (2) coping with loss of role, functional capacity, or health status; evaluating whether situations are amenable to change or, if not, whether reactions to unchangeable situations are modifiable; and monitoring for anxiety or depression, interpersonal conflict, and existential concerns; and (3) caregiving concerns, maximizing health system benefits, home environmental modifications, home care, and long-term care planning.

This structure was delivered using a nondirective health counseling format, patient education, and care coordination. It facilitated recognition and normalization of the consequences of living with ongoing health problems in domains of function beyond physical health per se. It promoted identification of psychosocial needs and supports and facilitated initiation of discussions about ways to adapt to and compensate for losses induced by reduced health status.

An electronic Web tool operationalized each session of AICCP by providing a checklist of health education topics and tasks to be completed in interviews. For example, at the second meeting, coordinators introduced advance planning. If an expected task was not addressed at a specified meeting, coordinators were given pop-up reminders to complete them at subsequent meetings. Health education also included as-needed information about health-related benefits within their health system and their community.

Outcome Measurement

The rationale for measurement selection was tripartite: (1) Among populations coping with life-limiting illness, in which medical interventions are unlikely to provide a return to full health, quality-of-life (QOL) variables take on impor-

tance. (2) Advance plans and do-not-resuscitate or do-not-intubate (DNR/DNI) orders and their timing are relevant measures in a population at risk for needing such planning. (3) Experiences with health delivery and service utilization are important for health plan administrators to determine the feasibility of program adaptation.

Participants were administered functional and QOL outcome questionnaires at enrollment and 4 months later. The questionnaires included the Short Form Health Survey (SF-12), which measures perceived physical and mental health function. It has well-established validity and reliability.¹⁰ The McGill Quality of Life Questionnaire measured total QOL.¹¹ The Social Provisions Scale assessed the provisions of social relationships (eg, attachment).¹² The Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale measures spiritual well-being.¹³ We included 11 of 25 items from the Revised Death Anxiety Scale, which were selected for inclusion as the most likely measures to be affected by AICCP.¹⁴

In addition, we used the AICCP questionnaire, which consists of 21 items designed to capture patients' perspectives about their involvement in care and the effectiveness of healthcare professionals' service delivery on AICCP-sensitive care domains (eg, coordinating care). We conducted factor analysis on these items. We found 6 factors that reflect patient reports about

■ **Table 1.** Participants' Demographic Characteristics

Characteristic	Patients (n = 403)				t
	Usual Care		AICCP		
	No.	Mean (SD)	No.	Mean (SD)	
Age, y	204	68.4 (12.1)	198	66.0 (12.1)	1.99 ^a
Total years married	109	34.8 (16.2)	113	34.4 (17.0)	0.19
Charlson comorbidity score	205	3.1 (2.4)	198	3.5 (2.6)	1.31
Diagnosis	Usual Care		AICCP		χ ²
	No. (%)		No. (%)		
Cancer	81 (39.5)		86 (43.4)		1.6
End-stage pulmonary disease, chronic obstructive pulmonary disease	41 (20.0)		36 (18.2)		
End-stage renal disease	44 (21.5)		46 (23.2)		
Congestive heart failure	39 (19.0)		30 (15.2)		
Sex	205		198		18.0 ^b
Male	108 (52.7)		63 (31.8)		3.7
Female	97 (47.3)		135 (68.2)		
Race/ethnicity	201		197		0.3
White	183 (91.0)		167 (84.8)		
Nonwhite	18 (9.0)		30 (15.2)		
Current marital status	199		198		0.7
Married	117 (58.8)		111 (56.1)		
Not married	82 (41.2)		87 (43.9)		
Living arrangement	201		198		2.1
Live alone	54 (26.9)		46 (23.2)		
With spouse	147 (73.1)		152 (76.8)		
Level of education	187		196		0.1
<High school	14 (7.5)		17 (8.7)		
High school	41 (21.9)		54 (27.6)		
>High school	132 (70.6)		125 (63.7)		
Employment status	198		197		6.3
Employed	27 (13.6)		25 (12.7)		
Not employed	171 (86.4)		172 (87.3)		
Household income, \$	162		180		2.4
<10,000	13 (8.0)		14 (7.8)		
10,000-14,999	25 (15.4)		22 (12.2)		
15,000-24,999	42 (25.9)		35 (19.4)		
25,000-34,999	21 (13.0)		31 (17.2)		
35,000-49,999	29 (17.9)		36 (20.0)		
50,000-74,999	16 (9.9)		27 (15.0)		
75,000-99,999	13 (8.0)		10 (5.6)		
>99,999	3 (1.9)		5 (2.8)		
Religious preference	189		197		2.4
No	52 (27.5)		41 (20.8)		
Yes	137 (72.5)		156 (79.2)		

(Continued)

■ **Table 1.** Participants' Demographic Characteristics (*Continued*)

	Caregivers (n = 185)				t
	Usual Care		AICCP		
	No.	Mean (SD)	No.	Mean (SD)	
Age, y	57	63.8 (13.1)	73	59.9 (14.6)	1.59
	Usual Care		AICCP		χ^2
	No. (%)		No. (%)		
No. of surrogates	85 (45.9)		100 (54.1)		1.2
Sex	75		97		17.7 ^b
Male	9 (12.0)		40 (41.2)		
Female	66 (88.0)		57 (58.8)		
Relationship to patient	83		100		0.6
Spouse	59 (71.1)		66 (66.0)		
Child	16 (19.3)		23 (23.0)		
Other relative	5 (6.0)		7 (7.0)		
Friend	3 (3.6)		4 (4.0)		

AICCP indicates Advanced Illness Coordinated Care Program.
^aP < .05.
^bP < .001.

their own effectiveness in communicating with healthcare professionals and their perceptions about the care they received. Six scores capture information about the effectiveness of communication in these subdomains: (1) The symptom communication and care score captures communication and care for physical and emotional discomfort (6 items [eigenvalue = 3.16, α = .79]). (2) The family communication and support score measures the effectiveness of patient communication with family about the nature and consequences of the patient's health (4 items [eigenvalue = 2.85, α = .84]). (3) The illness understanding and coping support score measures how effectively that professionals communicate with patients about their illness, prepare them for illness sequelae, and assist them in coping with illness (4 items [eigenvalue = 2.33, α = .78]). (4) The family decision-making support score measures health professional support in family decision making and problem resolution (3 items [eigenvalue = 2.12, α = .77]). (5) The spiritual support score captures communication about spiritual support and professional efforts to facilitate patients' obtaining help for those needs (2 items [eigenvalue = 1.90, α = .88]). (6) The advance planning score measures how effectively that health professionals discuss the development of advance plans and help patients formulate them (2 items [eigenvalue = 1.70, α = .77]).

We also measured caregivers' experiences with the healthcare system using a revised version of the Surrogate Integrated Care Systems After Death Interview from the *Toolkit of Instruments to Measure End-of-Life Care*.¹⁵

In addition to the questions about advance planning on the AICCP questionnaire, a medical record review at 9 months assessed the frequency at which participants completed advance

directives, including healthcare proxies and living wills. Also assessed was the frequency at which patients accepted DNR/DNI orders.

We also measured health service utilization by collecting data on 7 categories of service use. These included inpatient admissions, emergency department visits, home health visits, outpatient visits, radiology tests, laboratory tests, and pharmacy prescriptions.

Statistical Analysis

Patient and caregiver baseline characteristics were evaluated using *t* test (interval or ratio scale data) and χ^2 test

(categorical data). Communication in health delivery, patient QOL, caregiver posttest interviews, and service utilization were analyzed using analysis of variance. We analyzed medical record-based advance planning data using χ^2 test, regression analysis, and Kaplan-Meier method. For descriptive purposes, we compared survival in AICCP and UC at 1 year using logistic regression analysis.

RESULTS

The electronic Web tool that guided the treatment protocol was also used to assess treatment integrity.¹⁶ Key AICCP tasks were delivered with high frequency (eg, 82.8% for advance planning and 98.4% for psychosocial monitoring). On average, participants completed AICCP in 5.17 sessions.

Of 532 participants, 129 did not complete posttest measures. There was a higher prevalence of cancer among noncompleters (55.8%) versus completers (41.4%) ($\chi^2_1 = 11.3, P = .01$). Cancer deaths accounted for most of the nonresponse among diagnoses (56 cancer vs 32 other diagnoses; $\chi^2_1 = 6.9, P = .009$).

As already mentioned, 1 study site dropped out but had recruited 41 participants (19 AICCP and 22 UC). To provide a more complete data set and to depict outcomes from sites that fully implemented AICCP, the results summarized in the tables are from the 3 sites that completed the study. We also report how outcomes were affected by inclusion of the data from the dropped site.

Demographic Characteristics

Of 403 participants who completed posttest self-report

■ **Table 2.** Participants' Quality-of-Life Scores

Measure	Usual Care	AICCP	ANOVA	ANCOVA	Covariate		
	Mean (SD)	Mean (SD)	F	F	Baseline	Age	Sex
AICCP Questionnaire							
Symptom communication and care							
Baseline	3.60 (0.88)	3.45 (0.91)	2.81	—	—	—	—
Posttest	3.58 (1.02)	3.76 (0.93)	3.29	5.79 ^a	58.465 ^b	1.999	0.374
Family communication and support							
Baseline	3.53 (1.09)	3.76 (0.98)	4.90 ^a	—	—	—	—
Posttest	3.79 (1.03)	3.96 (0.93)	3.06	1.22	213.900 ^b	0.206	3.713
Illness understanding and coping support							
Baseline	3.95 (0.87)	3.98 (0.77)	0.10	—	—	—	—
Posttest	4.00 (0.94)	4.19 (0.83)	4.59 ^a	6.22 ^a	77.448 ^b	5.032 ^a	7.613 ^c
Family decision-making support							
Baseline	2.65 (1.37)	2.35 (1.17)	5.47 ^a	—	—	—	—
Posttest	2.80 (1.36)	3.05 (1.42)	3.19	10.10 ^c	103.101 ^b	0.031	0.745
Spiritual support							
Baseline	1.79 (1.22)	1.91 (1.25)	0.85	—	—	—	—
Posttest	1.93 (1.38)	2.48 (1.49)	14.23 ^b	13.05 ^b	12.298 ^c	0.025	0.298
Advance planning							
Baseline	2.59 (1.41)	2.67 (1.27)	0.36	—	—	—	—
Posttest	2.76 (1.47)	3.50 (1.25)	29.55 ^b	32.92 ^b	40.949 ^b	0.333	3.568
Short Form Health Survey							
Physical standardized score							
Baseline	33.45 (9.49)	33.26 (11.06)	0.03	—	—	—	—
Posttest	34.65 (10.66)	32.99 (10.31)	2.43	3.75	194.172 ^b	1.170	2.771
Mental standardized score							
Baseline	47.18 (10.68)	46.86 (10.71)	0.09	—	—	—	—
Posttest	47.99 (11.55)	49.09 (10.77)	0.94	1.44	62.489 ^b	4.291 ^a	4.026 ^a
McGill Quality of Life Questionnaire							
Total score							
Baseline	4.77 (0.97)	4.90 (0.89)	1.86	—	—	—	—
Posttest	4.89 (1.14)	5.03 (0.87)	1.93	0.65	154.243 ^b	4.048 ^a	1.653
Social Provisions Scale							
Attachment score							
Baseline	12.87 (2.81)	13.53 (2.08)	7.08 ^c	—	—	—	—
Posttest	13.38 (2.71)	13.46 (2.34)	0.09	1.42	161.137 ^b	8.089 ^c	2.779
Reliable alliance score							
Baseline	13.96 (2.27)	14.42 (1.87)	4.99 ^a	—	—	—	—
Posttest	14.29 (2.20)	14.36 (2.04)	0.11	0.37	84.509 ^b	8.138 ^c	2.890
Functional Assessment of Chronic Illness—Therapy—Spiritual Well-Being Scale							
Total score							
Baseline	31.16 (10.12)	33.28 (9.65)	4.64 ^a	—	—	—	—
Posttest	32.05 (10.53)	34.43 (9.03)	5.80 ^a	1.25	293.046 ^b	10.816 ^c	1.612
Revised Death Anxiety Scale							
Total score							
Baseline	14.68 (6.56)	14.97 (6.35)	0.20	—	—	—	—
Posttest	13.75 (6.69)	13.85 (5.78)	0.03	0.001	162.247 ^b	2.926	0.121

AICCP indicates Advanced Illness Coordinated Care Program.

^a*P* < .05.

^b*P* < .001.

^c*P* < .01.

■ **Table 3.** Caregivers' Interview Scores^a

Domain	Usual Care		AICCP		U
	No.	Mean (SD)	No.	Mean (SD)	
Attend to emotional and spiritual needs of the family	83	0.64 (0.28)	98	0.54 (0.32)	3366.50 ^b
Encourage advance care planning	55	0.19 (0.31)	73	0.18 (0.27)	1969.50
Inform and promote shared decision making	57	0.35 (0.35)	66	0.31 (0.28)	1853.00
Physical comfort and emotional support	35	0.33 (0.32)	50	0.22 (0.27)	698.00

AICCP indicates Advanced Illness Coordinated Care Program.
^aHigher mean scores indicate that more problems were reported in a domain.
^bP < .05.

questionnaires, patients in UC were significantly older by 2.4 years ($t = 1.99, P = .047$) and male ($\chi^2_1 = 18.0, P < .001$) (Table 1). We statistically controlled for these differences to reduce the likelihood that differences between AICCP and UC on these variables may account for observed results.

Of 185 caregivers completing questionnaires, more UC caregivers were female ($\chi^2_1 = 17.7, P < .001$) (Table 1). Given that a high percentage of caregivers were spouses (71.1% in UC and 66.0% in AICCP), this is most likely a reciprocal effect of the group sex difference.

Quality of Life

We compared the baseline QOL measures for AICCP and UC (Table 2). We found differences for 5 of 13 measures: (1) attachment ($F_{1,401} = 7.08, P = .008$), (2) reliable alliance ($F_{1,401} = 4.99, P = .03$) (Social Provisions Scale), (3) spiritual well-being ($F_{1,400} = 4.64, P = .03$) (Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale), (4) family communication and support ($F_{1,398} = 4.90, P = .03$), and (5) family decision-making support ($F_{1,397} = 5.47, P = .02$) (AICCP questionnaire). Scores were higher for AICCP on all significant measures except family decision-making support, indicating that AICCP participants were functioning significantly better overall at baseline for these variables.

Controlling for baseline scores, age, and sex, we found post-test differences favoring AICCP on 5 of 6 AICCP questionnaire scores (Table 2). AICCP providers and patients experienced (1) improved symptom communication and care for physical and emotional discomfort ($F_{1,391} = 5.79, P = .02$), (2) improved support from providers in understanding and coping with illness ($F_{1,388} = 6.22, P = .01$), (3) improved support from providers in managing family decision making and problem resolution ($F_{1,386} = 10.10, P = .002$), (4) significantly more help in coordinating needs for spiritual support ($F_{1,386} = 13.05, P < .001$), and (5) acquisition of more information about and implementation of advance planning ($F_{1,391} = 32.92, P < .001$).

We also examined the caregivers' evaluations of their experiences with the healthcare system (Table 3). Because of nonnormal data, we used nonparametric statistics to analyze caregiver data. Compared with UC caregivers, AICCP caregivers reported receiving significantly more attention for emotional and spiritual needs ($U_{179} = 3366.50, P = .04$). The difference remained significant when controlling for caregiver sex differences ($\beta = .12, SE = .05; t_{165} = 2.44, P = .02$).

Advance Planning

We found differences between the 2 groups in advance directives and in physician orders (DNR/DNI) (Table 4). To

■ **Table 4.** Participants' Advance Planning

Advance Planning	Usual Care	AICCP	χ^2	Wald
	No. (%)	No. (%)		
Advance directive, proxy, living will	194	166	27.0 ^a	25.86 ^a
Yes	41 (21.1)	78 (47.0)		
No	153 (78.9)	88 (53.0)		
Physician order to DNR/DNI	220	209	3.3	4.17 ^b
Yes	70 (31.8)	84 (40.2)		
No	150 (68.2)	125 (59.8)		

AICCP indicates Advanced Illness Coordinated Care Program; DNR/DNI, do not resuscitate or do not intubate.
^aP < .001.
^bP < .05.

Table 5. Participants' Healthcare Utilization

Measure	Usual Care	AICCP	ANOVA	ANCOVA	Covariate		
	Mean (SD)	Mean (SD)	F	F	Baseline	Age	Sex
Inpatient admissions							
Baseline	2.19 (5.95)	1.97 (3.35)	0.27				
Posttest	4.33 (16.26)	2.44 (5.11)	3.28	4.02 ^a	339.064 ^b	3.345	0.174
Emergency department visits							
Baseline	2.40 (4.17)	2.01 (2.88)	1.52				
Posttest	5.35 (12.87)	3.69 (6.14)	3.60	2.22	101.498 ^b	0.107	0.052
Radiology tests							
Baseline	3.76 (5.09)	4.12 (5.40)	0.63				
Posttest	3.89 (10.38)	3.13 (6.85)	0.98	1.47	65.175 ^b	0.133	0.205
Outpatient visits							
Baseline	32.21 (23.67)	32.41 (20.71)	0.01				
Posttest	29.42 (25.52)	32.01 (25.05)	1.40	1.15	234.548 ^b	14.502 ^b	0.346
Laboratory tests							
Baseline	169.57 (228.88)	162.14 (204.62)	0.16				
Posttest	200.35 (276.98)	217.91 (327.58)	0.45	0.66	249.114 ^b	2.142	1.414
Home health visits							
Baseline	2.23 (5.88)	2.86 (9.02)	0.91				
Posttest	3.55 (14.15)	4.67 (13.12)	0.90	0.10	61.934 ^b	6.156 ^a	4.646 ^a
Pharmacy prescriptions							
Baseline	59.19 (44.22)	65.41 (51.62)	2.22				
Posttest	64.22 (48.56)	69.89 (52.06)	1.69	0.28	197.837 ^b	4.485 ^a	0.004

AICCP indicates Advanced Illness Coordinated Care Program; ANCOVA, analysis of covariance; ANOVA, analysis of variance.
^a $P < .05$.
^b $P < .001$.

capture postenrollment differences, only participants who had not completed an advance planning document at baseline were included in the analyses. AICCP participants were 2.23 times more likely than UC participants to formulate an advance directive (47.0% AICCP vs 21.1% UC; Wald₁ = 25.86, $P < .001$) and 1.26 times more likely to agree to DNR/DNI (40.2% AICCP vs 31.8% UC; Wald₁ = 4.17, $P = .04$).

AICCP participants developed advance plans sooner. Specifically, 21.0% of UC participants formulated advance directives by 237 days, whereas 21.0% of AICCP participants formulated directives by 73 days (5.5 months sooner) (log-rank test₁ = 27.45, $P < .001$).

Healthcare Utilization

We compared baseline differences between AICCP and UC in 7 areas of healthcare utilization (Table 5). Results indicated no difference in service utilization between groups before the intervention.

We also compared AICCP and UC on posttest differences, controlling for baseline variables, age, and sex (Table 5). In

AICCP, less intensive and less expensive services tended to be used more frequently (eg, outpatient services), whereas in UC more intensive and more expensive services tended to be used more frequently (inpatient services and emergency department visits). This posttest pattern of utilization differences was significant when controlling for pretest baseline differences (Wilks_{7, 517} = 2.10, $P = .45$) but did not remain significant with the inclusion of age and sex covariates. However, AICCP participants on average had 1.89 fewer inpatient admissions (2.44 AICCP vs 4.33 UC; $F_{1, 525} = 4.02$, $P = .045$) when controlling for baseline admissions, age, and sex.

Survival

There was no significant difference in 1-year survival between the groups (Wald₁ = 0.07, $P = .80$). After 1 year, 32.5% of UC participants and 32.2% of AICCP participants were deceased.

Dropped Site Analyses

Addition of the data from the dropped site had only 1 ef-

fect on the results. Group differences favoring UC on the SF-12 physical subscale become significant ($F_{1,402} = 4.54, P = .03$).

DISCUSSION

This study reported on a coordination program for patients with advanced chronic illness. This program emphasized health counseling combined with education and coordination services. The rationale for the inclusion of health counseling is that serious illness results in substantial losses, which in turn require adaptation. By helping patients and families closely examine the effects of illness on their lives, coordinators help them identify strengths that promote adaptation to loss. Furthermore, coordinators engage patients and families in reflective dialogue about how illness has changed their circumstances. This enables them to help patients incorporate important information about their functioning into treatment planning. This approach may account for reported improvements on the AICCP questionnaire.

QOL benefits have been found in AICCP but are inconsistently reported in the literature.^{7,17} Also, the QOL findings reported herein may have been limited by “ceiling effects,” whereby baseline ratings indicated AICCP participants scored so high at enrollment that there was little room to improve. This may suggest targeting of AICCP to populations with impaired QOL to increase the effect on these outcomes.

AICCP improved how frequently advance plans were formulated and how much sooner they were developed. The value of advance plans, especially living wills, has been questioned because of the limits in portability, the lack of applicability for all circumstances, and the need to accommodate changing preferences over time.¹⁸ However, in the context of the intervention, coordinators interpreted advance planning as an indicator of recognition by patients that the need for care would be ongoing. Advance planning helped to increase family engagement as patients and families discussed care preferences. Ultimately, advance planning seemed to foster a deeper appreciation of the entire health situation.

AICCP effects on utilization indicated that participants tended to use less intensive and less expensive services compared with UC. Participants in UC tended to use more intensive and more expensive services more often. Because admissions are such an important component of total costs, these findings suggest the potential for a program cost offset or even a total cost-benefit by implementation of AICCP. Other counseling interventions for medically ill patients have demonstrated the capacity to reduce costs.¹⁹ As in a previous AICCP evaluation,¹⁷ no effect on survival was found in the present study.

The group differences favoring UC on the SF-12 physical subscale are hard to interpret for several reasons: (1) AICCP

was not fully implemented at the dropped site. (2) The effect is isolated, and there was no change in other important indicators of health (eg, survival and inpatient admissions). (3) Although this difference was statistically significant, the practical significance between scores of 34.5 and 32.9 on the SF-12 is ostensibly negligible. However, this result suggests that future studies of allied health programs should continue to monitor effects on health function.

This study had several limitations that constrain generalizability, including a homogeneous population (87.9% white). Also, the program was delivered primarily by 1 discipline. Cost data were unavailable, preventing an assessment on how AICCP may affect total healthcare expenditures.

AICCP improved communication and care for discomfort, support for decision making and problem resolution, and access to spiritual guidance. AICCP promoted more advance planning sooner and had fewer admissions, with no difference in survival compared with UC. Care coordination and health counseling seem matched to patient and family needs for communication and planning about health delivery in advancing illness.

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REFERENCES

1. Shojania KG, McDonald KM, Wachter RM, Owens DK, eds. *Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies*. Vol 7. Stanford, CA: Stanford University–UCSF Evidence-Based Practice Center, Agency for Healthcare Research and Quality; 2007.
2. MedPAC. *Report to the Congress: Promoting Greater Efficiency in Medicare*. June 2007:15-16. http://www.medpac.gov/chapters/Jun07_Ch01.pdf. Accessed October 14, 2008.
3. Bodenheimer T. Coordinating care: a perilous journey through the health care system. *N Engl J Med*. 2008;358(10):1064-1071.

4. **American College of Physicians.** *The Advanced Medical Home: A Patient-Centered, Physician-Guided Model of Health Care.* 2006. Philadelphia, PA: American College of Physicians. American College of Physicians Policy Monograph.
5. **Brown R, Peikes D, Chen A, Ng J, Schore J, Soh C.** *The Evaluation of the Medicare Coordinated Care Demonstration: Findings for the First Two Years.* Princeton, NJ: Mathematica Policy Research; 2007.
6. **McDonald KM, Sundaram V, Bravata DM, et al.** Care coordination. In: Shojania KG, McDonald KM, Wachter RM, Owens DK, eds. *Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies.* Vol 7. Stanford, CA: Stanford University–UCSF Evidence-Based Practice Center, Agency for Healthcare Research and Quality; 2007.
7. **Zimmermann C, Riechelmann R, Krzyzanowska M, Rodin G, Tannock I.** Effectiveness of specialized palliative care: a systematic review. *JAMA.* 2008;299(14):1698-1709.
8. **Callahan CM, Unverzagt FW, Hui SL, Perkins AJ, Hendrie HC.** Six-item screener to identify cognitive impairment among potential subjects for clinical research. *Med Care.* 2002;40(9):771-781.
9. **Urbaniak GC, Plous S, Lestik M.** *Research Randomizer.* Version 3. <http://www.Randomizer.org>. Accessed February 1, 2002.
10. **Ware J Jr, Kosinski M, Keller SD.** A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Med Care.* 1996;34(3):220-233.
11. **Cohen SR, Mount BM, Strobel MG, Bui F.** The McGill Quality of Life Questionnaire: a measure of quality of life appropriate for people with advanced disease: a preliminary study of validity and acceptability. *Palliat Med.* 1995;9(3):207-219.
12. **Cutrona C, Russell W.** The provisions of social relationships and adaptation to stress. *Adv Pers Relat.* 1987;1:37-67.
13. **Peterman AH, Fitchett G, Brady MJ, Hernandez L, Cella D.** Measuring spiritual well-being in people with cancer: the Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale (FACIT-Sp). *Ann Behav Med.* 2002;24(1):49-58.
14. **Thorson J, Powell F.** A revised death anxiety scale. In: Neimeyer RA, ed. *Death Anxiety Handbook: Research, Instrumentation, and Application.* Washington, DC: Taylor & Francis; 1994.
15. **Teno JM.** Surrogate integrated care systems after death interview. In: *The Toolkit of Instruments to Measure End-of-Life Care.* Providence, RI: Center for Gerontology and Health Care Research, Brown University School of Medicine; 1999.
16. **Unützer J, Choi Y, Cook IA, Oishi S.** A Web-based data management system to improve care for depression in a multicenter clinical trial. *Psychiatr Serv.* 2002;53(6):671-673, 678.
17. **Engelhardt JB, McClive-Reed KP, Toseland RW, Smith TL, Larson DG, Tobin DR.** Effects of a program for coordinated care of advanced illness on patients, surrogates, and healthcare costs: a randomized trial. *Am J Manag Care.* 2006;12(2):93-100.
18. **Fagerlin A, Schneider CE.** Enough: the failure of the living will. In: Silbergeld Jecker NA, Jonsen AR, Perlman RA, eds. *Bioethics: An Introduction to History, Methods, and Practice.* New York, NY: Jones & Bartlett Publishers; 2007:440-456.
19. **Ursano RJ, Sonnenberg SM, Lazar SG.** *Psychodynamic Psychotherapy: Principles and Techniques in the Era of Managed Care.* 2nd ed. Washington, DC: American Psychiatric Press; 2005. ■