

Patient Participation in Care Management: Are They Aware?

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ABSTRACT

OBJECTIVES: Care management (CM) in primary care aims to assist patients to better self-manage their chronic conditions; however, understanding the characteristics of patients who choose to engage in or decline CM is not well explored. The purpose of this study was to identify characteristics of patients who accept versus decline CM participation.

STUDY DESIGN: Provider-delivered CM survey study.

METHODS: Patients who presented for a healthcare visit were offered CM at one of 11 general internal or family medicine practices within 4 physician organizations. A written survey was constructed, which included the Patient Assessment of Chronic Illness Care (PACIC), Patient Activation Measure (PAM), participation in CM, and background/demographics.

RESULTS: Surveys were completed by 261 patients (73% response rate). Of the 230 that did have CM according to the medical record, only 139 (60%) self-identified as having had CM. Self-identified CM patients were not significantly different from non-CM patients in terms of gender, age, years at the practice, days of poor health, health status, employment, and number of chronic conditions. CM patients more often reported having depressive symptoms ($P = .019$), had higher prevalence of diabetes ($P < .001$), and lower education level ($P = .028$). There were no differences between the groups in patient activation (PAM) ($P = .421$); however, those in CM had higher PACIC scores ($P < .001$), indicating a more favorable assessment of the chronic illness care provided to them by the practice. The most common reasons for patients not participating in CM were lack of awareness that they had been offered CM, feeling that CM was not needed, and that patients wanted to work on their chronic condition by him/herself. Cost, time, and not wanting to work on health improvements were infrequently reported as reasons for not participating.

CONCLUSIONS: Some CM patients are unaware that they had been offered or participated in CM. Among those who participate in CM, there do not appear to be significant differences in activation; however, they report a higher level of chronic illness care provided by the practice.

Americans are increasingly plagued by chronic disease,¹ and evidence suggests not all patients are receiving self-care support for managing their disease.^{2,3} Care management (CM) is a patient-centered approach to “assist patients and their support systems in managing medical conditions more effectively,”⁴ and includes patient education, goal setting, and self-management support. Active involvement of patients in their care is fundamental to the Patient-Centered Medical Home (PCMH)⁵⁻⁸ and the Chronic Care Model.⁹⁻¹¹ Yet, as patients are offered CM, it is unclear what their reaction to it will be. Do they participate? Do they decline? Do they understand these changes to their healthcare delivery? Although much has been written about the quality and cost outcomes of CM, not much is known about the patient experience with CM interventions. A review of the literature revealed that little information is currently available on this topic. DeJesus et al have investigated the perspectives of patients and providers regarding an effective care manager. They list desirable care manager characteristics,¹² but they did not assess patients’ experiences with participation in CM as a whole.

Following an intervention study, we had the opportunity to study a group of practices that provided CM and decided that it would be helpful to glean perspectives from patients who were offered CM to better understand their reasons for participating or declining and if there were patterns to the types of patients that responded one way or another. Therefore, the focus of this study was to investigate reasons for participation or nonparticipation, characteristics of patients who participated, and if there were any relationships to perceived assessment of care from the practice or the patients’ level of activation.

METHODS

Provider-Delivered CM Study

In 2010, a large Midwestern health plan partnered with 5 physician

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organizations (POs) to implement a 2-year pilot program aiming to improve the health of chronically ill health plan members by financially supporting POs and their affiliated primary care practices to deliver in-person and telephonic CM, essentially reducing the number of members managed by the health plan's internal telephonic disease management program. Two POs used pilot funding to develop new CM programs and 3 expanded their existing programs. POs assumed full responsibility for administering their programs. This work was developed from the health plan's overall approach of partnering with primary care to improve quality of care. This includes a PCMH program that offers incentives to POs for increasing medical home-related capabilities, including CM, within primary care practices.¹³ Investigators at 2 university medical schools along with health plan analysts received funding (AHRQ 1 R18 HS020108-01) to study the effectiveness of 2 models of CM delivery: traditional health plan-delivered CM versus provider-delivered CM (PDCM). A goal of this research was understanding the patient reaction to CM delivered in the primary care setting. The study was approved by the Michigan State University and University of Michigan institutional review boards and those of the associated POs.

Setting and Participants

Data collected for this study were elicited from patients who were in practices participating in the PDCM study. Information about these organizational participants is contained in **Table 1**. Of the 5 participating organizations, 4 agreed to participate in collecting surveys directly from patients. Because it was determined that an adequate response could be gathered from a sample of practices instead of all

practices, an intentional sampling of practices representing the CM programs in the study was undertaken. We attempted to represent different geographic locations, organizational cultures, CM models, and patient populations. Eleven general or family medicine practices were selected, and all agreed to participate in the survey.

Patients eligible for the survey included those in the participating practices who presented for care during the data collection period and had been offered CM in the past year. Each PO was allowed to select patients appropriate for CM based on their own clinical data and claims-based data provided by the health plan. The methods for offering CM differed among the participating POs and included a combination of telephonic outreach, mailed letters, or recommendation from the physician at the time of the patient visit. Given that the goal was to determine the characteristics of patients who both participated in and declined CM, the sample consisted of patients who were offered CM regardless of whether they accepted the offer.

Measures/Instruments

We hypothesized that patients' participation in CM may be influenced by their assessment of the care they received from the practice and by their degree of willingness or interest in making behavior changes associated with care manager visits and counseling. To measure the assessment of care, we used the Patient Assessment of Chronic Illness Care (PACIC), a 20-item survey that measures specific actions or qualities of care that align with the Chronic Care Model by asking patients to report which elements they experienced in the primary care office.^{14,15} The PACIC consists of 5 scales and an overall summary score. Each scale is scored by averaging the items

Table 1. Physician Organization Descriptions*

	A	B	C	D
LOCATION	WEST MICHIGAN	SOUTHEAST MICHIGAN	SOUTHERN MICHIGAN	SOUTHEAST MICHIGAN
Types of practices	FM	FM & GM/IM	FM & IM	FM & IM
Size of practices	Small (3 providers) to large (13 providers)	Small (3 providers) to very large (26 providers)	Very small (single physician) to large (11 providers)	Medium (7 providers) to very large (37 providers)
Practice ownership	Independent/ partner with PO	University-owned	Independent/ hospital-owned/partner with PO	Hospital-owned
CMgr type	Nurses and Medical Assistants	FM: part-time RNs GM/IM: PharmDs	Nurses (RN, LPN) and medical assistants	RNs hired specifically as case managers
CMgr location	Centralized at PO/in practice	In practice	Centralized at PO/in practice	In practice
Patient mix	Complex chronic disease patients; high diabetes prevalence	FM: patients with chronic conditions (eg, diabetes, hypertension). GM/IM: complex chronic disease patients, elderly, patients with medication management issues	High-risk patients (stratified high, medium, low risk based on survey)	Complex chronic disease patients; noncompliant patients

CMgr indicates care manager; FM, family medicine; GM, general medicine; IM, internal medicine; LPN, licensed practical nurse; PO, physician organization; RN, registered nurse.

completed within that scale and the overall PACIC is scored by averaging scores across all 20 items.

Additionally, to measure patient knowledge, skills, and the confidence needed to manage one's own health, we used the Patient Activation Measure (PAM), which measures patients on a scale from 0 to 100 and provides insight into a patient's health-related characteristics, including attitudes, motivators, behaviors, and outcomes.^{16,17} Patients who measure high on the PAM typically understand the importance of taking a proactive role in managing their health and have the skills and confidence to do so.

To assess the patient's perception of his or her participation in CM, we used this question: "In the past year, have you been referred to a care manager by your doctor or someone at your doctor's office, which is someone who works with you to set and achieve goals to improve your health? This person may be a nurse or other health professional. Visits may be in person or on the phone." Additionally, the 2-question Patient Health Questionnaire (PHQ-2)¹⁸ assessed depressive symptoms and general health status.¹⁹ Patient background and demographic data (age, gender, years as a patient at the practice, employment status, and education status) were also collected.

Data Collection Process

Because there was concern regarding a low response rate based on experience with previous mailed surveys, the study team decided to utilize a practice intercept method in which patients are asked to complete a survey while they are at the practice for a visit. For each practice, a convenient but typical 2-week time period was selected. During this time period, the care manager would scan the schedule and identify any patients that were offered CM in the past year. This formed a list that was given to reception staff each day. If the patient showed for a visit, the reception staff member asked the patient if they were willing to be considered for a survey and be contacted by a research assistant (RA). If the patient agreed, the RA would approach the patient, explain the survey, obtain consent, and then collect the completed survey. Patients were given a \$15 gift card for the completed survey. The RA then entered the survey responses into a database. The list of patients who completed the survey was given back to the practice and a designated individual completed additional information obtained from the medical record, including the patient's number, and type, of chronic conditions, total number of prescribed medications, health insurer, and participation in CM. The practice data were then given to the RA to be combined with the completed survey information.

Data Analysis

To assess the overall percent agreement in CM status between patient self-report and medical record, the Cohen's kappa statistic and McNemar's test were used to determine the degree of concordance between the 2 sources of information (Table 2). The intended analysis was to differentiate patients who had CM from those who did

not, so we conducted comparisons between these groups. Because patients were clustered in practices, we used a cluster robust *t* test and χ^2 test to assess the distribution of continuous and categorical patient characteristics, including demographics, general health, and PACIC and PAM scores, between the 2 groups (Table 3). Finally, we used linear mixed models to control for potential confounders and examine the associations between the effects of self-reported CM or chart-confirmed CM with patient assessment of chronic care and activation measures as determined by scores on the PACIC and PAM assessments (Table 4).

RESULTS

A total of 261 surveys were completed, indicating a 73% response rate. An interesting finding emerged from the patient responses versus the medical record verification. There was a substantial difference in the patients' reports regarding whether they had participated in CM or not compared with what was provided from the medical record verification. Table 2 outlines the groups of patients by patient response and medical record verification. We found that of the 230 that actually did have CM according to the medical record, only 139 (60%) self-identified as having had CM. A similar percentage of the patients who did not have CM ($n = 31$) correctly identified as not having CM (64%; 20 of 31). The overall agreement percent was 60% and the kappa and McNemar's test indicated the 2 sources of information had low agreement (kappa = 0.118) and differed significantly ($P < .001$).

The analysis was intended to differentiate patients who thought they had CM from those who thought they did not; thus, we completed comparisons based on these groups. A description of the demographic and background characteristics of the patients by these groups is provided in Table 3. Those who thought they had CM were not significantly different from those not having CM in terms of gender, age, years at the practice, days of poor health, health status, employment, and number of chronic conditions. Significant

Table 2. CM Participation by Patient Report (survey) and Medical Record Verification

		MEDICAL RECORD		
		Had CM	Did not have CM	Total
Patient report	Had CM	139	11	150
	Did not have CM	91	20	111
	Total	230	31	261
Percent agreement	Kappa statistic (95% CI)	McNemar's χ^2 statistic (<i>P</i>)		
60.9%	0.118 (−0.117 to 0.140)	62.8 (<.001)		

CI indicates confidence interval; CM, care management

Table 3. Characteristics of Patients Who Had and Did Not Have CM According to Self-Report

	THOUGHT HAD CM (N = 150)	THOUGHT NO CM (N = 111)	TOTAL (N = 261)	<i>P</i> ^b
	N (% ^a)	N (% ^a)	N (% ^a)	
Male	65 (43.92)	42 (37.84)	107 (41.31)	.326
Some college or above	82 (55.78)	75 (67.57)	157 (60.85)	.474
Retired	72 (49.32)	47 (42.73)	119 (46.48)	.349
Health status: good general health	83 (55.70)	71 (63.96)	154 (59.23)	.181
PHQ-2: little interest or pleasure in normal activities in past 2 weeks	81 (54.73)	44 (40.00)	125 (48.55)	.020
PHQ-2: down, depressed or hopeless in past 2 weeks	70 (47.30)	40 (36.70)	110 (42.80)	.090
	MEAN (SD)	MEAN (SD)	MEAN (SD)	<i>P</i> ^b
Age, years	60.96 (14.00)	60.99 (13.78)	60.97 (13.88)	.784
Days couldn't do usual activities due to poor health in past 30 days	6.94 (9.95)	5.92 (9.09)	6.51 (9.59)	.405
Years in current practice	11.24 (10.62)	11.43 (9.26)	11.32 (10.03)	.718
Number of chronic conditions	3.15 (1.37)	2.69 (1.45)	2.95 (1.42)	.167
Patient Assessment of Chronic Illness Care				
Patient activation	4.12 (0.90)	4.09 (0.79)	4.11 (0.85)	.915
Delivery system design	4.15 (0.91)	4.07 (0.84)	4.11 (0.88)	.784
Goal setting	4.01 (0.90)	3.75 (0.95)	3.90 (0.93)	.035
Problem setting	4.03 (0.97)	3.72 (1.06)	3.89 (1.02)	.019
Problem solving	3.67 (1.14)	3.05 (1.16)	3.41 (1.18)	<.001
Overall PACIC	4.01 (0.85)	3.68 (0.82)	3.87 (0.85)	.014
Patient Activation Measure	71.49 (17.78)	69.01 (16.12)	70.43 (17.10)	.244

CM indicates care management; PHQ-2, 2-question Patient Health Questionnaire; SD, standard deviation.

^aColumn percentage based on nonmissing data.

^b*P* value adjusted for clustering of patients in practices in physician organizations using generalized linear mixed models for binary and continuous variables.

differences were that CM patients were more likely to report having depressive symptoms ($P = .019$), diabetes ($P < .001$), and lower education levels ($P = .028$).

Among the patients who reported that they did not participate in CM, the most common reasons for not participating were lack of awareness that they had been offered CM, that CM was not needed, and that patients wanted to work on their chronic condition by themselves. Cost, time, and not wanting to work on health improvements were infrequently reported as reasons for not participating in CM.

Analysis of the data revealed that there were no significant differences between the groups in patient activation (PAM) scores; ($P = .421$), however, those who thought they were in CM had higher PACIC scores ($P = .014$), indicating a more favorable assessment of the chronic illness care provided to them by the practice. Specific subscale results are reported in Table 3.

Because almost 40% of patients in the group that had CM as indicated by charts did not think they had CM, it was not surprising that effect of self-reported having CM (0.35; $P < .01$) was smaller than the effect of chart-confirmed having CM (0.48; $P < .05$) on patient assessment of chronic care PACIC measure after controlling for gender, education, retirement status, general health, PHQ-2, years in current practices, and number of chronic conditions (Table 4). The effects on PAM did not differ significantly in either comparison.

DISCUSSION

We found that although the majority of patients had CM, only 60% of those having CM correctly self-identified as participating in CM. Self-identified CM patients were not significantly different from non-CM patients in terms of gender, age, years at the practice, days of poor health, health status, employment, and number of

Table 4. Linear Mixed Models for PACIC and PAM*

	OVERALL PACIC	PAM	OVERALL PACIC	PAM
Self-report having CM	0.35** (0.15-0.65)	3.38 (-0.80 to 7.57)	-	-
Medical record CM	-	-	0.48* (0.09-0.89)	3.57 (-3.14 to 10.30)
Male	-0.08 (-0.30 to 0.15)	-2.90 (-7.03 to 1.22)	-0.05 (-0.29 to 0.18)	-2.61 (-6.74 to 1.52)
Some college or above	-0.004 (-0.23 to 0.23)	4.71* (0.40-9.03)	-0.007 (-0.24 to 0.23)	4.37* (0.06-8.68)
Retired	0.24 (0.01-0.46)	2.71 (-1.50 to 6.92)	0.26* (0.03-0.49)	2.80 (-1.43 to 7.03)
Health status: good general health	0.29* (0.05-0.54)	9.77** (5.24-14.29)	0.30* (0.05-0.55)	9.61** (5.07-14.16)
PHQ-2: little interest or pleasure in normal activities in past 2 weeks	0.10 (-0.26 to 0.45)	-2.37 (-8.84 to 4.10)	0.09 (-0.27 to 0.45)	-2.30 (-8.79 to 4.20)
PHQ-2: down, depressed or hopeless in past 2 weeks	-0.13 (-0.47 to 0.21)	1.38 (-4.86 to 7.63)	-0.12 (-0.46 to 0.23)	1.44 (-4.82 to 7.70)
Years in current practice	-0.01* (-0.03 to -0.003)	-0.17 (-0.39 to 0.04)	-0.01* (-0.03 to -0.003)	-0.18 (-0.40 to 0.03)
Number of chronic conditions	-0.03 (-0.12 to 0.07)	0.63 (-0.91 to 2.17)	-0.01 (-0.11 to 0.09)	0.66 (-0.90 to 2.22)
Intercept	3.64 (3.16-4.12)	60.26 (52.00-68.51)	3.36 (2.78, 3.95)	59.03 (49.67-68.39)

PACIC indicates Patient Assessment of Chronic Illness Care; PAM, Patient Activation Measure; PHQ-2, 2-question Patient Health Questionnaire.

** indicates $P < .05$; *** indicates $P < .01$.

*Patients nested in practices.

chronic conditions. CM patients were more likely to report having depressive symptoms and had a higher prevalence of diabetes and a lower average education level. There were no significant differences between the groups in patient activation as indicated by PAM scores; however, those in CM had higher PACIC scores, indicating a more favorable assessment of the chronic illness care provided to them by the practice.

One surprising finding from this study was that patients were often unsure whether they had been offered CM services. The fact that there was no standard outreach method used among the participating organizations likely contributed to this uncertainty. The outreach was conducted telephonically, in person, or by mail without using a standard script. Also, it may have been unclear to patients that the outreach was coming from their physician's office rather than their health plan or another entity. This highlights what appears to be a common scenario in the CM literature: the heterogeneity of the interventions often limits the ability to draw general and reproducible conclusions. As a research team, we are not sure whether patients not knowing if they had CM or not is a problem or a benefit. On the one hand, not knowing means that patients are

receiving a service that is not identifiable as a specific clinical effort worth supporting and appreciating. On the other hand, if CM is so integrated into the work of the practice that it seems seamless and part of their overall package of care, that might be a good thing. Although it is difficult to find literature on the topic, observations of CM in practice find that often CM is simply part of the care provided and patients are not "sold" or "talked into" participation like it is a separate service.

We hypothesized that patients' participation in CM may be influenced by their assessment of the care they received from the practice and by their degree of willingness or interest in making behavior changes associated with care manager visits and counseling. We did find that patients who participated in CM to a greater extent also had a more favorable assessment of the chronic illness care provided by the practice as indicated by PACIC scores. The question is whether the better assessment was because of the participation or facilitated by it. However, we did not find a relationship between CM participation and higher patient activation as measured by PAM scores. This may have been due to the fact that so many patients were confused about having had CM that it diluted any possible association.

Limitations

In conducting pragmatic, real-world research, circumstances and environments are not “controllable,” like they are in efficacy-based research.²⁰ The benefit is that these studies are likely to reflect true practice implementation. However, as in all studies, limitations exist. First and foremost, the study was not powered to detect differences between patients who simply thought they had CM and those who actually received it. Thus, the analyses may be underpowered to detect significant differences if they existed. Additionally, the survey data were self-reported, inherently biasing the results toward the null. Finally, it must be noted that this study was not designed to examine associations between those who received CM and those who thought they received it. It was designed as a trial to examine the effectiveness of CM on several clinical and patient-centered outcomes. Therefore, the observed results are hypothesis-generating and lend credence to further research in this area.

CONCLUSIONS

Some CM patients are unaware that they had been offered CM. Among those who participated in CM, there do not appear to be significant differences in activation; however, they report a higher level of chronic illness care provided by the practice. Future work should investigate the implications of this information and how to best facilitate patient engagement in and benefit from CM services available in primary care.

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