Activation, Self-management, Engagement, and Retention in Behavioral Health Care: A Randomized Clinical Trial of the DECIDE Intervention

By: Margarita Alegría, Nicholas Carson, Michael Flores, Xinliang Li, Ping Shi, Anna Sophia Lessios, Antonio Polo, Michele Allen, Mary Fierro, Alejandro Interian, Aida Jimenez, Martin La Roche, Catherine Lee, Roberto Lewis-Fernández, Gabriela Livas-Stein, Laura Safar, Catherine Schuman, Joan Storey, Patrick E. Shrout

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Abstract:

Importance: Given minority patients' unequal access to quality care, patient activation and self-management strategies have been suggested as a promising approach to improving mental health care.

Objective: To determine whether the DECIDE (Decide the problem; Explore the questions; Closed or open-ended questions; Identify the who, why, or how of the problem; Direct questions to your health care professional; Enjoy a shared solution) intervention, an educational strategy that teaches patients to ask questions and make collaborative decisions with their health care professional, improves patient activation and self-management, as well as engagement and retention in behavioral health care.

Design, Setting, and Patients: In this multisite randomized clinical trial performed from February 1, 2009, through October 9, 2011 (date of last follow-up interview), we recruited 647 English- or Spanish-speaking patients 18 to 70 years old from 13 outpatient community mental health clinics across 5 states and 1 US territory. A total of 722 patients were included in analyses of secondary outcomes.

Interventions: Three DECIDE training sessions delivered by a care manager vs giving patients a brochure on management of behavioral health.

Main Outcomes and Measures: Primary outcomes were patient assessment of activation (Patient Activation Scale) and self-management (Perceived Efficacy in Patient-Physician Interactions). Secondary outcomes included patient engagement (proportion of visits attended of those scheduled) and retention (attending at least 4 visits in the 6 months after the baseline research assessment), collected through medical record review or electronic records.

Results: Patients assigned to DECIDE reported significant increases in activation (mean $\beta = 1.74$, SD $= 0.58$; $P = .003$) and self-management (mean $\beta = 2.42$, SD $= 0.90$; $P = .008$) relative to control patients, but there was no evidence of an effect on engagement or retention in care.

Conclusions and Relevance: The DECIDE intervention appears to help patients learn to effectively ask questions and participate in decisions about their behavioral health care, but a health care professional component might be needed to augment engagement in care. DECIDE appears to have promise as a strategy for changing the role of minority patients in behavioral health care.

Trial Registration: clinicaltrials.gov Identifier: NCT01226329

Article:

Patient activation is receiving attention as a means to improve the quality of behavioral health care[1,2] and its outcomes.[3] Activation involves the acquisition of knowledge, skills, and beliefs to enable thoughtful action and active participation in decisions about one's health care.[1] Similarly, there is interest in improving self-management, which involves gaining knowledge and self-efficacy to better manage one's mental health and developing awareness of the factors that affect well-being.[4-6] Self-management is designed to develop patients' confidence in managing their illness, whereas activation focuses on aspects of communication (such as asking questions). However, few interventions to improve these outcomes have been tested by randomized trials. Patient involvement in decisions about mental health treatment may be important for improving treatment quality, particularly for minority patients who may hold traditional role expectations against participation in clinical encounters[7,8] and may leave treatment when services do not meet their needs.[9-13] These findings indicate the need for innovative strategies to increase patient activation and self-management, particularly among minority groups.

Patient activation is associated with a range of health outcomes.[14-16] Lower activation may explain an unmet need for medical care[17] and lower adherence with treatment because patients refrain from asking clarifying questions.[18-21] These processes are relevant to minority patients, who are less likely to state concerns,[22,23] seek information,[24,25] or inquire about medications[26] to make informed decisions with health care professionals. Lower levels of activation have been reported among minority groups,[27] which may be explained by socioeconomic and acculturative differences.[17] Minority patients may value warm relationships with health care professionals[8] and

worry that raising concerns might jeopardize the therapeutic relationship. Latinos may prefer avoiding confrontation,[28] whereas African Americans may have low expectations of care,[9,29] given previous experiences with discrimination.[30]

Several smaller trials have found efficacy in improving activation and self-management in mental health and primary care settings[14,31-33] using personalized programming[34] and peer-led trainings.[35] Some recent data demonstrate that patients with higher levels of activation have better health outcomes,[36] lower costs, and better experiences with treatment.[37,38] In pilot testing of an earlier version of the DECIDE (Decide the problem; Explore the questions; Closed or open-ended questions; Identify the who, why, or how of the problem; Direct questions to your health care professional; Enjoy a shared solution) intervention,[31] patient activation raised the odds of being retained and engaged in treatment.

The current study improves on prior research by using a randomized clinical design with patients from 13 outpatient community mental health clinics in the United States and Puerto Rico. The aims of the study are to (1) evaluate the effectiveness of the DECIDE intervention in increasing self-perceived activation and self-management in mental health services and engagement and retention in care; (2) investigate differences in intervention effects by race/ethnicity, sex, and educational level; and (3) examine whether intervention effects can be explained by changes in patient–health care professional communication or therapeutic alliance.

METHODS

Study Patients and Setting

We recruited 647 patients (approximately 28 patients monthly) from February 1, 2009, through October 9, 2011 (date of last follow-up interview), through direct contact in waiting rooms or by health care professional referrals at 13 community outpatient mental health clinics in Massachusetts (5 clinics), Minnesota (3 clinics), New Jersey (1 clinic), New York (1 clinic), North Carolina (2 clinics), and Puerto Rico (1 clinic). The study was presented to patients as helping them "find their voice" in clinical encounters by asking questions to be able to make decisions about their care. Patient follow-up ended in October 2011. The clinics generally served a high volume of low-income Latino and/or other minority patients. Most offered individual and group therapy and psychiatric services but varied in case management and outreach services. Eligibility criteria included ages 18 to 70 years, English or Spanish speaking, and enrollment in mental health care programs (ie, psychotherapy or psychopharmacology). Patients were excluded if they lacked capacity to consent (assessed via screener)[39] or disclosed recent suicidal behavior or ideation,[40] with only 69 patients ineligible for participation. Limited exclusion criteria were intended to make results generalizable, regardless of treatment modality.

Research Procedures

Bilingual care managers (CMs) recruited patients interested in participating, obtained informed consent, and delivered the DECIDE intervention. Figure 1 depicts the screening and enrollment process on the basis of the Consolidated Standards of Reporting Trials guidelines.[41] After being screened and providing written consent, 724 eligible patients were randomized to the intervention (n = 372) or control (n = 352) arm of the study. After randomization, some patients in both arms missed all research assessments. This selection factor was balanced between the groups, so the final sample for primary outcome analyses includes 647 individuals (329 in the intervention group and 318 in the control group) with baseline information and 722 individuals for analyses of secondary outcomes (engagement and retention). Of the 647 individuals, 428 (66.2%) were Latino. Patients who did (n = 647) and those who did not come back after the screen (n = 77) differed only in insurance status. The study was approved by the institutional review boards of the Cambridge Health Alliance and all participating clinics.
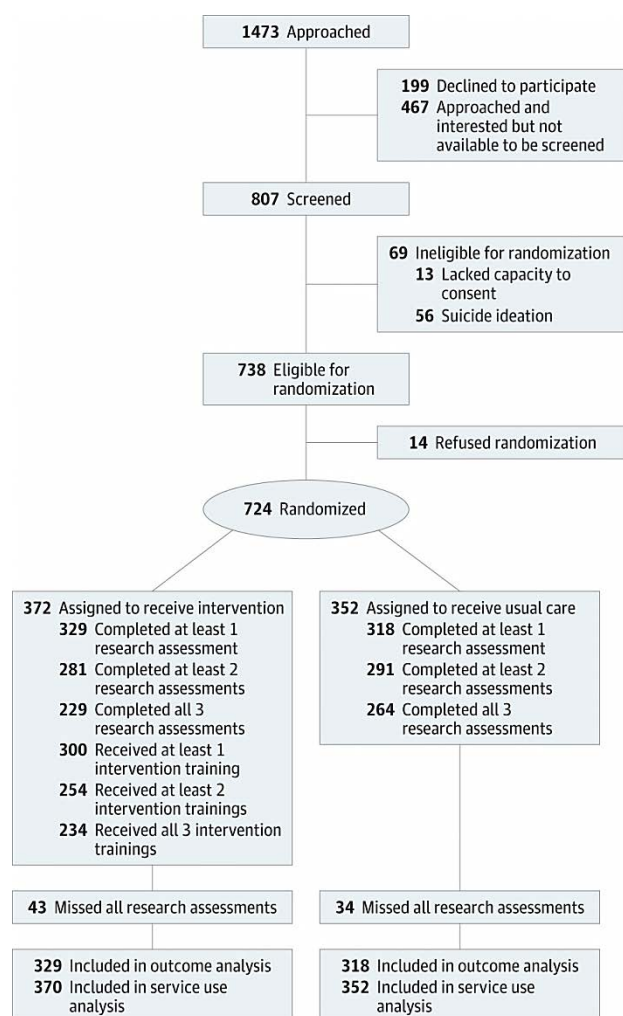

Figure 1. Flow of Study Participants Through Recruitment, Intervention, and Follow-up Assessment Of 1473 patients approached, 724 were randomized and 647 were included in the primary outcome analysis.

Randomization

The *R* statistical package[42] generated a block of random assignments for each site to the intervention or control groups in a 1:1 ratio. Randomization was conducted only after patients had given consent to CMs to prevent allocation bias. Stratified by site, each patient had a 50% chance of being assigned to the intervention group.

Study Design

DECIDE (NCT01226329) is a mixed efficacy-effectiveness trial,[43] involving an intensive standardized intervention (efficacy) while being adaptable to diverse patients and settings (effectiveness).[44] Intervention patients received 30- to 45-minute DECIDE trainings from CMs that were audiorecorded. The trainings were delivered during approximately 3 months in person or, rarely, by telephone. Patients in the control condition received a brochure on managing mental illness through physical health, stress management, and life balance. After screening, 647 patients completed a baseline research assessment with a bilingual research assistant who was masked to the patients' randomization status. Changes in primary outcomes were assessed at follow-up sessions at approximately 45 and 105 days (Figure 2). Patients received $25 for each of the 3 assessments but no incentives for trainings. Data for secondary outcomes (engagement and retention) were collected by research staff from electronic health records and/or medical record review.
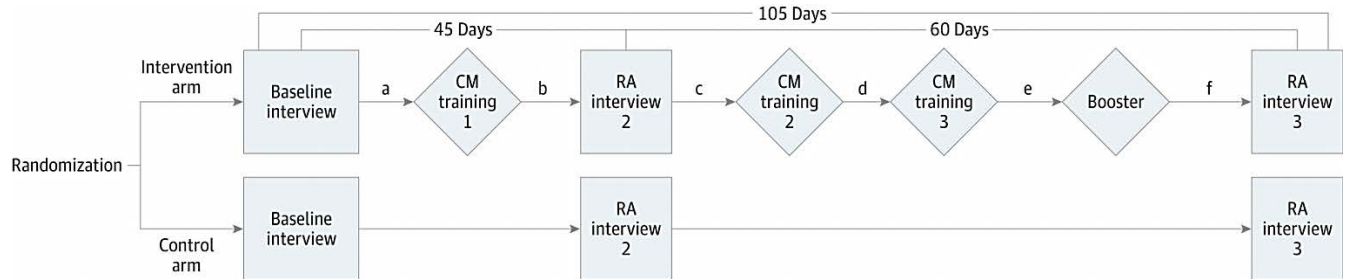

Figure 2. Timing of Interviews and Training for Participants in the Control and Intervention Arms CM indicates care manager; RA, research assistant.

Intervention

DECIDE is a bilingual, manualized intervention that teaches patients to (1) identify decisions regarding their behavioral health care, (2) generate and refine questions for their healh care professionals regarding these decisions, and (3) promote interactions with health care professionals that allow for patient needs to be shared and addressed. DECIDE consists of 3 training sessions that balance didactic presentation with opportunities for participation, role-play, and reflection. Training 1 (Decisions and Agency) sensitizes patients to their role in clinical interactions and encourages participation in decision making. Patients are taught question formulation ("brainstorming") and receive a planner summarizing the intervention content.

Training 2 (Role, Process, and Reason) frames treatment decisions in terms of the roles, processes, and reasons involved. Role-playing and practice assignments reinforce learning. In training 3 (Self-Efficacy and Consolidation) patients identify sources other than health care professionals to answer questions about their behavioral health or treatment. Skills are reinforced and reviewed in a booster session, if necessary.

Supervision and Adherence to Intervention

The CM preparation included a 2-day workshop that covered principles of patient activation and self-management with a thorough review of the DECIDE intervention using videotaped role-play with mock patients. The CMs received weekly telephone supervision from 2 DECIDE supervisors to support implementation of the intervention and solve problems with difficult trainings. Adherence to the intervention manual was evaluated with a random sample of the recorded trainings of 45 patients stratified by CMs. A 50-item checklist was used, reflecting the essential components of trainings. Training fidelity was rated high (received ≥80% of all possible points), medium (60%-79%), or low (<60%). High adherence across CMs was 87% for training 1, 84% for training 2, and 60% for training 3.

Measures

Measures were administered at baseline and follow-up assessments 1 and 2. Activation was evaluated using the Patient Activation Scale (PAS)[31] ($\alpha = .77$ in this sample), which assesses a patient's ability to obtain relevant information, discuss treatment options, communicate with health care professionals, and ask questions about treatment. Scores for the PAS ranged from 4 to 40, with higher scores indicating higher activation. Examples of PAS questions include the following: "How well do you communicate with your mental health care professional when you are feeling uncomfortable about your treatment?" and "How certain are you that you can get the information that you need to make decisions about your treatment?"

Self-management was assessed using the Perceived Efficacy in Patient-Physician Interactions questionnaire (PEPPI; $\alpha = .91$),[45] which evaluated patient confidence in knowing what questions to ask and getting health care professionals to answer questions and take patients' health concerns seriously. The PEPPI has been useful in measuring changes in communication that have been linked to activation with excellent psychometric properties.[46-48] Scores for the PEPPI ranged from 15 to 90, with higher scores indicating higher self-management.

Service use and diagnostic data came from medical records review or by querying electronic health records. *Engagement* was defined as the proportion of behavioral health visits attended of those scheduled in the 6 months after the baseline assessment, and *retention* was defined as attending at least 4 visits in the 6-month period after the baseline assessment.[31]

Patient–health care professional communication was assessed with the communications subscale of the Kim Alliance Scale,[49] which measures the patient's rapport, provision of information, and

expression of concerns (α = .70). Scores ranged from 15 to 44, with higher scores indicating higher quality of communication. Therapeutic alliance was measured using the Working Alliance Inventory–Short Form[50] (α = .89), with patient scores ranging from 13 to 84. The Working Alliance Inventory–Short Form assesses 3 domains of therapeutic alliance: goals, tasks, and bond.

Statistical Analysis

Analyses used intention-to-treat principles. We evaluated whether randomization balanced the control and intervention groups across demographic, diagnostic, and outcomes at baseline (Table 1). Of 647 consented patients in both the intervention and control groups who completed the baseline assessment, 75 dropped out after the baseline assessment and 79 dropped out after the first follow-up assessment (Figure 1). Missing data were imputed using demographic characteristics, time in study, and available outcome scores so that all patients could be included in the analyses. Multiple imputation was completed using the PROC MI procedure (SAS Institute, Inc), with the number of imputations repeated 10 times. Results were combined across multiple imputations using the methods described by Rubin and Schenker.[51]

Table 1. Baseline Characteristics of Patients Assigned to Usual Care and Intervention Groups

| Characteristic | Value[a] | | |
	Usual Care (n = 318)	Intervention (n = 329)	P Value
Sex			
Male	105 (33.0)	95 (28.9)	.25
Female	213 (67.0)	234 (71.1)	
Age, y			
18-34	93 (29.2)	103 (31.3)	.94
35-49	127 (39.9)	128 (38.9)	
50-64	91 (28.6)	90 (27.4)	
≥65 7	(2.2)	8 (2.4)	
Nationality			
US born	132 (41.5)	134 (40.9)	.87
Non–US born	186 (58.5)	194 (59.1)	
Race/ethnicity			
White	50 (15.7)	54 (16.4)	.68
Latino	213 (67.0)	215 (65.3)	
Black	36 (11.3)	33 (10.0)	
Other	19 (6.0)	27 (8.2)	
Educational level, y			
0-6	38 (11.9)	41 (12.5)	.06
7-11	83 (26.1)	62 (18.9)	
12	84 (26.4)	79 (24.1)	
≥13	113 (35.5)	146 (44.5)	

Language of interview			
English	127 (39.9)	133 (40.4)	.90
Spanish	191 (60.1)	196 (59.6)	
Employment status			
Nonemployed	222 (69.8)	219 (66.6)	.38
Employed	96 (30.2)	110 (33.4)	
Insurance status[b]			
No insurance	92 (28.9)	96 (29.2)	.96
Private only	37 (11.6)	36 (10.9)	
Public only	186 (58.5)	194 (59.0)	
Other	3 (0.9)	2 (0.6)	
Primary diagnosis			
Depressive disorder	185 (58.2)	202 (61.4)	.81
Anxiety	35 (11.0)	31 (9.4)	
Bipolar disorder	23 (7.2)	21 (6.4)	
Psychotic disorder	14 (4.4)	9 (2.7)	
Adjustment disorder	19 (6.0)	15 (4.6)	
Substance use	4 (1.3)	4 (1.2)	
Other	34 (10.7)	40 (12.2)	
Disability, mean (SE)			
Days worked (range, 0-30)	7.0 (0.57)	6.6 (0.53)	.61
Days in bed (range, 0-30)	4.6 (0.42)	4.0 (0.36)	.29
Activation score (PAS), mean (SE)	33.3 (0.37)	32.8 (0.38)	.31
Communication score (KAS), mean (SE)	41.1 (0.19)	41.3 (0.19)	.56
Working alliance score (WAI-S), mean (SE)	73.9 (0.57)	73.5 (0.64)	.62
Self-management score (PEPPI), mean (SE)	75.0 (0.75)	75.1 (0.65)	.94

Abbreviations: KAS, Kim Alliance Scale; PAS, Patient Activation Scale; PEPPI, Perceived Efficacy in Patient-Physician Interactions;WAI-S, Working Alliance Inventory‑Short Form.
a Data are presented as number (percentage) of patients unless otherwise indicated.
b One patient did not provide insurance status.

The analytic model assessed change in activation and self-management relative to baseline as primary outcomes. We combined data from both follow-up assessments and used an end-point analysis to test the intervention effect at the second follow-up. The model included intervention as an indicator variable (1 for intervention and 0 otherwise). We included a period indicator to

test the slope from follow-up 1 to follow-up 2 and an intervention by period interaction to test whether the period trajectory was the same for control and intervention groups.

The MIXED Procedure Model (SAS Institute, Inc) accounted for the nesting structure (patients within clinics and repeated assessments within patients) and included random intercepts for patients and clinics. In addition to intervention and period as variables of interest, the model adjusted for age, sex, race/ethnic group (non-Latino white, Latino, black, or other [mainly Asian or mixed race]), educational level (less than high school vs high school or more), and time in study (defined as days since baseline research assessment). Time in study was consistent with the variable period so that time in study was 0 at follow-up 2 if the individual completed follow-up 2 at exactly 105 days after baseline. These same analyses were conducted for the mediation analyses, adding communication and working alliance as covariates to evaluate a change in the intervention effect.

Engagement and retention were analyzed using generalized estimating equations with clinic as the clustering variable, accounting for the correlation among patients within a clinic. Differences were assessed between the 6 months before and after the baseline research assessment. Retention was a binary indicator of whether at least 4 postintervention visits were kept in a 6-month period after baseline. The requirement of 4 visits during a 6-month period (or 8 visits during a year) has been used to define minimum thresholds for guideline-concordant treatment.[52]

RESULTS

Intervention and control patients were comparable at baseline on demographic, diagnostic, and outcome measures (Table 1). No significant differences were found between those who completed the intervention and those who dropped out (data not shown) except that intervention dropouts scored higher on therapeutic alliance (75.7 vs 72.6, $P = .03$) (data not shown) than completers and control dropouts were more difficult to reach for follow-up than control completers (70 vs 40 days, $P < .001$).

Consistent with our hypothesis, significant intervention effects were found on activation (mean [SE] $\beta = 1.74$ [0.58]; $P = .003$) and self-management (mean [SE] $\beta = 2.42$ [0.90]; $P = .008$) at the second follow-up (Table 2). Our results suggest that the change appeared to increase from the first to second follow-up, but neither the period slopes ($P = .35$ for activation and $P = .10$ for self-management) nor the period by intervention interaction ($P = .47$ for activation and $P = .09$ for self-management) was significant. The 1.74 change in activation from baseline to follow-up 2 can be expressed as an effect size of d = 0.26, and the 2.42 change in self-management corresponds to an effect size of d = 0.22. These effect sizes represent the effects as a proportion of the SD of the respective outcomes in baseline measurements. Both results remain significant after adjusting for 4 comparisons. Contrary to our hypothesis, there was no evidence of an intervention effect on engagement ($P = .82$) or retention ($P = .51$) (eTable 1 in the Supplement).

Table 2. Mixed Regression on Difference in Activation and Self-management (Imputed)[a]

	Activation		Self-management	
Random Intercept	**β (SE)**	*P* **Value**	**β (SE)**	*P* **Value**
Intervention	1.74 (0.58)	.003	2.42 (0.90)	.008
Period (reference, follow-up 2)	0.41 (0.44)	.35	−1.37 (0.82)	.10
Period × intervention	0.45 (0.62)	.47	−1.79 (1.03)	.09
Age, y (reference, 18-34 years)				
35-49	0.25 (0.55)	.65	1.06 (1.02)	.30
50-64	−0.32 (0.60)	.60	−1.54 (1.06)	.15
≥65	−0.48 (1.87)	.80	−0.01 (2.76)	.99
Female (reference, male)	−0.66 (0.53)	.22	−0.14 (0.85)	.87
Race/ethnicity (reference, white)				
Latino	1.44 (0.71)	.04	1.54 (1.18)	.19
Black	0.37 (0.91)	.69	0.67 (1.56)	.67
Other race/ethnicity	1.09 (1.01)	.28	2.47 (1.70)	.15
Educational level (reference, ≤11 years)				
≥12	0.94 (0.51)	.07	1.26 (0.90)	.16
Time in study	−0.002 (0.004)	.67	−0.007 (0.006)	.26
Constant	−0.79 (1.01)	.44	0.79 (1.66)	.63
Sample size	647		647	

[a] Model includes random effects for each individual and site.

In addition to the confirmatory analyses of primary outcomes, we performed analyses to identify patients for whom the effects of the intervention were stronger or weaker, depending on the age, sex, ethnicity/race, or baseline outcome scores of patients. A significant interaction was found between the intervention and race/ethnicity for self-management ($P < .001$) among patients in the other race/ethnicity group (Asian and mixed race/ethnicity, eTable 2 in the Supplement). A significantly greater effect ($P = .02$) of the intervention was seen on activation scores among patients with lower baseline activation (eTable 3 in the Supplement).

We also tested whether changes in activation or self-management could be explained by changes in communication or therapeutic alliance (eTable 3 in the Supplement). When accounting for these mediators, the intervention effect on activation was reduced from 1.74 to 1.47 (a 16% decrease) but remained significant. Similarly, the intervention effect on self-management decreased from 2.42 to 1.96 (a 19% decrease) but remained significant.

DISCUSSION

Our findings demonstrate that the DECIDE intervention is associated with increases in patient activation and self-management compared with patients in enhanced usual care who received a behavioral health management brochure. Even under the conditions of a multisite design with limited exclusion criteria and a diverse patient population, the intervention shows promise in helping patients learn to effectively ask questions and participate in decisions about their behavioral health care. These results illustrate the relative value of CMs in teaching patient activation and self-management strategies in clinical settings.[53]

Although reliable, the magnitude of the effects of DECIDE was small. In future research, we need to determine who is most likely to benefit from the intervention. In post hoc analysis, we found that the effect size increased when excluding patients who already had activation and self-management skills at baseline. Effect sizes for effectiveness studies have been noted to be smaller than those of studies with homogeneous patients who have the greatest need (eg, low activation), as seen in meta-analyses of universal prevention studies.[54-57] The heterogeneous study sample included patients who were high at baseline on activation and self-management and could not benefit from the intervention (ceiling effects). The results, however, suggest that there is a firm empirical basis for further development of an approach that focuses on patient intervention.

This multisite trial included clinics that primarily offered short-term care, whereas others stressed long-term psychotherapy, which may have confounded the intervention effects. This approach created greater challenges for detecting a positive intervention signal but also moved the intervention along the translation pathway to real-world application.[58,59] Larger effect sizes could also have been detected had the control condition been usual care rather than a behavioral health brochure. However, using an enhanced control permitted us to sort out the added value of DECIDE over what could be a no-cost intervention.

Study limitations include the potential of differential reporting of outcomes by patients in the intervention vs control arm because of increased time spent and rapport established with the CM and low fidelity to training 3. Another limitation was that patient activation was measured with the PAS, instead of the more commonly used Patient Activation Measure,[60] curtailing comparisons to other studies.

The results of this study indicate that the DECIDE intervention does not seem to affect engagement and retention in care, in contrast to a previous study.[31] Several potential explanations can be considered. First, qualitative interviews with CMs indicated that health care professional reactions to activated patients were not uniformly positive,[61] as found in a previous study.[62] Ideally, health care professionals would welcome patient self-management and activation, but health care professionals typically limit patient-initiated talk.[7,8] With less-receptive health care professionals, the intervention could have created tension and diminished patient use of services. Addressing health care professionals' negative reactions to activated patients is an important area for future study.[63]

Second, economic hardship may have hampered patients' ability to remain in care, particularly for those receiving public assistance. In reviewing reasons for not remaining in care, patients cited having to return to home countries, high treatment costs, lack of transportation, childcare responsibilities, work hours, and limited clinic hours. Not addressing these barriers could limit an intervention's effect on engagement and retention in care, as discussed in previous work.[62]

Third, the DECIDE intervention was designed so patients would have time to meet with their behavioral health care professionals between trainings. However, because patients entered the intervention at different points in treatment, patients in clinics offering brief treatment may have ended treatment before completing the DECIDE training. Given the limitations of health records data, it was difficult to differentiate planned treatment completion from dropping out of care. Future studies should consider selecting only patients initiating care. Similarly, better documentation of engagement, retention, and treatment termination would be helpful.

Fourth, our finding that patients of Asian or mixed race/ethnicity had increased self-management compared with non-Latino whites could be linked to how respondents obtain health information outside health care settings[25] and cultural differences in navigating health care systems.[64] Because Asians are more reluctant to endorse behavioral health problems[65] and ask questions, they may have had more to gain from the intervention. Non-Latino whites may have seen a less substantial change because evidence suggests they are more likely to seek health information.[25]

CONCLUSIONS

Minorities with mental disorders in the United States continue to receive lower-quality behavioral health care,[66] and interventions to enhance patient activation and self-management in behavioral health treatment may be an important innovation in national health care strategies.[67,68] The DECIDE intervention can contribute to enhanced patient activation and self-management, but without greater health care professional receptivity to activated patients, the contributions may be limited. Changes in the locus of control in the clinical encounter through patient-directed interventions may decrease patient–health care professional communication[58] and in some cases create more tensions in the clinical encounter. Although changes in communication and therapeutic alliance were associated with changes in activation and self-management, other changes in patient-health care professional interaction explain the primary outcomes. Future studies should consider the importance of both patients and health care professionals in promoting patient activation.

ARTICLE INFORMATION

Corresponding Author: Margarita Alegría, PhD, Center for Multicultural Mental Health Research, Cambridge Health Alliance/Harvard Medical School, 120 Beacon St, Fourth Floor, Somerville, MA 02143 (malegria@charesearch.org).

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