

Association of Behavioral Factors with Activation in Patients with Age-Related Macular Degeneration or Diabetic Retinopathy

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Introduction: Activation is the degree that individuals have the knowledge, skills, beliefs, and behaviors necessary for effective health-care self-management. Those with higher activation are more likely to engage in behaviors associated with improved care outcomes, including increased medication and appointment adherence. Identifying and addressing patients' activation levels and associated behaviors at the outset of care can help to develop interventions to improve patients' participation in their healthcare. Our objective was to study the association of psychosocial factors with activation to identify behavioral factors that could increase activation.

Methods: Individuals with bilateral AMD or DR (n = 1146) were identified from electronic medical records at a single academic medical center. Randomly selected potential participants (n = 682) were sent a letter inviting their participation. Consenting participants (AMD n = 161; DR n = 94) were administered the Patient Activation Measure (PAM), the National Eye Institute Visual Function Questionnaire-8 (NEI-VFQ), Multidimensional Health Locus of Control - form C (MHLC), Perceived Medical Condition Self-Management Scale (PMCSMS), Patient Health Questionnaire-9 (PHQ-9), a measure of health literacy and a sociodemographic health questionnaire by phone.

Results: In multivariable analysis of participants with AMD, for each unit increase in MHLC Internal score, mean PAM score increased by 0.50 (P = 0.001). In multivariable analysis of participants with DR, for each unit increase in MHLC Chance, mean PAM score decreased by 0.48 (P = 0.0391). Differences on MHLC Internal and Chance scores among and between those with dry or wet AMD and non-proliferative or proliferative DR were all significant (P < 0.001).

Discussion: In this cross-sectional cohort study of 255 participants with bilateral diabetic retinopathy or age-related macular degeneration, higher internal LOC and lower external LOC were associated with higher activation scores. Interventions that increase patient activation may increase internal LOC and reduce external LOC, improving patients' participation in their care, and improve health-care outcomes.

Plain Language Summary: Actively participating in their healthcare can help patients to improve their care outcomes. Activation is the degree that patients have the knowledge, skills, beliefs, and behaviors necessary for effective self-management of their healthcare. Our objective was to study the association of behavioral factors with activation among patients with age-related macular degeneration or diabetic retinopathy that, if modified, could increase their activation. Locus of control refers to how much individuals believe their behavior affects their health status. Individuals with an internal locus of control believe their health outcomes are a result of their own behavior; those with an external locus of control believe their health outcomes result from chance or external factors. We found that higher internal locus of control scores were associated with higher activation scores on a measure of patient activation, suggesting that

locus of control can lead to increased patient participation in their healthcare and improved care outcomes, although we did not directly address care outcomes in this study. Increasing patients' activation can increase engagement with care providers, leading to a better understanding of their disorder and its treatment.

Keywords: patient activation, locus of control, patient behavior, adherence

Introduction

The...greatest opportunity to improve health ... lies in personal behavior [and is]... more likely to come from behavioral change than from technological innovation. SA Schroeder.¹

The proportion of the US population aged 65 and older is projected to increase dramatically and, by 2054, will comprise 23% of the population.² Because the incidence of diabetic retinopathy (DR) and age-related macular degeneration (AMD) increases with age, the prevalence of these conditions will also increase.³ AMD is the leading cause of permanent impairment of near vision in people aged 65 years or older, and accounts for approximately half of all legal blindness in the U.S.⁴ DR is the leading cause of blindness in US adults,⁵ affecting approximately 11.6% of the population.⁶ The duration of diabetes is the best predictor for the development and progression of DR. After 20 years of living with diabetes, virtually all persons with type 1 diabetes and more than 60% of those with type 2 diabetes will develop DR.^{7,8}

Actively participating in their care is important for all patients, especially those with chronic conditions, such as AMD and DR, where care needs are ongoing. Activation is the degree that patients have the knowledge, skills, beliefs, and behaviors necessary for effective self-management of their healthcare. Since its introduction, the Patient Activation Measure (PAM)^{9,10} has become the gold standard for assessing activation and incorporates self-efficacy and locus of control: self-efficacy is belief in one's competence and is task-specific, ie, self-perceived competence,¹¹ while LOC refers to the extent to which someone believes they can control events in their lives.¹² Individuals with higher PAM scores are more likely to engage in behaviors associated with better care outcomes.¹³ Patients with lower activation have been shown to be less likely to understand their diagnosis, to be less adherent to medication and care protocols, and more likely to delay necessary care.^{14,15}

Identifying and addressing modifiable behavioral factors in patients with chronic disease can improve care outcomes. Understanding the role of psychological variables is one key to improving patients' activation and involvement in their care,^{16,17} but this has not been studied in individuals with AMD or DR. Our outcomes of interest were the association of psychometric measures and sociodemographic factors with patient activation. This study aimed to identify behavioral factors in individuals with DR or AMD that, if modified, could improve patients' activation, and potentially improve treatment outcomes.

Methods

The Columbia University Irving Medical Center Institutional Review Board for Human Research granted expedited approval for this study (AAAT8964; received 05/06/22) and the study was conducted in accordance with the Declaration of Helsinki.

Patients who received ophthalmologic care at a single academic medical center, Columbia University Irving Medical Center, between 4/1/2020 and 3/30/2022 were identified from electronic medical records. The ICD-10¹⁸ diagnostic codes H35.3131 to 35.3134, H35.3231, H35.3232 and H35.353 were used to identify patients with bilateral AMD (n = 582). ICD-10 codes E08.3213, E10.3213, E08.3513, E10.3293, E10.3313, E10.3393, E10.3513, E10.3593, E10.3413, E10.3553, E11.37X3, E11.3213, E11.3293, E11.3393, E11.3513, E11.3523, E11.3593, E11.3413, E11.3493, E11.3553, E13.3593 were used to identify patients with bilateral DR (n = 564). With their ophthalmologist's approval, a sample of 682 patients (AMD n = 418; DR n = 264) was sent a letter informing them about the study, inviting their participation and providing them an opportunity to enroll or opt out by phone. Those who did not opt out received a phone call and were given information about the study necessary for their consent: a total of 255 participants – 161 (38.5%) of those

with AMD and 94 (35.6%) of those with DR – provided verbal consent and agreed to participate. Exclusion criteria were inability to speak and understand English or to provide consent for any other reason.

Research team members administered a protocol consisting of six instruments and a sociodemographic questionnaire, estimated to take a total of 30 minutes to complete. All interactions with participants were by phone, thereby eliminating concerns about communicable diseases, transportation issues, and vision as a factor for reading questions and entering responses. Data were entered in real time using Research Electronic Data Capture (REDCap).¹⁹ Outcomes of interest were the association of psychometric measures and sociodemographic factors with patient activation.

Psychometric Measures

1. The Patient Activation Measure (PAM) was developed to assess behaviors, attitudes and beliefs necessary for effective self-management of one's healthcare.^{9,10} It produces scaled scores ranging from 0 to 100, reflecting a developmental model of activation. The most commonly used version of the PAM, and the one used in this study, is the 13-item scale.¹⁰ The PAM was used under a research license from Insignia Health (Phreesia, Inc. Wilmington, DE) and scored using their proprietary algorithm.
2. The impact of vision loss on everyday life was evaluated with the NEI-VFQ-8,^{20,21} a validated 8-item version of the VFQ-9. It is a patient-reported quality-of-life assessment of: 1. general vision; 2. use of vision for near and distance activities; 3. overall mental health or role difficulties; and 4. peripheral vision, all activities that determine the impact of eye disease and vision loss on daily living.³
3. Health literacy was assessed using one question from the Brief Health Literacy Screen,²² "How often do you have someone help you to read hospital or healthcare materials?" This single, separately validated, item was best able to separate those patients who believed they needed help reading health-care materials from those more confident in their ability to do so (AUC = 0.87). Responses on a 5-level Likert scale were: Never, Occasionally, Sometimes, Often, or Always.
4. The Patient Health Questionnaire-9 (PHQ-9)²³ was used to screen for depression. Item scores can range from 0 to 3. Item scores are added to obtain a total score. Total PHQ-9 scores of 5, 10, 15, and 20 represent mild, moderate, moderately severe, and severe depression, respectively. Individuals with scores of 10 or greater reflecting moderately severe depression were offered referral for behavioral evaluation.
5. A demographic and social determinants of health questionnaire developed for this and related studies was used to capture age, sex, race, ethnicity, marital status, educational level, employment status, living arrangements, whether help is needed to travel to eye appointments or administer eye medications, family history of eye disorders, and self-reported comorbidities.
6. The Multidimensional Health Locus of Control, Form C (MHLC)²⁴ was developed using data from 588 patients with one of four chronic conditions: rheumatoid arthritis, chronic pain, diabetes, or cancer and designed to be condition-specific; it permits a specific condition, eg, AMD or DR, to be inserted into the stem of each statement so that locus of control responses²⁵ is with reference to individual's current disorder. There are 4 MHLC subscales: one addressing Internal LOC and three that categorize external LOC into Chance, Doctors, and Other (powerful) People.
7. The Perceived Medical Condition Self-Management Scale-4 (PMCSMS)^{26,27} is a revised, shortened version of the Perceived Health Competence Scale and designed to assess health self-efficacy and self-perceived competence to accomplish specific health activities, which have been identified as potentially important in self-management behaviors and health outcomes in patients with chronic disease.

The NEI-VFQ, PHQ-9, MHLC, and PMCSMS were scored with their published scoring methodologies (as cited above).

Statistical Analysis

Statistical analyses were performed using R Statistical Software²⁸ and IBM SPSS Statistics for Windows, V.28.²⁹ Participant characteristics were summarized using means and standard deviations. Frequencies and percentages were

reported for categorical variables and analyzed with chi-square tests. Continuous variable descriptive statistics were compared with 2-tailed *t*-tests. The associations of psychometric scores and sociodemographic factors with patient activation were assessed using multivariable linear regression adjusted for the effects of age, sex, and race. Significance levels for all analyses were set at $P < 0.05$.

Results

Demographics and Comorbidities

From 9/2/22 to 11/8/22, a total of 1146 patients with bilateral AMD or DR were identified from electronic medical records at a single academic medical center. Randomly selected potential participants ($n = 682$) were sent a letter inviting their participation. Consenting participants, 161 (38.5%) with AMD and 94 (35.6%) with DR provided verbal consent, enrolled, and completed the protocol by phone. As shown in Table 1, among those with AMD, 71.4% had dry AMD (mean age $68.7 \pm SD 14.7$) and 28.6% had wet AMD (mean age $79.8 \pm SD 8.5$), while among those with DR, 61.7% had non-proliferative DR (mean age $79.9 \pm SD 10.0$) and 38.2% had proliferative DR (mean age $77.1 \pm SD 10.9$). Of participants with AMD, 60.9% were female, while 30.9% of those with DR were female. Age differences among those

Table 1 Sociodemographics

	Age-Related Macular Degeneration (AMD)		Diabetic Retinopathy (DR)		Chi ² /Fisher's Exact Test Among All 4 Groups P-value	Total AMD N = 161	Total DR N = 94	Chi ² /Fisher's Exact Test Between AMD & DR P-value
	Dry AMD N = 115 (n, %)	Wet AMD N = 46 (n, %)	Non-Proliferative DR N = 58 (n, %)	Proliferative DR N = 36 (n, %)				
Variable								
Age (Mean $\pm$ SD)	68.7 $\pm$ 14.7	79.8 $\pm$ 8.5	79.9 $\pm$ 10.0	77.1 $\pm$ 10.9	<0.001	71.9 $\pm$ 14.2	78.8 $\pm$ 10.4	<0.001
Sex					0.272			<0.001
Female	66 (57.4)	32 (69.6)	41 (70.7)	24 (66.7)		98 (60.9)	65 (30.9)	
Male	49 (42.6)	14 (30.4)	17 (29.3)	12 (33.3)		63 (39.1)	29 (69.1)	
Ethnicity					0.870			0.790
Asian	2 (1.7)	1 (2.1)	1 (1.7)	0 (0.0)		3 (1.9)	1 (1.1)	
Black, non-Hispanic	9 (7.8)	3 (6.4)	4 (6.8)	0 (0.0)		12 (7.5)	4 (4.3)	
Hispanic	7 (6.1)	1 (2.1)	2 (3.4)	1 (2.7)		8 (5.0)	3 (3.2)	
Multiracial	3 (2.6)	0 (0)	1 (1.7)	0 (0.0)		3 (1.9)	1 (1.1)	
White	94 (81.7)	41 (87.2)	50 (84.7)	35 (94.6)		135 (83.9)	85 (90.4)	
Education					0.969			
High school	11 (9.6)	4 (8.7)	5 (8.6)	4 (11.1)		15 (9.3)	9 (9.6)	
Some college or more	104 (90.4)	42 (91.3)	53 (91.4)	32 (88.9)		142 (90.7)	85 (90.4)	
Employment Status					0.010			0.008
Employed (full- or part-time, or self-employed)	50 (43.5)	12 (26.1)	12 (20.7)	10 (27.8)	0.120	62 (38.5)	22 (23.4)	0.013

(Continued)

Table 1 (Continued).

	Age-Related Macular Degeneration (AMD)		Diabetic Retinopathy (DR)		Chi ² /Fisher's Exact Test Among All 4 Groups P-value	Total AMD N = 161	Total DR N = 94	Chi ² /Fisher's Exact Test Between AMD & DR P-value
	Dry AMD N = 115 (n, %)	Wet AMD N = 46 (n, %)	Non-Proliferative DR N = 58 (n, %)	Proliferative DR N = 36 (n, %)				
Unemployed	2 (1.7)	0 (0)	0 (0)	0 (0)	0.794	2 (1.2)	0 (0.0)	0.053
Retired	59 (51.3)	34 (73.9)	46 (79.3)	26 (72.2)	0.001	93 (57.8)	72 (76.6)	
Disabled/Unable to work	4 (3.5)	0 (0)	0 (0)	0 (0)	0.377	4 (2.5)	0 (0.0)	0.300
Marital Status					0.130			0.084
Single, divorced, separated, or widowed	39 (33.9)	22 (47.8)	29 (50.0)	17 (47.2)		61 (37.9)	46 (48.9)	
Married/Domestic partner	76 (66.1)	24 (52.2)	29 (50.0)	19 (52.8)		100 (62.1)	48 (51.1)	

Notes: Bolded values indicate $P < 0.05$. ANOVA was performed on age, a continuous variable. Chi²/Fisher's exact tests were done on categorical variables.

Abbreviations: AMD, Age Related Macular Degeneration; DR, Diabetic Retinopathy.

with AMD or DR, and between those with AMD or DR, were significant (each $p < 0.001$). Differences in employment status among groups were significant ($P = 0.008$) (Table 1).

As shown in Table 2, 6.1% of participants with dry AMD and 13% of those with wet AMD reported having diabetes compared with 70.7% of participants with non-proliferative DR and 94.4% of those with proliferative DR; comparing all

Table 2 Medical Comorbidities and Health Literacy

	Age-Related Macular Degeneration (AMD)		Diabetic Retinopathy (DR)		Chi ² /Fisher's Exact Test Among All 4 Groups P-value	Total AMD N = 161 (%)	Total DR N = 94 (%)	Chi ² /Fisher's Exact Test between AMD & DR P-value
	Dry AMD N = 115 (%)	Wet AMD N = 46 (%)	Non-Proliferative DR N = 58 (%)	Proliferative DR N = 36 (%)				
Self-Reported Comorbidities								
Diabetes	7 (6.1)	6 (13.0)	41 (70.7)	34 (94.4)	< 0.001	13 (8.1)	75 (79.7)	< 0.001
Hypertension	64 (55.7)	31 (67.4)	35 (60.3)	19 (52.8)	0.491	95 (59.0)	54 (57.4)	0.895
Cancer	36 (31.3)	9 (19.6)	4 (6.9)	1 (2.8)	< 0.001	45 (28.0)	5 (5.3)	< 0.001
Asthma, emphysema, other breathing issues	13 (11.3)	8 (17.4)	5 (8.6)	2 (5.6)	0.384	21 (13.0)	7 (7.4)	0.214
Depression	11 (9.6)	9 (19.6)	8 (13.8)	1 (2.8)	0.917	20 (12.4)	9 (9.6)	0.545
Hearing problems	44 (38.3)	20 (43.4)	7 (12.1)	6 (16.7)	< 0.001	64 (39.8)	13 (13.8)	< 0.001
All Other Conditions	14 (12.2)	0 (0.0)	10 (17.2)	11 (30.6)	< 0.001	14 (8.7)	21 (22.3)	0.004

(Continued)

Table 2 (Continued).

	Age-Related Macular Degeneration (AMD)		Diabetic Retinopathy (DR)		Chi ² /Fisher's Exact Test Among All 4 Groups P-value	Total AMD N = 161 (%)	Total DR N = 94 (%)	Chi ² /Fisher's Exact Test between AMD & DR P-value
	Dry AMD N = 115 (%)	Wet AMD N = 46 (%)	Non-Proliferative DR N = 58 (%)	Proliferative DR N = 36 (%)				
No other medical conditions	17 (14.8)	5 (10.9)	6 (10.3)	0 (0.0)	0.061	22 (13.7)	6 (6.4)	0.096
Health Literacy Needs help to read health materials					0.041			0.054
Never	89 (77.4)	32 (6.6)	53 (91.4)	28 (77.8)	0.032	121 (75.2)	81 (86.2)	0.039
Occasionally, Sometimes, Often	16 (13.9)	7 (15.2)	5 (8.6)	6 (16.7)	0.629	23 (14.3)	11 (11.7)	0.703
Always	10 (8.7)	7 (15.2)	0 (0.0)	2 (5.6)	0.012	17 (10.6)	2 (2.1)	0.013

Notes: Bolded values indicate $P < 0.05$. ANOVA was performed on continuous variables. Chi²/Fishers exact tests were done on categorical variables.

Abbreviations: AMD, Age-Related Macular Degeneration; DR, Diabetic Retinopathy.

those with DR and AMD, the difference in prevalence of reported diabetes was significant (each $P < 0.001$). Cancer was reported by 31.3% of participants with dry AMD and 19.6% of those with wet AMD ($P < 0.001$), compared with 6.9% of participants with non-proliferative DR and 2.8% with proliferative DR; differences in reported cancer were significant (each $p < 0.001$). Differences in the prevalence of other reported comorbidities were not significant (Table 2).

Health Literacy Outcomes

Overall, comparing those with AMD with those with DR, differences among all 4 groups (wet and dry AMD and non-proliferative and proliferative DR) in health literacy were significant ($P = 0.041$). Of participants with dry AMD, 77.4% reported never needing help to read health information compared with 6.6% of participants with wet AMD. Among participants with dry AMD, 13.9% reported occasionally needing help compared with 15.2% with wet AMD, while among those with dry AMD, 8.7% reported always needing help compared with 15.2% with wet AMD ($P = 0.012$). Among participants with non-proliferative DR, 91.4% reported never needing help compared with 77.8% of those with proliferative DR. ($P = 0.032$). Overall, between those with AMD and DR, those never needing help reading health materials and those always needing help were significant ($P = 0.039$ and $P = 0.013$, respectively) (Table 2).

Depression Outcomes

Depression was reported by 9.6% of participants with dry AMD and 19.6% of participants with wet AMD, compared with 13.8% of participants with non-proliferative DR and 2.8% of those with proliferative DR. Differences in self-reported depression among and between groups were not significant (Table 2). Of those with AMD, mean depression scores on the PHQ-9 were 3.6 ± 3.9 , with 8.1% reporting scores of 10 or greater, our threshold for referral for behavioral evaluation, while for those with DR mean depression scores were 3.3 ± 3.2 with 5.3% having scores of 10 or greater. These differences were not significant (Table 3).

Patient Activation Outcomes

As shown in Table 3, mean PAM scores were 65.3 ± 13.3 and 64.3 ± 13.2 for those with dry and wet AMD, respectively, and 68.7 ± 15.4 and 71.6 ± 14.4 for those with non-proliferative DR and proliferative DR, respectively. These differences

Table 3 Psychometrics

Variable	Age-Related Macular Degeneration (AMD)		Diabetic Retinopathy (DR)		ANOVA Among All 4 Groups P-value	Total AMD N = 161 ± SD	Total DR N = 94 ± SD	T-Test/ Fisher's Exact Test Between AMD & DR P-value
	Dry AMD N = 115	Wet AMD N = 46	Non-proliferative DR N = 58	Proliferative DR N = 36				
PAM Score (mean)	65.3 ± 13.3	64.3 ± 13.2	68.7 ± 15.4	71.6 ± 14.4	0.009	65.0 ± 13.2	69.8 ± 15.0	0.012
PAM Level	3.04 ± 0.9	3.0 ± 0.9	3.1 ± 1.0	3.3 ± 0.7	0.104	3.0 ± 0.9	3.2 ± 0.9	0.106
NEI-VFQ	79.7 ± 19.1	75.9 ± 19.6	82.3 ± 16.1	79.0 ± 15.6	0.300	78.6 ± 19.3	81.0 ± 15.9	0.276
Self-rated vision (VFQ q1)	70.1 ± 26.0	66.5 ± 25.7	73.8 ± 18.8	63.9 ± 20.2	0.764	69.1 ± 25.9	70 ± 19.8	0.747
MHLC								
Internal	16.7 ± 6.7	16.3 ± 7.5	22.4 ± 8.5	23.8 ± 8.0	<0.001	16.6 ± 6.9	23.0 ± 8.3	<0.001
Chance	17.1 ± 7.0	18.0 ± 6.6	13.6 ± 6.9	14.3 ± 7.3	0.002	17.4 ± 6.9	13.9 ± 7.0	<0.001
Doctors	16.8 ± 2.2	16.7 ± 2.2	16.8 ± 1.8	17.2 ± 1.0	0.416	16.8 ± 2.2	17.0 ± 1.6	0.378
Others	12.3 ± 4.2	12.9 ± 4.0	11.9 ± 3.7	11.2 ± 3.9	0.124	12.4 ± 4.1	11.6 ± 3.8	0.115
PHQ-9	3.6 ± 3.9	3.4 ± 3.2	3.2 ± 3.4	3.4 ± 2.8	0.537	3.6 ± 3.7	3.3 ± 3.2	0.519
PMCSMS	16.3 ± 3.1	16.8 ± 2.9	16.7 ± 3.0	16.9 ± 3.1	0.492	16.5 ± 3.0	16.7 ± 3.0	0.492

Notes: Bolded values indicate $P < 0.05$.

Abbreviations: PAM, Patient Activation Measure; NEI-VFQ, National Eye Institute Visual Function Questionnaire-9; PHQ-9, Patient Health Questionnaire; MHLC, Multidimensional Health Locus of Control; PMCSMS, Perceived Medical Condition Self-Management Scale-4.

were significant ($P = 0.009$). Among those with AMD, the mean PAM score was 65 ± 13.2 , while the mean PAM score for those with DR was 69.8 ± 5.0 . These differences were significant ($P = 0.012$).

Locus of Control Outcomes

The MHLC internal scale scores were 16.7 ± 6.7 and 16.3 ± 7.5 for those with dry and wet AMD, respectively, and 22.4 ± 8.5 and 23.8 ± 8.0 for those with non-proliferative and proliferative DR, respectively. Differences were significant within and between those with AMD and DR (for each, $P < 0.001$). The MHLC chance scale scores were 17.1 ± 7.0 and 18 ± 6.6 for those with dry and wet AMD, respectively, and 13.6 ± 6.9 and 14.3 ± 7.3 for those with non-proliferative and proliferative DR, respectively. Within and between groups, MHLC chance scale score differences were significant ($P < 0.002$ and $P < 0.001$, respectively) (Table 3).

Discussion

Our aim was to identify behavioral factors in patients with AMD or DR that, if modified, may improve patients' activation and potentially lead to improved treatment outcomes.

Among patients with chronic conditions, higher self-rating of overall health has been associated with internal LOC, believe their own actions and behaviors determine their health, while those with lower self-rated health are more likely to have external LOC and believe luck, fate, chance or others influences their health.³⁰ We identified locus of control as a modifiable behavioral factor that can improve activation in individuals with AMD or DR; for participants with AMD, for each unit increase in Internal LOC on the MHLC, mean PAM score increased by 0.5 while for those with DR, each unit increase in MHLC Chance LOC, mean PAM score decreased by 0.48.

Patient understanding of adherence and its role in treatment outcomes is neither routinely evaluated nor addressed. Approximately half of all patients with chronic disorders do not take their medications as prescribed,³¹ likely due, in part, to a lack of knowledge about their disorder, their health beliefs, their low activation or a combination of these factors. Moreover, adherence decreases as the number of health conditions patients manage increases.³² Among our participants, more than 90% reported having other chronic health conditions, in addition to their AMD or DR; almost 60% reported hypertension, a third reported cancer, 20% had asthma or other breathing issues, while only about 20% reported no other health conditions. For millennia, poor adherence has been recognized as contributing to poor health outcomes.³³ Patients with AMD or DR require regular and relatively frequent appointments to monitor disease progression and administer injections, to reduce or delay further vision loss. Failure to keep appointments undermines treatment efficacy, impairs patient outcomes and can result in otherwise avoidable loss of vision. Patients with higher levels of activation are more likely to understand their condition, more prepared for medical appointments and willing to ask questions,³⁴ less likely to delay necessary medical care, generally more adherent, and achieve better outcomes.³⁵

Self-reported loss of vision has been significantly associated with depression and contributes to poor adherence.³⁶ Estimates of depression among older adults with vision loss range from 5% to 7%, while subthreshold depression estimates range from 21% to 30% or more.³⁶ Our results approximate this: among our participants, 11.3% reported having depression; 7% had PHQ-9 scores over 10 or greater, the threshold for moderate or severe depression, while 4% had subthreshold depression. The progression of AMD and DR likely contributes to depression, which often is undetected among visually impaired older adults.³⁷ Higher PAM scores have been associated with reduced levels of depression,³⁸ although it is unclear whether improving activation reduces depression or reducing depression increases activation.

More than 30% of participants with non-proliferative DR and 5% with proliferative DR in our study did not report having diabetes, seemingly not understanding that their eye condition is a result of diabetes. Consequently, we would expect their glycemic control to be poor. Dietary control and use of prescribed medications can reduce the onset and progression of diabetes. More activated patients, those with higher PAM scores, without diabetes were less likely to develop pre-diabetes, while among those with diabetes or pre-diabetes their outcomes were better than less activated patients.³⁹ AMD has no similar antecedent diagnosis but there are several modifiable risk factors that, if addressed, reduce its incidence and progression: smoking has been associated with a 2 to 4 fold increase for developing AMD,^{40,41} while following a Mediterranean diet and reducing body weight also may slow AMD progression.⁴²

Limitations

Our study had some limitations. We used a single-question literacy measure to reduce protocol administration time, so reasons for needing help reading health-care materials was not able to be identified. Our health self-efficacy measure was brief; although incorporated in the PAM, a more robust measure of self-efficacy might be helpful in designing targeted care protocols. Our design was cross-sectional and, therefore, we were unable to assess the extent of increases in adherence. All of our participants had health insurance, were predominantly White, highly educated, with almost 90% completing at least some college, and from a single academic medical center; each of these could induce bias and limit the generalizability of our findings. The prevalence in cancer as a comorbidity between the AMD and DR groups, although likely attributable to the age difference between the cohorts, was not explored. There may be selection bias: of the 682 patients invited, 255 participated (a rate of ~37%). It is plausible that patients who are more “activated” and engaged in their healthcare were more likely to agree to participate.

Conclusion

Identifying patients’ activation at the outset of care and if addressed by an effective treatment plan, can increase their engagement, improve their disease knowledge and aid in improving treatment outcomes.^{43,44} Research on activation has primarily focused on 4 diseases – arthritis, asthma, cardiovascular disease, and diabetes,^{45,46} but lessons learned from these studies has generally not been applied to eye disorders. Developing cost-effective protocols that improve adherence for patients with eye disorders has potential to reduce the progression of their vision-threatening disorder and improving their quality of life. Further addressing the relationship between patient activation and eye disease-specific outcomes is an important area for further study.

Abbreviations

PAM, Patient Activation Measure; LOC, locus of control; NEI-VFQ, National Eye Institute Visual Function Questionnaire-8; MHLC, Multidimensional Health Locus of Control, Form C; PHQ-9, Patient Health Questionnaire-9; PMCSMS, Perceived Medical Condition Self-Management Scale, short form; AMD, age-related macular degeneration; DR, diabetic retinopathy; U.S, United States.

Data Sharing Statement

The data used in this study are part of a dataset that is not fully de-identified; to protect participant confidentiality, it cannot be shared.

Ethics Approval

This study received expedited approval from the Columbia University Irving Medical Center Institutional Review Board for Human Research (AAAT8964; 05/06/22) and was conducted in accordance with the Declaration of Helsinki.

Informed Consent

Verbal informed consent was obtained from all participants who were informed that we intended to publish our results from this study but that there would be no participant-identifiable data.

Acknowledgment

An abstract of an earlier version of this work was presented as a poster at the 2025 ARVO annual meeting and published in 'IOVS Poster Abstracts'. Invest. Ophthalmol. Vis. Sci. June, 2025; 66(8):699.

Funding

An unrestricted grant from Research to Prevent Blindness, Inc. (New York, NY) provided ongoing support to the Columbia University Department of Ophthalmology. The funding organization had no role in the design or conduct of this research.

Disclosure

None of the authors declared any potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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