Trust and Glycemic Control in Black Patients With Diabetic Retinopathy: A Pilot Study

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ABSTRACT

Diabetic retinopathy (DR) is more prevalent in blacks than whites because, compared to whites, blacks on average have worse glycemic control. Both of these racial disparities reflect differences in sociocultural determinants of health, including physician mistrust. This randomized, controlled 6-month pilot trial compared the efficacy of a culturally tailored behavioral health/ophthalmologic intervention called Collaborative Care for Depression and Diabetic Retinopathy (CC-DDR) to enhanced usual care (EUC) for improving glycemic control in black patients with DR (n = 33). The mean age of participants was 68 years (SD 6.1 years), 76% were women, and the mean A1C was 8.7% (SD 1.5%). At baseline, 14 participants (42%) expressed mistrust about ophthalmologic diagnoses. After 6 months, CC-DDR participants had a clinically meaningful decline in A1C of 0.6% (SD 2.1%), whereas EUC participants had an increase of 0.2% (SD 1.1%) (f[1, 28] = 1.9; P = 0.176). Within CC-DDR, participants with trust had a reduction in A1C (1.4% [SD 2.5%]), whereas participants with mistrust had an increase in A1C (0.44% [SD 0.7%]) (f[1, 11] = 2.11; P = 0.177). EUC participants with trust had a reduction in A1C (0.1% [SD 1.1%]), whereas those with mistrust had an increase in A1C (0.70% [SD 1.1%]) (f[1, 16] = 2.01; P = 0.172). Mistrust adversely affected glycemic control independent of treatment. This finding, coupled with the high rate of mistrust, highlights the need to target mistrust in new interventions to improve glycemic control in black patients with DR.

Rates of diabetic retinopathy (DR) and uncontrolled diabetes are higher among black than white people in the United States (1,2). Both of these racial disparities reflect differences in sociocultural determinants of health, including physician mistrust (3). Mistrust arises when patients doubt physicians' motivations (e.g., conflicts of interest), when patients' and physicians' understanding of symptoms and treatments are discordant, and when patients' low health literacy encounters physicians' cultural insensitivity to degrade the therapeutic relationship. As an example of the latter, black patients cite problems with trust and communication with eye doctors as obstacles to care, whereas eye doctors cite black patients' lack of understanding of treatment (4). This mismatch contributes to poor glycemic control, and black patients with poorly controlled diabetes are more likely than white patients to report negative health care experiences (5). These findings implicate mistrust as an important determinant of racial health disparities and suggest that culturally relevant interventions may help to achieve health equity.

We developed a culturally tailored behavioral health/ophthalmologic intervention called Collaborative

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Care for Depression and Diabetic Retinopathy (CC-DDR) to improve glycemic control in black patients with DR and compared its effectiveness to enhanced usual care (EUC) in a pilot single-masked, randomized controlled trial. In CC-DDR, race-concordant community health workers (CHWs) provided health information (e.g., regarding A1C and diabetes self-care) to ophthalmologists to guide their discussions with participants on glycemic control and delivered six in-home treatment sessions to participants to develop goals and action plans to improve glycemic control. EUC consisted of usual ophthalmologic care plus the provision of diabetes educational materials at baseline. Here, we report treatment effects on glycemic control and the influence of mistrust.

Methods

CHWs recruited participants from the retina clinic of Wills Eye Hospital, in Philadelphia, Pa., who met the following eligibility criteria: *1*) African-American race; *2*) age ≥65 years; *3*) type 2 diabetes; *4*) mild or moderate nonproliferative DR; *5*) depressive symptoms (i.e., Patient Health Questionnaire-9 [PHQ-9] [6] score ≥5); and *6*) A1C ≥7.0%. Institutional review board approval was obtained, and all participants provided written informed consent.

The CHWs received training to conduct clinical assessments and deliver the study interventions. They received 15 hours of didactic and skills-based training on diabetes, DR, and lifestyle strategies for glycemic control and 4 hours on interviewing and supportive psychological techniques (e.g., empathy), managing time, and gathering research-quality data. Training for the CHWs who delivered CC-DDR consisted of a daylong workshop, including readings and supervised role-play, and supervision of five training cases. The investigators met twice monthly with the CHWs to discuss ongoing cases. To maintain treatment masking, different CHWs collected follow-up data and delivered the intervention.

Prior to randomization, a CHW used a standardized protocol to assess the following variables:

Personal characteristics. Collected data included age, sex, education, marital status, duration and type of diabetes, socioeconomic status, and health literacy (using the Literacy Assessment for Diabetes, which tests pronunciation of diabetes-related terms) (7).

DR stage and visual acuity. These data were abstracted from medical records. DR was staged as background, mild, moderate, or severe nonproliferative disease, proliferative DR, or indeterminate. Visual acuity was based on Snellen charts and converted to logarithm of the minimum angle of resolution (logMAR) scores to facilitate statistical analyses.

Trust. A single item tapping trust in ophthalmologists' diagnoses (i.e., "Sometimes eye doctors make me wonder if their diagnosis is correct") was taken from the Duke Eye Clinics Patient Satisfaction Questionnaire and rated as strongly agree, agree, uncertain, disagree, or strongly disagree (8). Mistrust was considered present if a participant agreed or strongly agreed with the statement.

Diabetes self-care. The Diabetes Self-Care Inventory–Revised (DSCI) was used to assess self-reported adherence to 12 diabetes self-care behaviors (e.g., glucose monitoring, exercise, and diet). Items are rated on a 5-point Likert scale from 1 = "never do this" to 5 = "always do this." Scores range from 0 to 100; higher scores indicate better adherence (9).

Depressive symptoms. The PHQ-9 was used to assess depression. This instrument yields a continuous measure of symptoms and has known reliability and validity in older black respondents (6,10). Scores range from 0 to 27, with higher scores indicating worse depression.

Functional vision. The 39-item National Eye Institute Visual Function Questionnaire (NEI-VFQ) plus Supplement was used to assess difficulty with vision-related activities, social functioning, mental health, role difficulties, and dependency. Scores range from 0 to 100; higher scores indicate better function (11).

A1C (primary outcome). A1C levels represent glycemic control over the preceding 3 months and provide a valid surrogate marker of DR progression (12). The CHWs used the DCA Vantage point-of-care A1C analyzer (Siemens Healthineers, Los Angeles, Calif.) per study protocol to measure A1C at baseline and 6 months, masked to treatment assignment. The CHW who delivered CC-DDR provided the results to the ophthalmologists to inform care of the patients.

Statistical methods. Continuous and categorical data were analyzed using one-way analysis of variance (ANOVA) and χ^2, respectively. To determine whether trust moderated treatment effects, a two (CC-DDR vs. EUC) by two (trust vs. mistrust) ANOVA was computed, in which change in A1C was the dependent variable.

Results

Thirty-three participants with complete data were recruited and randomized to CC-DDR (n = 16) or EUC (n = 17). Their mean age was 68 years (SD 6.1 years), and 76% were women. The mean A1C was 8.7% (SD 1.5%). There were no treatment group differences at baseline in any study variable (data not shown). Fourteen participants (42%) expressed mistrust about their ophthalmologic diagnoses. Table 1 shows that the demographic and clinical characteristics of participants with and without trust did not differ significantly.

Four participants (three CC-DDR; one EUC) withdrew from the study protocol by 6 months (two with mistrust). Table 2 shows treatment group differences in A1C over time and treatment group differences by trust. CC-DDR participants had a clinically meaningful decline in A1C of 0.60% (SD 2.1%), whereas EUC partici-

pants had an increase of 0.20% (SD 1.10%) (f[1, 28] = 1.90; P = 0.1760). Within CC-DDR, participants with trust had a reduction in A1C (1.40% [SD 2.50%]), whereas participants with mistrust had an increase in A1C (0.44% [SD 0.70%]) (f[1, 11] = 2.11; P = 0.177). EUC participants with trust had a reduction in A1C (0.10% [SD 1.10%]), whereas those with mistrust had an increase in A1C (0.70% [SD 1.10%]) (f[1, 16] = 2.01; P = 0.172). Table 2 also shows a statistically significant main effect for trust. This finding indicates that mistrust adversely affected glycemic control independent of treatment effects.

Discussion

This pilot clinical trial suggests that a CHW-ophthalmologist intervention that is culturally relevant to black patients with DR can improve glycemic control to a greater extent than usual care that is enhanced with diabetes educational materials. Neither treatment, however, improved glycemic control in participants who mistrusted their ophthalmologic diagnosis. These participants doubted the accuracy and veracity of ophthalmologists' diagnoses; some participants believed that ophthalmologists wanted them to take more medications so that doctors and pharmacies could make more money. In general, if patients doubt that diabetes has damaged their eyes and mistrust the goals of treatment, they are unlikely to perceive the need to control their diabetes. This perception is important because 42% of participants held this view, and their glycemic control worsened over time regardless of treatment.

These findings are limited by the small sample size, short duration of follow-up, absence of information that might relate to study outcomes (e.g., type of diabetes care provider and prescribed medications, prior experiences with a diabetes educator, living arrangements, and anthropomorphic data), and uncertain psychometric properties (i.e., reliability and validity) of a single item assessing trust in the diagnosis of DR. Nevertheless, the high rate of mistrust is notable and is similar to the 44.7% rate of low trust in physicians reported by black

TABLE 1. Baseline Characteristics of Participants With High and Low Trust

	High-Trust Participants (n = 19)	Low-Trust Participants (n = 19)	P
Age, years	66.8 (3.7)	69.9 (8.2)	0.165
Education, years	12.4 (2.2)	12.0 (3.4)	0.707
Female, *n* (%)	14 (74)	11 (79)	0.746
A1C, %	8.8 (1.8)	8.6 (1.1)	0.703
PHQ-9 score[1]	10.2 (4.5)	10.2 (5.1)	0.993
MoCA score[2]	22.7 (3.7)	20.7 (4.2)	0.152
DSCI score[3]	55.9 (14.1)	59.4 (11.7)	0.448
LogMAR[4]	0.16 (0.16)	0.20 (0.15)	0.532
NEI-VFQ score[5]	73.1 (17.3)	75.6 (18.9)	0.693

Data are expressed as mean (SD) unless otherwise noted. [1]PHQ-9 score range is 0–27; higher scores indicate more severe depressive symptoms. [2]MoCA, Montreal Cognitive Assessment; score range is 0–30; higher scores indicate better cognitive function. [3]DSCI score range is 0–100; higher scores indicate better adherence to diabetes self-care behaviors. [4]Higher LogMAR scores indicate worse visual acuity. [5]NEI-VFQ score range is 0–100; higher scores indicate better self-reported vision function.

TABLE 2. Two (CC-DDR vs. EUC) by Two (Trust vs. Mistrust) ANOVA of Change in A1C From Baseline to 6 Months

	n	Baseline A1C, %	6-Month A1C, %	Change in A1C, %*	F	P
CC-DDR total group	12	8.7 (2.1)	8.1 (0.9)	–0.6 (2.1)		
Trust subgroup	7	9.1 (2.7)	7.7 (0.8)	–1.4 (2.5)		
Mistrust subgroup	5	8.2 (1.1)	8.5 (0.9)	0.36 (0.7)		
EUC, total group	17	8.5 (0.9)	8.7 (1.6)	0.2 (1.1)		
Trust subgroup	10	8.5 (1.0)	8.4 (1.8)	–0.1 (1.1)		
Mistrust subgroup	7	8.4 (0.8)	9.1 (1.2)	0.7 (1.1)		
Main effect of treatment group					1.7	0.202
Main effect of trust group					4.5	0.044
Treatment by trust interaction					0.6	0.441

*Data are expressed as mean (SD). *6-month minus baseline A1C; negative signs indicate improved glycemic control.*

respondents (vs. 33.5% reported by white respondents) in a national study of race, ethnicity, and medical care in the United States (13).

Trust in physicians depends on physicians' appreciation of patients' knowledge, beliefs, and attitudes and, for black patients in particular, on patients' perceived racism (14). The latter predicts lower rates of physician visits, medication adherence, and preventive care, which compromise glycemic control and increase the risk of progression of DR to blindness (15). Because blindness is one of the most feared complications of diabetes, ophthalmologists have the opportunity to collaborate with other diabetes health professionals to emphasize the importance of glycemic control to prevent vision loss. However, mistrust undercuts that opportunity, as does a lack of time, expertise, and resources available to ophthalmologists to address this problem.

We devised and tested a retina clinic-to-community intervention to improve glycemic control in black patients with DR. Although the small sample size precludes definitive conclusions, this pilot study suggests that the experimental intervention, despite its cultural relevance, failed to improve glycemia in participants with mistrust. For this reason, these participants remain at increased risk for progressive vision loss.

Preserving vision can prevent medication errors and reduce hospitalizations and the considerable costs of vision loss (16–18). These benefits are relevant to new outcomes-based reimbursement strategies in which ophthalmologists, as well as primary care providers (e.g., physicians, physician assistants, and nurse practitioners) will be responsible for vision outcomes. Our data highlight the need to target mistrust in interprofessional collaborative clinical interventions that aim to improve glycemic control in black patients with DR. Larger studies are needed to establish the efficacy and cost-effectiveness of this approach, which may improve care quality and prevent progressive vision loss.

Duality of Interest

No potential conflicts of interest relevant to this article were reported.

Author Contributions

B.W.R. and R.J.C. researched data, wrote the manuscript, contributed to discussion, and edited the manuscript. B.W.R. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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