

ARTFULLY ADVANCING TREATMENT OF DIABETES

■ Jeremy Nobel, MD, MPH; Lewis E. Kazis, ScD; Howard Cabral, PhD, MPH; Marina Soley-Bori, PhD, MA; and Harris Allen, PhD

In this article ...

A study into creative expression as a way to increase patient activation in the management of Type 2 diabetes shows promising results as a high-value, low-cost tool for improving health in underserved populations.

DIABETES POSES A LARGE SOCIAL AND

economic burden to the U.S. population with important consequences. Although the disease affects 29.1 million Americans (9.3 percent of the population) and its prevalence and costs are expected to at least double in 25 years,^{1,2} only 7 percent of patients meet evidence-based recommendations for A1C, blood pressure and LDL cholesterol.³

Diabetes complications range from compromised quality of life to serious health consequences, such as cardiovascular disease, kidney disease, neuropathy and blindness.^{3,4,5,6} Barriers to following medical recommendations include disease complexity, system factors and patient behavior.^{7,8,9} Diabetes management requires lifestyle changes and self-care behaviors: healthy eating habits, regular exercise, medication adherence and scheduled preventive measures such as immunizations and periodic exams.

Despite the benefits, it's often difficult to engage people fully in their own care. Patients sometimes don't understand the importance of taking care of themselves, commonly feeling overwhelmed by the demands of the disease.^{10,11,12,13,14,15} These challenges often are amplified in underserved populations such as African-American women, who have a higher prevalence of diabetes and its complications.^{14,16,17,18,19,20}

Storytelling and other creative arts expression techniques can help alleviate the burden, by educating patients about their medical condition through peer-encouraged learning and promoting self-care.

Storytelling capitalizes on the value of exchanging personal experiences with peers, facilitating emotional and cognitive engagement, and sharing of information.^{21,22,23,24} Creative arts include visual arts, music, movement and expressive writing.²⁵

These techniques invite patients to be more aware of their illness, more comfortable with its challenges and more active in their own care.^{26,27,28,29,30}

Such behavioral change is important for improving health, improving care processes and reducing costs. Previous studies support positive effects on anxiety, energy levels and symptom assessment across several conditions, including cancer,^{31,32,33,34} heart disease^{35,36} and mental health issues.^{36,37,38,39}

"Diabetes: Sharing Your Story" is an intervention consisting of once-weekly creativity circle meetings for six weeks. Patients share personal experiences in a structured and facilitated program that includes mindfulness, creative arts expression and narrative elements. Its goal is to ease the emotional burden and stress associated with diabetes, increase understanding of it, and promote self-care and practice-based medical care.

This article describes a recently completed pilot study, assessing the contributions of creativity circles to health-related quality of life for African-American women with Type 2 diabetes.

STUDY DATA AND METHODS

PARTICIPANTS — Twelve middle-age African-American women diagnosed with Type 2 diabetes were recruited from Boston Medical Center. Its diabetes center serves approximately 12,000 patients annually, representing approximately 20 percent of Boston's diabetic population. More than half of these patients have an annual income below \$20,420. More than 70 percent of BMC's patient population is a racial or ethnic minority, and almost half have publicly funded third-party coverage: Medicaid (24 percent), Medicare (14 percent) or



Complications from diabetes are well-known and serious. Managing the disease requires lifestyle changes, so it's difficult to engage patients in their own care. But expression techniques involving the creative arts can help by getting patients to open up and learn while sharing.

Commonwealth Care (4 percent), the state's subsidized health plan for low-income residents.

INTERVENTION — This facilitated and collaborative group process was designed and delivered by the Foundation for Art and Healing. It lasted six weeks, meeting 2½ hours weekly. A consulting group of diabetes experts, art therapists, psychologists, survey research specialists and educators assisted in program development as well as in assessing the medical efficacy of arts-based therapy on wellness and reducing barriers to diabetes care.

The creativity circles that resulted combined creative arts and storytelling with medical and community health expertise to reduce the negative emotions of chronic illness and to cre-

ate awareness of important health information. Modalities included paper-based collage, expressive writing, meditation exercises and movement-based relaxation exercises. Group discussion included questions posed by the facilitator that let participants describe aspects of their experience with diabetes as well as the thoughts and feelings associated with those experiences. Participants were invited to reflect on others' comments and expand their own sharing.

MEASURES — The influence of the intervention was assessed using a hybrid self-report approach. Participants answered a questionnaire including validated instruments relevant to diabetes care before and after the intervention. Participants also were asked an open-ended question upon completion,

inviting them to share their opinions on the intervention and whether it benefited their diabetes management and their lives in general. The questionnaire included:

- The Veterans Rand 12-Item Health Survey⁴⁰ covers eight domains including physical function, role limitations because of physical problems, bodily pain, general health perceptions, energy and vitality, social functioning, role limitations because of emotional problems and mental health. It contains 12 items, summarized, into physical and mental components standardized to the U.S. population. Scores can be interpreted based on the normal U.S. population with a mean of 50 points and standard deviation of 10 points. Higher scores imply better functional status.
- The Diabetes Distress Screening Scale⁴¹ captures diabetes-related emotional distress including emotional burden, physical stress, regimen stress and interpersonal distress. Higher scores denote higher levels of stress.
- The Patient Activation Measure⁴² measures patients' knowledge and confidence in managing their health. There are four levels of activation based on total scores, including the commencement of a social role, building knowledge and confidence, taking action and maintaining behaviors.
- The Overall Emotional and Social Loneliness Scale⁴³ is a six-item measure of social well-being. It is organized into two components: emotional loneliness (missing an intimate relationship) and social loneliness (missing a wider social network). Lower scores are more desirable than higher scores.
- Finally, a participant satisfaction questionnaire evaluated satisfaction with the intervention. Questions asked whether it helped participants discuss their health-related problems with their doctors, improved their ability to manage their condition, reduced diabetes stress, made them become more socially active, helped them interact with friends and, in general, made them feel good. This was rated on a five-point scale, from poor to excellent.

ANALYSIS — The statistical analyses conducted were purely descriptive and noninferential because of the small sample size. Accordingly, descriptive statistics (mean, median, standard deviation and confidence intervals) were computed for the different scales before and after the intervention as well as the difference in scores. We considered effect sizes of 0.20 of one standard deviation as small, 0.50 of one standard deviation as moderate and greater than or equal to 0.80 of one standard deviation as large.⁴⁴ Individual trajectories in scores stratifying by risk categories also were evaluated.

TABLE 1: MEAN GROUP SCORES BEFORE AND AFTER ART THERAPY INTERVENTION

	BEFORE	AFTER
VETERANS RAND 12-ITEM HEALTH SURVEY¹		
Physical component	39.25 (10.25)	40.96 (10.05)
Mental component	46.43 (10.66)	53.04 (8.80)
DIABETES DISTRESS SCREENING SCALE²		
TOTAL	2.31 (0.79)	2.13 (0.86)
Emotional Burden	2.53 (0.90)	2.30 (0.99)
Physical Stress	2.00 (0.78)	2.08 (0.83)
Regimen Stress	2.37 (0.97)	1.88 (0.85)
Interpersonal Stress	2.25 (0.74)	2.31 (1.05)
PATIENT ACTIVATION MEASURE³		
TOTAL	54.83 (5.90)	55.83 (6.93)
EMOTIONAL AND SOCIAL LONELINESS SCALE⁴		
TOTAL	16.17 (1.85)	15.25 (2.26)
Emotional Loneliness	6.5 (1.93)	5.83 (1.89)
Social Loneliness	9.67 (2.06)	9.42 (1.93)

Standard deviation in parentheses. Notes: 1. Higher values denote better mental health. 2. Lower values denote lower levels of stress. 3. Higher values denote higher levels of activation. 4. Lower values denote lower levels of loneliness

STUDY RESULTS

BASELINE — The mean physical score was 39.25, which indicates a low level of functioning; it's about 10 units (one standard deviation) below the mean of 50 defining a normal population (see Table 1). This may be because of diagnosed diabetes, comorbid conditions and sociodemographic characteristics of the study sample. It's similar to a Medicare Advantage population.⁴⁵ The mean mental score was 46.43, signaling lower mental health than the normal population — about 4.5 points below, a moderate difference signaling a sample with some mental health problems and 5 to 6 points lower than the average Medicare Advantage population.

Participants were below what's considered moderate stress, as the mean scores across the different diabetes distress screening scales were all lower than 3 (scores above 3 suggest needing clinical attention). This was corroborated by the mental health scores. The mean Patient Activation Measure score of 54.83 suggests lacking confidence and knowledge to take action managing one's own health and care. The average value for loneliness was 16.17, which considering its maximum is 20, suggests medium to high levels of loneliness.

POST-INTERVENTION — Table 1 also indicates noteworthy improvement in most of the scales, especially in the mental and stress components. The mean mental summary component increased by 6.6 points, which is a moderate effect (greater than 66 percent of one standard deviation). The total mean score for the distress scale also improved (reduced by 0.18 points, small effect size of 0.23), particularly for the subscales of emotional burden (reduced by 0.23, small effect size of 0.25) and regimen stress (reduced by 0.49, moderate effect size of 0.51).

TABLE 2: MENTAL HEALTH AND REGIMEN STRESS SCORES BY RISK GROUP

Patient ID	MENTAL HEALTH ¹			REGIMEN STRESS ²		
	Time 1	Time 2	Difference	Time 1	Time 2	Difference
HIGH-RISK GROUP						
5	39.86	48.6	8.75	3.4	2.8	-0.6
8	24.72	32.82	8.1	3.4	2.8	-0.6
9	41.13	52.65	11.53	2.6	1.6	-1
12	45.6	47.5	1.9	3.8	3.2	-0.6
13	35.21	61.12	25.91	2.8	1.4	-1.4
MEAN	37.3 (7.95)	48.54 (10.29)	11.24	3.2 (0.49)	2.36 (0.80)	-0.84
95% CI			6.72,15.76			-1.24,-0.44
LOW-RISK GROUP						
2	50.57	59.17	8.6	2	1.4	-0.6
4	59.06	61.79	2.73	1	1	0
6	50.3	52.11	1.81	2	1.2	-0.8
10	46.43	53.23	6.8	1.6	1.4	-0.2
11	51.76	60.22	8.46	1.6	1	-0.6
16	47.13	44.69	-2.44	3.2	3.2	0
17	65.37	62.56	-2.81	1	1.6	0.6
MEAN	52.9 (6.86)	56.25 (6.52)	3.31	1.77 (0.75)	1.54 (0.76)	-0.23
95% CI			0.78,5.84			-0.65,0.18

Standard deviation in parentheses. Notes: 1. Higher mental health values denote better mental health. 2. Lower regimen stress values denote lower levels of stress.

CHANGES OVER TIME — The study sample was divided into high- and low-risk groups (see Table 2) based on their MCS scores at baseline. Individuals with an MCS below the sample mean (46.43) were considered to be part of the high-risk group. Among them, there was an average difference of 11.24 points between before and after the art therapy intervention — a large improvement of more than one standard deviation. There were similar findings for the DDS questionnaire. Patients in the high-risk group particularly felt less stressed about their condition after the intervention. An average difference of 0.84 points between “before” and “after” was seen in the high-risk group, implying a large effect size of 1.71.

PATIENT SATISFACTION — Participants were highly satisfied with the intervention (see Table 3). All would recommend it to others, rating it as excellent. Ten out of 12 participants strongly agreed with the statement “the intervention was a very positive experience” or “the intervention made me feel better.” Interestingly, 10 participants thought the intervention made them feel better, yet eight also felt sad, which might indicate it surfaced some repressed negative emotions. But given the overall improvement in mental health, it’s possible that exploring one’s true feelings might have mentally eased participants overall — a phenomenon accepted as part of insight-oriented therapeutic models, where generating awareness and basis for emotions is thought to lead to acceptance

TABLE 3: HOW PARTICIPANTS ANSWERED SATISFACTION QUESTIONNAIRE

ABOUT THE INTERVENTION	5 STRONGLY AGREE	4 AGREE	3 NEUTRAL	2 DISAGREE	1 STRONGLY DISAGREE
Very positive experience	10	2	0	0	0
Made me feel better	10	2	0	0	0
Helped me interact with friends	8	2	2	0	0
Made me feel sad and blue	8	3	1	0	0
I became more active in my social life	4	3	2	3	0
I was better able to manage my diabetes	6	4	1	1	0
Helped discussion about diabetes with doctor	5	4	3	0	0
Contributed to my discussion with doctor	6	3	3	0	0
Contributed to reducing my diabetes stress	7	5	0	0	0
I would recommend this to a friend	12	0	0	0	0
Overall rating	12	0	0	0	0

and integration with daily experience, improving resilience and coping skills.^{46,47}

OTHER FEEDBACK — Three main themes (see Table 4) emerged in the open-ended section of the survey: learning about diabetes and themselves, obtaining emotional and mental support, and improving self-care routines. Participants considered the intervention an opportunity to learn more about the disease and their own experiences. Most considered it a source of emotional and mental support to ease burdensome self-care demands. Some highlighted the comforting and surprising experience of storytelling and artistic expression.

DISCUSSION AND IMPLICATIONS

Results suggest the intervention had an overall positive influence on participants’ health. Managing diabetes demands following a strict medication, diet and exercise regimen. Patients can feel overwhelmed and, without proper motivation, might not comply. This intervention’s goal was to ease the emotional burden through creative arts expression. Our results should be interpreted with caution because of the small sample size and lack of comparison group, but they suggest that the intervention had the intended result.

TABLE 4: SAMPLE OF OPEN-ENDED PARTICIPANT FEEDBACK

Learning about the disease and themselves:

- "It helped me understand me with diabetes, not just the diabetes."
- "It was education, basically. I am not a big talker but it has made all the difference in the world to me."
- "I could sit down with people and learn from them about what their health issues were."

Emotional and mental support:

- "I don't feel like such an odd duck anymore. I have never been in a group talking about my diabetes before, always just a doctor or a nurse talking at me, not with me."
- "I saw other women going through the same thing and I could identify with some of the stories. I know I am not by myself now. I know I am not crazy."
- "That gave me strength to help myself and not see myself as a failure."

Improvement in self-care routines:

- "I was not sticking my finger very often, but now I do it every day. Maybe not at the same time, which I try, but I do it every day."
- "I am paying more attention to my body, and I want to love me more than I love the food that is bad for me."
- "Now I test every day. I got lazy. This group motivated me to take better care of myself again."

We observed a large improvement in mental health. While the exact mechanism was unclear, the positive outcome likely was generated by three interrelated activities and their consequences:

- Engaging in the creative activity itself, establishing a sense of mastery and control.
- Sharing of creative output with others, augmenting self-esteem and self-validation.
- Receiving feedback from others, fostering a sense of connection and reducing isolation.²⁵

The stratification by risk level helped identify the patients who potentially could benefit the most from behavioral intervention. The large signal of positive change observed for high-risk mental health patients might have been partly because of metric effects such as regression to the mean, given the lower scores at baseline, and the consequent greater opportunity for change to occur between "before" and "after." However, it seems likely that some fraction of the change was due to the intervention itself. The data presented is heartening and provides impetus for future, more-rigorous studies designed with specific hypotheses.

Previous research suggests that active patients have better health care experiences and better health care outcomes, and they might be less expensive for the health care system after risk adjustment.^{48,49} Creativity circles are an attractive, flexible and affordable patient support resource to improve patient engagement. Our study becomes part of the mounting body of evidence that supports the benefits of creative arts on psychological and social aspects of disease management.

Arts-based interventional modalities have beneficial effects on medical conditions in which effective management is linked to sustained behavior change — vital in chronic diseases such as diabetes. The goal is to empower patients to find better paths to manage their care. These modalities are relatively low-cost, easy to deliver in many settings, and do not require licensed professionals. Anyone with knowledge of the creativity circle method and facilitating techniques should be equipped to successfully lead a group.

Sometimes, the biggest barriers to health are not the absence of treatment or medical knowledge of disease processes, but instead reside in a patient's lack of engagement and resistance to adopting behaviors that would benefit them. Creativity circles are innovative and powerful resources that facilitate self-care by easing fears, educating and empowering patients.

At a time when health care delivery systems are under pressure to deliver better care and better health outcomes at a lower cost, this potentially powerful approach to improving patient engagement deserves serious attention. Its low cost, ease of delivery and high patient acceptance suggest consideration for inclusion in the rapidly proliferating models for fully integrated primary care, often referred to as patient-centered medical homes or advanced primary care.^{50,51}

Promoting patient engagement as the blockbuster mechanism for improved population health, creativity circles and similar arts-based programming can help reduce the cost of health care, contribute to better physical health outcomes, and foster an improved and sustained sense of well-being.



Jeremy Nobel, MD, MPH, is a faculty member of the Center for Primary Care at Harvard Medical School in Massachusetts. He is medical director at the Northeast Business Group on Health in New York City, and is the founder and president of the Foundation for Art and Healing in Massachusetts.

jnobel@hsph.harvard.edu



Lewis E. Kazis, ScD, is a professor of health policy and management and director of a health outcomes research program at Boston University School of Public Health in Massachusetts.



Howard Cabral, PhD, MPH, is a professor of biostatistics at Boston University School of Public Health, a director of the Boston University biostatistics graduate program, and director of the biostatistics and research design program at Boston University Clinical and Translational Science Institute in Massachusetts.



Marina Soley-Bori, PhD, MA, is a research economist in the health care financing and payment group at RTI International in Massachusetts.



Harris Allen, PhD, is founder and principal of Harris Allen Group, an independent health care consultancy based in Georgia. He also is a senior lecturer in health care leadership at Brown University in Rhode Island.

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