PUBLIC HEALTH & PRIMARY CARE | RESEARCH ARTICLE

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A community-based diabetes group pilot incorporating a community health worker and photovoice methodology in an urban primary care practice

Jenny Jia[1]*, Lisa Quintiliani[1], Ve Truong[1], Cheryl Jean[1], Jerome Branch[1] and Karen E. Lasser[1,2]

Abstract: **Objective**: The purpose of this study is to evaluate a three-month, community-based, diabetes self-management pilot intervention using photovoice, a community health worker (CHW), and group education sessions in an urban, African-American safety-net population, a group disproportionately affected by diabetes, in order to identify promising diabetes management approaches.
Design: We invited patients with poorly-controlled diabetes from diabetes "hotspots" in Boston, located in African-American communities, to participate in six group sessions at a public library. Sessions included photovoice, a methodology whereby patients use photography and written narratives to facilitate deeper reflection about a specified issue. We designed three photovoice missions with different prompts about participants' day-to-day lives related to diabetes. After each mission, a CHW facilitated discussions of participants' experiences, coordinated educational presentations (e.g, dentistry), and connected participants to services. We created an age- and sex-matched control group to compare A1C levels

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Dr. Jenny Jia is a resident physician in Internal Medicine and Preventive Medicine at Boston Medical Center. Her research interests include food environments and preventing chronic disease, food insecurity, and health disparities. She is currently pursuing an M.S. in Epidemiology at the Boston University School of Public Health. Our research group focuses on community-based solutions to improving diabetes outcomes. Previous projects include GIS mapping of concentrated areas of patients with poorly-controlled diabetes, resource mapping of the food store environment in Boston, and community-based education and patient navigation groups.

PUBLIC INTEREST STATEMENT

Diabetes mellitus is a chronic disease with unequal outcomes between African Americans and whites. We evaluated a three-month, community-based, diabetes self-care program using photovoice, whereby participants take photos and write narratives about their experiences, a community health worker, and group education sessions in an urban, African-American safety-net population to find effective tools for future programs. The evaluation showed that blood sugar control did not improve during or after the program. However, participation in group sessions was high, likely related to holding sessions at an accessible, public location. Participants expressed difficulty in following diabetes self-care guidelines, were both motivated and discouraged by their blood sugar control, and had strong and often negative emotional responses to performing diabetes self-care tasks. Our results suggest that diabetes can cause feelings of burnout that adversely affect diabetes self-care, and future programs should target emotional responses to living with diabetes in populations with poor diabetes outcomes.

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at baseline and post-intervention. We coded transcripts of sessions for themes of barriers to and motivators of diabetes control, using grounded theory.

Results: Hemoglobin A1C levels did not improve in the intervention group relative to the control group. Barriers included non-adherence to diabetes self-management behaviors, lack of dietary knowledge, and frustration and fatigue towards diabetes self-management. Participants attributed frustration and fatigue to the chronic nature of diabetes and lack of improvement in disease control markers.

Conclusion: The combination of lack of adherence and frustration and fatigue is concerning for the development of burnout in the diabetic patient population. Interventions to build resilience in these individuals and communities should be explored.

Subjects: Community Health; Diabetes; General Medicine

Keywords: diabetes; chronic disease; photovoice; community health workers

1. Introduction

Diabetes mellitus is a chronic disease with disparities in outcomes between African Americans and whites. Glycemic control is generally worse among African-American patients with diabetes compared to whites (Kirk et al., 2006), and poor glycemic control leads to a higher prevalence of end-stage renal disease, retinopathy, neuropathy, and lower-extremity amputations in black individuals (Lewis et al., 2015; Suckow et al., 2015; Zhang, Saaddine, & Chou et al., 2010). Even with access to primary care, racial disparities in diabetes control and complications persist (Vimalananda, Rosenzweig, Cabral, David, & Lasser, 2011). Furthermore, studies show that black patients may have difficulty attending clinic and hospital-based chronic disease management groups (Geller, Orkaby, and Cleghorn 2011).

In previous work, we geocoded registry data of the general internal medicine practice at Boston Medical Center (BMC), the largest safety-net hospital in New England. We identified 13 diabetes hot spots, census tracts in the Boston area with high numbers (>20) of patients with poorly controlled diabetes (hemoglobin A1C level >9). A unifying feature of these communities was lack of a direct bus line to the hospital (Lasser et al. 2015), which may have deterred patients from attending group interventions (Berry, Williams, Hall, Heroux, & Bennett-Lewis, 2016; Rendle et al., 2013), and the fact that they were largely African-American. Previous work in an urban family practice demonstrates that group visits have the potential to improve diabetes control (Reitz, Sarfaty, Diamond, & Salzman, 2012).

To improve understanding of factors that prevent patients in these hotspots from achieving better diabetes control, and to inform future interventions, we previously conducted a study incorporating photovoice methodology (Florian et al., 2016). Photovoice is a participatory research method where participants use photography and accompanying narrative to describe their lived experiences in relation to a certain topic, in this case, diabetes self-management. Our study showed that photovoice had the potential to help participants gain insight to their illness, motivate behavioral change (Florian et al., 2016), and could be a useful intervention to improve diabetes control.

Given that multicomponent interventions have shown the most promise in reducing health disparities (Chin, Walters, Cook, & Huang, 2007), in the present study, we combined photovoice with a community health worker (CHW) to connect participants to existing resources. In previous work with the target population, themes that emerged from photovoice sessions included the importance of access to healthy food, restaurants, and prepared foods; food assistance programs; exercise facilities; and church (Florian et al., 2016). Incorporating photovoice into a community-based diabetes intervention may bring awareness to underutilized neighborhood resources that

can help people control their diabetes. We chose to utilize a CHW, hypothesizing that the CHW could link participants to these resources. Research has shown that interventions which engage CHWs help patients manage their diabetes (CPSTF, 2017). We conducted a three-month pilot intervention to improve glycemic control among patients with poorly controlled diabetes residing in diabetes hotspots. Previous studies on group interventions to improve diabetes outcomes have had promising results (Housden & Wong, 2016) but tend to occur in clinical environments, which can pose multiple barriers, including transportation issues (Berry et al., 2016; Rendle et al., 2013). For this study, we chose a community-based setting, a public library in one of the hot-spot census tracts, to host the group sessions (CPSTF 2002).

The objective of this study was to determine the acceptability, feasibility, and preliminary efficacy of the photovoice-community health worker intervention using both quantitative and qualitative evaluation methods.

2. Methods

2.1. Study design and setting
We used a quasi-experimental, two-group, pre-post study design. Patients residing in any one of 13 diabetes hot spots who agreed to participate in the photovoice groups made up the treatment group; age- and sex-matched patients who also resided in the diabetes hot spots served as the control group.

We selected one patient from a photovoice group held in April 2015 to serve as a patient advisor to the research team. We chose this patient because he was articulate and insightful. Prior to his involvement in the project, he participated in human subjects training designed for community members. We held an initial planning meeting with this patient, invited him to attend the groups, and sought his feedback after each group. He also participated in a meeting where we reviewed themes that emerged in the photovoice groups. The Boston University Medical Campus Institutional Review Board approved the study.

2.2. Study recruitment
We included individuals age ≥18 with poorly controlled diabetes (A1C >9) who resided in a diabetes hot spot, spoke English as their primary language, and were patients of 19 different primary care providers (PCPs) at BMC. While African-American race was not an explicit inclusion criterion, patients residing in the diabetes hot spots were more likely to be black relative to patients who did not live in diabetes hot spots (Ke et al., 2015). Of 187 eligible individuals, PCPs excluded 30 for reasons including the patient was too ill to attend group sessions, or no longer lived in Boston. We mailed recruitment letters to 157 patients; of those, 96 patients also received one phone call inviting them to participate. Through letters and phone calls, we enrolled 13 participants. We also invited 10 participants from the prior photovoice pilot study (also with poorly controlled diabetes residing in the diabetes hot spots), and five agreed to participate. Thus, we enrolled a total of 18 participants. For the control group, we recruited age- and sex-matched individuals from PCPs who did not participate in the study.

2.3. Photovoice-community health worker groups
We conducted six, biweekly two-hour group meetings from October–December 2015 at the Dudley Branch Public Library in Roxbury, MA. Participants received a $25 gift card for attending each group. A CHW with a college degree facilitated the meetings and incorporated the photovoice methodology in the group discussions. She also maintained telephone contact with participants between groups, assessing participants' barriers to diabetes care and linking participants to resources (e.g. food pantry, home delivery of medications, enrollment in EHR patient portal) as indicated. We assigned three photovoice missions, where we asked participants to take photographs using the following prompts: 1) What does having diabetes mean for you and your family?; 2) What barriers or challenges do you face in taking your diabetes medicine?; and 3) What motivates you in managing or controlling your

diabetes? What helps your diabetes to stay in better control? We also invited guest speakers from Boston University, Boston Medical Center, and community-based organizations to educate participants in topics raised in the group discussions, such as nutrition, dental care, and stress management. For the three months following the six group sessions, the CHW continued to link participants to resources to improve diabetes self-management.

2.4. Outcome measures

For both treatment and control groups, we assessed clinical outcomes (hemoglobin A1C) using the participants' electronic health records (EHRs). One participant did not provide consent to have her EHR reviewed. For the treatment group, we also collected baseline and three-month survey data in person, and six-month survey data by telephone. To characterize our study sample, we surveyed participants at baseline regarding their demographics, health literacy (Chew, Bradley, & Boyko, 2004), food security (Alley et al., 2011), medication adherence (Krapek et al., 2004; Morisky, Ang, Krousel-Wood, & Ward, 2008; Morisky, Green, & Levine, 1986), chaos using a validated 6-item Chaos Scale (Matheny, Wachs, Ludwig, & Phillips, 1995), hassles using a validated 9-item Abbreviated Hassles Index (Kanner, Coyne, Schaefer, & Lazarus, 1981), and diabetes-related social support. At baseline, three, and six months, we surveyed participants regarding diabetes-related quality of life (Fisher, Glasgow, Mullan, Skaff, & Polonsky, 2008; Polonsky et al., 2005), and administered the validated Diabetes Self-Management Questionnaire (DSMQ) (Schmitt et al., 2013). Finally, at baseline and six months, we surveyed participants about stress using the validated 4-item Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983).

2.5. Data analysis

We conducted descriptive analyses of participants' social, demographic and clinical characteristics. As our sample size was small and thus mean estimates are prone to random error, we did not perform tests for statistical significance between the control and intervention groups.

We audio-recorded and transcribed all group sessions. We utilized the text of the initial library session to identify themes of diabetes control to create codes with definitions of each theme, which we compiled into a codebook. Two research team members, one who was present at the group sessions (CJ) and one who was not (JJ), coded the remaining transcripts using the codebook. We added any new themes that arose in the analysis of subsequent sessions to the code book. With each new code creation, coders reviewed previously analyzed transcripts to ensure that the new codes were not missed. We compiled coded quotes into a document, which we reviewed with the patient advisor to ensure that the themes represented the perspectives of participants and that we interpreted dialogue appropriately.

3. Results

3.1. Participant characteristics

The results of participant surveys completed at the beginning of the intervention are shown in Table 1. While we enrolled 18 participants in the study, three participants did not attend any groups or complete surveys. Of the 15 participants who attended at least one session, most participants were African-American, female, and Medicaid-insured; the mean age was 56. Few were employed or living with a partner; one-third experienced food insecurity, and over one-fourth were unable to afford their prescriptions.

3.2. Acceptability/feasibility

Table 2 displays participation in group sessions. The patient adviser attended four of six group sessions. Only 27% of participants attended all six sessions, but more than half (60%) attended five of the six. Session 5 had a particularly low attendance. One-third of participants did not complete any photovoice missions. Participants mentioned hand injury, lack of enjoyment of photography, and vision problems as reasons why they did not complete the photo missions. In Session 1 (photovoice introduction) and 2 (photovoice mission #1), when we

Table 1. Participant characteristics	
Characteristic	**Intervention group** **n = 15**
Female, %	73%
Mean age in years	56.2 (sd 13.5)
African-American	14 (93%)
Married or living with a partner	2 (13%)
High school graduate or less	9 (60%)
Employed	1 (7%)
Disabled	7 (47%)
Medicaid recipient	14 (93%)
Household income ≤ $20,000 per year	8 (53%)
Food insecurity[a]	5 (33%)
Unable to afford prescriptions	4 (27%)
Skipped medication doses or delayed prescription fills due to affordability	3 (20%)
Mean level of chaos[b]	17.7 (sd 4.5)
Mean level of hassles[c]	3.5 (sd 1.9)
Stress[d]	6.4 (sd 2.1)
Diabetes-related quality of life[e]	3.2 (sd 1.6)

[a]We considered participants to be food insecure if they answered no to "In the last two years, have you always had enough money to buy the food you need?" or had received Supplemental Nutrition Assistance Program (SNAP) dollars in the past 2 years.

[b]Confusion, Hubbubm, and Order Scale (CHAOS) range, 6–30, higher scores indicate more environmental confusion.

[c]Hassles Scale range, 0–9, higher scores indicate more hassles.

[d] Perceived Stress Scale range, 0–16, higher scores indicate more stress.

[e]Diabetes Distress Scale 4-question range, 0–6, ≥3 indicates moderate distress.

Table 2. Participation in group sessions	
	Number (percentage) **n = 15**
Group sessions	
Attendance by session number	
Session 1	12 (80%)
Session 2	14 (93%)
Session 3	12 (80%)
Session 4	11 (73%)
Session 5	4 (27%)
Session 6	10 (67%)
Attendance by participant	
Attended all of 6 sessions	4 (27%)
Attended 5 of 6 sessions	5 (33%)
Attended 4 of 6 sessions	2 (13%)
Attended 3 of 6 sessions	1 (7%)

asked participants to write narratives accompanying their photographs, five and six partici-pants in the respective groups were unable to write their own photovoice narrative and needed assistance. We used oral narratives in place of written narratives to debrief photo-voice missions #2 and #3.

3.3. Community health worker intervention

Eight of 15 participants completed a telephone assessment with the CHW; the CHW referred three of these participants to the food pantry and five to hospital cooking classes. The CHW did not enroll new participants into home delivery of medications or the EHR patient portal as some participants were already enrolled and the others were not interested. Only one participant was interested in texting with others in the group to maintain contact after the group sessions concluded.

3.4. Preliminary efficacy

A1C levels worsened in both groups. For the treatment group, in the pre-intervention period, A1C averaged 9.1% (sd 2.4%; 76 mmol/mol); in the post-intervention period it averaged 10.1% (sd 2.4; 87 mmol/mol). For the control group, in the pre-intervention period, A1C averaged 10.2% (sd 1.6; 88 mmol/mol); in the post-intervention period it averaged 10.8% (sd 3.0; 95 mmol/mol).

Intervention participants' level of stress improved from baseline to six months with mean 6.4 (sd 2.1) to mean 5.7 (sd 3.8). Diabetes self-management scores worsened from baseline to three months, mean 34.5 (sd 7.0) and 31.9 (sd 6.3), respectively, and returned to nearly baseline levels at six months (mean 34.4 (sd 6.5)). Diabetes-related quality of life remained stable from baseline to three months, mean 12.9 (sd 6.4) and 13.0 (sd 6.3), respectively, and increased after the intervention with a mean of 16.9 (sd 6.4) at six months.

3.5. Qualitative results

In qualitative analyses of the six group sessions, we identified themes related to diabetes control, including barriers and motivators to diabetes control in participants' daily lives. Table 3 lists each theme and representative photos and quotes.

3.5.1. Participants had difficulty following diabetes self-management practices

Many participants used the word "try" to convey their effort to adhere to diabetes self-management strategies, suggesting imperfect adherence. Some participants elaborated on specific challenges they faced. One individual acknowledged the difficulty in consistent adherence: "But it's hard. It's not always easing making the right choice." Another expressed a lack of control in certain situations, primarily involving unhealthy foods: "Bread, potato, pasta, they said you can have some but if I see this plate, I will eat it all."

3.5.2. Adhering to diabetes self-management practices generated frustration and fatigue

Sources of frustration and fatigue included following diabetes self-management strategies without observing improvement in markers of disease control (hemoglobin A1C, finger stick blood glucose), limited choices when following self-management strategies, a fatalistic attitude towards self-management strategies, time spent performing self-management strategies, and the long duration of the illness. Among some participants, frustration and fatigue led to lapses in adherence to self-management behaviors. Some participants had negative feelings about certain activities, such as performing finger sticks and taking insulin: "I chose the finger stick [photo]. This lady's face shows how I feel. This stick controls my life. As small as it is, I don't like it." Several participants reported that their blood glucose influenced their mood on a regular basis: "A normal reading makes my day feel like it's going to be a good day. A high reading makes me wonder what I did wrong the day before. This reading affects my mental health for that day."

3.5.3. Glycemic control and preventing health complications motivated participants

In discussing motivators, participants focused on disease-specific themes, especially markers of glycemic control and potential health complications. Participants followed the hemoglobin A1C and blood glucose levels as markers of their disease control and expressed motivation to improve their control when these levels were not at goal. For several participants, a dislike of

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Table 3. Examples of themes identified in group sessions

Theme	Example from transcript
Participants had Difficulty with Following Diabetes Self-Management Practices	
	"This is a photo of purgatory. The meal consists of pasta (over cooked) in a soupy red sauce with over cooked gummy rice pilaf, a stale piece of chocolate cake, stiff bread, and iced coffee, extra cream, extra sugar, and a beautiful red delicious apple. This is my life right now and it sucks. Being homeless created a state of depression, exasperation, and helplessness."
	"When I wake up, that's when the bad begins. Then I'll wake up at like 1 or 2 o'clock in the morning. I'll eat like 15 grapes. I eat like two bananas, and if that's not enough then I'll compromise and make a peanut butter sandwich. If that's not enough, then I'll add jelly to it. I'll drink half a bottle of Pepsi. I'll wake up and my blood sugar is at 201 and when I went to bed it was at 137. It's like disciplining yourself and I try but it's also that craving. I don't know if it's a mind over matter thing but once you've been a diabetic for so long, and you have information on what you should eat but it's not fulfilling. I want to be full. I want to go back to sleep. I crave it but it's not healthy. That's the only problem that I need to do because it's a challenge."
Adhering to Diabetes Self-Management Practices Generated Frustration and Fatigue	"Diabetes is me. It affects whatever I do. Whether I'm eating right, whether I choose the right beverage to drink, whether I take my medication, how much to take, it's rough, it's hard. I went to my appointments, see my doctors, I get frustrated a lot of times...I mean I go to the doctors a lot, it feels like I'm living in Boston Medical...I'm constantly making changes... I can relate to everyone says about not taking their medicine. I inject myself six times a day. Plus, I got to prick myself. I got to prick myself before I eat and after I eat. So if I sound a little frustrated, it's because I am frustrated."
	"I'm just sick of being diabetic and I hate to stick my finger and I hate the insulin. I hate the smell of it. I hate having to pick my food. I hate it."

(Continued)

Table 3. (Continued)

Theme	Example from transcript
Glycemic Control and Preventing Health Complications Motivated Participants	
	"I see a firehouse. This reminds me of my diabetes because they put out fires and I want to be able to put out my diabetes. It reminds me when my sugar goes up and when my sugar goes down, just like fire. Also, I wonder why my sugar is not standing still. This picture of the firehouse is standing still, not moving. I want my diabetes to stand still and not move. When I look at this firehouse, it makes me want to control my diabetes as much as I can."
	"My birthday is coming up so I gained a pound back because it was kind of like depressed eating. But I know that I can bring my A1C down and that's my goal. Yes, I have to start taking my insulin again. I'm working on it."
	"I had a grandma who had diabetes. She died from it. She would get open wounds and the operation didn't heal. That's keeping me on the right track—eating right, checking blood sugar, taking care of myself."

(Continued)

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Table 3. (Continued)

Theme	Example from transcript
Participants Identified Interpersonal Relationships as Motivators Towards Self-Management Practices	"I took a picture of my family's photo because it helps me get better control of my diabetes and be healthy. I would live longer and be around for my future grandchildren."
	"I enjoy coming down here because you don't feel so alone because a lot of times you don't mention diabetes but it's always in your head. The TV and all of that stuff, the literature and stuff. I really feel like I can relate, having it in my own back yard and stuff. I might see you all in the street and we have a kinship because we have diabetes."

insulin and the threat of becoming insulin-dependent motivated disease control. Participants also cited preventing multiple long-term consequences of poor glycemic control, including lower extremity ulcers, amputations, diabetic retinopathy, dental infections, and death as a motivator to better disease control.

3.5.4. Participants identified interpersonal relationships as motivating self-management practices

Participants identified different types of social supports as motivators in their disease management. Participants viewed the group sessions favorably; some came to seek help, and others left feeling more motivated. They valued interacting with other individuals with diabetes, which allowed for peer support. They also appreciated sharing experiences they had in common, including struggles with diabetes.

Participants also identified caregivers and family members as motivators. Though caregivers could also be related to the participant, they were distinguished by regularly performing some action related to healthy self-management behaviors for the participant, such as performing finger sticks or administering insulin, or cooking for the participant.

4. Discussion

Our findings demonstrate that most participants found the photovoice-CHW intervention to be acceptable. Many participants identified the group session as a motivator to performing diabetes self-management behaviors. As participants appreciated the peer counseling element, mixing patients from similar backgrounds with and without well-controlled diabetes could be explored. A majority of participants attended at least five sessions. We held these sessions at the public library, a non-clinical community facility located close to a major bus station, which may have bolstered attendance. Previous research to identify diabetes hot spots in Boston showed that they were often located in areas where patients required two or more bus transfers to reach our medical center (Ke et al., 2015). Multiple health interventions have found success in reaching vulnerable populations through non-clinical settings, including libraries (Goldberg, 2016) and salons and barbershops (Linnan, D'Angelo, and Harrington 2014).

Participation in photovoice missions was lower than group session attendance. Of the individuals who participated in the photovoice missions, some did not fully understand the intention of the method, which may have prevented them from completing subsequent missions. Photovoice may not be feasible for individuals with functional limitations. Future interventions might include only a single photovoice mission.

Though participants viewed the intervention favorably, and levels of stress and diabetes-related quality of life in the follow-up period appeared to improve compared to pre-intervention levels, clinical outcomes did not improve between pre- and post-intervention periods. The group sessions took place in November and December, prior to the holiday season. It is possible that participants were less adherent to diet over the holidays, which caused their disease control to worsen.

One striking theme that emerged was participants' experience of frustration and fatigue. The chronicity of diabetes, complexity and limitations of diabetes self-management strategies, and varying degrees of unpredictability of glycemic measures in each individual with diabetes produced a sense of failure. Negative emotional effects of diabetes, referred to as "diabetes distress," are linked to poorer glycemic control (Dennick, Sturt, & Speight, 2017). Individual perceptions of diabetes and the emotional response towards diabetes appear to modulate adherence to diabetes self-management (Hudson, Bundy, Coventry, & Dickens, 2014). The potential for chronic disease to cause burnout could be further explored with consideration for interventions to promote resilience. Studies should consider measurement of diabetes distress to allow future interventions to address this issue.

Our study has several limitations. The findings of our study, conducted in a low-socioeconomic status, African-American female sample residing in an urban area, may not be generalizable to other populations. The intervention and control groups differed, as the former excluded some patients whose PCP felt they were not appropriate for the intervention, while the latter included all patients. In the qualitative analysis, while we used two separate coders and reviewed data with our patient advisor, coding may be subjective.

In summary, our study showed that a multicomponent intervention with photovoice and a CHW was acceptable and feasible but may not be efficacious without incorporation of additional program elements. Future interventions should explore promoting resilience among individuals and communities with high rates of uncontrolled diabetes.

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Competing interests

The authors declare no competing interests.

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