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Vision Voice: A Multimedia Exploration of Diabetes and Vision Loss in East Harlem

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Abstract

Background—East Harlem, New York, is a community actively struggling with diabetes and its complications, including vision-related conditions that can affect many aspects of daily life.

Objectives—Vision Voice was a qualitative community-based participatory research (CBPR) study that intended to better understand the needs and experiences of people living with diabetes, other comorbid chronic illnesses, and vision loss in East Harlem.

Methods—Using photovoice methodology, four participants took photographs, convened to review their photographs, and determined overarching themes for the group's collective body of work.

Lessons Learned—Identified themes included effect of decreased vision function on personal independence/mobility and self-management of chronic conditions and the importance of informing community members and health care providers about these issues. The team next created a documentary film that further develops the narratives of the photovoice participants.

Conclusions—The Vision Voice photovoice project was an effective tool to assess community needs, educate and raise awareness.

Keywords

Needs assessment education; anthropology; sociology and social phenomena; vision loss; community-based participatory research; diabetes

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East Harlem is located in the northeast corner of Manhattan in New York City. A culturally diverse and vibrant community, the residents, who are predominantly Latino (55%) and Black (35%), shoulder numerous health burdens.[1] Members of this community have the poorest self-rated health, highest obesity prevalence,[1] and diabetes-related mortality in New York City.[2] In a community where those living under the poverty level approaches 40%, there are many contributors to the high prevalence of diabetes, diabetic complications, and diabetes-related mortality, including limited access to healthy foods, education, medical care, and social services.[3]

Diabetes, especially when undiagnosed and unmanaged, can result in a number of vision-related conditions such as diabetic retinopathy and glaucoma.[4] Because one in seven adults has diabetes in East Harlem, the prevalence of vision impairment and blindness is also likely high.[5,6] Tracking with the diabetes epidemic, racial and ethnic disparities in vision health also exist. The estimated national prevalence of diabetic retinopathy, for example, is 26% among all people with diabetes compared with 38% among African Americans and 34% among Mexican Americans.[7] Despite increased risk for diabetes-related eye disease, African Americans and Latinos are much less likely to receive comprehensive eye examinations, a standard of care for people with diabetes.[8,9] There is also evidence that once suffering from vision impairment, African Americans with diabetes suffer worsened quality of life from the reduced vision function than their White counterparts.[10]

Poor vision health has profound implications for medication adherence, patient safety, clinical outcomes, and quality of life. People with diabetes usually require oral medications or insulin, self-monitoring of blood sugar, reading food labels, cooking healthful meals, and engaging in regular physical activity, all which require a certain level of visual acuity. Despite the barriers to diabetes self-management posed by vision loss, health care providers often do not consider their patients' vision function unless severe in nature.[11] In East Harlem, early strategies to address diabetes and vision loss are in fact emerging from the community at large, not only from health care providers and researchers.

Communities IMPACT Diabetes Center, a community–academic coalition, came together to address the diabetes epidemic in East Harlem. Community partners, including Lighthouse International, suggested that the coalition focus some attention specifically on vision health when devising diabetes prevention and control interventions. Moreover, through a series of assessments, including a survey of older East Harlem residents, the coalition discovered that even while wearing glasses, one half of respondents reported vision function problems that make it difficult for them to do the things they like to do, recognize faces of family and friends, walk safely, and read regular size print and medication labels.[12] One of IMPACT's vision health initiatives, *Vision Voice*, sought to better understand and portray people's experience with decreased vision function and chronic illness through the in-depth descriptive qualitative method of photovoice, and to use the information gained to improve vision awareness and health through advocacy for improved early detection and screening within the local community. In health care settings, this project sought to highlight the barriers impaired vision function can have on chronic illness management, with the potential result of shifting health care processes for improved health care quality, delivery, and cost savings.

Lighthouse International, one of IMPACT's community partners, was involved in recruitment, study design, content decisions, review of results, and dissemination plan. The IMPACT Vision Health workgroup, which was composed of members of local community groups including Lighthouse International, met every two to four weeks to discuss the *Vision Voice* project in addition to other vision health initiatives. *Vision Voice* was also reviewed at IMPACT's quarterly community action board meetings over the course of project development, evaluation, and dissemination. Once the project was ready for dissemination, IMPACT partners provided suggestions for modes and locations for exhibition and engagement surrounding the photovoice exhibit and film. Once the formal study sessions were completed, the *Vision Voice* participants themselves played an active role in both the Vision Health Workgroup and community action board, making key contributions regarding dissemination of the film and photographs for community change

PHOTOVOICE

The research team used photovoice to explore participants' personal experiences with vision loss and diabetes. Photovoice has been used in the United States and internationally among diverse demographic groups to examine varied community health issues and to effectively reach larger audiences including policymakers.[13] To our knowledge, photovoice has never before been used to explore issues related to decreased vision function.

Photovoice uses a CBPR approach to empower participants to take photographs around a specific theme, and to give voice to individuals and communities that have been historically marginalized.[13,14] As clearly articulated by Carlson et al.,[15] photovoice, a Freirian-based process modified by Wang and Burris, "has four major goals: 1) to engage people in active listening and dialogue 2) to create a safe environment for introspection and critical reflection 3) to move people toward action and 4) to inform the broader, more powerful society to help facilitate community changes."[15–18]

As previous studies have outlined using the socialecological model, photovoice can have potential effects on individual, organizational, and community/societal levels.[19] Photovoice has been found to increase individual empowerment and raise personal critical consciousness,[15,17] which in turn can promote community engagement and incite systems and policy change.[15]

Although the use of a visual medium to explore the subject of vision health may seem unconventional or even paradoxical, the study team sought to empower participants to create photography by directly engaging—and not despite—their visual impairments. Furthermore, the study team speculated that such a photography project would engage audiences on a deeper level. By implying a simple, obvious question— "How did individuals with vision loss create a photography exhibit?"—*Vision Voice* invites audiences to think more critically about how the participants living with chronic illness and vision loss might accomplish something like taking a photograph, a simple task for most. In an increasingly visual and technological society where cameras, phones, and communication are in many ways synonymous, both the photograph and the act of photographing can be revisited in a project like *Vision Voice* to help audiences put themselves in participants' shoes and generate meaningful, relatable dialogue.

The study team also believed that this project could influence the organizational level, namely, health care providers, and in turn health care culture and processes. Finally, the group also hoped this project could be used for advocacy for policy change, depending on priorities created through the group process.

METHODS

Recruitment and Consent

Approval to conduct this project was obtained by a medical school institutional review board and all participants provided their written consent. Participants joined the study through community recruitment and via local medical clinics. Participants were eligible based on reported problems with vision function and a willingness to use photography to express their thoughts and ideas and. Ten potentially eligible people, both men and women, were approached to participate in the project. Four people declined participation at the initial recruitment encounter and six participants enrolled in the study. Two participants withdrew (one moved out of state and one owing to personal time constraints) and four completed the project. After signed consent, the participants filled out a demographic questionnaire and the Lighthouse Functional Vision Screening Questionnaire.[20]

Photovoice Process

In the first of three workshop sessions, trained facilitators introduced participants to the concept of photovoice, provided them with digital cameras and instructions on how to use them, and asked them to use the cameras to explore the impact of diabetes and vision loss on themselves and their communities. The study team modified the cameras to be “low vision friendly,” by adding bump dots and magnifiers, which the participants found helpful and sufficient to use the camera effectively. The project staff also ensured that, during group sessions, the display images were on a well-lit screen with bolded font for the narratives, to allow for easier viewing. Participants were instructed to obtain written consent from any identifiable individuals who appeared in their photographs. After two weeks, each participant met individually with the study team to download her photographs, and to indicate which photographs (minimum two and no maximum limit) to share with the group during the second group session. During session two, participants shared their selected photographs and then worked separately using the SHOWeD method (What did you *s*ee here? What is really *h*appening? How does this relate to *o*ur lives? *W*hy does this problem or strength exist? What can we *d*o about it?) to explore the themes in their photographs and compose individual narrative captions to accompany each image.[21,22]

In the third and final session, the group worked together to identify common themes among their collective body of photographs to create group narratives. After that, the group discussed how they wanted to exhibit the photographs, and defined how they wanted to use *Vision Voice* (the name participants decided on for the project) to create change in the community. In this session, the group discussed ways to engage people’s perceptions and feelings regarding diabetes and its complications as a way to shift community members, including health care providers, toward greater awareness and action for community and systems change. During the discussion, the group discussed possible venues for project exhibition and opportunities for activism, including the local community board.

Analysis

In addition to collecting all narratives that accompanied the photographs, one member of the research team took extensive notes of the tape-recorded group sessions. The study team analyzed both notes and narratives that accompanied each photo; identified recurrent language, patterns, and ideas; and organized these recurrent ideas into codes. From the codes, particular categories of data were established. Categories helped to identify salient themes; categories fell under one overarching theme or several themes.

RESULTS

All four participants were women and self-identified as Hispanic/Latina. Participants' ages spanned 31 to 65 years old, with the majority in the late 40- to 50-year-old age range. All had completed high school or some college/technical school and qualified as low income (annual income $15,000–$30,000). Three of the participants had diabetes, one had a diagnosis of pre-diabetes, and all participants had additional multiple chronic illnesses including eye diseases. Participants' respective issues with vision function were not all owing to diabetes, but rather from varied causes. The participants had varied degrees of vision function, ranging from three to nine positive Lighthouse Functional Vision Screening Questionnaire items (nine warranting evaluation by an ophthalmologist and even one identified problem possibly warranting a referral to an Association for the Blind local affiliate).[20] Example questions from the Lighthouse questionnaire include: "When you are walking in the street, can you see the 'walk' sign and street name signs?" and "Does trouble with your vision make it difficult for you to see labels on medicine bottles?" [20]

Issues Addressed

The participants identified a range of themes over the course of the study. Issues included lack of mobility or independence, managing their disease with vision impairment (e.g., monitoring blood sugar levels, properly administering medication, reading food labels, health information seeking), and other everyday tasks that have become "a daily struggle." Participants also discussed the importance of "breaking the cycle" of diabetes and vision loss for the next generation through raising awareness among family, community members, and health care providers. Finally, photographic expression allowed participants to characterize their vision loss through visual representation, through darkness and light, blurriness and clarity in the photographs. Most of the participants' expressed concerns were common to all photovoice projects. However, one observation more specific to this vision impaired population was compensatory mechanisms, such as taking many photos in hopes that one comes out well, born of the concerns that they might not capture something quite right. Digital photography was a true strength for this project because it allowed for rapid-fire image acquisition and storage of multiple images.

Personal Mobility/Independence/Self-Care—One recurring theme was lack of security in navigating public spaces owing to vision loss. In a photograph of a man at a five-lane crosswalk, one participant explained, "If I was that man I'd be scared to cross the street. I have to make sure the light is red. I have to watch my step." Another participant reflected on her inability to drive owing to vision loss: "Instead of driving, I'm now a passenger…. It makes me feel like life is zooming past me." The participants also highlighted the multitude of ways that vision impairment can interfere with important self-care tasks, including reading to stay informed about one's health, taking medications correctly, reading food labels, being physically active, or even performing seemingly simple acts like putting on makeup (Figures 1 and 2).

Need to Raise Awareness among Community Members and Health Care Providers—In the group discussions, all participants reported the importance of "breaking the cycle" of diabetes and vision loss for the next generation—which they hoped to accomplish through information sharing. This concern was reflected in photographs of family portraits, friends, and children that showed how the participants' communities had been affected by diabetes. Where one woman spoke about the responsibility to inform elders, another discussed the importance of maintaining eyesight to read to her children. Participants also highlighted the need to enlighten the health care community about people's beliefs on eye screening and treatment. They described how many people never report vision loss to their health care providers nor loved ones, but rather subtly and quietly compensate for loss of vision function without complaints. The participants aimed to relay a message to this cohort about the importance of seeking care to preserve their vision or services to better cope with current vision loss (Figure 3).

Characterizing Vision Loss—One unforeseen outcome was the value of visual media in investigating vision loss: three out of the four participants used the photographs to characterize their own vision problems. Two participants selected blurry prints to illustrate how they perceived an image (Figure 4). One of these participants also selected several prints that were taken at night and showed extreme contrast between light and dark. Conversely, a third participant compared her vision to the sharpness of her photograph, noting that the camera had given her a "second pair of eyes" to see what exactly she had been missing. In her second photo, a self-portrait on a ferry, the same participant referred to the fog as "how I see without glasses."

Vision Voice Film—The project team believed that a diversity of media would deepen the educational and advocacy potential of the project. Therefore, the team created a short documentary film that further explores the themes of the photographs, the personal narratives of three featured participants, and their community's needs. The project team conducted semistructured interviews with participants in their homes, local public spaces, and Mount Sinai Medical Center over the course of several months. Participants took part in regular meetings with the team during the filming and editing process.

Vision Voice Multimedia Exhibition and Dialogue—The participants decided they wanted a mobile photography exhibit that appears in multiple locations throughout the community. The *Vision Voice* participants have appeared at photography exhibit and film openings, to engage all visiting community members, members of the local health care community and community leaders in a thoughtful, critical dialogue while they view the photographs and during a discussion period following the film. During these events, the *Vision Voice* group (participants and study team) emphasize the importance of eye screening and treatment for a community with high rates of diabetes, with an added message to health care providers to think about possible functional vision loss when working with patients.

The photography exhibit appeared for four to six weeks in each location at community-based organizations (many of which were IMPACT partners), community health fairs, a university, and health care settings within the East Harlem community and beyond. The group attempted to bring the photography exhibit to a state office building located in the community; however, numerous administrative factors precluded exhibition at this location.

The *Vision Voice* film first premiered at a local graduate school of social work and public health, accompanied by the photography exhibit. Members of the local community, a local chapter of a national diabetes organization, and medical and social work professionals attended the film premiere. Elected officials were invited to the film opening but did not attend owing to prior commitments. The film was also screened at an international film festival located in East Harlem, an East Harlem arts organization, a national academic public health film festival, and an academic conference on community-partnered health research. It was accepted to an international diabetes conference, but the study team was unable to participate owing to the distance required to travel. The film has also appeared in clinic waiting rooms and as part of health workshops in various locations throughout New York City. In 2013, a physician who works with the first author at Mount Sinai Medical Center created a pilot at their hospital-based primary care clinic that involves showing the Vision Voice film on clinic examination room computers, while the medical team confers on the treatment plan. The film is also publicly available online; it has appeared in local social media campaigns, and in a national organization webinar for community-based organizations. The film and photographs are available for viewing and further dissemination (available from: http://visionvoice.cinemedical.com).

Vision Health Tool Kit

To raise further awareness in the community about the themes expressed in their work, a Vision Health Toolkit entitled “Don’t Lose Sight of What’s Important” was developed by the IMPACT Vision Health Work Group, a diverse group of community and academic collaborators including a Certified Diabetes Educator/Nurse Practitioner, public health educators, vision experts, seniors, and Vision Voice participants. The tool kit aims to use existing social networks (i.e., local social service providers, clergy) to promote the importance of vision health and comprehensive eye examinations among their members, particularly for those with or at risk for diabetes and hypertension. Above all, Vision Voice participants wanted their narratives to serve as examples to others and to convey to people of all ages that vision loss and, as a result, the difficulties in doing the things you need and love to do in life can be prevented through early detection and treatment. Program staff listened and applied their concepts and ideas relying on two main theoretical approaches to health promotion, namely The Health Belief Model and Social Support.[23] Key messages and information included in the toolkit materials, particularly the brochure and comic strip poster, were selected based on elements of the Health Belief Model, which theorizes that an individual’s health-related behavior depends on his or her perception of 1) susceptibility to illness, 2) potential severity of illness, 3) benefits of taking preventative action, and 4) barriers of taking that action. Additionally, Social Support Theory underpinned our use of familiar social service agents in the community as providers of the important informational support presented in the tool kit materials.

In addition to social service and faith-based organizations, the tool kit was disseminated to local health care settings, where they used the tool kit materials to identify members with vision function problems and encourage or facilitate eye screening among members with diabetes. Anecdotally, we can report that two health care clinics, both with patient-centered medical home designations, created eye care patient navigation protocols for high-risk patients and used the tool kit educational materials in their intervention, showing the chain effect *Vision Voice* may have had on health care process redesign.

DISCUSSION

This project demonstrated the power of community–academic partnerships to elevate important health conversations, in which local community members educate health care providers about their lived realities, and researchers provide evidence-based information on the importance of regular, comprehensive eye screening and care for people with diabetes. The use of photovoice and film as components of a qualitative study has the potential not only to assess the needs of a community at risk,[13,14] but also to inform that community, [24,25] bring to life a health issue for health care providers, [11] and shape interventions that aim to increase rates of comprehensive eye screening in minority populations, such as the vision health tool kit.

Vision Voice provided a concrete visual depiction of people's experiences with vision loss and chronic illness, namely diabetes. The participants identified an overarching theme regarding their personal mobility and safety, expressing the need for more amply lit, accessible environments as well as increased social support. They depicted how loss of vision function can affect diabetes self-management skills, such as reading health information, cooking, walking, and taking medications—suggesting that more must be done to support people with vision loss who do not meet the legal criteria for blindness or low vision. Finally, this collection of photographs seems to have been useful in distinguishing the specific symptomatology of each participant's visual impairment.

The *Vision Voice* project incited engaged and activated participants to become change agents in their community. As one participant stated long after the study period had ended, *Vision Voice* connected her to the world, that she feels empowered to carry on the message, which is consistent with Carlson et al.'s "intention to act," a higher level of critical consciousness that involves a vision for future action.[15] Along with the Vision Health Tool Kit, the photography exhibit and film promoted community dialogue and inspired health care organizations to develop new patient care and educational interventions.[19] The study team hoped that the project would have more impact on the policy level, but the work thus far has not closely connected with elected officials and policymakers.

Another notable drawback of our study is the small sample size. In exchange for statistical data, photovoice studies such as *Vision Voice* are tasked with finding a group of participants who are willing to explore their experience—in this case diabetes and problems with vision function—photographically, and who are invested in creating change in their community. Other limitations are that the study sample lacks racial, ethnic and gender diversity, and that the study was conducted in English only. The team wishes to strategize recruitment of men, to ensure racial and ethnic diversity that is more representative of East Harlem, and to translate the photovoice protocol into Spanish for future iterations of this research method in East Harlem.

The study team and participants jointly proposed the following next steps and recommendations:

1. Showing the film to health care providers for medical education purposes.
2. Working with clinicians to create vision function screening protocols in primary care settings, and to improve care for patients with vision loss through ophthalmology screening and increased referral to low vision services.
3. Advocating among community leaders and elected officials for improved support for people with vision loss who do not meet criteria for blindness, but whose visual impairment still impacts their daily lives and their ability to manage chronic disease (e.g., larger print on medicine bottles, tactile insulin syringes, talking glucometers).
4. Promoting among elected officials the redesign of built environments to allow for passable sidewalks, audible crosswalk indicators, and other safety features.

When examining the subject of vision loss, and when properly adapted for visually impaired participants, photovoice can be a very powerful tool to educate and create awareness. We believe that the study findings suggest that this methodology is applicable to other multicultural urban communities dealing with similar health narratives. Results from this and future studies can identify needs and promote resources for communities affected by diabetes and vision loss. We look forward to a wider application of photovoice in local and national policymaking to incite larger scale community change.

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Figure 1.

I took this picture without glasses on the tram. At the time I took it, the cars looked blurred to me, and the camera was the second pair of eyes I didn't have. If I was that man, I'd be scared to cross the street. I have to make sure the light is red. I have to watch my step.

Figure 2.

I feel very self-conscious about my vision loss. Every day, when I do my makeup, I have to depend on someone else to tell me if it looks right. What used to be a simple routine is now a daily struggle.

Figure 3.

My mother, she was blind by the time we realized she was having problems … I want doctors to be aware that people [compensate for their vision loss] so they can treat the patients properly. People can be helped before they go blind.

Figure 4.

Sitting in the back of the car, I think of things I used to enjoy, like driving—that's no longer an option. Instead of driving, I'm now a passenger. When I look out the window, I want to capture everything, and I can't. It makes me feel like life is zooming past me.