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Understanding Patient Experience with Past Barriers to Eye Care and How Barriers were Addressed in the Michigan Screening and Intervention for Glaucoma and Eye Health through Telemedicine Program

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Abstract

Purpose: To use community engaged research to understand barriers to eye care utilization and explore participant experiences with free glaucoma screenings through the Michigan Screening and Intervention for Glaucoma and eye Health through Telemedicine (MI-SIGHT) program.

Design: Qualitative study

Subjects, Participants, and/or Controls: Purposive sampling of 42 participants out of 254 total participants from two community clinics in Flint and Ypsilanti, Michigan enrolled between 10/29/21 and 12/22/21.

Methods, Intervention, or Testing: We conducted semi-structured interviews that explored past barriers to eye care, motivations for attending and overall experience with the MI-SIGHT program. Interviews were transcribed then coded using Grounded Theory; and thematic analysis was completed.

Main Outcome Measures: Themes were compared between 1) the two clinics; 2) those who did and did not screen positive for glaucoma; and 3) of those who screened positive for glaucoma, comparing between those randomized to standard care and those randomized to personalized coaching and education.

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Results: The most common past barriers to eye care included cost, insurance status, and transportation. Motivations to attending glaucoma screenings with the MI-SIGHT program included affordability, location of community clinics, and having a trusted referral source endorse the program. Overall, participants most valued the rapport and communication received when interacting with the ophthalmic technicians who also acted as care navigators as part of MI-SIGHT.

Conclusions: The MI-SIGHT program was able to address barriers such as cost and transportation through having free eye screenings located at the community clinic. Developing trust and rapport with the participants and the community clinics was critical to the program's high satisfaction rates.

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Participants in the free clinic and Federally Qualified Health Center who enrolled in the Michigan Screening and Intervention for Glaucoma and Eye Health through Telemedicine Program highly valued the rapport and care navigation provided by the ophthalmic technicians in the program, the affordability of the glasses and eye disease screening, the location, as eye care was provided in community clinics, and the trust they had in the referral sources to the program.

Keywords

Community-engaged research; screening; glaucoma; barriers to eye care

Introduction

Access to quality eye care remains a critical issue for underserved populations, especially those at higher risk for conditions such as glaucoma. Glaucoma, a leading cause of irreversible blindness in the world, disproportionately affects Black Americans and those living with lower socio-economic status.¹ The prevalence of glaucoma in the United States is expected to grow from 3.1 million people to 4.2 million by 2030.^{2,3} Despite these serious health risks, many people in these high-risk communities face significant barriers to accessing eye care, as over 50% of people with glaucoma will remain undiagnosed and untreated using our current screening and detection programs.⁴ The National Academy of Science, Engineering & Medicine (NASEM) issued a call to action to address these barriers and improve eye health in underserved populations and address disparities to minimize vision loss in the United States.⁵ Since glaucoma is a leading cause of blindness in the United States, scientists and clinicians are centering attention towards improving glaucoma detection, diagnosis and care.

Community-engaged research (CER) provides an opportunity for understanding and addressing these barriers by directly involving communities in the research who have populations at high risk of disease. CER aims to bridge the gap between the research and the targeted population the research is intended to reach.⁶ By learning from community members how to best enhance their experience in glaucoma and eye disease screening, a CER framework can help tailor interventions to the unique needs and preferences of the community.

The Michigan Screening and Intervention for Glaucoma and Eye Health through Telemedicine (MI-SIGHT) program used the principles of CER to help design the program to address disparities in eye care access and outcomes. Currently, glaucoma screenings take place in eye doctors' offices when a person comes in for routine eye care. However, eye doctors' offices are often distant from the homes and trusted care providers of those who are uninsured and medically underserved. Navigating to a separate eye clinic away from trusted clinics can raise significant logistical, socioeconomic, and psychological barriers to accessing glaucoma screening. Telemedicine could enable specialty glaucoma screening programs to be available at trusted local primary care community clinics, making high-quality glaucoma screening much more accessible for populations at high risk of disease. The MI-SIGHT program integrates telemedicine into two trusted community clinics - a free clinic and a Federally Qualified Health Center - making glaucoma screening more accessible to populations that might otherwise face significant barriers to specialized care. Embedded within the MI-SIGHT program is a randomized controlled trial testing whether personalized coaching and care navigation compared to written education and care navigation improve recommended attendance at follow for those who screen positive for glaucoma.⁷

While the primary goal of the MI-SIGHT program is to improve glaucoma and eye disease detection, the focus of this paper is on the qualitative outcomes related to community engagement and identifying barriers to care. Specifically, this paper centers on the participant's experiences with the program and the broader impact of community-based interventions on care utilization. The study has three primary objectives: 1) to understand barriers to past eye care utilization and motivations for participating in the current eye disease detection program; 2) to assess participants' experiences with the MI-SIGHT program, and 3) to compare experiences of participants who screened positive for glaucoma/suspected glaucoma who were randomized to either receive personalized coaching and care navigation or receive standard written education and care navigation.

Methods

Study Sites

The Michigan Screening and Intervention for Glaucoma and Eye Health (MI-SIGHT) Program is provided with a partnership between the University of Michigan Kellogg Eye Center, the Hope Clinic, a free clinic in Ypsilanti, MI, and the Hamilton Clinic, a Federally Qualified Health Center (FQHC) in Flint, MI. The MI-SIGHT Program operates during regular clinic hours to increase the ease of scheduling and improve accessibility compared to other screening initiatives that come with mobile services but are only available for on limited dates. The Hope Clinic serves approximately 5,000 patients per year and the Hamilton Clinic serves approximately 25,000 patients per year. As a free clinic, the Hope Clinic serves a population that is under-insured and uninsured, while Hamilton Clinic primarily serves a population insured by Medicaid but also serves those without insurance.

MI-SIGHT Structure & Motivational Interviewing Coaching Program

At the two community clinics, the ophthalmic technician performs the ophthalmic testing and imaging and then transmits the data through the electronic medical record to the

readers (eye doctors at the University of Michigan).⁷ The readers interpret the testing and send recommendations for further care to the technician, who communicates the recommendations to the participant. The MI-SIGHT program offers low-cost glasses starting at \$12 for single vision lenses and \$30 for bifocals through a publicly available internet-based retailer ([ZenniOptical.com](https://www.zenni.com)). This service provides a tangible reason for people to participate in the glaucoma screening. If a participant requires further ocular health follow-up care, the MI-SIGHT program provides education and assistance with care navigation. Those who screen positive for glaucoma/glaucoma suspect are randomized to receive either standard written education and care navigation or personalized coaching and care navigation. The technician uses motivational interviewing and a tailored online educational program to identify barriers, provide education and evoke motivation to attend recommended glaucoma follow-up visits in the intervention arm. Motivational interviewing (MI) is a collaborative style of communication that guides people towards finding the intrinsic motivation to facilitate a behavior change and one of the first tenets of establishing an MI-based relationship is establishing rapport between the patient and provider.⁸ Technicians are trained in glaucoma-specific motivational interviewing and receive booster sessions.⁹

Study Population and Interview Process

Participants were recruited between 10/29/21 and 12/22/21, when a total of 254 participants were enrolled in the MI-SIGHT program study. When research assistants were available, consecutive participants were approached to assess their interest in completing a 20–30 minute semi-structured interview (Appendix A) and receiving an honorarium of \$20 following their MI-SIGHT program study visit. Only MI-SIGHT participants who spoke English were eligible to participate in the interviews and informed consent was obtained from all participants. The interviewer explored motivations to attend the MI-SIGHT appointment, barriers to past eye care use, and overall experience with the program. All interviews were audio recorded and transcribed verbatim the data gathered contained no identifiers; the study was approved by the University of Michigan Institutional Review Board.

To determine the sample size for the interviews, we followed the principle of thematic saturation in qualitative research, which suggests that thematic saturation, or the point at which no new ideas or themes are brought up by participants, is the point at which the research should conclude, and this has been found to be on average 9–17 interviews.¹⁰ The goal was to recruit enough participants for interviews to reach thematic saturation, which was reached after 13 participants. We continued enrolling participants until we had at least ten participants represented in each stratum to ensure that we could understand perspectives from participants from each of the following groups from both the free clinic and Federally Qualified Health Center (FQHC): (1) those who screened positive for glaucoma and were randomized to personalized coaching, 2) those who screened positive for glaucoma and were randomized to standard education, 3) those who had no evidence of glaucoma on screening (Figure 1).

Analysis

All interviews were transcribed verbatim and coded by two researchers using the principles of grounded theory, an inductive approach to extract themes.^{11–13} Grounded theory is a qualitative research methodology focused on deriving theories from the data collected. Rather than starting with a hypothesis, grounded theory begins with data collection and follows an iterative approach to discovering themes or relationships among concepts within the data to build theory.^{11–13} Researchers followed the step-wise approach of grounded theory: 1) familiarization, 2) open coding, 3) axial coding, 4) focused coding, and 5) theory building. Following the completion of all interviews, two coders (MS, EW) read through all transcripts to familiarize themselves with the content, and then took notes describing participants' experiences using open coding. A code book was generated as a larger research team using axial coding to identify and define recurring concepts from the semi-structured interviews. Then, working separately, the two coders (MS, EW), used the codebook to code the transcripts. A third party (PANC) was brought in to help resolve any inconsistencies between the coders when a consensus could not be reached. Once >80% agreement was achieved on >95% of the codes, the two coders re-analyzed and coded the remaining transcripts.¹⁴ The total number of times a given code was expressed and the number of patients who commented on them was tallied. Themes were qualitatively and quantitatively compared between participants at the two clinics, participants who did and did not screen positive for glaucoma/suspected glaucoma, and participants who were screened positive for glaucoma/suspected glaucoma and were randomized to either the intervention or control arm of the trial. The qualitative analysis was coded using Dedoose 8.3.17 (Los Angeles, CA).

Results

We approached and enrolled a total of 42 participants (100% participation rate). Of the 42 interviewed, 22 were from the free clinic and 20 were from the FQHC. We ultimately included 22 participants who screened negative for glaucoma, 20 participants who screened positive for glaucoma, and among those, 10 who had been randomized to personalized coaching and care navigation and 10 who had been randomized to standard education and care navigation (Figure 1). These sampling strata met the purposive sampling goals discussed in the methods. The median age of participants was 58.7 (range 27–90). Fifteen participants self-identified as male and 27 as female. 57.5% of participants identified as Black (n=23), 32.5% as White (n=13), 5% as Asian (n=2), 5% as other (n=2), and 3% identified as Hispanic or Latino. The demographic information is summarized in Table 1.

Thematic saturation was reached after analyzing thirteen of the forty-two interviews; at this point no new themes were identified from additional interview transcripts, but all were analyzed to ensure sufficient content in each sub-group. The kappa value for inter-rater reliability between the two coders was 0.87. The main themes that arose were rapport, overall program satisfaction, eyeglasses satisfaction, and communication. Each theme had both positive and negative valences with the coded text tallied by valence in Figure 3. Within previous barriers to accessing eye care and motivations for participating in the MI-SIGHT program, previous barriers and specific motivations were identified and these are tallied and visualized in Figure 2a and 2b.

Barriers to Accessing Eye Care Among a Medically Underserved Population

Cost: Cost was the most significant barrier that participants faced to receiving eye care; it was mentioned 32 times (n=22/42). Participants cited the high price of eyeglasses and lack of insurance coverage as the main cost-related barriers. One participant shared how the high prices even with insurance prevented them from wearing eyeglasses “I picked out one of the cheapest [eyeglasses] and it was still going to be like 200 and something dollars after the insurance scripted. So that’s why I didn’t.” A few participants cited financial concerns and loss of insurance coverage due to the COVID-19 pandemic as a barrier to care, and this was illustrated in the quote “Due to the whole pandemic thing, I lost my job that I had had for 21 years and including my insurance,” and “[s]ince COVID, my business was shut down and it is now bankrupt.” For some participants with insurance coverage, high copays for eye exams despite insurance hindered them from scheduling appointments. A participant commented on this when they said, “I went to my ophthalmologist ... and they said pay a \$60 fee. I am a low-income mom, low-income grandma, and a widow, and I didn’t have it.”

Schedule: Scheduling was mentioned 9 times as a barrier (n=8/42). Participants discussed difficulty scheduling around work and school and the inability to take days off due to financial constraints. One participant described their situation as “I could have probably gone to the VA, but I was just too busy... So every day I really didn’t take a day off. Yeah, I worked all the time because I was always playing catch up on bills or whatever.” Another participant shared their experience with work schedules as a barrier when they said “I think just having to make the schedule of working full time. That was the hardest part. I would kind of feel guilty taking time off of work and hours available.”

Treatment Avoidance: Treatment avoidance was mentioned 9 times as a barrier (n=7/42). Treatment avoidance was discussed as emotional factors that hindered a participant’s ability to receive care. Emotional factors included pride, fear, embarrassment, and guilt. One participant shared how they avoided scheduling appointments because “it’s really hard to accept help when you need it” with others speculating that people may avoid treatment because they “don’t want nobody to know that they don’t have any insurance or that type of thing ... their pride gets in their way.”

Remaining Barriers: Transportation was mentioned 6 times as a barrier to care (n=5/42). Participants discussed long distances from clinics and difficulty coordinating transportation with ride-share services and buses. One participant shared that it was often difficult for them to attend appointments on time with the free and reduced cost ride-share services available because “it was a little uncomfortable because I had to ride the YourRide. Sometimes it was early, and sometimes they would pick me up late.” Others using the same services would sometimes experience last minute ride cancellations that would prevent them from attending their appointments, as one participant said, “they might call a day before or two hours early and say they can’t give her a ride.” One participant shared how their lack of transportation was a barrier to obtaining eyeglasses when they said, “when we were able to get glasses at work, you’d have to go to a designated place... and if you didn’t have a car, you were just kind of screwed.” Childcare and elder care was mentioned 3 times (n=3/42) as a barrier to care. Participants mentioned family obligations and a lack of child or elder care as getting

in the way of attending their appointments. One participant shared their experience “I had to work ... I had to watch the kids. I couldn’t afford [childcare].”

Motivations to Participate in a Free Eye Disease Screening Program

All participants mentioned at least one motivator for participating in the MI-SIGHT Program (Figure 2b), including affordability, convenient location, trusted referral source, low cost and high quality of eyeglasses, accessibility in terms of the community clinic sites being on the bus lines, receiving a medical doctor’s review of their eye health, trust in the university, and personal issues with their eyes or their family’s eyes motivating them to seek care.

Affordability: Affordability was the most frequently mentioned motivation for participants coming to the MI-SIGHT program, as it was mentioned 67 times (n=29/42). Participants discussed that the free exam allowed them to receive care that they might not have received otherwise. This sentiment is reflected in the quotes “I’m unemployed and have no income, it was a great opportunity for me to get my eyes checked” and “It’s free and it’s an excellent exam, thorough... Cause I know people who don’t have, you know, they can’t afford to get their eyes checked.” Many participants acknowledged the absence of a copay as a motivator to seek out care they needed, with one participant sharing that “I was excited because I wasn’t intimidated by a lot of money, prices and I was happy, eager to get my eyes checked.”

Location: The location of the two community clinics played an important factor, as it was mentioned as a motivation 54 times (n=36/42). Participants commented on the close proximity of the clinics and access to bus routes as motivations, with some sharing that “[Hamilton] was right up the street from my house” and “I can walk or have a friend drive me.” One participant shared, “even if you don’t have a vehicle, [Hope Clinic] is right on the bus route so it drops you off right in front there.” The location of the clinics provided participants with multiple transportation options to help ease any transportation barriers, with someone stating that the community clinic was “a lot more convenient. And you know, I could get a neighbor to take me down to Hamilton” instead of using the ride-share services they had used to get to other appointments. Another participant discussed the importance of the clinic location when scheduling their appointments as they said, “I had been to other eye doctors ... But like I said, this was right in my neighborhood so I was even more interested.”

Trusted Referral Sources: Trusted referral sources to the program were mentioned 47 times as a motivation (n=39/42). These referral sources mostly included family or friend recommendations. Word of mouth was how one participant discovered the program, as they said “[My wife] told me about [the MI-SIGHT program], that her cousin told her about it, that her friend told her about it. So, I’m telling other people about it.” Some participants discovered the program through their doctor or another staff member at the clinic, while others found advertisements such as flyers through trusted sources. A participant shared that “If it wasn’t for [Hope Clinic] calling me up to help me make the appointment I don’t think I would have like ended up here.”

Eyeglasses: Affordable eyeglasses were discussed as a motivation 42 times (n=24/42). Many participants commented on the high price of eyeglasses and mentioned how they

had been going without wearing glasses even though they needed them. For example, one participant expressed “I was driving around with no lenses in my glasses ... I mean, I had to. I had no money to buy glasses” and another “I just went without [glasses] because I couldn’t afford it.” Because of the low-cost of the eyeglasses offered through MI-SIGHT, another participant shared that the program “allows someone who has no income to be able to go get glasses.”

Eye Health: Eye health as a motivation was discussed in two contexts 55 times total: eye health problems or eye health prevention (n=34/42). Participants expressed how personal and/or family eye health affected their motivation to seek out care. Participants mentioned how they were motivated to seek out glaucoma care due to personal problems with their eyesight and symptoms of other eye diseases. One participant shared “I started having problems where I wouldn’t see stuff then would trip over it. My peripheral side vision was bad. I stopped driving because I was afraid I would have a bad accident because I just wouldn’t see stuff coming from the sides.” Other participants mentioned how a family member’s experience with glaucoma or other eye disease motivated them to seek out glaucoma care in the hope of preventing future problems. One patient recounted “I have relatives who have glaucoma and because of my grandmother and my uncle, both went blind ... so I was interested in getting on top of everything before it became a crisis.”

Remaining Motivations

Accessibility of the program was mentioned 35 times (n=18/42). Participants commented on the ease of scheduling and appointment availability, with one participant sharing how much they appreciated scheduling an appointment “within a week or two [...] you know, it wasn’t 30 days or two months out.” Furthermore, program inclusivity proved to be a motivating factor for many. One participant shared that the program is accessible to all, “It doesn’t matter where you work, if you have insurance, if you don’t have insurance” while also commenting that when “people don’t have insurance, so they don’t get their eyes checked or done.”

Telemedicine/MD review was mentioned 31 times as a motivation (n=28/42). Participants discussed feeling comfortable with receiving their eye exam and results from the technician, and knowing a doctor was reviewing their exams remotely. This was illustrated when one participant said “I think because the doctors going to look over the information to make sure everything is what was said. So I felt comfortable.”

Affiliations with the community clinics and the University of Michigan Kellogg Eye Center were identified 31 times as motivations (n=16/42). Participants felt comfortable with the community clinics, as they were established in their neighborhood as “community oriented” and “good local facilities.” Trust with the University of Michigan and the Kellogg Eye Center was reflected in the quotes “you guys are associated with the university and I mean, I figured I would get the best care” and “with Kellogg being involved, I knew it was going to be top notch.”

Experience with the MI-SIGHT Program

Rapport: Rapport was mentioned by all 42 participants, a total of 117 times, with 113 mentions displaying positive feedback (Figure 3). Participants discussed how the staff's professional, patient, and friendly demeanor elevated their experience with the program. One participant shared how important it was for them that the technician "treated [me] like a person." During the study visit, participants valued how much the technicians seemed to enjoy their role, as one mentioned "I like that she likes what she's doing, and it shows by how much she cared" and another stated that "he was great at his job, and it was pretty obvious that, you know, he cared." The observed job satisfaction of the technicians made participants feel more comfortable and satisfied with the care they were receiving. Overall, the positive rapport from the study staff was paramount in program satisfaction as was reflected through a participant's statement, "Like, that's why I wanted to come back and do it because you guys are so nice."

Communication: Communication was mentioned by most participants (n=35/42) a total of 66 times. Participants commented on how they valued how patient the technicians were while explaining the details of the exam and results, as they were used to being rushed during medical appointments. Others shared that the clear communication lacking medical jargon was "how [medical explanations] should be. So people can understand it." A few others cited and appreciated the technician's openness to questions because "I think sometimes people get a little intimidated with doctors and they just don't really want to ask questions ... but I was very comfortable with her and she was good."

Eyeglasses Satisfaction: Satisfaction with eyeglasses was mentioned by most participants (n=35/42) a total of 81 times. One participant stated that they were "100 percent satisfied with the quality and style" of their eyeglasses, and they were "definitely worth it. Best 65 bucks I've spent." Participants expressed their satisfaction with the different options, styles, and colors that were offered through the program, with one participant remarking "feels like I spent a lot of money on something that I spent hardly nothing on because of the University of Michigan."

Differences in Experience between Participants who Received Personalized Coaching and Care Navigation vs Standard Written Education and Care

Navigation: Participants who screened positive for glaucoma and received personalized coaching more frequently cited satisfaction with rapport (38 times vs. 24 times), a positive experience with communication (25 times vs. 17 times), and a positive experience with glaucoma education (24 times vs. 15 times), in comparison to the standard education received (Figure 4a and 4b). When asked how well they understood glaucoma, one participant said that they felt "Really confident ... a ten [out of ten]" after receiving the personalized coaching program. Another mentioned that the most emotionally motivating and salient aspect of the coaching program was the visual aid depicting what the world would look like with glaucomatous vision loss over time saying "Giv[ing] them something to be weary of, you know, particularly if the intent of neglect, you know, treating it... I think a lot of us respond to [visual representation] or when we can see the visual changes." Participants who were randomized to the personalized coaching program mentioned how

they felt that the technicians put them at ease and made them feel comfortable. One participant discussed how the coaching program and the technician eased some of their anxieties about receiving the diagnosis, when they said “It was scary to hear that. Cause I ain’t know what it was. But she explained everything to me.”

Program Suggestions: Participants provided feedback and suggestions during the interviews to improve the program. Participants mentioned wanting more colors and styles added to the collection of eyeglasses available to try on at the clinic, and so additional styles were added to the physical selection available. Participants appreciated being able to physically see and try on the frames instead of just looking online. Many of the participants were older and found it more difficult to navigate online.

Discussion:

Overall, using community-engaged research methods and involving clinic staff, physicians, administrators and patients in creating the MI-SIGHT Program¹⁵ was effective in creating a program that addressed many of the barriers people reported to utilizing eye care in the past. People reported barriers to accessing eye care (prior to their participation in the MI-SIGHT program) that included the high cost of eye care including costs for the appointment and for glasses, a lack of insurance to offset these costs, having difficulty taking off work to attend an appointment, needing to take care of children or elders, having difficulty accessing reliable transportation and not being aware that people should be screened for eye disease as they age. The barriers the MI-SIGHT program was able to address were 1) cost, as the screening program was free and offered low-cost glasses; 2) transportation as the program was located in easily accessible neighborhood locations along bus lines; 3) more accessible appointment times as they were offered whenever the medical clinic was open as opposed to on just select dates when a mobile screening program was in town; and 4) trust, as people had trust both in the university and in their community clinic. An important motivator for people to engage in the program was hearing about the program through word-of-mouth. After participating, members of the community trusted the MI-SIGHT program and in turn, referred their family and friends. Every participant interviewed expressed how the rapport and communication between the ophthalmic technician in the clinic and participants was excellent and that this rapport was an important engagement tool. Participants were very satisfied with their eyeglasses – with the style, the function, and the price. This satisfaction with how they were treated and how the glasses fit led participants to tell their friends and family about the program and this engendered more trust in the program.

Participants experienced many barriers to utilizing eye care prior to the MI-SIGHT program, with cost as the most significant barrier. Many were uncertain about whether their medical insurance covered vision and eye health-related expenses. Historically, the lack of insurance coverage and high costs, even for those with insurance, have been identified as obstacles to using eye care services and correcting refractive error with eyeglasses.^{16,17} The MI-SIGHT program addressed these barriers by providing affordable and accessible eye care, including free eye disease screenings and low-cost eyeglasses. A participant in the program emphasized that individuals without insurance just don’t get their eyes checked, even with chronic conditions like glaucoma or diabetes, and another said, “if this program didn’t exist,

I wouldn't know what my eye health looked like." Lipton and colleagues have shown that those with Medicaid who have vision coverage for eyeglasses were 17% more likely to have seen an eye doctor in the past year and 35% less likely to have a functional limitation due to vision compared to those without insurance coverage for eyeglasses.¹⁸ In the landmark study by RAND randomizing participants to a cost-sharing insurance plan vs. a free services insurance plan, participants with low income who were randomized to the cost-sharing group were less likely to utilize appropriate medical care when compared to the free services insurance plan group.¹⁹ Appropriate utilization of vision and eye care services would be enabled if vision care, including eyeglasses and eye disease screening exams, was part of covered care through standard medical insurance plans instead of having these benefits siloed off into vision insurance plans. That strategy has the potential to mitigate adverse health outcomes associated with poor visual acuity.²⁰

Transportation was a significant barrier to utilizing eye care. In prior work, 34.8% of patients included in a study at the free clinic reported that transportation was the reason they missed their free eye care appointment.²¹ Nearly one-quarter (24.0%) of counties in the United States do not have an ophthalmologist or optometrist, so it is somewhat common for people to travel long distances for eye care.²² Additionally, limited reliable public transportation can heighten the effects of this barrier, a known barrier in the state of Michigan, where MI-SIGHT took place. Though Detroit, the state's largest city and metro area, used to have one of the most robust streetcar public transit systems, it was dismantled in 1956 for a number of reasons, including a suburban design focused on automobiles and highways and decreased federal and state funding for public transportation.²³ In one community in Minnesota that added a new rail line to a clinic, the probability of outpatient clinic non-attendance dropped by 4.5% overall, from 11.1% to 6.6%, and dropped by 9.5% among patients insured by Medicaid, from 16.9% to 7.4% compared to the time period before the rail line was available.²⁴ In a clinic in Texas, covering patient bus fare and providing a shuttle bus from the bus station to the clinic decreased clinic non-attendance from 37% to 20%.²⁵ These studies demonstrate the power of investment in public infrastructure on public health outcomes. MI-SIGHT participants cited the convenience of the program as an important facilitator for participation, as both clinic locations were on the neighborhood bus route.

It is a common misconception that people do not utilize eye care because they do not care about their eye health or do not take their eye health seriously. When people do not seek medical care until they notice symptoms, healthcare providers comment, at times, that the person did not come to seek care soon enough. Among the MI-SIGHT participants, no one mentioned not valuing their vision as a barrier to utilizing eye care. On the contrary, some participants mentioned their motivation to receive eye health screening was due to watching a friend or family member lose vision. One participant said "[y]ou know, I have concerns because I have relatives who have glaucoma and because of my grandmother and my uncle. Both went blind." Participants' emotional drivers for avoiding treatment were centered around the stigma of not having insurance or the stigma of needing to ask for help, a known barrier also for receiving timely medical care in low-income families.²⁶ Allen and colleagues found that among people with low-income, insurance status can confer additional stigma, and that people reported feeling this stigma from their interactions with

the provider.²⁷ Research has shown that if patients feel as if they are disrespected by their physician, they are more likely to delay obtaining medical care and less likely to follow advice.^{28,29} Establishing rapport can help counter some of the concern around the stigma of not having insurance and build trust with the health care team.

The importance of building rapport and using effective communication in each participant encounter in the MI-SIGHT program must be underscored. The most widely cited themes from all participants interviewed were rapport and communication. When asked if they would return for another eye exam through MI-SIGHT in a year, one participant said, “The [technician] is very kind, like warm person in general... that’s the kind of person you would want to go see at a doctor’s office.” Rapport, empathy, and good communication from the provider lay the foundation for patients to share their medical problems easily and to be further engaged with their care, while dismissive behaviors from providers can often leave a patient feeling anxious.^{30,31} Clear communication by the technicians in MI-SIGHT fostered a more comprehensive understanding of the patient’s condition, as one participant mentioned, “[The technician] takes her time. She breaks it down. If something doesn’t, you don’t understand, she will tell you in a way that you do understand, and she makes sure that you understand whatever it was that you didn’t understand.” A study spanning 11 countries surveyed patients on their health care experiences and found that the most engaged patients self-reported better quality healthcare, decreased rates of medical errors, and increased satisfaction with the health system.³² Participants who were randomized to receiving motivational interviewing-based coaching compared to those who received standard education cited more instances of rapport with the counselor (38 times vs 24 times) and more instances of positive experiences with glaucoma education (24 times vs 15 times). The quantitative analysis is underway on whether the MI-based coaching improved adherence to follow-up visit attendance compared to standard education, but the qualitative analysis demonstrates the importance of building rapport and facilitating intrinsic motivation in improving people’s experience with health education. Building rapport and using clear clinical communication are critical facilitators in improving engagement in healthcare. Developing a trusting relationship with both individual participants during a clinic visit and within the surrounding community is essential when establishing a new screening program like MI-SIGHT, especially in a community with high rates of poverty whose members may not have had positive experiences with health care providers in the past.

One limitation of this study was that participants were given a \$20 incentive to take part in the interviews, and this may have influenced their willingness to share negative feedback about the MI-SIGHT program with the researchers as the incentive may have influenced their desire to please the researchers. However, the \$20 incentive payment also yielded 100% participation from all subjects approached, limiting non-response bias. Additionally, satisfaction scores were very high for the entire cohort where 97.7% of MI-SIGHT participants reported being either satisfied or very satisfied with the program; the high expressions of satisfaction among the participants included in the qualitative analysis appear to be representative of the entire sample. Furthermore, the interviews were conducted between October 2021 and December 2021, during the ongoing COVID-19 pandemic. The pandemic brought upon clinic closures, social distancing, massive layoffs, and social isolation.³³ While the impact of COVID-19 was not an aim of the interviews,

we acknowledge that the pandemic may have shaped participants' recent attitudes and experiences within the healthcare system.

The strengths of this assessment include the purposive sampling of the first 42 participants in the two-month window during which interviews were conducted who met inclusion criteria – representation from both clinical sites, from those who did and did not have glaucoma, and from those who did and did not participate in the personalized education and glaucoma coaching program. Additionally, the study design – semi-structured interviews – was a strength as qualitative research delves into the “hows?” and the “whys?” of a participant's subjective experience and gives context to the complex sociocultural factors affecting health behavior. For example, this study gives a much richer and more nuanced understanding of what a 97% program satisfaction rate means.^{34,35}

Using community-engaged research to develop an eye health screening and treatment program resulted in high levels of program engagement and program satisfaction. Being able to address previous barriers to eye care utilization such as being able to develop rapport and trust with participants was crucial to program satisfaction and the resulting word-of-mouth that bolstered community participation. Understanding the nuanced experiences of participants in a novel screening program like MI-SIGHT is useful to assess the program's future sustainability in terms of continued patient engagement.

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Declaration of interests

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Appendix A:

Screening and Intervention for Glaucoma and eye Health through Telemedicine

(SIGHT) Post Program Interview Guide

Instruction to begin the interview

Introduce yourself to the participant

Review with the participant

- The purpose of the interview is to discuss how they feel the SIGHT program components are helpful/unhelpful and areas for improvement.

- The interview will take up to 30 minutes.
 - That participation is completely voluntary, confidential, and can be stopped at any time.
 - That we would like to record the interview so that we are sure to capture their words accurately but that all recordings and transcripts will remain confidential to the best of our ability. Indicate that recording the interview is not required and that they can opt out of being recorded. The only people who will have access to any identifiable data will be those on the project who have a need to access it. The recording will be destroyed following the completion of this project.
 - We plan to use the information from these interviews to help improve our program.
 - That they will receive a \$20.00 dollar Visa gift today (if in-person) or we can mail them a check (in-person, telephone or Zoom). The mailed check will take up to 2 weeks to reach their home.
 - Ask the participant if they have any questions.
1. How did you hear about the SIGHT Program?
 2. What motivated you to come to get your eyes checked today?
 - a. Some people say it was the low cost glasses, or concern for their vision and eyes, or they were interested in the research findings, or they trusted the person/friend who referred them – do any of these apply to you or maybe there were other reasons you chose to come to get your eyes checked today?
 3. What was it like to come to [Hope/Hamilton] for glasses and eye health screening?
 4. What things have gotten in the way of getting your eyes checked in the past?
 5. What if anything did the SIGHT program do to make it easier to get your eyes checked?
 6. What was it like to work with the eye care providers [technicians]?
 7. How was it to learn about your screening results from [technicians] instead of directly from a doctor?
 8. How, if at all, did the conversation with the counselor help you to think about caring for your eyes?
 9. If it was recommended that you follow up with an eye doctor, were you able to do so? Why or why not?
 10. What if anything did the SIGHT program do to make it easier to get the appointment or get to the appointment?
 11. How, if at all, could the SIGHT program have been more helpful in supporting you to get to an eye doctor appointment?

12. What did you think about the eyeglass frame selection?
 - a. What did you think about the styles? The cost? The fit?
13. Have you referred any friends or family to the SIGHT program? Why or why not?
14. What feedback, if any, do you have for us on how we could improve the SIGHT program in the future?
15. What feedback, if any, do you have for how we could promote the SIGHT program better in the community?
16. Would you be willing to return for a follow up exam next year through the SIGHT Program? Why/why not?
17. Is there anything else that I missed that you think we should know about your experience participating in the SIGHT program?

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Highlights:

- Participants in a free glaucoma screening program in a community clinic identified cost and issues with transportation as impediments to utilizing eye care
- Motivations to attending the free MI-SIGHT glaucoma and eye disease screening program included affordability, location within the community clinic, and a trusted referral source
- Positive rapport with the program staff was mentioned by every participant and was a critical facilitator both in participants referring their friends and family to the program and overall satisfaction with the program

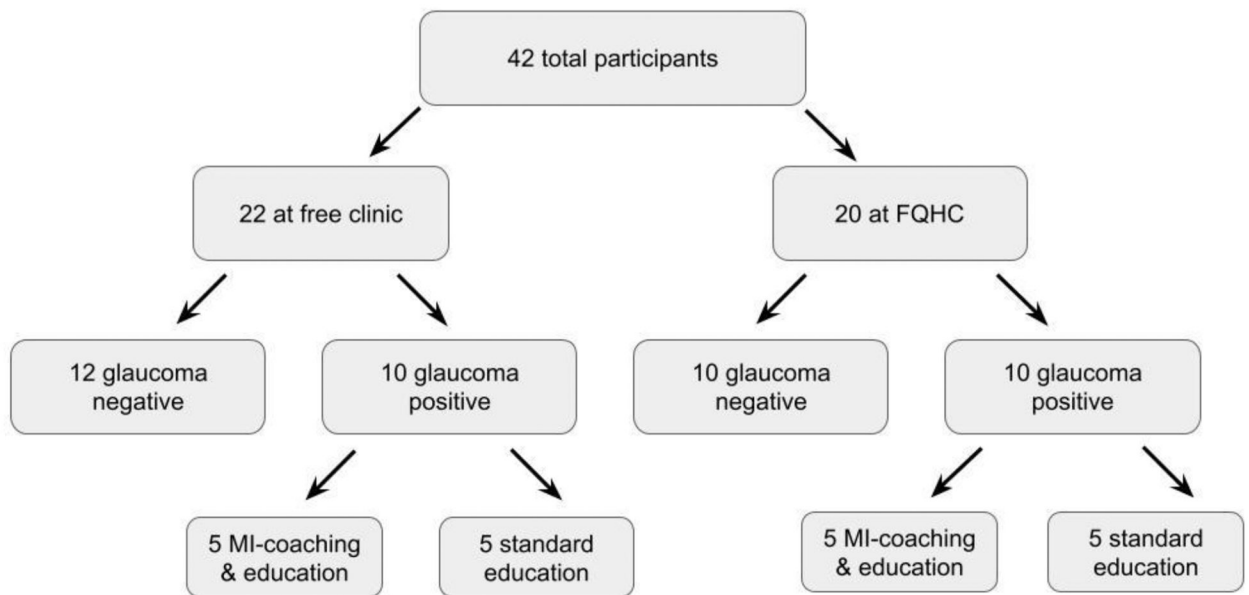


Figure 1.
Participant Recruitment

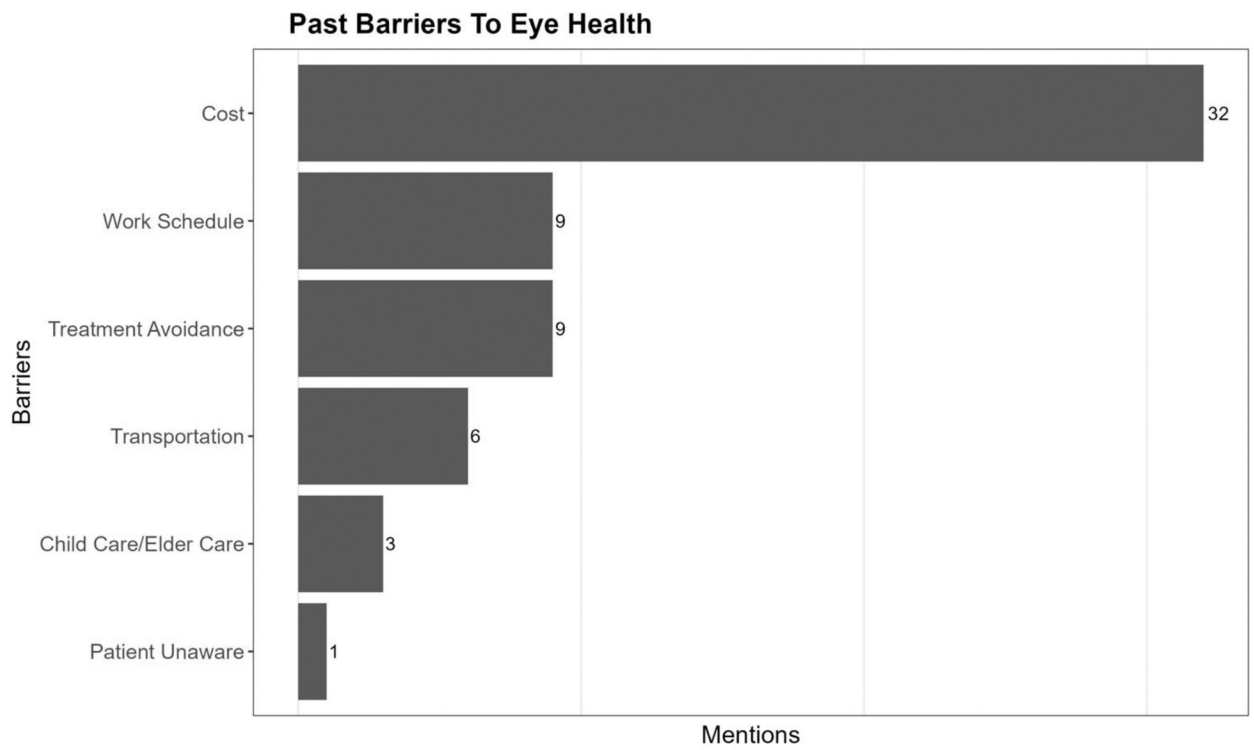


Figure 2a.

Bar graphs showing the number of representative mentions per theme when discussed as a barrier

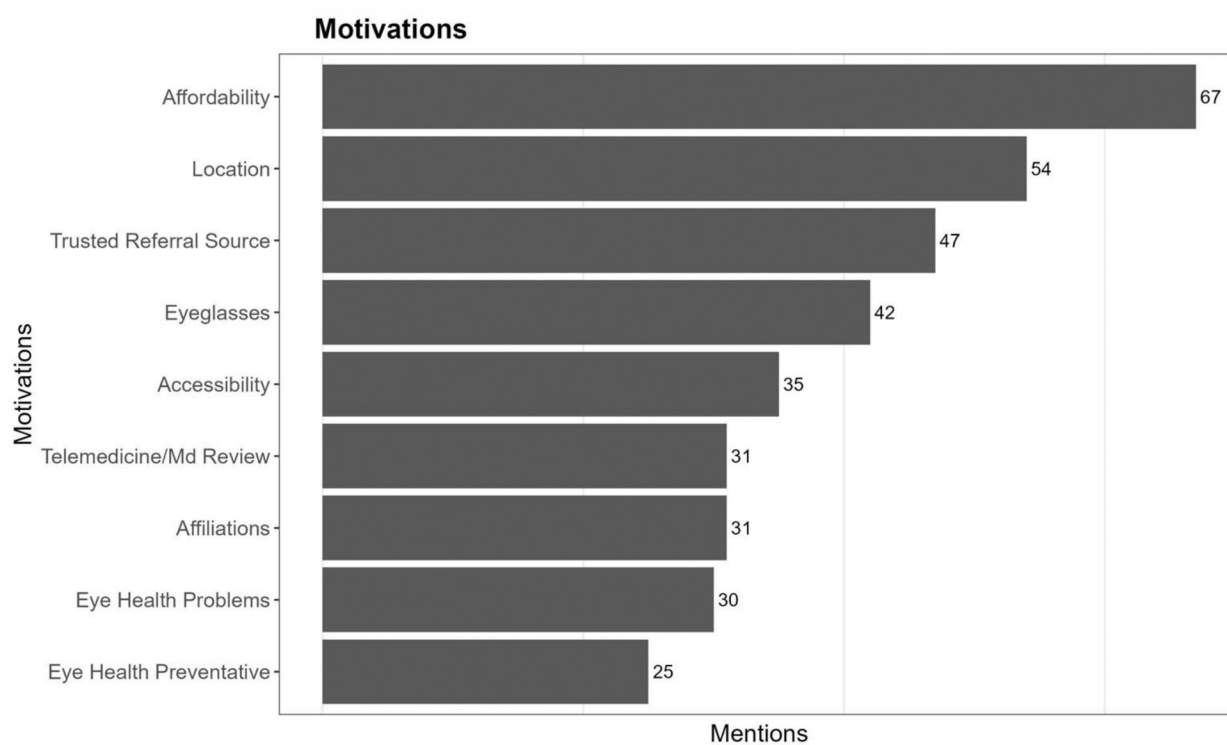


Figure 2b.

Bar graphs showing the number of representative mentions per theme when discussed as a motivation

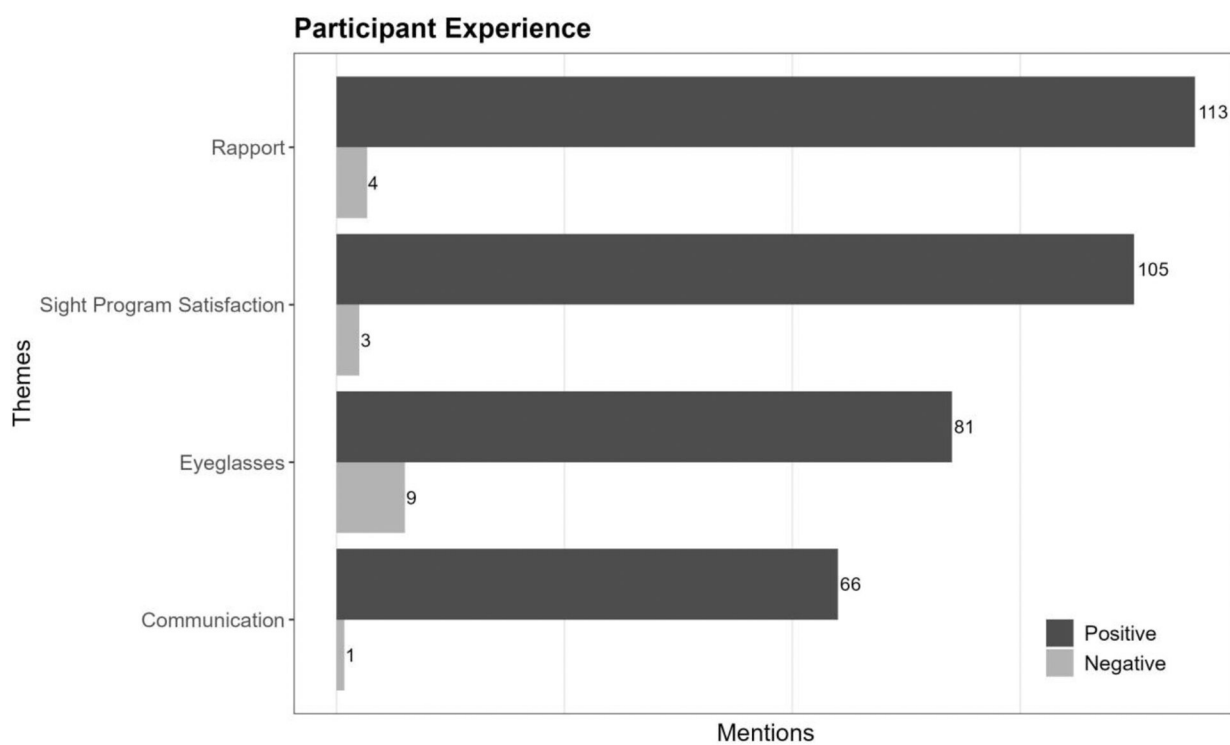
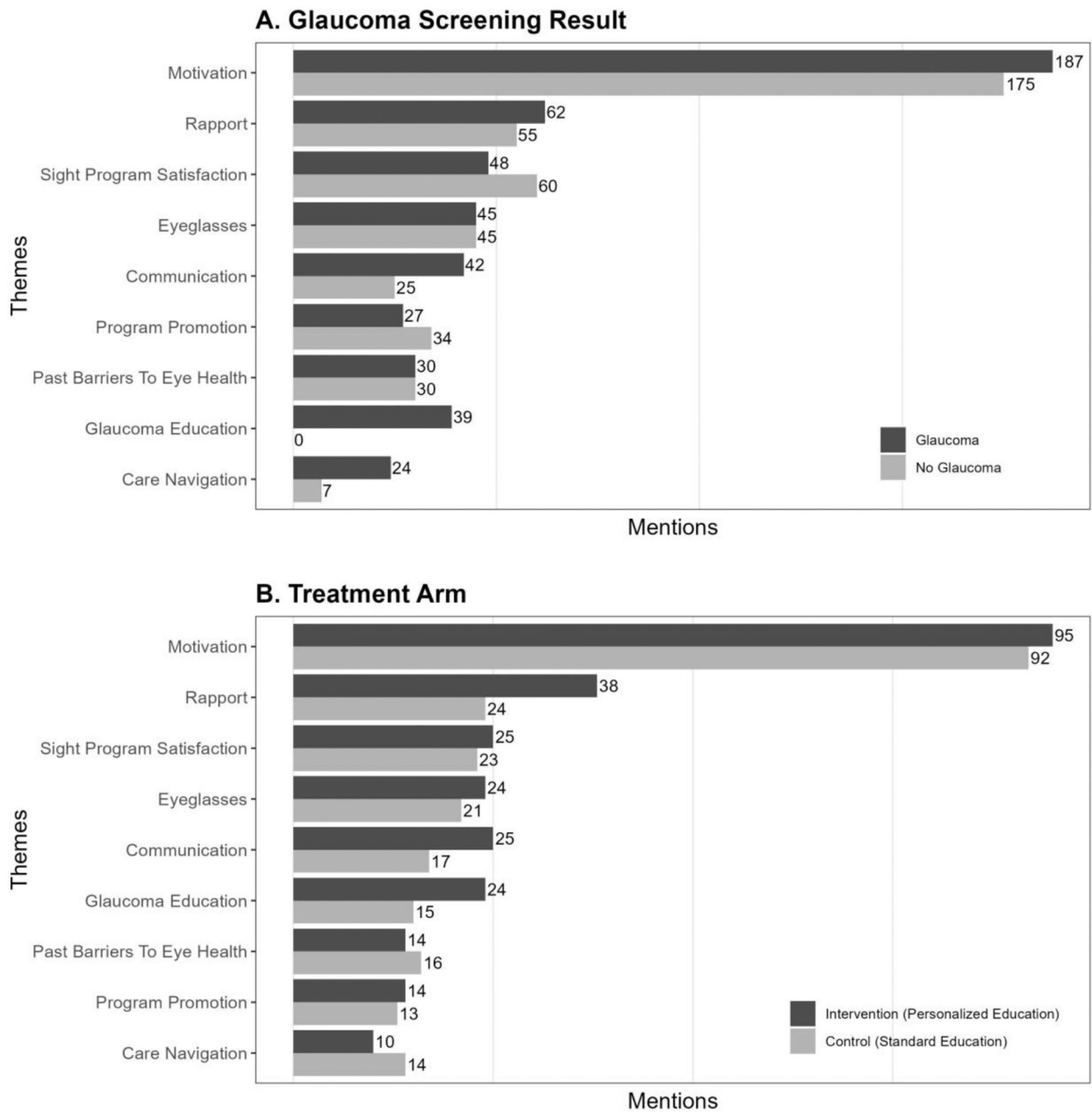


Figure 3.
Bar graph showing the number of representative mentions per positive and negative valences of major themes

**Figure 4.**

a. Bar graph showing the number of representative mentions per theme between the groups who screened positive and negative for glaucoma

b. Bar graph showing the number of representative mentions per theme between the intervention (standard education) and control groups (personalized education and coaching) for the participants who screened positive for glaucoma

Table 1.

Participant Characteristics (n=42)

Continuous Variable	Mean (SD)	Min, Max
Age (years)	58.7 (14.9)	27.3, 90.1
Categorical Variable	Frequency (%)	
Screening Result for Glaucoma		
Positive	20 (47.6)	
Negative	22 (52.4)	
Treatment Arm		
Control (Standard Education)	10 (50.0)	
Intervention (Personalized Education)	10 (50.0)	
Gender		
Male	15 (35.7)	
Female	27 (64.3)	
Ethnicity		
Hispanic	1 (3.0)	
Non-Hispanic	32 (97.0)	
Race		
White	13 (32.5)	
Black	23 (57.5)	
Asian	2 (5.0)	
Other	2 (5.0)	
Education		
<HS	3 (7.3)	
HS	5 (12.2)	
Some College	20 (48.8)	
College Degree	7 (17.1)	
Grad Degree	6 (14.6)	
Income		
<\$10k	9 (26.5)	
\$10k–\$19,999	10 (29.4)	
\$20k–\$29,999	7 (20.6)	
\$30k–\$49,999	2 (5.9)	
\$50k–\$69,000	1 (2.9)	
\$70k+	5 (14.7)	
Medical Insurance		
No	7 (16.7)	
Yes	35 (83.3)	
Dilated eye exam		
≤ 2 years	17 (54.8)	
> 2 years	14 (45.2)	

Note: percentages are reported on the non-missing sample SD, standard deviation. HS, high school. K, thousands of dollars.