

# Diabetic Retinopathy in Underserved Communities: The SoloKiko Program

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## ABSTRACT

Despite major improvements in detection and treatment, diabetic retinopathy is a sight threatening disease which affects underserved communities disproportionately. Minority populations are particularly vulnerable to complications of diabetes, which can be prevented with early lifestyle changes. Oftentimes, there are also cultural and linguistic barriers that delay health-related diagnoses and treatment. This makes sufficient medical education of patients and healthcare providers a potentially effective solution. The SoloKiko program addresses these issues through a culturally competent and sensitive medical educational system about poor lifestyle choices and their outcomes.

This study analyzes the effectiveness of the SoloKiko symposia in educating healthcare providers and community members about DR. No children or members of vulnerable populations were included in the survey. There were 289 adult respondents across four symposia, of whom 47.1% were healthcare providers, and 52.9% were community members. Of the healthcare providers and community members, 80.15% and 62.09% identified as bilingual respectively. These symposia resulted in improvements in the general understanding of DR and its treatment of 94.77% of healthcare providers as compared to 99.35% of community members. The symposia resulted in improved understanding of the importance of addressing healthcare barriers in 94.12% of healthcare professionals and 96.73% of community members. The symposia were equally effective for both bilingual and monolingual members of both groups. Of the six core components of the SoloKiko educational platform, teaching with the language and cultural needs, the use of pictures and storytelling to bridge cultural and linguistic barriers, and using connections with the family experiences appeared most important to both community members and healthcare providers that were either bilingual or monolingual. These are principles that can be used to bridge healthcare interactions between healthcare providers and community members to improve health outcomes.

## 1. Introduction

Type 2 diabetes has been found to be more prevalent in the United States among racial/ethnic minorities, with an incidence of 8.0-15.1%, as compared to 7.4% in Caucasians.<sup>1</sup> Diabetic retinopathy is a significant potentially blinding complication of diabetes.<sup>9-12</sup> There are two primary forms of diabetic retinopathy. The first is nonproliferative diabetic or exudative retinopathy, which can result in macular edema, or edema of the retina. The second form of diabetic retinopathy is associated with neovascularization of the retina secondary to ischemia from chronic damage to retinal vasculature, resulting in intraocular bleeding and scarring. Health outcomes of diabetic retinopathy can be improved significantly with adequate control of diabetes, early detection, and early care. The use of laser treatment and anti-VEGF agents have significantly improved treatment of both types of diabetic retinopathy.<sup>2-4</sup> If untreated, diabetic retinopathy can progress to diabetic macular edema, which can significantly damage vision. Poor visual acuity secondary to untreated diabetic retinopathy is suggested to occur at higher rates in medically underserved communities. Studies have shown that

both diabetic retinopathy and macular edema is significantly higher in Black Americans (36.7% and 11.1%) and Hispanics (37.4% and 10.7%) compared to that of Caucasians (24.8% and 2.7%) and Asians (25.7% and 8.9%).<sup>5</sup> Furthermore, diabetic retinopathy is often underdiagnosed by healthcare professionals and referral to sight saving treatment is often delayed. Diabetic macular edema is presently underdiagnosed approximately 35% of the time.<sup>8</sup> Diabetic macular retinopathy is also frequently associated with systemic complications such cardiovascular, cerebrovascular, peripheral vascular disease, and renal disease.<sup>9-12</sup> In order to prevent systemic complications, novel medical interventions are needed to effectively prevent and treat this diagnosis.

In 2010, The National Diabetes Prevention Program was created to address the increase of prediabetes and type 2 diabetes in the United States and reduce its complications. One feature of this program was the Center for Disease Control Lifestyle Change Program, which suggested that people with prediabetes who take part in a structured lifestyle change program can cut their risk of developing type 2 diabetes by 58%.<sup>7</sup> While lifestyle changes can significantly decrease type 2 diabetes related complications, making these changes can prove difficult for many underserved communities given significant cultural, linguistic, economic and access barriers to healthcare.<sup>16-20</sup> One medical intervention to address cultural and linguistic barriers to healthcare may be through patient education.

The SoloKiko Program was established to empower underserved communities with the medical education needed to improve health outcomes of diseases such as diabetic retinopathy. A main part of the program was to promote healthy lifestyle changes by incorporating social structure, culture, and language needs into the learning process. In order to address health barriers these communities face, the SoloKiko educational platform was built around six key core components. Furthermore, its learning platform was also designed to improve awareness in the healthcare workforce serving these communities and to improve detection and treatment.

We report on the results of four symposia given to community members and healthcare providers between December 2022 and April 2023. This research received IRB approval from the California Northstate College of Medicine and was supported by a Health Equity Regional Symposia Sponsorship through Genentech.

## **2. Materials & Methods**

### *Study Design*

This study surveyed healthcare and community members with the aim to assess responses to the symposium, “Diabetic Retinopathy in Underserved Bilingual Communities”. The study utilized a questionnaire to assess responses to and gather individual reflections on the topics addressed in the symposium. The study followed a cross-sectional survey design and sampled populations from the community and healthcare providers.

### *Materials*

The survey was conducted across four symposia supported by a Health Equity Regional Symposia from Genentech. Participants engaged in a symposium before completing the questionnaire. Each symposium consisted of a series of talks given in partnership with SoloKiko Program, a non-profit 501(c)(3) organization committed to health education in bilingual communities historically underserved in healthcare. SoloKiko operates off of the principles of: empowering students and their families through health prevention and education, developing bilingual age-appropriate educational material for students and their families, and promoting health education in underserved communities by partnering with leaders and families.

Upon completing the symposium, participants filled out a questionnaire designed to investigate responses to the topics addressed. Participants were grouped as either healthcare providers or community members. Next, participants were asked to rate the information presented in the symposium on a 4-point Likert scale (‘Excellent’, ‘Good’, ‘Fair’, ‘Poor’). The next question asked whether the information improved the participant’s understanding of diabetic retinopathy and the possible treatments in underserved communities, with answer choices on a 3-point Likert scale (‘Improved Significantly’, ‘Improved’, ‘Did Not Improve’). The following question asked whether the information improved the participant’s understanding of the importance of addressing cultural and linguistic barriers in underserved communities, with answer choices on a 3-point Likert scale (‘Improved Significantly’, ‘Improved’, ‘Did Not Improve’). The following question provided five answer choices to a question asking what the participant believed to be the two most important

aspects of bilingual medical education. The possible selections were listed as follows: “Teach using appropriate language and cultural needs”, “Teach using connections with the family experiences”, “Use bilingual open-ended questions to make the family nucleus think”, “Use of pictures and storytelling to bridge cultural and linguistic barriers”, “Expand vocabulary with repetition and emphasizing words”. The final question asked if the participant spoke more than one language, with the option to select either “Yes” or “No”.

*Data Collection & Analysis*

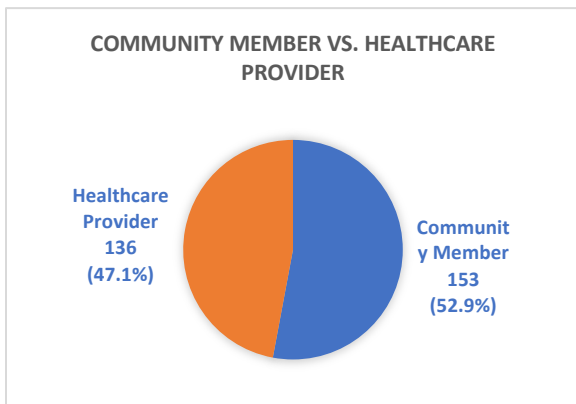
No identifiable information was collected from participants of the survey. From December 5, 2022, to April 30, 2023, a total of 289 questionnaires were filled out completely and submitted for analysis. The data from completed questionnaires was immediately filed into spreadsheets designed to organize data collection. A chi-squared test was used to examine the distribution of responses based on the different variables: self-identification (healthcare provider or community member) and bilingual or monolingual participants.

**3. Results**

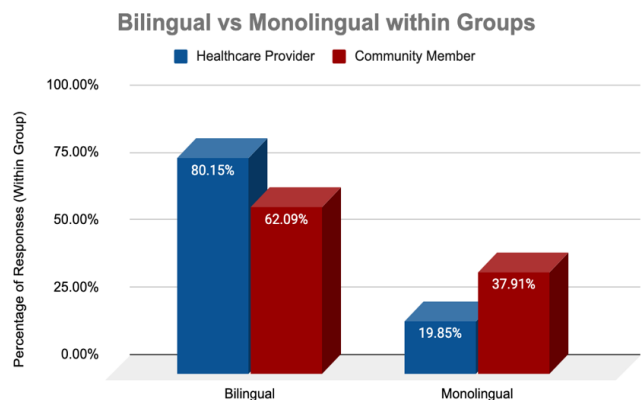
*Sample size and distribution*

Our sample size comprised 289 respondents across 4 symposia held between November 5, 2022, and April 30, 2023. The demographic breakdown included 47.1% healthcare providers and 52.9% community members, as depicted in Figure 1. Among the healthcare providers, 80.15% identified as bilingual, whereas 62.09% of community members reported being bilingual. Of the healthcare providers were 19.85% were monolingual, while 37.91% of community members identified as monolingual, as shown in Figure 2.

**Figure 1: Sample Size**



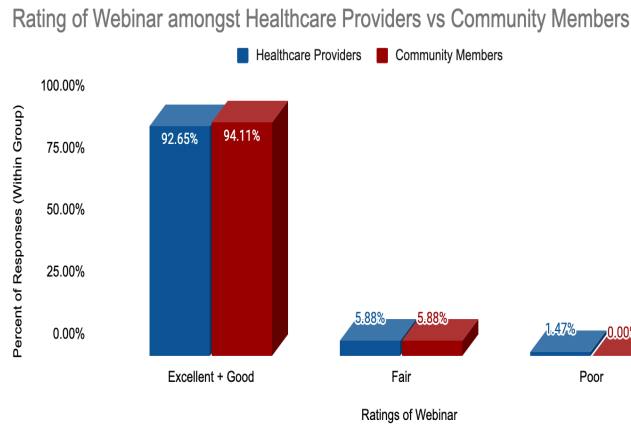
**Figure 2: Bilingual vs Monolingual within Groups**



*Symposia content rating*

Participants were asked to rate the overall symposia content. Among Healthcare Providers, 92.64% rated the symposium as either “Excellent” or “Good,” while 94.12% of Community Members rated it as either “Excellent” or “Good.” The results of the chi-squared analysis revealed no statistical significance at  $p < 0.05$  between the ratings of Healthcare Providers and Community Members ( $X^2 = 2.68$ ,  $df = 3$ ,  $p = 0.444$ ). This is shown in Figure 3.

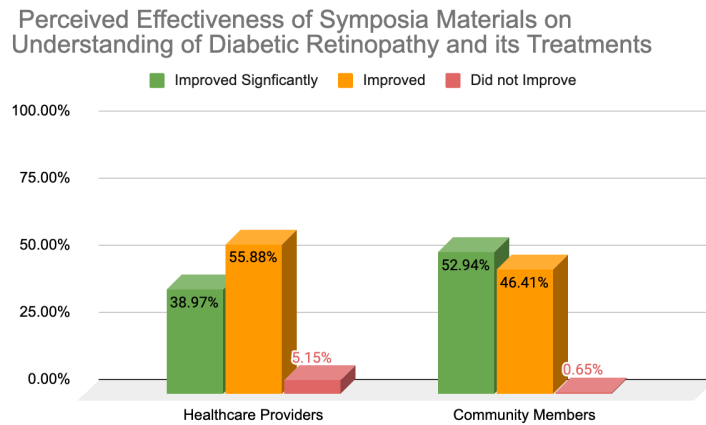
**Figure 3: Webinar Content Rating by Group**



*Improvement in understanding of diabetic retinopathy and its treatment*

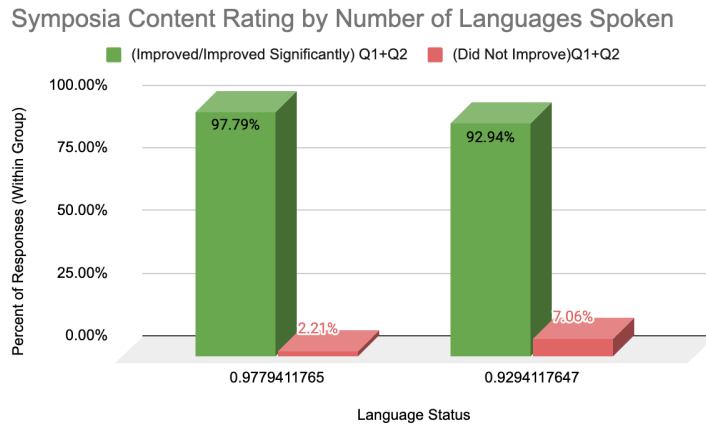
Respondents were then asked to rate the effectiveness of the symposium in improving their understanding of diabetic retinopathy and its treatment. Of the healthcare providers 94.77% responded as either “Improved Significantly” or “Improved” as compared to 99.35% of community members, as shown on Figure 5. Significant Improvement of diabetic retinopathy and its treatment was greater in the community members as compared to healthcare providers. The chi-squared analysis yielded significant results at  $p < 0.05$ , indicating a significant association between participant type and the level of improvement of understanding of Diabetic Retinopathy and its treatments ( $X^2 = 9.5539$ ,  $df = 2$ ,  $p = 0.008422$ ).

**Figure 4: Perceived Effectiveness of Symposia Materials on Understanding of Diabetic Retinopathy and its Treatments of Healthcare Providers and Community Members**



Survey results also revealed that 97.79% of bilingual respondents had an “Improved” or “Improved Significantly” response to the improvement of understanding of diabetic retinopathy, whereas 92.94% of monolingual respondents had an “Improved” or “Improved Significantly” response as shown on Figure 5. The chi-squared analysis for Symposia Content Rating by Number of Languages Spoken revealed a significant association at  $p < 0.05$  between the number of languages spoken and the symposia content rating for both the “Improved/Improved Significantly” and “Did Not Improve” categories ( $X^2 = 8.0718$ ,  $df = 1$ ,  $p = 0.004496$ ).

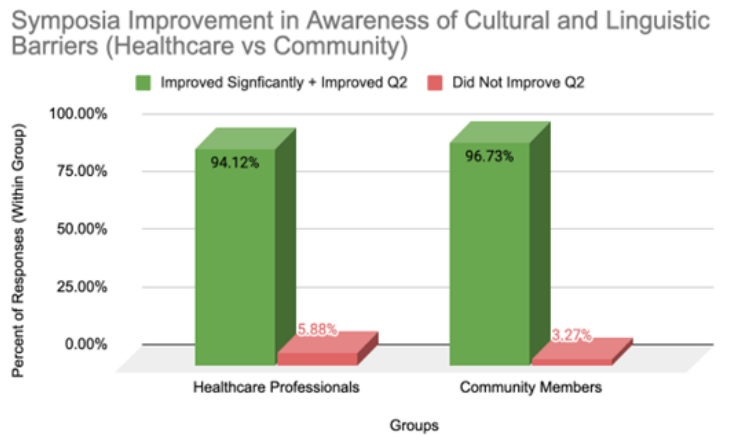
**Figure 5: Perceived Effectiveness of Symposia Materials on Understanding of Diabetic Retinopathy and its Treatments of Healthcare by Number of Languages Spoken**



*Improvement in understanding of cultural and linguistic barriers*

Respondents were then asked to rate the effectiveness of the symposia in improving their awareness of the cultural and linguistic barriers of underserved communities. Among healthcare professionals, 94.12% experienced either an “Improved” or “Improved Significantly” while 96.73% of community members reported either an “Improved” or “Improved Significantly” as shown on Figure 6. The results were not statistically significant at  $p < 0.05$ , indicating no significant difference between healthcare professionals and community members in their improved understanding of the importance of addressing linguistic barriers ( $X^2 = 1.1455$ ,  $df = 1$ ,  $p = 0.284483$ ).

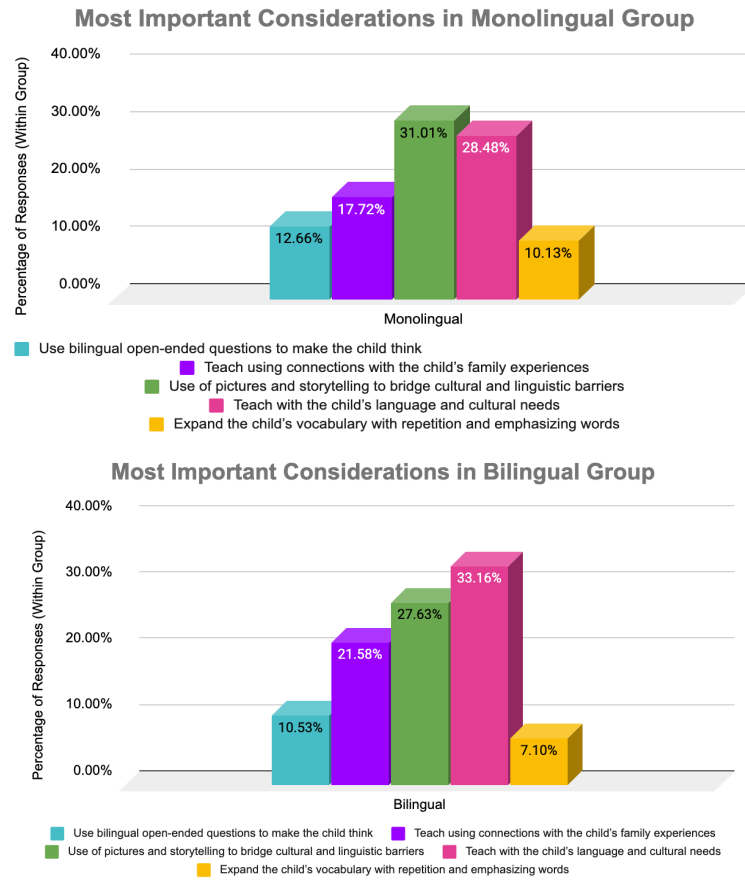
**Figure 6: Symposia Improvement in Awareness of Cultural and Linguistic Barriers (Q2)**



*Importance of the six core educational components of the SoloKiko educational platform*

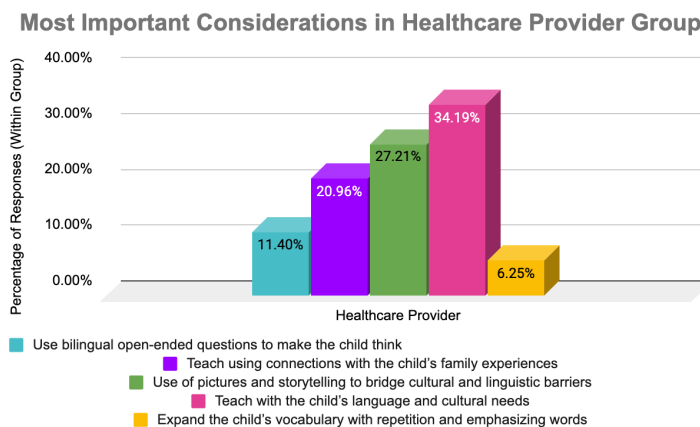
Participants were instructed to choose the two most important core components of the SoloKiko bilingual educational platform based on whether respondents were bilingual or monolingual. “Teach “using language and cultural needs”, “using connections with the family experiences”, and “Use of pictures and storytelling to bridge cultural and linguistic barriers” were rated highest by both groups as seen in Figure 7.1. We used the chi-squared test to examine the distribution of the three most voted for responses. The chi-squared analysis revealed no statistical significant difference between Bilingual and Monolingual groups in the top three most considerations ( $X^2 = 1.7056$ ,  $df = 3$ ,  $p = 0.426218$ ).

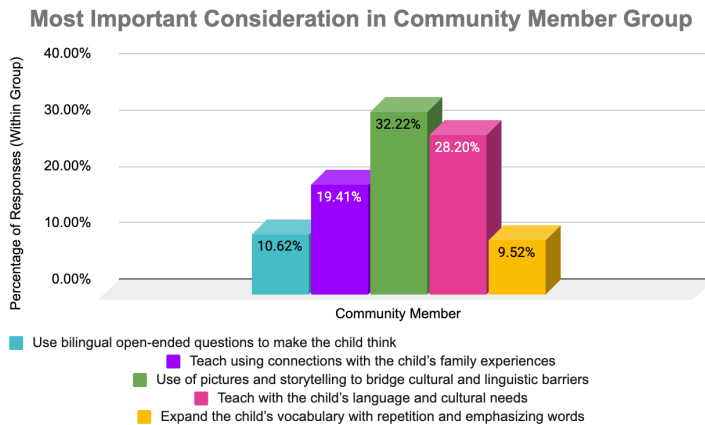
**Figure 7.1: Most Important Consideration in Teaching Bilingual Children based on Number of Languages Spoken**



Responses were then analyzed on whether respondents were healthcare providers or community members. “Teach “using language and cultural needs”, “using connections with the family experiences”, and “Use of pictures and storytelling to bridge cultural and linguistic barriers” were rated highest by both groups as seen in Figure 7.2. The chi-squared analysis revealed no significant difference at  $p < .05$  between group type and perception of most important considerations ( $\chi^2 = 12.7803$   $df = 3$ ,  $p = 0.249041$ ).

**Figure 7.2: Most Important Considerations in Teaching Bilingual Children per Group**





#### 4. Discussion

Diabetic retinopathy is one of the leading causes of irreversible blindness in individuals with diabetes.<sup>13-14</sup> In 2012, Yau et al estimated around 93 million individuals had diabetic retinopathy through projections of the prevalence rate from the 2010 world diabetes population with the prevalence rate expected to rise over the next several decades.<sup>15</sup> Early screening, diagnosis, and treatment can significantly reduce the risk of vision loss in individuals with diabetic retinopathy. Despite advancements in diabetic retinopathy, underserved communities still face significant challenges in accessing resources due to various barriers such as limited access, lack of awareness, and other socioeconomic factors.<sup>16-20</sup> These barriers are further compounded by differences in language, culture, and education and can result in lapses in diabetic retinopathy care and subsequent delays in ophthalmic treatment.<sup>21-22</sup>

The National Diabetes Prevention Program results indicate great success in reducing risk of developing type 2 diabetes and its complications through lifestyle modifications.<sup>23-24</sup> However, the ability to access the curriculum and other related educational resources remains to be evaluated.<sup>25</sup> Inadequate health literacy can compound diabetes-related complications such as diabetic retinopathy, indicating the necessity of interventions in vision care health literacy.<sup>26</sup> Also, only about 14.3% of uninsured patients utilize vision care and select population groups such as Hispanics can benefit from tailor-made vision care education.<sup>27</sup> It is important to expand and diversify the patient educational resources to bring better awareness to the importance of lifestyle changes to such affected communities. These lapses in care are also compounded by the intricacies and complexities of the healthcare system. In clinical visits, diabetic retinopathy is frequently underdiagnosed, with a significant rate of 35% in underserved communities.<sup>8</sup> This can be attributed to the insufficient provision of educational materials by healthcare providers to these patients. In other words, this is a problem of lack of access for the community and under detection for the healthcare workforce that serves it. It is important to note that the progression of diabetic retinopathy can lead to a severe condition known as diabetic macular edema, which carries a heightened risk of systemic diseases like cardiovascular, cerebrovascular, peripheral vascular disease, and renal diseases.<sup>28-29</sup> To address the disparities prevalent in these communities, there is a critical need for a collaborative effort between medical professionals and communities to establish a middle ground in terms of educational materials. By achieving this balance, we can effectively reduce the disparities and improve the overall understanding and management of diabetic retinopathy in underserved populations.

This study aimed to evaluate the effectiveness of the educational platform to convey the understanding of diabetic retinopathy and care for underserved communities. In the study, most respondents, both healthcare providers and community members, rated the symposium highly effective and found improvement in their understanding of diabetic retinopathy and its associated care from the symposium. Most respondents, both healthcare providers and community members, indicated the symposium improved their understanding of addressing cultural/linguistic barriers in underserved communities. Of interest was that in all groups, healthcare providers, community members, bilinguals, and monolingual participants, the symposia proved effective. This is in many ways a validation of the effectiveness of systems like the SoloKiko program that are designed specifically to improve health outcomes for these underserved communities.

Overall, the symposium was effective in improving knowledge of diabetic retinopathy amongst both healthcare providers and community members regardless of language status. Although diabetic patients have basic knowledge about diabetic retinopathy, they have little awareness and connections regarding ongoing care and lifestyle changes. To address this gap, it is crucial to establish public awareness and education programs that emphasize the significance of early detection, lifestyle and treatment for diabetic retinopathy<sup>30-31</sup> Encouragingly, previous studies similarly show webinars, such as diabetic retinopathy educational programs, improved awareness and understanding in targeted populations.<sup>32-33</sup> By implementing such educational initiatives, a substantial difference can be made in improving community awareness and comprehension of diabetic retinopathy, particularly within underserved communities.

In addition, both monolingual and bilingual respondents, whether healthcare providers or community members, indicated the three most important considerations for healthcare teaching were “Teach using the language and cultural needs,” “Use of pictures and storytelling to bridge cultural and linguistic barriers,” and “Teach using connections with family experiences,” respectively. Healthcare providers can incorporate these three principles into their interactions with bilingual patients as well as the educational material they distribute to them. Addressing the disparities in patient-provider communication in underserved areas is needed to improve healthcare quality and safety for patients and families.<sup>34</sup> One of the goals of the Solo Kiko Program is to promote understanding of diseases and lifestyle changes much earlier in underserved community. Schools could potentially have an impact on improving community awareness and understanding of diabetic retinopathy and its impact on underserved communities through student education. Several studies have explored the empowerment to lead and encourage students to value diversity and how teachers can approach teaching bilingual children.<sup>35-37</sup> Future educational materials should consider these approaches and gradually become integrated into methods of treatment from healthcare providers.<sup>38-39</sup> To accomplish these further studies are needed to establish methods and materials for the teaching standards of effective medical education in underserved communities.

Given little is known about the barriers between communities and healthcare providers, community involvement and outreach leads can lead to greater impact on society when it takes into account the support and social aspect of diabetic retinopathy. The SoloKiko educational platform was established to fill this large void and empower community members to attain health literacy and take control of their eye health. SoloKiko provides culturally-appropriate educational materials that are communicated at the patient’s level for clear understanding and includes up-to-date, evidenced-based explanations to be disseminated amongst family and the community. In the process, SoloKiko brings light to the social determinants of health in diseases such as diabetic retinopathy care and integrates innovative teaching methods into educational materials.

Moreover, investigating the impact of healthcare providers' and community members' language proficiency on patient understanding and care of diabetic retinopathy could yield valuable insights. By identifying the most effective teaching approaches, or a combination thereof, we can aspire to disseminate knowledge about this sight-threatening condition from educational programs to patients' homes, thereby potentially preserving their vision.

Underserved communities require better access to resources, such as the SoloKiko educational platform, provided by healthcare professionals, to bridge the gap and overcome barriers in healthcare services. This can potentially contribute to improving health outcomes for individuals affected by diabetic retinopathy.

The main limitations of our study were those inherent to survey studies. Clearly with such a complex subject we were restricted to a few questions which limited the depth of our information. Most of our respondents were bilingual which is reflective of some though not all underserved communities. We were also not able to capture nonverbal cues or level of limited engagement. Finally, all our respondents were adults which excluded the participation of children.

## **5. Conclusion**

Despite major improvements in detection and treatment, diabetic retinopathy is a sight threatening disease which affects underserved communities disproportionately. These communities face significant health barriers which include access, cultural and linguistic barriers. Even when members of these communities obtain the needed care, diabetic retinopathy can be underdiagnosed as much as 35% by healthcare providers. The SoloKiko educational system can be effective in improving community and healthcare provider knowledge abouts diabetic retinopathy and its treatment. By design, it appears effective in teaching both bilingual and monolingual members of both groups. Of the six core components of the



SoloKiko educational platform teaching with the language and cultural needs, the use of pictures and storytelling to bridge cultural and linguistic barriers, and using connections with the family experiences appear most important to both community members and healthcare providers that are both bilingual and monolingual. These are principles that can be used to bridge educational interactions between healthcare providers and community members to improve health outcomes.

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