

**DIABETIC RETINOPATHY SCREENING PROGRAMS IN URBAN
POPULATIONS: AN URBAN BIOETHICS ANALYSIS**

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ABSTRACT

The Temple University Hospital System Ophthalmology Department implemented a telemedicine screening program for diabetic retinopathy to improve patient care and community engagement. The program screened over 1900 patients in the Philadelphia area from March 2016 to March 2020 and identified a significant number of patients who required further in-person examination and treatment. The implementation of a telemedicine screening program for diabetic retinopathy raises important ethical issues and merits discussion of the impact of social determinants of health on healthcare outcomes. In these community initiatives, the principles of agency, beneficence, non-maleficence, social justice, and solidarity in bioethics should be considered as they pertain to the specific needs of the community in which they are implemented. Overall, the COVID-19 pandemic has highlighted the importance of considering the ethical implications of healthcare practices, including diabetic retinopathy screenings. The risks and barriers to access must be taken into account, especially for vulnerable populations in urban areas. As such, promoting primary care engagement, providing accurate and culturally appropriate education and outreach, and addressing social determinants of health can help ensure that all patients have access to comprehensive and equitable care. By considering these factors, diabetic retinopathy screenings can be conducted in an ethical and effective manner.

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INTRODUCTION

The uncertainty of the COVID-19 pandemic forced clinicians and patients to reevaluate the ways they use resources and communicate in healthcare. In this paper I will consider the ethical implications of screening for diabetic retinopathy and review the efficacy of a telemedicine screening program that was implemented by the Temple University Hospital Systems Ophthalmology Department from March 2016 to March 2020 that screened over 1900 patients in the Philadelphia area for diabetic retinopathy. The paper is focused on how the challenges posed by the COVID-19 pandemic catalyzed changes in the screening process for diabetic retinopathy and how this disease highlights the impact of social determinants of health on diabetic care and health outcomes. I will discuss the screening programs' ethical implications, and recommend that diabetic retinopathy screenings, based on ethical considerations, should be reduced in their frequency and necessity.

COVID-19 Changes in Screening

During the pandemic, ophthalmologists reevaluated the risks and benefits of screening and routine exams with their patients. For example, patients with diabetes are advised to see their ophthalmologist regularly to monitor any changes in their eye health that are resultant from their systemic disease (Vujosevic, 2020). In the beginning of the COVID-19 pandemic, given the risks and uncertainty of the communicable and potentially deadly disease, doctors and patients alike had to reassess whether a physical trip to the doctor's office for a routine screening would be the best decision for their health. The recommendation at the time of the pandemic according to the published guidelines in June 2021 was to screen annually for diabetic retinopathy (Yonekawa et al.,

2020). Patients and doctors discussed patient specific risk factors and weighed the risks of their annual visit on a case-by-case basis.

The consensus on the benefit of screening has been blood sugar management reduces the risk of diabetic retinopathy and can be vision saving (DCCT, 1995). It is important to recognize that complications from diabetic retinopathy that cause vision loss are slow in their onset. The primary and most effective medical management of diabetic retinopathy, a pathology of the eyes, is to manage systemic disease. In practice, a routine screening visit often ends without any change in management, diagnosis, or prognosis. It is the insidious onset that calls into question the appropriate resources and risk that patients should assume to get screened. On one hand, blindness is a catastrophic outcome and every measure to avoid or delay it should be taken, but on the other hand, there were at the time serious risks and uncertainties around the coronavirus pandemic that were particularly dangerous for the overlapping demographic that is at risk for diabetic retinopathy. In fact, at the time patients who suffered from diabetes were recognized as an elevated risk group for complications of the coronavirus infection (www.cdc.gov, 2019).

CHAPTER 1: DIABETIC RETINOPATHY AND SOCIOECONOMICS

Diabetic Retinopathy Standard of Care

Diabetic retinopathy is an eye disease that is the result of longstanding diabetes; it is a common complication of diabetes that can lead to blindness. This condition occurs when chronically elevated blood sugar levels cause damage to the small blood vessels in the eye (Jampol et al., 2020). Disease prognosis and severity is correlated to a patient's ability to maintain good glycemic control. Unfortunately, given enough time, all patients with diabetes will develop some degree of microvasculature damage leading to retinopathy.

Because diabetic retinopathy is the result of a chronic systemic disease, it has been understood as an indicator for blood sugar control in a population. This is from the assertion that a greater severity and incidence of diabetic retinopathy in a population would indicate comparatively poorer glycemic control. This was supported by prior studies that show the impacts of glycemic controls in ophthalmic studies, like the ACCORD Eye Study trial in 2014 (Chew et al, 2014). Imperatives for controlling blood sugar are well established in guidelines for care set forth by the Diabetes Control and Complications Trial (DCCT) in 1995, and include managing diet, exercise, medications, stress, sleep, weight management, regularity in monitoring, and adherence to treatment. These factors are understood to be under the direct influence of the patient, unlike genetics, and are frequently targeted for intervention.

Socioeconomic Factors and Chronic Disease Management in Diabetes

It is important to consider that a person's ability to manage all these facets of their health may be hindered by their socioeconomic status. Having a poorer socioeconomic status makes it more difficult to control these factors and as a result these factors can negatively impact the disease progression as opposed to being understood as part of managing it. In other words, a greater prevalence and severity of diabetic retinopathy in a population may be an indicator of poorly managed systemic disease. The Los Angeles Latino Eyes Study (LALES) in 2010 measures quality of life outcomes over 1000 Latinos with type 2 diabetes showed that "greater severity of DR was associated with lower general and vision-specific health related quality of life," and they published quantified outcomes based on standardized questionnaires (Mazhar et al., 2011). Therefore, if we consider diabetic retinopathy as an indicator of a patient's ability to manage their diabetes, it can be extrapolated to be an indicator of the impact of environmental and societal factors influence in a population demographic's health outcomes.

The factors discussed by the LALES, the impact of socioeconomic factors on diabetic care and health outcomes is apparent. Access to healthcare is a hurdle in resource limited populations, making it difficult to manage diabetes as the disease progresses, and as the patient ages. There are many aspects of healthcare that are impacted by the socioeconomic status of a patient or of a community; for example, access to basic needs, access to care, and access to cutting edge technology can all greatly advance the quality of care and health outcomes for some patients, while for others can be a great hinderance.

Many patients, particularly those with limited financial means, may face significant challenges in accessing the latest and most effective treatments. This can

result in a situation where some patients are unable to receive the healthcare that they need to manage their diabetes (and other health conditions). Additionally, as new treatment options are discovered, they are less available to patients. Many patients make sacrifices or ration to allocate finances to their health. A study that was published in 2018 in the Journal of General Internal Medicine examined the relationship between out-of-pocket costs for medications and adherence to medication regimens among patients with chronic diseases (Kesselheim et al. 2018). The study found that patients who faced higher out-of-pocket costs for their medications were more likely to skip doses or fail to fill their prescriptions, leading to worse health outcomes. The ability to afford the cost of medical care, well established and cutting edge alike, cannot be assumed. Visits and appointments that are made to perform screening tests incur costs for the patients that are involved, both direct and indirect.

In addition to access to care, their access to education and information about diabetes is similarly limited. This can create hurdles to understanding and implementing proper diet, exercise, medication management and adherence to care for chronic disease. Many patients may not fully grasp the severity of their systemic and insidious condition or be privy to the alarm signs that it has gone out of control. Without the proper access to care and educational resources, patients are at risk of poor outcomes, rapid disease progression, and ultimately, disability. Screening programs can alleviate or exacerbate the issues, depending on the skill of the provider involved and the outcome of the screening program. A positive screening result indicating disease can be distressing for a patient but can also educate them on the importance of managing their health to avoid disability.

Other external factors in the patient's community are also determinant of their diabetic control. Food security is not guaranteed, and lower quality foods tend to have higher glycemic index, more fats, and are generally correlated with worse health outcomes. Lower socioeconomic neighborhoods suffer from food insecurity as well as food deserts, which limit the ability of the community to maintain easily and effectively a diet healthy enough to combat systemic disease. By informing patients of the importance of their diet in managing their diabetes, they can be distressed if tight glycemic control is complicated by poor nutritional options. This merits further discussion of the impact of tight glycemic control on patients with diabetes.

As healthcare continues advancing, communities without access to technology like smart phones, wearable devices and high-speed Wi-Fi will lag and have difficulties communicating with their providers as well as interfacing with blood sugar management technologies. All these components of diabetic care in resource limited communities cause stress, which directly increases a patient's blood sugar both acutely and chronically (Fisher et al., 2018). A study published in the Journal of Psychosomatic Research in 2017 found that higher levels of stress were associated with poorer diabetes control, as measured by HbA1c levels. Unfortunately, advances in technology and the constant communication can be distressing for patients as they manage their diabetes, and the inability to communicate due to lack of access can be even more distressing, leaving more unknown information in a patient's care. The outlook is grim for resource poor communities as technologically advanced resources become mainstay diabetic care.

Although further discussion of comorbidities would be outside the scope of this paper, it is important to note that diabetes is also impacted by blood pressure and blood

cholesterol levels, and that these, too, are impacted by social determinants of health.

Poorer control of blood pressure and cholesterol is a significant risk factor to the development and progression of diabetic retinopathy. These comorbidities complicate the already daunting diagnosis of diabetes.

CHAPTER 2: TELEMEDICINE SCREENING

One solution to barrier to access was the implementation of telemedicine in diabetic retinopathy screening. Telemedicine screening for signs of diabetic retinopathy could be accomplished remotely, using digital retinal imaging technology, which captures images of the retina that are analyzed to detect signs of disease. This allowed patients to get screened without an office visit to a specialist, their ophthalmologist. An important shift in healthcare reimbursement took place to make this more feasible. The reimbursement price for a telemedicine screening visit was coupled to the reimbursement of a regular screening, called payment parity. Once telehealth payment parity took hold among insurance companies, telemedicine screening for diabetic retinopathy had greater incentive and was more cost effective for providers. Telemedicine screening can increase access to eye care for people with diabetes, particularly those in rural or underserved areas, and can help prevent blindness caused by diabetic retinopathy.

Autonomy and Agency

In any bioethical decision, a patient's autonomy must be considered, and screening programs ought to give the patient the ability to make their own decisions about their body. Screening for diabetic retinopathy is one way for patients to regain more autonomy over the management of their chronic disease by informing them about their medical condition, status, and treatment options. It is important that the screening program is non-committal and non-binding, that it serves only as a bridge to care and in the case of diabetic retinopathy screening, as a liaison to a specialist, but not as a commitment on contractual agreement to medical intervention. In this way, getting

screened does not impinge on a patient's autonomy in any way, regardless of the screening result.

Potential Harms

However, in addition to the benefits of telemedicine to increase access to care, there are also risks and ethical concerns surrounding the use of telemedicine for diabetic retinopathy screening. There are several ways in which a screening program can cause harm to a patient, and non-maleficence of the program must be considered when assessing the ethical implications of expanding or contracting screening efforts. Issues such as patient autonomy, privacy, the potential for misdiagnosis, and the assumed responsibility of the care providers are important hazards in screening that should be considered.

One of the ways a screening program can cause harm is by misdiagnosis. Misdiagnosing a patient can cause great distress and psychological harm, and this is especially important to consider at a screening program because by design no treatment options are available for immediate use or remedy. Patients routinely report blindness as one of their most feared medical outcomes, and for that reason erroneously telling someone that they are going blind should be avoided. Screening programs generally accomplish this by recommending follow up care but not providing a definitive diagnosis, which can also be distressing. Given that screening for a disease offers no treatment options, it is imperative that the screening procedure is completely benign so as not to do any unnecessary harm to the patient without benefit. Screening for diabetic retinopathy only requires non-invasive imaging, a fundus photo. Improvements in technology have made it possible to photograph the retina without dilating the pupil.

Causing physical harm in the diabetic retinopathy screening process is now entirely avoidable, save the minor inconvenience of posing for a photo and a camera flash in your eyes.

Although the advancements in imaging technology have removed the need for painful eye drops and blurry vision after the visit, they also pose new challenges to privacy which should be recognized as potential for harm. As providers and patients navigate healthcare with increased connectivity and availability, the advent of electronic medical records has allowed for faster transfer of information between all parties. Unfortunately, this information is valuable personal information, and so safety measures have been put in place to protect it. Even with the safety measures, the number of times the information changes hands or is transferred from one entity to another, the potential for misuse, theft or breach of privacy is increased. HIPAA compliant communications typically mitigate this risk, but not entirely, because of the number of times protected health information changes hands. Patients are usually informed of how their information will be handled and stored on consent forms so that they may have some agency over who uses it. Computers and servers at remote screening sites as well as medical offices must encrypt and protect data from the screening exams as the results of these exams can have dire implications on a person's insurance policies or employment. For example, a person who professionally operates a vehicle may have a positive screening. This may raise concerns about their ability to operate a motor vehicle even though a diagnosis has not been established and no changes in their vision have been reported. Their career may unfairly be impacted by the mishandling of their private health information, and because

we are dealing with disability and major changes to quality of life, proper protection is paramount.

Technological advances demonstrate progression in the science of medicine, but also highlight disparities in access to care. Because high tech screenings require specialized equipment and trained technicians, a large capital investment is required for assets and staff for whomever is conducting the screening. This hinders low socioeconomic communities from accessing advances in the standard of care. Even if these services are accessible, there are often longer wait times and limited availability, causing more harm and stress to the patients as they navigate healthcare.

When evaluating the benefits and risks of screening exams for diabetic retinopathy, it is also important to consider the emotional burden on patients. Screening exams can be distressing for patients, particularly if they are uncomfortable or painful, or if patients are anxious about the results. A study, published in the journal *Ophthalmology* in 2005, aimed to investigate the prevalence of fear of blindness and the factors associated with it in patients with newly diagnosed open-angle glaucoma, which is a comparable chronic ocular pathology that leads to blindness (Janz et al., 2007). Visual field progression was significantly associated with increased fear of blindness, while visual acuity loss was not. This is incredibly important because glaucoma is associated with loss of visual field while diabetic retinopathy typically is not. The study also showed that self-reported visual function measures were more strongly associated with fear of blindness over time than any demographic, clinical, or physical or psychosocial variables. In other words, a patient's emotional burden from their disease was less correlated to their objective clinical measurements. The study concluded that reducing fear of

blindness in glaucoma patients at diagnosis and over time is important, and that fear of blindness is related more to how much an individual is bothered by their inability to perform visual tasks than to their visual acuity or visual field assessments. A patient centered approach would emphasize limiting the disease burden on activities of daily living, therefore, and not on clinical outcomes that are not manifest in patient satisfaction.

CHAPTER 3: CHANGES IN DIABETIC RETINOPATHY CARE

The annual diabetic retinopathy screening is generally regarded as the standard of care, but the utility of the screening process was called into question during the COVID-19 pandemic as ophthalmologists and primary care providers weighed the unknown risks of the communicable disease against the benefits of early detection of looming disability. Recent studies have called into question the impact of tight glycemic control in visual outcomes in diabetic retinopathy and in conjunction with discussions of risks for the screening process, the benefit may be currently overstated in the standard of care. Although it may be understood that the duty of a physician is to diagnose and treat the disease, in the case of diabetic retinopathy the practical implications of the screening and treatment can be understood to cause an undue burden on both the patient and physician.

The Diabetes Control and Complications Trial

First, consider the potential outcomes of continuing to perform regular, annual screening exams for diabetic retinopathy. While these exams may detect the early stages of retinopathy, studies suggest that they may not lead to meaningful improvements in vision for many patients (Zhang et al., 2001). Researchers analyzed data from the Diabetes Control and Complications Trial (DCCT), focusing on patients without retinopathy at baseline. They assessed the risk of developing retinopathy in patients with extreme metabolic control compared to patients with poor metabolic control based on their mean HbA1c levels, with the lower 20% considered as good and the upper 20% as poor. This study found that good metabolic control did not completely prevent the development of retinopathy, and it also found that poor metabolic control did not

guarantee the development of retinopathy. The researchers then used logistic regression to predict retinopathy from covariates used in the DCCT retinopathy study.

The Limitations of the DCCT

This analysis suggested that other factors are involved in the development and progression of the disease, not just glycemic control specifically. This calls into question the utility of early detection of diabetic retinopathy in a focused screening program. The Diabetes Control and Complications Trial was a clinical trial that demonstrated some benefits of intensive blood glucose control in reducing complications of diabetic retinopathy in patients with type 1 diabetes. However, there were some limitations to the study, including its limited applicability to type 2 diabetes, limited diversity among participants, short follow-up period and potential cost-effectiveness concerns.

The DCCT study is nearly 20 years old, and limitations of the study are present that cast doubt on its generalizability. First, it only treated patients with type 1 diabetes and therefore the only medication used for glycemic control in the study was insulin, dose four times daily for tight control and only twice daily for the control group. This is a very different regimen than what is standard for type 2 diabetes in modern medicine. Furthermore, insulin is not a medication that is cheap or readily available to patients with type 2 diabetes and is used as an adjunct medicine in type 2 diabetes for glycemic control, rather than as the standard of care. Additionally, the study had very limited numbers overall compared to comparable studies today. The study population in the DCCT was predominantly white, which also limits generalizability of its findings. Finally, the study horizon was 6.5 years, and this is a relatively short period of time for a lifelong disease. When considering the appropriate screening recommendation for a

patient, understanding the limitations of the Diabetes Control and Complications Trial are important because they impact the generalizability and interpretation of the trial's findings in clinical practice.

A study was conducted in 2011 using the data from the DCCT to assess and predict the risk of developing retinopathy in type 1 diabetic patients with extreme metabolic control. It was thought that the results from this study could help better understand the results of the DCCT. The study found that retinopathy developed in approximately 10% of patients with type 1 diabetes under good metabolic control, whereas over 40% of patients with type 1 diabetes remained free of retinopathy despite poor metabolic control. The study also identified HbA1c at baseline and BMI as significant prognostic factors for the development of retinopathy. Overall, the study highlights the complex relationship between metabolic control and the development of retinopathy in patients with diabetes. Importantly, this study does not provide direct support for tight glycemic control using the same study data as the DCCT. What the new study found is that good metabolic control did not completely prevent the development of retinopathy, it also found that poor metabolic control did not guarantee the development of retinopathy. The study suggests that other factors, such as previous glycemic exposure and BMI, may play a role in the development of diabetic retinopathy.

Furthermore, performing these screening exams also places a burden on physicians and healthcare systems, requiring time, resources, and personnel to administer and interpret the results. The burden of diabetic retinopathy screenings on physicians can vary depending on several factors such as the number of patients requiring screenings, the frequency of screenings, and the resources available to the physician. In general,

screenings require time, equipment, and specialized training, which can be a burden for primary care physicians who may already have a heavy workload. Additionally, patients that require referral to an ophthalmologist for further evaluation or treatment, can add to the physician's workload and potentially create a delay in care. These resources could be better allocated towards interventions that have been proven to make a greater impact on patient outcomes and patient satisfaction.

Given these factors, a consequentialist risk benefit analysis could be made in favor of reducing the frequency or necessity of these screening exams. By doing so, healthcare resources could be redirected towards more effective interventions that improve patient outcomes that are significant to patient satisfaction. Additionally, reducing the burden of screening exams on patients could improve their overall experience with healthcare and potentially increase their engagement with other preventative measures.

CHAPTER 4: TEMPLE TELEMEDICINE STUDY

It is imperative in a consequentialist argument to assess the real-world application of a practice in ethical discussion. Temple University Hospital conducted a study of the application of a telemedicine screening program from March 2016 to May 2017. The study conducted a retrospective review of 15 months of data on diabetic retinal screening using telemedicine at Temple University Hospital. The results showed that 689 digital retinal screening exams were conducted on 1377 eyes of diabetic patients. Among all screening exams, 357 (51.8%) triggered a request for a referral to ophthalmology, and 67 patients (9.7%) were suspected to have another ophthalmic condition based on other findings in the retinal photographs. However, only 34 patients (4.9%) completed a referral visit to Temple ophthalmology. The study concluded that there were other factors inhibiting the efficiency in the screening process, and that a lot of patients were lost to follow up.

Ethical Arguments in Consideration of the Study

The study was not intended to explicitly discuss the consequentialist view of the ethics of a screening program, but one could argue that the study's results highlight the importance of considering the consequences of a screening program on patient outcomes. On the one hand, the screening program was successful in identifying patients who needed a referral to ophthalmology for further evaluation and treatment. On the other hand, a significant proportion of patients who were identified as needing a referral did not follow up for an eye exam, which suggests that the screening program alone may not be sufficient to improve access to appropriate retinal care. This was Dr. Benjamin et al.'s conclusion that "[m]ere identification of referral-warranted diabetic retinopathy and other

ophthalmic conditions is not enough” and that a successful program would extend further into the screening workflow, for example by closing the communication gaps that exist.

From a consequentialist perspective, the success of a screening program should be evaluated based on its ability to improve patient outcomes, such as reducing the incidence of diabetic retinopathy and preventing vision loss. Dr. Benjamin et al.’s results suggest that the telemedicine screening program had mixed success in achieving these outcomes, as it identified patients who needed further evaluation and treatment but did not always result in timely follow-up care. Therefore, a consequentialist view of the ethics of a screening program would require considering both the positive and negative consequences of the program on patient outcomes and evaluating whether the overall benefits outweigh the harms.

From a deontological perspective, the success of the screening program should be evaluated on its ability to fulfil the duty to provide appropriate care to patients. Considering the ethical principle of beneficence, healthcare providers ought to act in the best interests of their patients and provide health care to those in need. Dr. Benjamin et al.’s study results suggest that the telemedicine screening program successfully identified patients who needed a referral to ophthalmology for further evaluation and treatment. However, a significant proportion of these patients did not follow up for an eye exam, which casts doubt about the program's ability to fulfill the duty of beneficence to these patients.

Additionally, considering the principle of non-maleficence, in which healthcare providers avoid causing harm to patients, the study's results suggest that the telemedicine screening program may have faced challenges related to that as well. A significant

proportion of the screening photographs were uninterpretable by the clinician. This raises questions about the accuracy and reliability of the telemedicine screening process, and whether patients may have been harmed because of missed diagnoses or delayed care. There is also certainly an emotional burden to be told that you are at risk for blindness without any plan of action, assessment, or even evaluation. Therefore, a deontological view of the ethics of a screening program would require considering the program's ability to fulfill the duties of beneficence and non-maleficence to patients and evaluating whether the program meets the ethical standards of providing appropriate and effective care. Due to the extremely low number of successful patients' follow-ups, it is difficult to say that this screening program was beneficent and non-maleficent to the patients.

Temple University Hospital Study Impact and Extended Data

Dr. Benjamin's finding that so few patients completed their follow up exam spurred discussion and revision of the screening process with notable improvements. The study continued collecting data on patient visits through March of 2020. Augmentations to the procedures, training and workflow showed iterative improvements in the screening program. A further 1955 patients were studied by Temple as the processes improved up until the pandemic. A total of 494 (25.2%) patients were found to have a referable exam, either positive for diabetic retinopathy in at least one eye or an ungradable exam. Of those, 229 (46.3%) were found to have diabetic retinopathy based on their slit lamp examination. The improvements set forth because of the original study improved the follow up rates and were able to get more patients in touch with an ophthalmologist for evaluation of their disease. As the screening program matured and procedures and

training were more established, the follow-up rate increased from 5% to 25%. However, even at 25% the ethics of the screening program ought to be questioned, especially given the studies that show early detection and tight glycemic control are not shown to reduce disease burden and improve visual acuity.

Bioethics

In conclusion, while deontological principles dictate that physicians have a duty to diagnose and treat disease to the standard of care for all patients equally, it is important to consider the practical implications of screening and treatment, such as emotional burden on patients and the burden on physicians and healthcare systems. Additionally, recent studies have called into question the impact of tight glycemic control on visual outcomes in diabetic retinopathy, suggesting that the benefit of screening exams may be overstated. The Temple University Hospital study highlights the importance of considering the consequences of a screening program on patient outcome. A consequentialist analysis argues in favor of reducing the frequency or necessity of these exams to redirect resources towards more effective interventions and alleviate burdens that are significant to patient satisfaction and quality of life.

CHAPTER 5: URBAN BIOETHICS ARGUMENTS

Bioethics considers the impact of social determinants of health, such as race, poverty, and access to care, on healthcare outcomes. Urban bioethics view the principles of agency, beneficence and non-maleficence, and distributive justice with explicit consideration of the social determinants of health that are pervasive in urban populations. In the case of the telemedicine screening program at Temple University Hospital, it is important to consider the impact of social determinants on the success of the program. Of note, the demographic of the Temple study best reflects one of an urban community.

Populations from urban areas have higher percentages of patients who are low-income, uninsured, or underinsured may face significant barriers to accessing healthcare, including transportation, time off work, and cost of care. These factors can contribute to a lack of follow-up care and ultimately affect the success of the screening program. These factors ought to be considered in the implementation and evaluation of a screening program. Furthermore, racial, and ethnic disparities in access to care and healthcare outcomes can also play a role. African American and Hispanic patients, for example, are at higher risk for diabetic retinopathy and may face barriers to accessing care. The results of the Temple Study reflect this reality in the low follow-up rates.

Beneficence

From the perspective of an urban bioethicist, it is crucial to evaluate whether the telemedicine screening program is providing a benefit to patients in the community, regardless of their social determinants. If the program is not beneficial overall to the patients, it may contribute to health disparities and widen the gap between those who have access to care and those who do not. The diagnosis of impending disability and

blindness comes with the burden of appointments requiring transportation, childcare, or days off from work. This is in addition to any out-of-pocket costs of care that they may incur on their visit. These are an undue burden in the absence of evidence-based improvements in outcomes for patients from these screening programs. Therefore, an evaluation of the program's impact on different socio-economic groups and racial/ethnic populations is necessary to ensure that a screening guideline or program is equitable and just. When considering urban patient populations, screening programs may not be justifiably beneficial.

Agency

When discussing the ethics of screening for diabetic retinopathy in urban populations, it is important to consider how agency is impacted. Efforts should be made to ensure that individuals have access to accurate information about the benefits and risks of screening, as well as the ability to make informed decisions about participation. This may involve providing audience-appropriate education and resources, as well as addressing social and economic factors that may limit agency. Ultimately, the goal of screening programs should be to empower individuals to make the best decisions for their own health, while respecting their autonomy and agency.

In urban populations, there may be a range of factors that affect an individual's agency in relation to screening for diabetic retinopathy. For example, socioeconomic factors such as poverty, lack of access to healthcare services, and limited health literacy may impact an individual's ability to understand the benefits and risks of screening, as well as their ability to make informed decisions about participation.

Solidarity

Solidarity in bioethics would encourage us to promote more primary care engagement in diabetic retinopathy care and glycemic control as a means of improving health outcomes and patient wellbeing. This is because primary care providers are often the first point of contact for individuals seeking healthcare services and are well positioned to provide comprehensive and coordinated care that addresses both the medical needs and social determinants of health. It is important to recognize that in the Temple study, hundreds of patients were screened in the primary care setting, but only dozens decided to follow up with their specialist appointments. Urban communities have demonstrated qualitatively that the most effective way to engage with them is in the primary care setting, recognizing that this is exacerbated by social determinants of health limiting community access to specialist care.

Encouraging primary care engagement in diabetic retinopathy screenings and glycemic control would involve addressing barriers that prevent individuals from accessing these services, such as lack of health insurance, transportation, or adequate healthcare facilities in underserved areas. It may also involve promoting education and awareness among primary care providers about the impact of early detection and management of diabetic retinopathy, as well as providing training and resources to help them better manage patients with diabetes with cutting edge technologies and medicines.

In contrast, encouraging specialist visits for diabetic retinopathy screenings and glycemic control may not always be feasible or accessible for all individuals, particularly those from underserved communities. Specialist care may also be more expensive and may not be covered by insurance, which could limit access for many individuals. By

promoting primary care engagement, we can ensure that more individuals have access to high-quality care that is comprehensive, coordinated, and cost-effective.

Overall, promoting primary care engagement in diabetic retinopathy screenings and glycemic control aligns with the principle of solidarity in bioethics by recognizing that everyone has the right to access high-quality healthcare services that promote health and well-being. By working together to improve access to primary care services, we can create a more just and equitable healthcare system that benefits all individuals and communities in an ethical and informed manner.

Social Justice

By refocusing resources to the primary care setting as they are concerned with diabetic retinopathy screenings, we could ensure that all individuals have access to diabetic retinopathy screenings, we need to address barriers that prevent individuals from accessing these services. Further, as frontier technologies are made available to providers, if they are accessible to primary care in urban communities then they can reach patients who may not have access to those resources if they are limited to specialists. It is important not to limit patients from getting to reap the benefits of artificial intelligence, new monitors, interfaces, online portals, etc. just because of the barriers and social determinants of health that they may face.

In addition, social justice in bioethics would also emphasize the importance of addressing disparities in diabetic retinopathy outcomes among different populations. This may involve providing culturally and linguistically appropriate education and outreach to underserved communities. It should also address the social determinants of health that can impact access to care and health outcomes, such as poverty and discrimination.

Social justice in bioethics would influence diabetic retinopathy screenings by promoting access to these services for all individuals, regardless of their social, economic, insurance, immigration, or health status.

CONCLUSIONS

In conclusion, the impact of social determinants of health on healthcare outcomes and the principles of agency, beneficence, non-maleficence, distributive justice, and solidarity in bioethics are crucial in considering the implementation and evaluation of a diabetic retinopathy screening program in urban populations. In urban areas, low-income, uninsured, or underinsured patients may face significant barriers to accessing healthcare, and racial and ethnic disparities in access to care and healthcare outcomes can also play a role. Promoting primary care engagement in diabetic retinopathy screenings and glycemic control can ensure that more individuals have access to high-quality care that is comprehensive, coordinated, and cost-effective. Efforts should be made to ensure that individuals have access to accurate information about the benefits and risks of screening, as well as the ability to make informed decisions about participation. Furthermore, providing culturally and linguistically appropriate education and outreach to underserved communities is paramount and an advantage of the primary care setting. By addressing the social determinants of health that can impact access to care and emphasizing the importance of primary care engagement in diabetic retinopathy all patients can achieve more equitable care. In addition, identifying and targeting those at high risk for diabetic retinopathy through a refined screening protocol that is specific to patient populations and their needs can be a more ethical and cost-effective solution, as it can help avoid unnecessary screening for those at low risk while ensuring that those at high risk receive the appropriate care. By targeting screening efforts to those who would benefit the most, healthcare providers can optimize the use of limited resources and prioritize equitable care.

REFERENCES

- Chew, Emily Y et al. "The effects of medical management on the progression of diabetic retinopathy in persons with type 2 diabetes: the Action to Control Cardiovascular Risk in Diabetes (ACCORD) Eye Study." *Ophthalmology* vol. 121,12 (2014): 2443-51. doi:10.1016/j.ophtha.2014.07.019
- Fisher L, Hessler DM, Polonsky WH, Masharani U, Peters AL, Blumer I, Strycker LA. Prevalence of depression in Type 1 diabetes and the problem of over-diagnosis. *Diabet Med*. 2016 Nov;33(11):1590-1597. doi: 10.1111/dme.12973. Epub 2016 Jan 5. PMID: 26433004.
- <https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinicalcare/underlyingconditions.html>
- Jampol, Lee M et al. "Evaluation and Care of Patients with Diabetic Retinopathy." *The New England journal of medicine* vol. 382,17 (2020): 1629-1637. doi:10.1056/NEJMra1909637
- Janz, Nancy K et al. "Fear of blindness in the Collaborative Initial Glaucoma Treatment Study: patterns and correlates over time." *Ophthalmology* vol. 114,12 (2007): 2213-20. doi:10.1016/j.ophtha.2007.02.014
- Kesselheim, Aaron S et al. "Prescription drug insurance coverage and patient health outcomes: a systematic review." *American journal of public health* vol. 105,2 (2015): e17-30. doi:10.2105/AJPH.2014.302240
- Mazhar, Kashif et al. "Severity of diabetic retinopathy and health-related quality of life: the Los Angeles Latino Eye Study." *Ophthalmology* vol. 118,4 (2011): 649-55. doi:10.1016/j.ophtha.2010.08.003
- "Progression of retinopathy with intensive versus conventional treatment in the Diabetes Control and Complications Trial. Diabetes Control and Complications Trial Research Group." *Ophthalmology* vol. 102,4 (1995): 647-61. doi:10.1016/s0161-6420(95)30973-6
- Vujosevic, Stela et al. "Screening for diabetic retinopathy: new perspectives and challenges." *The lancet. Diabetes & endocrinology* vol. 8,4 (2020): 337-347. doi:10.1016/S2213-8587(19)30411-5
- Yonekawa, Yoshihiro et al. "American Society of Retina Specialists Clinical Practice Guidelines on the Management of Nonproliferative and Proliferative Diabetic Retinopathy without Diabetic Macular Edema." *Journal of vitreoretinal diseases* vol. 4,2 (2020): 125-135. doi:10.1177/2474126419893829

Zhang, L et al. "Risk of developing retinopathy in Diabetes Control and Complications Trial type 1 diabetic patients with good or poor metabolic control." *Diabetes care* vol. 24,7 (2001): 1275-9. doi:10.2337/diacare.24.7.1275