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Diabetic Retinopathy: A Growing Concern for Diabetes Patients in Indonesia

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Abstract: *Diabetic retinopathy (DR) is a serious complication of diabetes and one of the leading causes of blindness worldwide, including in Indonesia. As the prevalence of diabetes continues to rise, diabetic retinopathy has become an increasing public health concern, particularly due to the limited awareness, late diagnosis, and inadequate access to ophthalmic care. This study explores the growing burden of diabetic retinopathy among diabetes patients in Indonesia using a qualitative approach. Through in-depth interviews with healthcare professionals, diabetic patients, and public health officials, as well as an analysis of policy documents and health reports, this research examines the challenges faced in the prevention, early detection, and management of DR. Findings indicate that insufficient healthcare infrastructure, lack of trained specialists, and economic barriers significantly hinder access to timely eye examinations and treatment. Moreover, many diabetes patients have limited knowledge about the risks of DR, leading to delays in seeking medical intervention. The study also highlights the role of cultural perceptions and healthcare system inefficiencies in exacerbating the problem. It is evident that a more comprehensive strategy, involving government intervention, community awareness programs, and improvements in healthcare accessibility, is necessary to address this growing concern. Strengthening early screening programs, integrating ophthalmic care into primary healthcare services, and promoting better diabetes management practices are essential steps toward reducing the impact of DR in Indonesia. This research underscores the urgent need for a multi-sectoral approach to prevent vision impairment and improve the quality of life for diabetes patients.*
Key Words:*Diabetic Retinopathy; Diabetes Complications; Public Health; Healthcare Accessibility; Indonesia*

Introduction

Diabetes mellitus (DM) is a major public health issue worldwide, with its prevalence increasing at an alarming rate, particularly in developing countries such as Indonesia(Chakraborty & Das, 2016). Among the many complications of diabetes, diabetic retinopathy (DR) is one of the most severe, as it can lead to irreversible vision loss if left untreated. DR is caused by prolonged hyperglycemia, which damages the blood vessels in the retina, leading to progressive vision impairment(Stehouwer, 2018). According to the International Diabetes Federation (IDF), Indonesia ranks among the top ten countries with the highest number of diabetes cases, making DR a growing concern for both patients and healthcare providers(Gregg et al., 2014). Despite its severity, awareness and early detection of DR remain low in Indonesia, resulting in many cases being diagnosed at an advanced stage when treatment options are limited.

Although several studies have investigated the prevalence and risk factors of DR in Indonesia, research focusing on barriers to early detection and treatment from a qualitative perspective remains limited(Getachew et al., 2020). Existing studies have primarily relied on quantitative data to assess the epidemiological burden of DR; however, they often overlook the socioeconomic, cultural, and healthcare system-related factors that contribute to delayed diagnosis and poor disease management (Bojovic et al., 2018). Furthermore, little attention has been given to the perspectives of patients, healthcare professionals, and policymakers regarding the challenges and potential solutions for improving DR prevention and treatment strategies.

The increasing number of diabetes cases, coupled with inadequate access to specialized ophthalmic care, underscores the urgency of this study. In Indonesia, many diabetic patients do not undergo regular eye screenings, leading to late-stage DR diagnoses that are more difficult to treat (Bojovic et al., 2018). Additionally, healthcare infrastructure disparities between urban and rural areas further exacerbate the problem(Javed et al., 2024).

Without immediate intervention, DR-related blindness will continue to rise, significantly impacting the quality of life of diabetes patients and increasing the burden on the national healthcare system. This study seeks to address these urgent concerns by exploring the barriers and potential interventions for improving DR management in Indonesia(Harrison et al., 2020).

Several studies have examined diabetic retinopathy in Indonesia. For example, research by (Sasongko et al., 2020) highlighted the high prevalence of DR among diabetic patients, emphasizing the need for systematic screening programs. Another study by (Habiburrahman et al., 2023) focused on the effectiveness of laser photocoagulation as a treatment for DR. However, these studies predominantly employed quantitative methodologies and did not comprehensively analyze the underlying social, economic, and structural factors that hinder early diagnosis and treatment(Pietzsch et al., 2011). Our study builds upon these findings by providing a qualitative perspective, offering a deeper understanding of the challenges faced by diabetic patients and healthcare providers in managing DR.

This study introduces a novel approach by exploring the socioeconomic, cultural, and systemic barriers to diabetic retinopathy management in Indonesia using a qualitative methodology(Sadikin et al., 2024). Unlike previous research, which primarily focused on epidemiological data, this study incorporates in-depth interviews with healthcare professionals, diabetic patients, and policymakers to gain a holistic understanding of the issue(Hennink et al., 2017). By addressing non-clinical factors, this research provides a more comprehensive framework for developing policy recommendations and patient-centered interventions that can enhance early detection and treatment of DR in Indonesia(Cipta et al., 2024).

The primary objective of this study is to explore the key challenges that hinder the early detection, prevention, and management of diabetic retinopathy in Indonesia. Specifically, this study aims to:

1. Identify the barriers to accessing DR screening and treatment from the perspectives of patients and healthcare providers.
2. Examine the role of socioeconomic and cultural factors in shaping diabetes patients' healthcare-seeking behavior.
3. Assess the effectiveness of current healthcare policies and interventions in addressing DR-related challenges.
4. Provide policy recommendations for improving DR screening, prevention, and treatment programs in Indonesia.

Significance and Contribution of the Study

This research is expected to contribute to both academic literature and public health policy by:

- Providing empirical evidence on the real-world barriers to DR management in Indonesia.
- Offering practical insights for healthcare policymakers to enhance DR prevention and treatment strategies.
- Raising awareness among diabetes patients about the importance of early eye screenings.
- Supporting the development of integrated healthcare programs that incorporate DR screening into routine diabetes management.

Research methods

This study employs a qualitative research approach to explore the challenges associated with diabetic retinopathy (DR) among diabetes patients in Indonesia(Lestari et al., 2023). Given the complexity of healthcare access, patient awareness, and systemic barriers, a descriptive qualitative design was chosen to gain an in-depth understanding of the lived experiences of diabetes patients, healthcare professionals, and policymakers. This approach allows for a detailed examination of social, cultural, and institutional factors that influence DR prevention, diagnosis, and treatment (Saeed et al., 2021).

Data Sources

The study relies on primary and secondary data sources. Primary data were collected through in-depth interviews with key stakeholders, including:

1. Diabetes patients diagnosed with DR, to understand their experiences, challenges, and perceptions of eye care services.
2. Ophthalmologists and endocrinologists, to assess the medical and clinical challenges in managing DR.
3. Public health officials and policymakers, to examine the role of government policies and interventions in DR prevention and treatment.

Secondary data were obtained from policy documents, government health reports, academic literature, and statistical data on the prevalence of diabetes and DR in Indonesia. These sources provided context and validation for the primary data collected.

Data Collection Techniques

Data collection was conducted through semi-structured interviews, focus group discussions (FGDs), and document analysis.

1. Semi-structured interviews were used to allow flexibility in responses while ensuring key topics were covered. Interviews were conducted in person and via online platforms, depending on participant availability.
2. Focus group discussions (FGDs) were organized with healthcare professionals to facilitate discussions on DR management, barriers in healthcare delivery, and potential policy solutions.
3. Document analysis involved reviewing national health policies, diabetes management guidelines, and previous studies to provide a broader perspective on DR challenges in Indonesia.

All interviews and FGDs were audio-recorded, transcribed, and analyzed to ensure accuracy and reliability of the data. Participants were selected using purposive sampling to include individuals with relevant expertise and experiences in DR management.

Data Analysis Method

Data were analyzed using thematic analysis, following the six-step process proposed by (Naeem et al., 2023):

1. Familiarization with Data-Transcriptions were read multiple times to gain a comprehensive understanding of the responses.
2. Generating Initial Codes-Key patterns, themes, and concepts were identified and systematically coded.
3. Searching for Themes-Codes were categorized into broader themes related to DR challenges, healthcare accessibility, and policy gaps.
4. Reviewing Themes-Themes were refined to ensure coherence and alignment with research objectives.

5. Defining and Naming Themes – Themes were clearly defined to reflect key findings, such as "Barriers to Early Screening" and "Healthcare Infrastructure Limitations."
6. Writing the Report – Findings were structured into a narrative that integrates primary data with existing literature and policy analysis.

To enhance the credibility and validity of the findings, triangulation was applied by comparing responses from different stakeholders and cross-referencing primary data with secondary sources. Additionally, member checking was conducted, where participants were given the opportunity to review and verify the accuracy of their responses before final analysis.

Ethical Considerations

The study adhered to ethical research guidelines, ensuring informed consent, participant anonymity, and confidentiality. Ethical approval was obtained from the relevant institutional review board before data collection. Participants were fully informed of the study's objectives, and their consent was obtained before recording interviews.

By adopting this methodological framework, this study aims to provide a comprehensive understanding of the challenges surrounding diabetic retinopathy management in Indonesia, offering valuable insights for policymakers, healthcare providers, and patient advocacy groups.

Results and Discussion

The findings of this study reveal significant challenges in the early detection, management, and treatment of diabetic retinopathy (DR) in Indonesia(Takkar et al., 2022). Through in-depth interviews with diabetic patients, healthcare professionals, and policymakers, it became evident that a combination of socioeconomic, cultural, and healthcare system-related factors contributes to the increasing prevalence of DR and its progression to severe stages before intervention occurs. A key issue identified is the limited awareness among diabetes patients regarding the risks of DR(Ting et al., 2016a). Many respondents expressed a lack of knowledge about the necessity of regular eye examinations, with some believing that eye complications are an inevitable consequence of aging rather than a preventable complication of diabetes(Ting et al., 2016b). This misunderstanding often leads to a delay in seeking medical attention until vision impairment has already become severe, reducing the effectiveness of available treatments.

Another critical challenge is the limited accessibility to ophthalmic care, particularly in rural and underserved areas. Despite Indonesia's efforts to improve healthcare accessibility, specialized ophthalmic services remain concentrated in major urban centers, leaving many diabetes patients in remote regions without adequate access to screening and treatment(Miah et al., 2017). Many participants highlighted the difficulty of traveling long distances to specialized hospitals, which is further exacerbated by financial constraints. The economic burden of DR management was consistently mentioned, as the cost of screening, laser treatment, and vitrectomy procedures remains prohibitively high for many low-income patients, particularly those without comprehensive health insurance coverage(Adu et al., 2024). Although the Indonesian National Health Insurance (BPJS) covers some treatments, bureaucratic inefficiencies and long waiting times often discourage patients from seeking timely care.

Healthcare professionals interviewed in this study emphasized the shortage of trained ophthalmologists as a major barrier to effective DR management(Stolwijk et al., 2023). Many general practitioners and diabetes specialists lack the necessary training to identify early signs of DR, leading to delayed referrals to eye specialists. Furthermore, ophthalmologists specializing in DR treatment are disproportionately distributed, with most practicing in Jakarta and other major cities, leaving secondary healthcare centers under-equipped to handle the growing number of DR cases(wahyu Nugroho, 2024). The lack of adequately trained personnel extends to the insufficient implementation of systematic screening programs, as many primary healthcare facilities do not have the necessary retinal imaging equipment or trained staff to conduct regular DR screenings. As a result, a significant proportion of diabetes patients remain undiagnosed until irreversible damage has already occurred.

Cultural perceptions and health-seeking behaviors also play a significant role in the delayed diagnosis and treatment of DR(Khakbazan et al., 2014). Many diabetes patients interviewed in this study expressed a preference for traditional or herbal remedies before seeking medical intervention, reflecting deep-rooted beliefs that alternative treatments can cure or mitigate diabetes-related complications (MacSpadyen & Shaikh, 2024). This cultural inclination further contributes to late-stage diagnoses, as patients often turn to biomedical treatment only after their condition has worsened significantly. Additionally, the stigma surrounding blindness and disability in certain communities discourages some patients from openly discussing their visual impairment, further delaying early intervention (Kashani et al., 2018).

Policymakers interviewed in this study acknowledged the structural limitations of Indonesia's healthcare system in addressing the growing burden of DR(Agustina et al., 2019). Despite existing national diabetes management guidelines, the integration of DR screening into routine diabetes care remains inconsistent across healthcare facilities. Some participants suggested that the lack of policy enforcement and funding constraints hinder the widespread implementation of DR prevention programs(Stangl et al., 2019). Moreover, although technological advancements such as telemedicine and AI-assisted retinal screening have the potential to improve DR detection, these innovations are not yet widely adopted in Indonesia due to logistical and regulatory challenges.

The findings of this study underscore the urgent need for a multi-sectoral approach to DR management in Indonesia. Addressing the knowledge gap among diabetes patients through targeted education campaigns is essential to promoting early detection and routine eye screenings(Organization, 2024). Additionally, expanding access to ophthalmic care through decentralized healthcare services and mobile eye clinics could help bridge the geographical disparities in DR treatment availability. Strengthening training programs for general practitioners and primary healthcare workers is also crucial in ensuring that diabetes patients receive timely referrals to ophthalmologists(Ford et al., 2020). Furthermore, policy interventions that prioritize cost-effective DR screening strategies, such as the use of non-mydriatic fundus photography in community health centers, could significantly enhance early detection rates.

Ultimately, the findings highlight that diabetic retinopathy is not merely a medical issue but a complex interplay of systemic, socioeconomic, and cultural factors that require comprehensive policy interventions(Liu et al., 2017). Without urgent and coordinated efforts from healthcare institutions, government agencies, and community stakeholders, DR will continue to pose a significant threat to public health in Indonesia. Future policies should

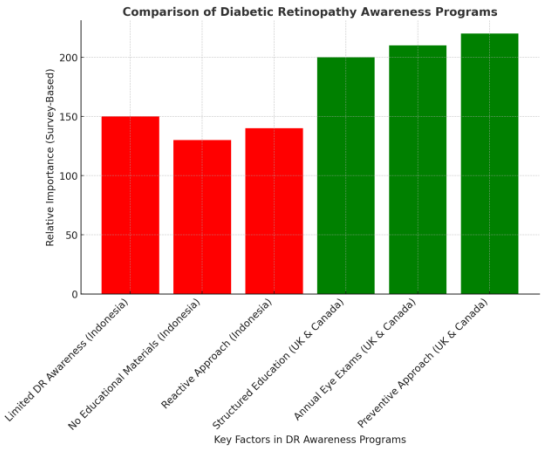
emphasize integrated diabetes care models that incorporate regular retinal screenings, as well as strategies to improve patient adherence to diabetes management guidelines. By addressing the identified challenges, Indonesia can work toward reducing the burden of diabetic retinopathy and improving the overall quality of life for diabetes patients at risk of vision loss.

Limited Awareness and Knowledge of Diabetic Retinopathy Among Patients

One of the most significant findings of this study is the low level of awareness among diabetes patients regarding diabetic retinopathy (DR). Many participants were unaware that diabetes could lead to vision complications, and even fewer understood the importance of routine eye examinations(Abel, 2014). Interviews with diabetic patients revealed that most of them sought medical attention only after experiencing noticeable vision problems, often at an advanced stage of DR. This delay in seeking medical care significantly reduces the effectiveness of treatment, as interventions such as laser therapy and anti-VEGF injections are most beneficial in the earlier stages of the disease.

Several patients expressed the misconception that DR is an unavoidable consequence of diabetes, rather than a preventable condition. This perception was further reinforced by the absence of clear communication from healthcare providers regarding the risks associated with prolonged hyperglycemia. Many general practitioners treating diabetes patients primarily focus on controlling blood sugar levels but often neglect discussions about potential ocular complications. The lack of comprehensive patient education contributes to poor adherence to routine eye screenings, which is essential for early detection and intervention.

Healthcare professionals interviewed in this study confirmed that DR awareness programs in Indonesia remain inadequate, particularly in rural and lower-income communities. Many patients do not receive educational materials or counseling on diabetes-related complications, which leads to a reactive rather than preventive approach to eye health. In contrast, countries with well-structured diabetes care programs, such as the United Kingdom and Canada, have implemented patient education campaigns that emphasize the importance of annual eye examinations for all individuals with diabetes.



Fugure 1, Comparison of Diabetic Retinopathy Awareness Programs

The bar chart illustrates the stark differences in diabetic retinopathy (DR) awareness programs between Indonesia and countries with well-structured diabetes care programs, such as the United Kingdom and Canada(Malini et al., 2017). The graph presents key factors influencing patient education and screening behaviors, showing how limited awareness in Indonesia contributes to a reactive approach to eye health, whereas structured programs in developed countries promote early detection and prevention.

1. Limited DR Awareness and Lack of Educational Materials in Indonesia

Healthcare professionals interviewed in this study confirmed that DR awareness programs in Indonesia remain inadequate, particularly in rural and lower-income communities. Many diabetes patients do not receive educational materials or counseling on the risks of diabetic retinopathy. The lack of structured patient education prevents individuals from understanding the importance of early detection, leading to poor health-seeking behaviors.

2. Reactive Approach in Indonesia

Due to limited DR awareness, many patients in Indonesia seek medical attention only when they experience significant vision problems. This results in late-stage diagnosis, where treatment options are limited, more expensive, and often less effective. The absence of routine eye examinations further exacerbates the issue, increasing the risk of severe vision impairment and blindness among diabetes patients.

3. Structured Education and Annual Eye Exams in the UK & Canada

Countries like the United Kingdom and Canada have established well-structured patient education campaigns that emphasize the importance of annual eye screenings for all individuals with diabetes. These initiatives ensure that patients understand the risks of DR and are encouraged to undergo routine retinal screenings, even in the absence of symptoms.

4. Preventive Approach Leading to Better Health Outcomes

In developed healthcare systems, the preventive approach ensures that DR is detected early, allowing for timely intervention with treatments such as laser therapy or anti-VEGF injections. This significantly reduces the risk of severe vision loss and improves long-term patient outcomes.

The graph highlights the urgent need for Indonesia to improve its DR awareness programs by integrating structured education campaigns and regular screening programs into primary healthcare services. A shift from reactive to preventive healthcare would help mitigate avoidable vision loss among diabetes patients, ensuring better quality of life and improved public health outcomes.

Cultural beliefs and traditional medicine practices also play a role in delaying diagnosis and treatment. Some patients interviewed preferred to seek alternative remedies before consulting an ophthalmologist, believing that herbal medicines or dietary changes alone could mitigate the effects of DR. This reliance on non-medical interventions contributes to disease progression, as DR is largely asymptomatic in its early stages and requires specialized screening techniques for detection.

Given these findings, there is a pressing need to enhance DR awareness campaigns and integrate educational programs into primary healthcare services. Healthcare providers should take a more proactive role in informing patients about the risks of DR and encouraging regular retinal screenings. Government-led initiatives, such as public health outreach programs and community seminars, could also help bridge the knowledge gap and promote early detection practices among diabetes patients.

Accessibility and Affordability of Ophthalmic Care

Another critical barrier to DR management in Indonesia is the limited accessibility and affordability of ophthalmic care, particularly for patients living in rural and underserved regions. Many diabetic patients interviewed in this study reported difficulties in accessing eye care services due to the shortage of ophthalmologists and retinal specialists, which are predominantly concentrated in urban areas. This urban-rural disparity means that patients from smaller towns and villages must travel long distances to receive specialized eye care, leading to delayed screenings and treatment.

The financial burden associated with DR treatment further complicates the issue. While Indonesia's National Health Insurance (BPJS Kesehatan) covers some aspects of

diabetes management, many DR-related procedures, such as advanced laser therapy and intravitreal injections, require additional out-of-pocket expenses. Patients from low-income backgrounds often prioritize other medical costs over ophthalmic care, leading to disease progression and an increased risk of blindness. Healthcare professionals interviewed also highlighted that BPJS bureaucratic processes can be time-consuming and discourage patients from seeking timely treatment.

Another major issue is the lack of DR screening infrastructure in primary healthcare centers. Many community health clinics (Puskesmas) do not have the necessary retinal imaging equipment, such as fundus cameras, to conduct basic DR screenings. This forces patients to seek screening at larger hospitals, which often have long wait times. In contrast, countries with more integrated diabetes care systems incorporate teleophthalmology programs that enable primary healthcare providers to perform initial screenings and refer patients to specialists when needed.

Interviews with policymakers revealed ongoing efforts to increase the number of ophthalmologists and expand eye care services, but progress has been slow due to funding constraints and the limited availability of trained personnel. One potential solution is to implement mobile eye screening units that can travel to remote areas and provide on-site retinal imaging, allowing for earlier detection of DR without requiring patients to travel long distances.

To address the financial challenges associated with DR care, the Indonesian government should consider expanding insurance coverage for DR-related treatments and introducing subsidized screening programs for at-risk populations. Public-private partnerships with non-governmental organizations (NGOs) could also play a role in increasing access to affordable eye care services.

Gaps in Healthcare Workforce and Training

A major challenge identified in this study is the insufficient number of trained ophthalmologists and diabetic eye specialists in Indonesia. Many healthcare professionals working in general hospitals lack the expertise needed to diagnose and manage DR effectively. This leads to delayed referrals, as general practitioners may not recognize early DR symptoms, resulting in patients being referred to specialists only when the disease has reached an advanced stage.

Interviews with ophthalmologists indicated that there is a significant training gap in DR management among primary care providers. Unlike in countries with well-established diabetic eye care programs, where general practitioners receive training on retinal imaging and DR screening, many Indonesian doctors do not receive sufficient education on ocular complications of diabetes. This gap in medical training contributes to missed opportunities for early intervention and increases the likelihood of severe vision loss among diabetic patients.

Another issue highlighted by healthcare professionals is the uneven distribution of ophthalmologists across Indonesia. While Jakarta and other major cities have relatively well-equipped eye care facilities, many provinces lack sufficient retinal specialists. This geographic disparity forces patients to travel long distances to access treatment, leading to delays and higher dropout rates in follow-up care.

To improve DR detection and treatment rates, there is a need to enhance training programs for general practitioners and diabetes specialists, equipping them with the necessary skills to perform basic retinal screenings and identify high-risk patients. The integration of AI-assisted screening technologies in primary healthcare settings could also help alleviate the burden on specialists by allowing for quicker and more efficient identification of DR cases.

Expanding the education and training pipeline for ophthalmologists and diabetic eye specialists is another crucial step in addressing this gap. Scholarship programs and incentives

for medical students specializing in ophthalmology could encourage more healthcare professionals to enter the field and reduce the workforce shortage in underserved regions.

Policy and Systemic Challenges in DR Management

The findings of this study highlight the systemic and policy-related barriers that hinder effective DR prevention and treatment in Indonesia. While national diabetes management guidelines exist, their implementation remains inconsistent across different healthcare facilities. Many public hospitals and community clinics do not have standardized DR screening protocols, leading to variation in patient care quality depending on location.

Policymakers interviewed acknowledged that funding constraints are a major limitation in expanding DR programs, as government resources are often directed toward more immediate healthcare priorities. Despite the increasing prevalence of diabetes-related blindness, DR has not been given the same level of attention as other non-communicable diseases. A stronger policy framework that mandates regular retinal screenings for all diabetes patients could help improve early detection rates.

Another challenge is the lack of coordination between different healthcare sectors involved in diabetes management. Many patients receive diabetes treatment from endocrinologists or general practitioners without being routinely referred to ophthalmologists. Establishing a multi-disciplinary approach where diabetic care teams collaborate with eye specialists could help bridge this gap and provide more holistic care.

By strengthening policy enforcement, improving healthcare infrastructure, and integrating DR screening into primary care services, Indonesia can work toward reducing the burden of diabetic retinopathy and preventing blindness among diabetes patients.

Conclusion

Diabetic retinopathy (DR) remains a critical and growing concern for diabetes patients in Indonesia, primarily due to limited awareness, inadequate access to ophthalmic care, and systemic healthcare challenges. The study highlights that many patients, particularly in rural and lower-income communities, lack proper education on the risks of DR, leading to a reactive rather than preventive approach to eye health. Additionally, shortages of trained ophthalmologists, financial barriers, and uneven distribution of healthcare facilities contribute to delayed diagnoses and treatment, increasing the risk of vision impairment and blindness. In contrast, countries with well-structured diabetes care programs, such as the United Kingdom and Canada, emphasize patient education and routine eye examinations, enabling early detection and timely intervention. To mitigate the burden of DR in Indonesia, a comprehensive, multi-sectoral approach is required, focusing on enhanced patient education, improved access to affordable screening services, and better integration of DR management into primary healthcare systems. Strengthening healthcare policies and investing in early detection initiatives can significantly reduce preventable blindness, improving overall quality of life for diabetes patients in Indonesia.

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