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Original Research Article

Assessment of Diabetes and Diabetic Retinopathy Management system in Bihar- A Mix Method study

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Abstract

Background: Diabetic retinopathy is an ocular complication of diabetes and occurs in five to ten percent of diabetic patients. Regular screening and timely management is important for good visual prognosis. This study was done to see the coordination and preparedness of stakeholders involved in Diagnosis, Screening, referrals and management of diabetes and diabetic retinopathy in Bihar. Experts from different departments i.e. endocrinologists, ophthalmologists and primary care physicians are also involved.

Methods: The study was carried out from 1 February to 30 April 2025. The tool for assessment of diabetic retinopathy and diabetes management systems was developed by the World Health Organization. It was used for the assessment of major stakeholders like endocrinologists, ophthalmologists, and ophthalmic assistants, nurses involved in diabetes care, patients and human resources from Ministry of Health and Population and international non-governmental organizations dealing with eye care services in Bihar. It was a directly administered questionnaire based interview as well as in depth qualitative assessment.

Results: State program officers, ophthalmologists, diabetic patients, Resident doctors, Nurses and nongovernmental organizations were interviewed. A total of 150 diabetic patients and 35 personnel involved either in policy making or management of diabetes and diabetic retinopathy were interviewed. The interview was done using structured questionnaire and in depth discussions. There were no diabetes associations. Services are offered mainly by private physicians, nursing homes and district level govt. hospitals, medical colleges and tertiary referral centres. Sometimes diabetes and diabetic retinopathy are diagnosed when patient has irreversible symptoms. The information to community is provided occasionally and through national/state level media, Health Mela, sporadic screening camps. All forms of diabetes care in private hospitals were funded out-of-pocket by the patients themselves. Few drugs are available at govt. hospitals, but stock out is frequent and utilized by less than 10% of patients.

Conclusions: Coordination should be strengthened for an effective and holistic management of diabetes mellitus making diabetes care and diabetic retinopathy services more accessible. Diabetes mellitus and its complications are becoming a public health threat in India and Bihar.

Keywords: Assessment; diabetes; diabetes retinopathy; Out of Pocket, Non-Governmental organization.

Introduction

Our Country hosts more than 100 million diabetic cases and it is increasing continuously due to life style and genetic factors. [1] Nearly 10 percent of adult population in India suffers from diabetes. Among the diabetics nearly half of them are unaware of their diabetic condition leading to systemic complication due to uncontrolled blood glucose level. Visual damage due to diabetic retinopathy is a challenging public health concern which may be checked if coordination and referral mechanism between the diabetes management services and diabetic retinopathy services take place in timely manner. Prevalence of diabetic retinopathy in Bihar is more than 30 % among the diabetic cases [2]. In hospital based studies and 16% in RAAB Survey. It is more as compared to other parts of India. Reasons may be lack of awareness about complications of Diabetes, Lack of proper screening and referral facilities. WHO projects that diabetes will be the seventh leading cause of death in 2030. [3] Simple lifestyle measures (healthy body weight; physical activity; healthy diet) have been shown to be effective in preventing or delaying the onset of type 2 diabetes.

Early diagnosis can be accomplished through relatively inexpensive blood testing. Treatment of diabetes involves lowering blood glucose and the levels of other known risk factors that damage blood vessels. Diabetic retinopathy (DR) is the fifth leading cause of visual impairment and the fourth leading cause of blindness in the world. Diabetic retinopathy is the cause of visual impairment for 4.2 million people. The onset of diabetic retinopathy is the result of long-lasting diabetes; the condition is worse if diabetes is poorly controlled. Prevention of visual impairment from diabetic retinopathy is achieved principally through control of diabetes, early detection of retinal changes, and timely treatment of sight-threatening lesions of the retina once the damage from diabetes is established. Anti-VEGF (vascular endothelial growth factor) are the mainstay of treatment. [4] Economic burden of diabetes and diabetic retinopathy is substantial, often more damaging to economically weaker population [5]. Diabetes and diabetic retinopathy are chronic in nature therefore it gives considerable time to the patient as well as health system to manage it in manner that controls the symptoms, prevents complications thereby reducing economic burden to the patient as well as health system. [6]

The primary objectives of the study is to

1. Assess the existence, availability and accessibility of health care services for diabetes mellitus (DM) and diabetic retinopathy (DR) in Bihar
2. To find out the existence and effectiveness of links between management of patients with diabetes and management of diabetic retinopathy
3. To identify the challenges faced by different levels of a health system in providing eye care for patients with diabetes

Methods: It was a cross sectional mix method study using structured questionnaire and in depth interview with the respondents. There were two groups of participants. One group included policy makers, State program officer, program implementers/managers, Nurses and Optometrists. The other group included Diabetic patients (with or without diabetic retinopathy) at all levels including tertiary center and Govt/private hospitals. The study was carried out from 1 February 2025 to 30 April 2025. The tool for assessment of diabetic retinopathy and diabetes management systems was developed by the World Health Organization. A customized and applicable version of this tool was used.

Sample size: Considering 15 percent diabetic patients having some knowledge about diabetes being a systemic disease especially diabetic retinopathy sample size comes to 138. Considering 10 percent attrition we aim to interview 150 diabetic patients.(absolute precision-5% and 90% confidence level).Other important stake holders to be interviewed were 35 in no. Ethical considerations were taken into account. Study was approved by institute Ethics Committee. Informed consent was obtained from all the respondents.

Type of study: Cross sectional study.

Inclusion Criteria: Diabetic patients with or without diabetic retinopathy.

Exclusion Criteria: Those who were severely ill.

Result: State program manager for Non communicable diseases and Blindness control program both were interviewed. Total eight service providing facilities were included into the study. There were two tertiary referral centers, two district hospitals and four sub district level facilities where either diabetes or diabetic retinopathy screening /management services are being provided. No of personnel interviewed were 35, including state level program managers. One community ophthalmologist, Two resident ophthalmologists, two physicians, two private ophthalmologists, eight MOICs, Ten optometrists and ten NGO/development partner representatives involved in managing diabetes and diabetic retinopathy were interviewed.

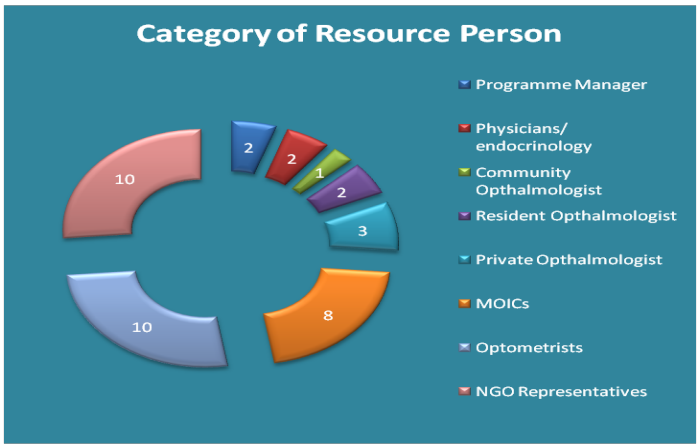

Figure 1: Category of Resource person

Diabetic retinopathy is taken care by blindness control program. According to both the state level program managers there is no structured coordinated program for referral of diabetic patients to get screened for diabetic retinopathy.

However under Public private partnership mode 200 vision centres are to be made operational for common ophthalmic conditions including diabetic retinopathy. It has facilities for Diabetic retinopathy screening. These centres are being operational in phase wise manner. There is no diabetic screening at village level in regular manner.

However Health Mela, Screening camps, compulsory blood sugar testing before any surgery have contributed in increasing awareness about diabetes and diabetic retinopathy. Despite diabetes being a public health challenge in our part of world consolidated efforts to put it at forefront of health care are missing.

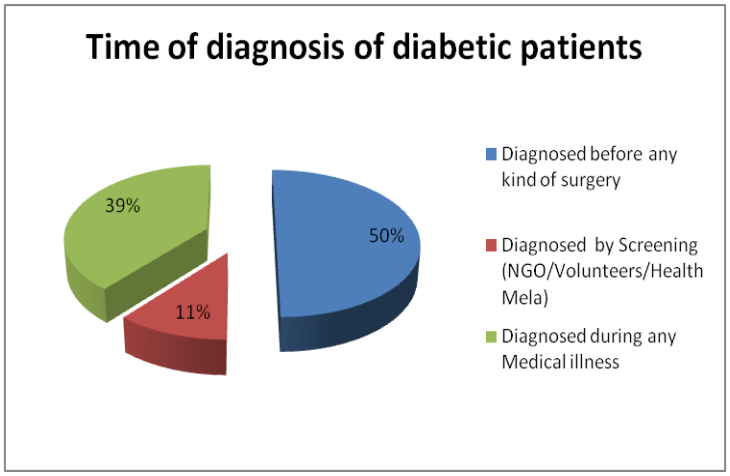

Figure 2: Time of diagnosis of diabetic patients

Total 150 Diabetic patients were interviewed. Age range was 38 to 81 years. Mean age was 54 years. Only 25% of them had any knowledge about diabetic retinopathy. There were 82 males and 68 females. Of the total 150 cases only 9 (6%) had diabetic retinopathy. Diagnosis of diabetes was done by screening program me in only 11% of the cases. Among all the cases 50% were diagnosed before some kind of surgery. Rest were diagnosed when they had some medical illness for which blood sugar test was prescribed. There was no financial or any other problem till diagnosis of diabetes. Almost all of them were advised for dietary and lifestyle changes. All Diabetic Retinopathy cases knew about diabetic retinopathy and importance of timely follow up. Reason being Diabetic Retinopathy is managed at specific tertiary referral centres or private ophthalmologists with good facilities. None of them were member of any diabetic registry or diabetic patients group. However Diabetes being common health conditions, almost everyone had friends or relatives (diabetic) with whom they could exchange information or seek general advice.

Table 1: Priorities, Policies and programmes (Service Providers N1- 35)

Q. No.	Questions	Yes	No	Don't know
1.	Is Diabetes Listed as a National Health Priority	30	0	5
2.	Is diabetic retinopathy listed as a priority in the National Programme	20	6	9
3.	Is there any national programme for nutrition	30	0	5
4.	Is there any plan /strategy for Diabetes control	24	0	11
5	If yes what does this plan cover			
	Awareness	24	NA	NA
	Screening	24	NA	NA
	Treatment	24	NA	NA

Table 2: Clinical Management Guidelines (Respondents-Service providers N1-35)

Q. No	Questions	Yes	No	Don't know
1.	Are there guidelines for management of diabetes	28	0	7
2.	Are there evidence based guidelines for management of Diabetic Retinopathy	25	0	10
3	Is regular training done for health personnel	0	20	15
4.	Are the guidelines being followed or used	15	8	12
5.	Are majority of involved workforce in diabetic care is following standard guidelines	10	10	15

Table 3: Networks and Linkages (Respondents-Patients)

Q. No.	Questions	No. of responses	
1.	Where are the newly diagnosed patients of diabetes identified		
	Community level	8	
	PHC	10	
	District	70	
	Tertiary referral centre	5	
	Private facility	57	
2.	Where are the newly diagnosed patients of diabetic retinopathy identified		
	Community level	0	
	PHC	0	
	District	12	
	Tertiary referral centre	80	
	Private facility	58	
3.	Where are follow up and ongoing care services located		
	Private facilities	60	
	Govt Facilities	82	
	Any other	8	
		Yes	No
4.	Is there a timely and proper referral mechanism present for diabetes	30	120
5.	Are the services provided for diabetes care included in Ayushman Bharat	10	140
6.	Is there a timely and proper referral mechanism present for diabetic retinopathy	8	142
7.	Are the services provided for diabetic retinopathy care included in Ayushman Bharat	2	148
8	Does out of pocket expenditure occurred during treatment at referral centre for a diabetic patient	140	10
9	Does out of pocket expenditure occurred during treatment at referral centre for a diabetic retinopathy patient	144	6
10	Did you spend money in travel to the referral centre	143	7

Result

Among the respondentsall the doctors were aware that diabetes is a priority as far as policies and guidelines are concerned. Nearly 2/3rd of the respondents knew that the policies to control diabetes have all components covered, but infrastructure and trained manpower is lacking. Regular training for manpower is not being done. Of the total respondents 57% said that training is not being done. Rest 43% didn't even know that there is a training program for diabetes or diabetic retinopathy management.

Knowledge about the guidelines was present among 43% of respondents. Few of them (22%) said that guidelines are not being followed. Rest 35% didn't know about any guidelines being in place. For disease diagnosis and treatment related questions we interviewed 150 diabetic patients of which 9 patients had diabetic retinopathy at the time of interview. Nearly 38% cases of diabetes get diagnosed at any private facility, either before surgery or during checkup for some illness, directly or indirectly related to diabetes. Some get tested for diabetes when any wound is not healing, or they are losing weight. Some get tested when they come to ophthalmologist for routine eye checkup. Nearly half of them were diagnosed at district level govt hospital for the same reasons. Very few were diagnosed at community level or PHC level; 5% and 6% respectively. The cases of diabetic retinopathy are diagnosed mostly at a tertiary referral centre or a private facility. Most of the patients are not aware of the referral mechanism when asked lead questions. But during discussion they opened up that if the doctor or health worker asks them to go to higher centre they don't go when they don't have symptoms. Regarding Ayushman

bharat scheme for diabetes and its complications only inpatient and complications are being covered so most of the patients are not aware of it. For treatment of diabetes and diabetic retinopathy patients are paying from their own pocket for travel as well as treatment. Very few less than 5% of patient didn't pay for treatment at referral centre because they were admitted for some other problem and their diabetes was taken care of.

Discussion

Considering the alarming situation of diabetes and diabetic retinopathy govt of India has revised the National Guidelines for management of Diabetic Retinopathy. India has one of the highest numbers of people with diabetes globally, with tens of millions affected and numbers rising due to lifestyle changes and aging population [7].

A significant proportion of people with diabetes are unaware of complications like diabetic retinopathy because early stages may be symptom-free[8]. Urban centers and major hospitals offer good diabetes management, including blood glucose monitoring, endocrinology clinics, and related care. Primary care and rural access are more limited, with fewer specialized providers and less frequent routine screening, meaning thereby many cases of complications go undetected until advanced. Many people don't get regular eye screening even when recommended. Regular screening for diabetic retinopathy is low (around 10%) among people with diabetes in India, well below recommended levels. [10,11,12]

Major tertiary hospitals and eye centers have retina specialists and treatment options (laser therapy, injections, surgery). However, many public health facilities lack sufficient equipment, trained personnel, or systematic screening programs, especially in rural and underserved areas. India is rolling out AI-based screening tools (like MadhuNETrAI developed by AIIMS and partners) to expand early DR detection, especially in settings without ophthalmologists. Some states have begun AI screening initiatives and government-backed programs to strengthen early diagnosis. People in rural or low-resource areas often lack access to retinal screening, endocrinologists, and retina specialists. Cost barriers may affect Advanced DR treatments (like laser therapy, injections, and surgery) outside public hospitals. [13,14,15,16] Ayushman bharat covers in patient treatment of diabetic retinopathy in private hospitals but patients are not aware of it. Private facilities utilize Ayushman bharat mostly for cataract cases.

Many primary and rural health facilities (PHCs, CHCs) lack essential diabetes medicines and diagnostic tools — surveys have found regular stockouts of diabetes drugs in rural centres. Without basic monitoring services (e.g., HbA1c testing, funded eye screening), early detection and routine follow-ups are limited, pushing diagnosis to later stages.

Routine diabetic eye screening isn't systematically integrated into diabetes care pathways; many diabetologists do not regularly refer patients for retina exams, and referral linkages between primary care and specialists are weak [17,18,19]. Many patients only get retinal exams when symptoms appear, by then, significant permanent damage has often occurred. Chronic disease management (including annual eye screening) carries out-of-pocket costs that many patients can't afford. This is compounded by limited insurance coverage for long-term management and complications. High costs of treatment and monitoring discourage regular follow-up and testing, leading to delayed diagnosis and worse outcomes.

Recommendations

Considering the enormity and challenging situation all the guidelines need to be brought down in practice. Routine diabetes screening at primary care level for pregnant women and adults >30 years may be followed across all primary health centers. Integrated eye screening at the time of diabetes diagnosis must be practiced. Tele-ophthalmology and AI-based retinal screening in rural areas, public awareness campaigns in local languages, strengthening primary healthcare under programs like Ayushman Bharat may improve quality and coverage of diabetes and diabetic retinopathy management systems.

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