

# An Assessment of Diabetic Retinopathy and Diabetes Management System in Nepal

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## ABSTRACT

**Background:** Visual damage due to diabetic retinopathy is a major concern which can be reduced through appropriate coordination and cooperation between the diabetes management services and diabetic retinopathy services. The study assessed the existence, availability and accessibility of health care services for diabetes mellitus and diabetic retinopathy in Nepal.

**Methods:** The study was carried out from 1 April to 24 June 2015. The tool for assessment of diabetic retinopathy and diabetes management systems developed by the World Health Organization was used for the assessment of major stakeholders like endocrinologists, ophthalmologists, 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 Nepal.

**Results:** Thirty-seven key stakeholders were selected for the study. Six out of fifteen ophthalmologists were unaware about the prioritization of diabetes as national health concern. The main function of diabetes association included patient education and awareness 18(48.6%), clinician education and awareness 16(43.2%). Thirteen professionals (35.1%) said that the patients were not found to be aware about diabetic patients' organizations. The information to community is provided occasionally and only through national-level media. All forms of diabetes care were funded out-of-pocket by the patients themselves.

**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 Nepal.

**Keywords:** Assessment; diabetes; diabetes retinopathy; Nepal.

## INTRODUCTION

A few decades ago Non-Communicable Diseases (NCD) were believed to be limited to developed countries and affluent societies, but now, NCDs have rapidly spread to the developing world, which are still struggling to control communicable diseases and estimated 80% of diabetic deaths occur in low and middle income countries.<sup>1</sup> Diabetic retinopathy (DR) may not directly lead to death but it is becoming a leading cause of blindness worldwide.<sup>2</sup> The global prevalence of diabetic

retinopathy was 34.6% among the diabetic population.<sup>3</sup> In Nepal, the prevalence of diabetes among people aged 20 years and above was 14.6% while the prevalence among people aged 40 years and above was 19% in a study conducted among the urban population and 14% prevalence of DR was also identified by some hospital based studies.<sup>4-9</sup> Curative, preventive and medical health services are provided by the government and other private sectors.<sup>10-12</sup> Expanding the services to far, inaccessible and remote areas is the challenge to be overcome during the second decade of Vision 2020.<sup>13</sup> The

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main purpose of this study was to assess the existence, availability and accessibility of health care services for diabetes mellitus and diabetic retinopathy in Nepal.

**METHODS**

The study was conducted from April 1st 2015 to June 24th 2015 among various stakeholders involved in eye care services of Nepal. The design was cross sectional and the study population were stakeholders responsible for diabetes and diabetic retinopathy care, health policy makers, government health workers and health professionals. Major stakeholders like the Ministry of Health and Population, Diabetes Association of Nepal, Non-governmental organizations (NGOs) and International Non-governmental organizations (INGOs) involved in provision of diabetes and eye care services, endocrinologists, ophthalmologists, and diabetes nurse and patients were included by using convenience sampling method among 37 people. Ethical approval was taken from Ethical Review Board of the Nepal Health Research Council (NHRC). Verbal consent of participants was taken before commencing the interview and confidentiality and anonymity was maintained.

The World Health Organization’s Tool for Assessment of Diabetic Retinopathy and Diabetes Management Systems (TADDS) was used for the assessment.<sup>1</sup> The questionnaire consisted of six sections with different subheadings like priorities, policies and programs, service delivery, health workforce, health technology, health information management systems, health promotion for diabetes and diabetic retinopathy and a section about health financing. The various sections included close ended, multiple response and some open ended questions. Desk review was done to collect information on the prevalence and status of diabetes and diabetic retinopathy in Nepal. Key informants identified from the organizations responsible for diabetes and diabetic retinopathy care were interviewed to collect information on the existence, availability, accessibility of diabetes and diabetic retinopathy care services and networking between these services. Qualitative information were coded and analysed and the quantitative data was managed using Statistical Package for Social Sciences (SPSS) version 21 for Windows.

**RESULTS**

Among 37 stakeholders i.e. ophthalmologists, endocrinologists, physicians, ophthalmic assistant, nurses, patients, human resource (HR) from ministry of health and population (MOHP) and HR from I/NGOs and maximum respondent were male 22(59.45%) in the study

(Table 1).

**Table 1. Demographic information of the respondents (n=37).**

Eastern	Number (percentage)
Male	22 (59.45)
Female	15 (40.55)
Stakeholders	(n=37)
Ophthalmologists	15 (40.55)
Endocrinologists	3 (8.10)
Physicians	4 (10.81)
Ophthalmic assistant	2 (5.40)
Nurses	5 (13.51)
Patients	3 (8.10)
Human resources from INGOs	4 (10.81)
Human resource from MoHP	1 (2.70)

Among the respondents, 16(43.2%) were aware about diabetes as a national health priority whereas 13(35.1%) were unaware. About 35% respondent replied that DR is listed as a national priority. Most of the respondents 16(43.2%) were aware of the national policy on food and nutrition and 17(45.9%) were well known about the national program on food and nutrition. Thirty two percent respondents said that there is no policy and program on diabetes prevention in Nepal. About 19 percent of the participants responded that the national plan covers primary prevention of diabetes and community awareness with patient education followed by clinical care, services and supply (Table 2).

**Table 2. Priorities, policies and programs diabetic retinopathy (n=37).**

Priorities, policies and programs	Yes (%)	No (%)	Don't know (%)
DM as national health priority	16 (43.2)	8 (21.6)	13 (35.1)
DR as a priority	13 (35.1)	9 (24.3)	15 (40.5)
National diabetes plan	10 (27)	15 (40.5)	12 (32.4)
National policy on food	16 (43.2)	5 (13.5)	16 (43.2)
National program on food	17(45.9)	7 (18.9)	13 (35.1)
National policy on DM prevention	8 (21.6)	12 (32.4)	17 (45.9)
National diabetes prevention program	7 (18.9)	12 (38.4)	18 (48.6)
National diabetes association	27 (73)	2 (5.4)	8 (21.6)

Guidelines for the management of DM	15 (40.05)	13 (35.1)	
Inclusion of DR in guidelines	14 (37.7)	11 (29.7)	12 (32.4)
Human resource from MoHP			

According to the respondents the main functions of diabetes association include patient education and awareness 18(48.6%), clinician education and awareness, policy development and advocacy and networking between service providers and people with diabetes (Table 3).

Coverage of the national plan	Number (percentage)
Primary prevention of diabetes	7 (18.9)
Complications (including vision impairment)	5 (13.5)
Community awareness and patient education	7 (18.9)
Clinical care, services, and supplies	6 (16.2)
Functions of national diabetes association	
Patient education and awareness	18 (48.6)
Clinician education and awareness	16 (43.2)
Policy development and advocacy	13 (35.1)
Networking between service providers and diabetics	13 (35.1)

Thirty five percent respondents told that the international guidelines were mostly used in tertiary level of health care system. The intended target audience for the international guidelines includes mostly the specialists 15(68%) and 7(32%) covers the primary health care workers. Forty three percent professionals believed that international evidence based guidelines cover the prevention of vision loss from diabetic retinopathy and 15(40.5%) believe that it covers treatment and follow up. Most of the respondents said that the international evidence-based guideline is mostly applicable at the tertiary level 16(43.2%) and secondary level 10(29.7%) of health care system. Majority of the respondents 23(62.2%) said that there were no recommended guidelines from the ministry of health. Evidence-based guidelines were also not available in Nepal. One of the most commonly used international guideline was the American Diabetes Association's Guideline 2015 (Table 4).

Applicability of the international guidelines for treating DM/DR	Number (percentage)
Primary	5 (13.5)
Secondary	11 (29.7)
Tertiary	13 (35.1)
Intended target audience for the guidelines	
Specialist	15 (68)
Primary health care worker	7 (32)
Availability of evidence-based guidelines	
Prevention	16 (43.2)
Treatment	15 (40.5)
Follow up	15 (40.5)
Applicability of the evidence based guidelines	
Primary	11 (29.7)
Secondary	10 (27)
Tertiary	16 (43.3)
Guidelines for clinical management of DM	
There are no ministry of health recommended guidelines	23 (62.2)
Ministry of health guidelines have been formulated but health professionals are unaware of their availability and thus they are not widely used	5 (13.5)
Missing (don't know)	9 (24.3)

The services for diagnosis and ongoing care of diabetes are available at the zonal, regional and tertiary level hospital and medical colleges. These services are provided by both private and public health care facilities. About 60% of respondents opined that the service location for newly diagnosed diabetics was in district region. According to the stakeholder the major barriers that prevent access to these services for the major part of the population were; poor socio-economic status, cost of the services, geographical distance to the services, lack of awareness, ignorance about the health status, poor transportation facilities and poor coverage

of health facilities throughout all geographical region.

Community screening programs for diabetic retinopathy, although very few were available. Known cases of diabetes were recruited for the screening program who were often referred by physicians or endocrinologists. Mostly ophthalmologists were involved in DR screening. Some private institutions with eye health care facilities were providing out-reach screening programme for DR, but the coverage was very minimal and limited to some geographical areas only. The cost of the screening was partly covered by the undertaking institution and partly by the participants (Table 5).

**Table 5. Diabetic retinopathy screening.**

Variables	Yes (%)	No (%)	Missing (%)
For patient identification and risk assessment	14 (37.8)	23 (62.2)	-
Patient education For diabetes	19 (51.4)	18 (48.6)	-
For diabetic retinopathy	10 (27)	27 (73)	-
Specialist diabetes centre	17 (45.9)	9 (24.3)	11 (29.7)
Routinely referred for DR	22 (59.5)	13 (35.1)	2 (5.4)
Referral of people who are asymptomatic	20 (54.1)	11 (29.7)	6 (16.2)
Referred only in vision loss	15 (40.5)	17 (45.9)	5 (13.5)
Eye examination for patients annually	21 (56.8)	8 (21.6)	8 (21.6)
Community screening program for DR	19 (51.4)	13 (35.1)	5 (13.5)
Outreach screening provided	13 (35.1)	8 (21.6)	16 (43.2)

The existing referral pathway for diabetes and eye care is a one way referral system. The practitioners were found to not to share information on diabetes status, diabetes control status and measures and complications with each other in any academic activities like continuing medical educational (CME) sessions. Non-governmental organizations are extensively involved in the care of people especially with diabetic retinopathy because majority of the eye hospitals are run by NGOs in Nepal.

The primary health care workers, especially the ophthalmic assistants, are taught about early detection and prevention of complications of diabetes. Awareness and health education are the main aspects of diabetic management included in the workshops. Likewise formal training by government is also seen essential on every aspect of continuing medical education to primary health care workers. Based the findings, the training opportunities and quality for DM and DR care providers are largely inadequate in Nepal.

The investigations/equipments for DM and DR available in Nepal are; biochemical laboratory tests for blood sugar, HbA1c (glycated haemoglobin), lipid profile, renal function test (RFT), urinary protein and microalbumin, blood glucose meter owned by the patients with diabetes or by health service, slit lamp, direct ophthalmoscope, sphygmomanometer, measuring tape, weighing machines, etc. Among the investigations availability dilated eye examination by ophthalmologist is the main technology used followed by retinal imaging- mydriatic camera, dilated eye examination by refractionist and retinal imaging -non mydriatic camera.

Almost all the respondents i.e 19(51.4%) stated that complications including diabetic retinopathy, treatment and follow up respectively are mostly recorded in their patient medical records in the hospitals followed by previous eye examination for DR 18(48.6%) and risk factors 16(43.2%).

The information about signs and symptoms, risk factors, complications and management of diabetes is disseminated in the community. Most of the professionals 13(35.1%) said that the people were not aware about diabetic patients' organizations.

## DISCUSSION

Nepal has adopted Vision 2020 and has formulated a strategic plan. As per the strategic plan for eye care services of the Ministry of Health and Population 2002-2019, DR has been acknowledged as an emerging threat to eye health in Nepal. Nepal is far behind in addressing diabetes in terms of prevention compared to the neighboring countries.<sup>10</sup> The prevalence of diabetic retinopathy was found to be 44.7% in a hospital based study in Nepal.<sup>5</sup> Similarly, another study conducted in fourteen centres by the WHO has also shown a prevalence of 35.8%, and studies from different areas of India found a prevalence rate of 34.1% and 37%.<sup>11-13</sup> National Diabetes Association of Nepal, and Diabetes and Endocrine Association of Nepal (DEAN) exist in the country. These associations are conducting some awareness activities using media like TV and radio programs for the dissemination of educational material related to diabetes prevention and advocacy for the policy development on diabetes care.

Nepal has a national policy on food and nutrition which targets the most prevalent nutritional problems in Nepal like: protein energy deficiency, Vitamin A deficiency, Iodine Deficiency, Iron Deficiency and other micronutrient deficiency.<sup>14</sup>

Diabetes occurs mostly in those over eating and consuming unhealthy diets leading to central obesity and inactive lifestyle, but it also occurs in children born to mothers who had poor nutrition during pregnancy. A non-communicable disease action plan is upcoming in Nepal and plans to cover and address the issues for the aspects on policy, plan, food and nutrition.

There is no national clinical management guideline for diabetes. The process for preparing the guidelines is being undertaken by the Ministry of Health and Population, Primary Health Care Revitalization Division (PHCRD).

Individual practitioners were found to use different international guidelines. The Ministry of Health and Population has still not framed any policies about the NCDs in the absence of evidence-based findings.<sup>15</sup>

The services for diagnosis of diabetes are available at the zonal, regional and tertiary level hospital and medical colleges. There is no authentic data available on the accessibility of the services, however almost all study participants pointed out that less than 40 % of the population can access the services.<sup>16</sup>

Diabetic patients were not routinely referred to seek eye care services for monitoring complications resulting from diabetes. Studies have shown that DR is a major challenge and is different in certain respects from other curable ophthalmic diseases.<sup>17</sup> Research has shown that early screening for DR is cost effective to reduce the morbidity rates.<sup>18</sup> About only 6.7% of patients were aware of the possible complications due to diabetes and had visited an ophthalmologist in a study done in India.<sup>19</sup> Another study examined the proportion of patients aware of possible diabetic complications in Nepal, and found that the knowledge is very low as compared to researches done in other countries.<sup>20-22</sup> The number of treating physicians from all the sectors is 10,197, i.e., 3.64 /10,000 population.<sup>23</sup> Community screening programs for diabetic retinopathy, although very few, are available. The services for diabetic retinopathy are available in few places and for few people. Evidence is seen where information sharing during CMEs has been beneficial for better understanding and sharing for diabetes management and DR.<sup>24, 25</sup> A country like Nepal depends on services from various Non-governmental organizations (NGOs) and International Non-governmental organizations (INGOs) who tend to be closely connected with the local communities.

The categories of health professionals available in Nepal and involved in diabetes management are

endocrinologists, ophthalmologists, primary care physicians, ophthalmic assistants and dieticians. The knowledge of primary health workers is updated through formal trainings by organizations and regular informal updates. Thus, the training opportunities and quality for DM and DR care providers is largely inadequate in Nepal.

Mainly dilated eye examination by ophthalmologist and retinal imaging using a mydriatic camera is used to perform retinal examination for diabetic retinopathy which are available only at the tertiary level of eye health care services.

The hospitals services do have a recall system for people with diabetes and for this purpose personal record books and information cards are used. The knowledge of disease burden is inadequate in Nepal with very few of the indicators being monitored on a regular basis. However the estimates of prevalence of DM and DR are available through some researches but the patients' records are not utilized.

Information about the signs and symptoms, risk factors, complications and management of diabetes is disseminated in the community but these events are sporadic. Health awareness creating activities for diabetic retinopathy are also undertaken. Studies have shown that media have played an important role for creating awareness among diabetics.<sup>16, 22</sup> A study done in Nepal has highlighted the lack of awareness in 51% of diabetic patients about their ophthalmic evaluations with a history of diabetes for more than 10 years duration which shows the lack of awareness among the patients and poor referral rates from primary-care physicians for ophthalmic evaluation.<sup>16</sup>

The treatment cost of DR and DM has been paid through out-of-pocket. Health insurance policy has been recently added for the patients in selected districts of Nepal and there is funding and subsidization for certain health care costs.<sup>26</sup>

## CONCLUSIONS

Nepal has taken a step forward by listing non-communicable diseases as a priority health concern but specific health policies, plans and programs are lacking to address the specific problem of diabetes and diabetic retinopathy. National clinical management guidelines are not available for management of diabetes and diabetic retinopathy in Nepal. The health care services available in district and above, especially the tertiary level health care centres are providing diabetes and diabetic retinopathy care services. Lack of awareness,

urban centred services, difficult geography, lack of transportation and poor socioeconomic status are the major barriers to accessing these health care services. The health care centre providing services for DM and DR are not found to collaborate with each other. Training on health worker for overall management and modern technology for DM and DR is required. Nepal also lacks a health information management system that collects epidemiological information about DM and DR. The coordination should be strengthened for an effective holistic management of DM making diabetes care and DR services more accessible to the people.

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