SPECIAL COMMUNICATION

Assessment of diabetic retinopathy and diabetes management systems in Pakistan using a WHO tool

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Abstract

Using WHO questionnaire known as TADDS(Tool for Assessment of Diabetic Retinopathy and Diabetes Management System), a country wide survey was conducted to assess the health care system for diabetes mellitus (DM) and diabetic retinopathy (DR). This would also provide any evidence of the presence and usefulness of links between the two. A total of 190 key informants for DR and DM services from 47 districts were interviewed. The answers were reviewed and any disagreement was resolved through discussion with stakeholders'. The final results were disseminated. The results showed that diabetes is listed as a priority; national plan exists but programme has not been implemented. Health professionals are unaware about Ministry of Health guidelines. There is infrequent networking between DM and DR care providers. Transport and cost are the main barriers for accessing these services. Out of pocket expenses provide 55% of health care financing.

Keywords: WHO, TADDS, Diabetes, Diabetic Retinopathy, Health System.

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Introduction

Pakistan is one of the top ten countries of the world for number of adults with diabetes.[1] These ten countries account for 67% of diabetics and 70 % of global healthcare expenditure on diabetes1. According to the IDF Diabetes Atlas 9th Edition 2019, 463 million were living with diabetes in 2019. Another 374 million are at risk of developing diabetes. At least half of diabetic population is unaware that they have the disease. Projections estimate that by 2045, 700 million people will have diabetes. Four out of the five diabetics live in low- and middle income countries. About half of the 4 million people dying from diabetes are below 60 years of age.[1]

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The prevalence of diabetes (DM) in Pakistan has been recently estimated to be 17%.[2] There is insufficient data on the prevalence of diabetic retinopathy (DR) in Pakistan. The reported DR prevalence rates vary widely from 10.6% to 91.3%.[3-13] In a recent systemic review,[3] the pooled prevalence of DR in Pakistan was found to be 28.78% in all diabetics and that of VTDR was 28.2% of all DR and 8.6% of all diabetics. Knowledge of diabetes risk factors, management, and care is low in Pakistan's general population.[14] A recent study from Pakistan that conducted analysis of 202 patients in 25 centers across the country found out that over three-fourths (77.2%) of the patients had never been assessed for DR.[13]

The World Health Organization (WHO) recommended stakeholder-based interviews for assessing DM and DR care systems at a national scale. Known as Tool for Assessment of Diabetic Retinopathy and Diabetes Management System (TADDS),[15] this can help in estimation of available resources and their access to the patients in need and thus helping in improvement of theDM and DR health services. The current study presents the results of WHO-TADDS Survey in Pakistan that was completed in year 2015.

This study is the first of its kind in Pakistan using WHO TADDS survey. It will enable health authorities to obtain an estimate of available resources and their accessibility by patients in need and to plan improvements in health services related to DM and DR. In addition, it corresponds to the health system building blocks and allows WHO member states to generate evidence and conduct advocacy to improve eye health and prevent avoidable blindness.

The primary objectives of the study were to:

1. Assess the existence, availability and accessibility of DM and DR health care services;
2. Assess the existence and usefulness of links between management of patients with diabetes and diabetic retinopathy;
3. Find out the problems at various levels of the health system in provision of eye care for diabetic patients;
4. Apprise different stakeholders of those aspects of health system that needs priority for future research and development.

Methodology

The study was conducted from July to October 2015 using the semi-structured questionnaire -TADDS. Proper approval was obtained from the Ethical Research Committee of the institution. The scope of study comprised of a national health systems approach and was not focused on individual care providers or institutions.

The TADDS consists of seven sections and 43 questions:

Section 1: Priorities, policies and programmes

Section 2: Service delivery

Section 3: Health workforce

Section 4: Health technology

Section 5: Health information management systems

Section 6: Health promotion for diabetes and diabetic retinopathy

Section 7: Health financing

Each section consists of both open and close-ended questions. At the end of each section, a Likert-type scale is given, ranging from 1(worst) to 4(best) along with matching answers. Each participant then independently chooses the most appropriate score that best represents the situation.

There are a total of 119 districts in the administrative units of Punjab (36), Sindh (29), KpK (34), Gilgit-Baltistan (10) and Azad Jammu and Kashmir (10). We aimed to include 50% of these districts which is equivalent to 60 districts. All the 119 districts were arranged alphabetically and were numbered in that order. Through computer generated random numbers, 60 districts were selected for the survey. Fifteen of these districts were excluded because of inability to get written or telephonic response from the stakeholders for various reasons. From Baluchistan only the capital city Quetta could be included due to security reasons.Islamabad was selected as it was the capital making a total of 47 districts for the final compilation.

The national stakeholders and key informants for DR and DM services (Tables 1 and 2), were identified and interviewed. The data was analyzed and results were shared with participants.A meeting was held with the National Committee of Eye Health and to finalize the results and eventually submit them to the government of Pakistan and the WHO.

A total of 190 stakeholders were interviewed from 47 different districts (Table 2). Of these, 136 were from the public sector while 54 belonged to the private sector. In addition to health care professionals and patients, following categories of respondents were included as stakeholders.

- Ministry of Health – National Coordinator for Prevention of Blindness
- World Health Organization country office - NCD programme officers
- National Committee of Eye Health (NCEH) members
- International non-governmental organizations (INGOs) involved in the provision of diabetes and eye care – Sigthsavers, Fred Hollows Foundation, CBM, and local Lions Clubs

The printed survey forms were posted to the selected professionals and on the appointed date, direct face to face interviews were conducted either by the principal author (TA) or by the pre-selected volunteers who were earlier briefed about the survey and its contents. The filled in survey forms were then collected either directly or by post. This methodology was adopted for 142 professionals where as 23 professionals who had a regular access to the internet were requested to fill the survey forms and send them by email as an attachment.

To facilitate the analysis, responses were recorded under the individual sections of the survey. The results were reviewed and discussed with the stakeholders to remove

Table-1: Stakeholders interviewed and their geographical representationa in the country.

	StakeholdersAdministrative subdivisions and districts covered within (number)							
	Capital Territory (01)	Punjab (22)	Sindh (11)	KpK (06)	Baluchistan (01)	GB (03)	AJK (03)	Total (47)
Ophthalmologists	04	36	09	11	01	02	05	68
Optometrists	01	06	01	0	0	0	0	08
Diabetologists	02	04	04	03	0	0	0	13
Physicians	05	37	09	07	0	03	03	64
Public health professionals	03	01	01	02	01	01	01	10
Diabetes Educators	0	01	01	0	0	0	0	02
Patients	11	14	0	0	0	0	0	25
Total Participants interviewed	26	99	25	23	02	06	09	190

KpK = Khyber Pakhtoonkhwa province GB = Gilgit Baltistan administrative region. AJK = Azad Jammu and Kashmir region

Table-2: Districts and Respondents in TADDS Survey.

SN	District-Province	People interviewed						
		Ophthalmologists	Optometrists	Diabetologists	Physicians	Public Health Professionals	Diabetic Educator	Total
A	Capital Territory							
1.	Islamabad	04	01	02	05	03		15
B	Punjab Province							
2.	Norowal	01			02			03
3.	Jhelum	01			01			02
4.	Dera Ghazi Khan	01			01			02
5.	Vehari	01			01			02
6.	Jhang	01			02			03
7.	Lahore	05		02	05		01	13
8.	Bahawalpur	03			02			05
9.	Lodhran	01			01			02
10.	Okara	01			01			02
11.	Muzaffargarh	01			01			02
12.	Rawalpindi	03	05		06	01		15
13.	Murree	01			01			02
14.	Chakwal	01			01			02
15.	Khanewal	01			01			02
16.	Attock	02			02			04
17.	Sargodha	02			01			03
18.	Gujranwala	01		02	01			04
19.	Rajanpur	01			01			02
20.	Faisalabad	04			02			06
21.	Gujrat	01			01			02
22.	Sheikhupura	01			01			02
23.	Multan	02	01		02			05
C	KpK Province							
24.	Peshawar	04		02		01		07
25.	Kohat	02			01	01		04
26.	Abbottabad	01		01	02			04
27.	Swabi	01			01			02
28.	Mardan	02			02			04
29.	D I Khan	01			01			02
D	Sindh Province							
30.	MirPur Khas	01			01			02
31.	Karachi (six districts)	04	01	03	04	01	01	14
37.	Sukkur	01			01			02
38.	Hyderabad	01		01	01			03
39.	Larkana	01			01			02
40.	Nawabshah	01			01			02
E	Baluchistan Province							
41.	Quetta	01				01		02
F	GB Province							
42.	Gilgit	01				01		02
43.	Skardu	01			01			02
44.	Astore				02			02
G	AJK Region							
45.	Mirpur	02			01	01		04
46.	Muzaffarabad	02			01			03
47.	Bagh	01			01			02
Total	47 Districts	68	08	13	64	10	02	165
		Ophthalmologists	Optometrists	Diabetologists	Physicians	Public Health	Diabetes Educators	respondents

TADDS = Tool for Assessment of Diabetic 8 Retinopathy and Diabetes Management System, KpK = Khyber Pakhtoonkhwa province. GB = Gilgit Baltistan administrative region. AJK = Azad Jammu and Kashmir region

Table-3: Section Seven: Health Financing .

Activity	% of cost funded by government	% of cost funded by private insurance	% of cost funded by patient	% of cost funded by NGO	% of cost funded by others
Part I: Diabetes					
Medical treatment	20-30	x	50-70	x	x
Hospital treatment	30-50	x	50-70	x	x
Drugs	30-50	x	50-70	x	x
Lab tests	50	x	50	x	x
Others	-	x	-	x	x
Part II: Diabetic Retinopathy					
Prevention (retinal screening)	x	x	x	100	100
Laser	30	x	70	x	x
VR surgery	30-50		50-70		
Others	x	x	x	x	x

VR Surgery = Vitreo-retinal surgery, NGO = Non-governmental organization

any disagreement. The final score for each section was the most frequently scored answer and which was shared with the participants. Finally a stakeholders' workshop was organized to achieve uniform consensus. All stakeholders were in agreement with the final TADDS results and endorsed the document.

Results

With 190 stakeholders interviewed from 47 districts all over the country it can be presumed to be one of the largest such study published to be conducted. Similar studies from Iran[16] and Nepal[17] have also been published where the numbers of respondents have been 14 and 37 respectively.

Not all the sections of the survey were answered by everyone. The public health professionals were more prompt and informative about section one, while patients were specifically asked about health financing – section seven. The physicians and ophthalmologists were more forthcoming for sections two to six and to some extent for section seven also.For the first six sections results along with the final score for each section which is the most frequent score among all transcripts, is given below. The results for section 7 are tabulated separately in Table 3.

Section One: Priorities, policies and programmes- Part I: Existence of priority, policies and programmes for DM

2-DM is listed as a priority; there is a national plan but no programme has been implemented.

While the draft of the national health policy 2010 and at least two provincial health sector strategies make specific references to control of NCDs including diabetes, there is at present no action plan to implement the strategies, nor have resources been allocated for these components of the strategies. A national action plan for NCDs exists but was never implemented and this may need updating before the provinces adopt it for implementation. WHO Country Cooperation Strategy can play an important role in development of multi-sectoral public policies through a national commission or task force for coordination.

Section One Part II: Guidelines for clinical management of DM and DR

2 - Ministry of health guidelines have been formulated but health professionals are unaware of their availability and thus they are not widely used.

The key professionals involved in management of DM and DR are not aware of any policies and plans. Government should ensure that all relevant policies and plans are regularly shared with key stakeholders including professionals and administrators. There is insufficient engagement of National Task Force for Diabetic Retinopathy with other key stakeholders working for preventing and controlling diabetes and this is limiting the impact and outreach of diabetic retinopathy services. The Task Force should be mandated to interact with key stakeholders for implementation of national policies and guidelines.

Section Two: Service Delivery- Part I: Location of DM services and accessibility to population in need

2 - Some services are available to part of the population

Section Two: Service Delivery -Part II: Networks between the care providers for DM and DR

2 - There is occasional collaboration between separate providers of care for DM and DR. Few centers provide patient-centered care.

There does not generally exist a well laid out screening process nor is the collaboration with medical or endocrinology departments well established to conduct screening for diabetic retinopathy in patients attending the diabetic clinics. There are a certain number of referred patients who never reach the eye physician and are lost on the way. Thus there is a strong need to strengthen the

referral channel.

The diabetes care and diagnostic services are available at secondary and tertiary care level, while DR care and diagnostic services are available mostly at tertiary level and above. The top four most common barriers identified by the respondents were poverty, illiteracy, lack of transport and facilities. The health sector strategies of Punjab and KpK aims to improve the quality and access to DM services. If these strategies are given the chance to take practical shape, the access to quality services will increase by diluting number of barriers identified by the respondents in the survey.

Section Three: Health Work Force- Training opportunities and quality for DM and DR care providers

3 - Training is available only in large cities and hospitals.

Diabetic eye disease can be managed through medical or surgical options. There are very few vitreo-retinal (VR) surgeons in the country. There is a need to develop separate cadres for medical and surgical retina training programmes and enhance facilities and support for VR surgical training. Training of optometrists in screening for diabetic retinopathy is generally lacking and so is the collaboration with centers for training of diabetic educators. Therefore special training for optometrists in diabetic retinopathy screening programmes should become a regular feature at the tertiary level. Similarly there is a strong need to expand and strengthen the diabetic educators training programme in the public sector.

Section Four: Health Technology- Accessibility of health technology

2 - Modern examination technology is available only in major hospitals and private clinics.

Essential health technology is available at secondary and tertiary level of health care. However, there is a significant lack of back up services for repair and maintenance. The biomedical engineers are mostly not available; the procedural and financial bottlenecks further complicate the issue. The training facilities for equipment engineers are very limited in the country. Therefore training programmes for instrument engineers/maintenance technicians should be expanded and strengthened.

Section Five: Health information management systems - Knowledge of disease burden

3 - Prevalence of both DM and DR is known or has been estimated; patients' records are used to analyze data at national level.

The District Health Information System (DHIS) provides an important inroad into planning and monitoring of services for diabetes mellitus. However, data on diabetic retinopathy and treatment with laser or surgery are not readily available or disaggregated by gender. Further detailed reporting for diabetic retinopathy may not be feasible under a DHIS, but scope can be piloted for incorporation as part of an add-on Eye Health Information System.

Section Six: Health promotion for DM and DR: Information / education provided to the community/patients on DM and DR

2 - Information to the community is provided occasionally and only through national-level media; not all patients receive education.

Policy makers need to be taken into confidence about the fast emerging epidemic of diabetes and its adverse effects on health and economy of the country. Patients are not aware of the different aspects of diabetes and its management and they are also not aware of the facilities available for this purpose. Therefore relevant education at professional, public and patient level is mandatory and all communication channels must be regularly used. As a part of Corporate Social Responsibility, the private sector must be engaged for this purpose.

Section Seven: Health Financing: See Table 2

Public sector health facilities and hospitals try and provide free anti-diabetic medicines and insulin, but their availability is sporadic. Furthermore, no specific budgetary allocation is made for diabetic services at public sector hospitals. The hospitals are not mandated to charge for services like laser or costly vitreo-retinal surgery. While centers run by NGOs and private sector do charge for most services, health insurance schemes at present provide cover for outpatient treatment like medicine and in-patient surgery for diabetics but with a substantially higher premium and with very limited scope. Laser treatment is apparently not covered under the insurance scheme. Laser services should be provided as a social protection measure for the poor. Collaboration with other organizations involved in diabetes work needs to be facilitated to leverage financing for treatment of diabetes and screening high risk patients for diabetic retinopathy.

Conclusion

In Pakistan, diabetes is listed as a priority; but no programme has been implemented. Health professionals are unaware of MoH guidelines. Transport to the health facilities and the cost of service are the main barriers to access DM and DR services. There is occasional collaboration between separate providers of care for DM and DR. Training opportunities for DM and DR care are

available only in large cities and hospitals. Information and education to the community is provided occasionally and only through national-level media. About 35% financing of health care is by government, 55% is through out of pocket expenses and 6% by health insurance.

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