

Situational Analysis and evaluation of existing services for Diabetic Retinopathy in India: Preliminary results

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Background

- 60 million in India have diabetes.
- Estimated that 6 million of them have sight threatening retinopathy
- Early detection and management is the key to control of blindness/ visual impairment due to DR
- There is no organized screening program for DR in India
- Varied approaches are used for screening and treatment
- Evidence on what works and how effectively is lacking
- Results from the present study will be used to develop need-based strategies which can be scaled up in the region and globally

Methods

- Study conducted in 10 biggest cities in India as per the 2011 census
- Bhubaneswar (Orissa) added to give adequate representation to the eastern part of India
- Study adopted a multi method approach (both quantitative and qualitative)
- Not planned to be representative but the cities covered 7% of Indian population
- Time line of 3 months for data collection
- 5 teams collected data simultaneously after 2 day training at Hyderabad

INDIA



Methods

Protocol adopted:

- In-depth interviews with heads of ophthalmology departments/ eye clinics/ retina units if available
- In-depth interviews with heads of diabetology/ internal medicine units
- Interviews with counselors and dieticians
- Interviews with Patients attending diabetic clinics
- Interviews with patients attending diabetic retina clinics in eye hospitals
- Evaluation of existing/ known diabetic retinopathy models being used in India

Coverage

Institution	Proposed to be covered	Covered and data entered	% Achievement till date
Eye hospital diabetic services	85	80	94.1
Diabetic clinics	75	71	94.7
Counselors/ Dieticians	26	22	84.6
Patient interviews in diabetic clinics	300	285	95.0
Patient interviews in retina clinics of eye hospitals	375	366	97.6
Evaluation of Diabetic Retinopathy models	14	10	71.4
Total Units	875	834	95.4

Observations from Eye Hospital Retina Units

Hospital Parameters	No.	%
Public funded institutions	20	25.0
Private not-for-profit	10	12.5
Private for profit	50	62.5
Specialist eye hospitals with satellite clinics	34	42.5
Specialist eye hospitals with no satellite units	27	33.8
Eye department in a general hospital	19	23.7
Mean beds available for in patient care	40	
Mean annual out patient consultations	35,452	
Mean annual lasers for DR	437	
Mean vitreo-retinal surgery	155	

Major Observations from eye hospital retina units

- Registration systems are generally inadequate and are not able to provide disaggregated information i.e. 52% hospitals could not provide break up of how many STDR were seen
- 2/3 hospitals provided dedicated retina clinics
- 37.5% of eye hospitals did not have laser facilities
- 44% did not perform vitreo-retinal surgery
- 50% of hospitals stated that their ophthalmologists needed training in medical retina
- 69% hospitals did not have a retinal photographer even though fundus cameras were available

Major Observations from eye hospital retina units

- Public funded hospitals were worse off in relation to retinal photographers
- In more than half the hospitals there were no counselors available
- 60% eye units had equipment available for DR diagnosis and treatment
- Only 1/5 of the hospitals had written protocols on DR treatment available in the clinics
- Only 50% provided information sheets to patients
- Only 35% hospitals had community out-reach services

Observations from Diabetic Clinics

Hospital Parameters	No.	%
Public funded institutions	25	35.2
Private not-for-profit	8	11.3
Private for profit	38	53.5
Multispecialty hospitals	39	54.9
Polyclinics	4	5.6
Stand alone diabetic clinics	28	39.4
Teaching hospitals	27	38.0
Dedicated diabetic clinic	41	57.7
No network with eye units	19	26.8

Major Observations from diabetic clinics

- Most units did not have counselors /dietitians
- Only 30% of diabetic clinic personnel trained in direct ophthalmoscopy
- Most diabetic units had in-house facilities for diabetic lab investigations
- A fifth of the clinics also had a fundus camera (Private for profit sector was better equipped)
- 66% of the diabetic units did not have any vision charts (Public funded hospitals had the least)

Major Observations from diabetic clinics

- Printed protocols for management/ detection of eye problems were uncommon
- 50% clinics received regular referrals from ophthalmologists
- 2/3 provided information sheets for diabetics in the clinics
- Only a quarter of the clinics send a reminder to patient for follow-up visit
- Physicians regularly refer diabetic patients for an eye examination

Observations: patients attending diabetic Clinics

Hospital Parameters	No.	%
Public funded institutions	129	45.3
Private not-for-profit	36	12.6
Private for profit	120	42.1
Patients in Metros	161	56.5
Patients from non metros	124	43.5
Mean age of interviewees	54.2 yrs	Range (18-84 yrs)
Male	143	50.2
Female	138	48.4
Graduates or above	98	34.4
Cannot read or write	85	29.8
Mean duration since diagnosis of diabetes	8.1 years	
Diabetic state > 10 years	77	27%

Major Observations: patients attending diabetic clinics

- 50% visit their physicians every month
- A third of the diabetics are on insulin
- 6% take traditional medicines
- 62% depended on their counselors for information
- 30% also depend on friends/ family for information
- Only 13% depend on mass media (Radio/ TV/ Papers)
- A fifth of diabetics perceive stress as the cause for their diabetes
- 50% of diabetics have another family member who is also diabetic
- 41% of diabetics also have high blood pressure

Major Observations: patients attending diabetic clinics

- Most lab tests are done at the clinic itself
- Less than half reported that their eyes were examined at the clinic
- Median time spent by treating physician with patient is 10 minutes
- 2/3 do not monitor their sugar levels at home
- The biggest challenge faced by patients is control of diet (44%)
- 60% are aware that blindness/ visual impairment is a major complication
- Only 1/5th knew that diabetes affects the retina

Observations: diabetics attending DR Clinics

Hospital Parameters	No.	%
Public funded institutions	114	31.1
Private not-for-profit	61	16.7
Private for profit	191	52.2
Patients in Metros	226	61.7
Patients from non metros	140	38.2
Mean age of interviewees	55.5 yrs	Range (26-87 yrs)
Male	202	55.2
Graduates or above	96	26.2
Cannot read or write	33	9.0
Mean duration since diagnosis of diabetes	11.5 years	
Diabetic state => 10 years	199	54.5%

Major Observations: diabetics attending eye hospitals

- 1/3 of patients were on injectable insulin
- 2/3 of patients stated that they depend on private physicians for diabetes
- Only 10% used general physicians for diabetic control
- Only 1/3 patients monitor their glucose status at home
- Only half stated that good control meant keeping sugars in check
- Nearly half the patients stated that they had visual impairment at the time diabetic retinopathy was detected

Major Observations: diabetics attending eye hospitals

- 55% (204) detected with DR at base hospital
- 25% (97) at outreach camps or vision centres
- Only 5% (20) were detected at diabetic clinics or were referred from diabetic clinics
- 27% stated that distance was a barrier to accessing services of eye hospitals
- A third stated that they did not receive any information on diabetic retinopathy at eye hospital
- 25% felt information provided was inadequate
- Only 10% accessed information from mass media
- 40% attributed DR to long duration of their diabetic state

Conclusions

- 60% eye hospitals equipped for DR diagnosis & treatment
- Low output of lasers/ surgery in many eye hospitals
- Need for training in medical retina identified
- Ophthalmologist led services for DR predominates in India
- Most diabetics presented very late and after vision loss at eye clinics
- Written protocols for patient management not enforced
- Only a third of the eye hospitals were engaged in extending services for DR into the community
- Hypertension was a common risk factor in those with diabetic retinopathy

Conclusions

- Self monitoring of diabetes is poor
- Knowledge that diabetes affects the retina is low
- Vision examination at diabetic clinics is inadequate
- Need for better networking between diabetic clinics and eye hospitals
- Health Information Systems are not being optimally utilized
- Tracking systems for follow up of diabetic patients inadequate
- Inter personal communication channels were most effective for awareness.
- Existing mass media approaches not very popular
- Information gap for credible information for diabetics

Next Steps

- A consultative summit on diabetic retinopathy is being organized at Hyderabad, India (12th-14th April 2014) with support from the Trust
- Findings from the study will be presented to agencies, professional bodies, institutions and individuals across the Commonwealth that provide services for people with diabetes and diabetic retinopathy
- The aim is to develop ways to increase public awareness of diabetic retinopathy, identify priorities for control, and delineate short and medium term plans.
- Expected outcomes include agreement on strategies to be adopted, a detailed plan of action for the next 12 months followed by an outline of activities from years 2 to 5.