Community Perception and Service Utilization of Diabetic Retinopathy Management Project in Gaddap Town

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Purpose: To find the changes in the community perception and service utilization of diabetic retinopathy management project in Gaddap Town.

Study Design: Cross sectional study.

Place and Duration of Study: The first phase of the project covered Jannuary 2006 to December 2008, second from Jannuary 2009 to Dec. 2011 and final from Jan 2012 to March 2015 in Gaddap town.

Material and Methods: A community based project was initiated by Al-Ibrahim Eye Hospital Karachi to devlop a replicable model for prevention and control of diabetic retinopathy in Gaddap town. All individuals in the age group 30 years were included except those with history of any addiction or any chronic disease. Post prandil (2.5 hours after breakfast) blood sugar levels was checked with Glucometer. Blood glucose level of 140 mg/dl was considered non diabetic, 199 mg/dl was considered latent diabetes and 200 mg/dl was considered as diabetes. Diabetics were screened for retinopathy. Diabetics with retinopathy were referred to tertiary center for management.

Results: Blood screening was availed by 42,998 persons with combined mean age of 36.26 ± 9.8. During three phases response to blood screening was 23%, 14.1%, 13.8% and to retinal screening was 26.57%, 55.6%, 81.1%. Turn out at tertiary center was 18.1%, 24%, 42.2%. Acceptance of Laser therapy was 17.3%, 83.3%, 68.4%.

Conclusion: Service utilization is a challenge; but it can be improved with persistant awareness, councilling, quality and patient friendly service.

Key words: Service acceptance, Diabetic retinopathy; Diabetic Screening.

D iabetic retinopathy (DR) is the fifth-leading cause of global blindness affecting 1.8 billion people worldwide and is the cause of 4.8% of the world blindness. It is the most common cause of blindness among people of working age in the developed world[1-3]. Prevalence of diabetes in Member States of the WHO Eastern Mediterranean Region ranges from 3.5% to 30%.[16] National studies have shown that 10% of the people in age group of ≥ 30 years[4,5] have diabetes type 2 in Pakistan. Prevalence of DR in Pakistan as reported in Gaddap study was 27.43%[6] and according to DAP study was 24.7%[7]. An

important aspect of diabetes and its complication is its silent nature. At least 25% diabetic remain unknown[8] and DR remains asymptomatic until it causes damage and can lead to blindness without giving any warning symptom. There exists enough evidence that if diabetes is detected early and controlled properly risk of DR is greatly reduced. Not only that; but optimum control of blood glucose, blood pressure, and possibly blood lipids remains the foundation for reduction of risk of retinopathy development and progression[9]. If DR is detected early, its progress can be checked or even regressed. If DR progresses to sight threatening

diabetic retinopathy (STDR) and is detected early, timely laser therapy with or without anti VEGF is effective for preservation of sight in proliferative retinopathy and macular edema[9,10]. Once DR reaches advanced stages surgery is indicated which is very costly due to scarcity of trained human resources and advanced equipment. In low-income countries like ours, local health-care systems do not have the personnel and financial capacity to cope. That is why emphasis is put on primary prevention by detecting diabetes, DR and STDR as early as possible to ensure early intervention[11]. another important constrains in developing countries is poor "utilization" of the available services. According to WHO globally only a quarter of people in need currently use eye services[12]. A method is to be evolved which can respond to this challenge and provide an accessible method of management of diabetes retinopathy.

With this intention in mind a community based project was initiated in Gaddap Town with the support of Sightsavers to find out a replicable model for the prevention and management of diabetes related blindness (DRB) with special attention to DR. Project continued for ten years (January 2006 to March 2015). This study reports challenges and changes in behavior of the community during project.

MATERIAL AND METHODS

This was an observational, cross sectional study with Non-probability convenient sampling at Gaddap town as service project from January 2006 to March 2015. An approval from "Research Ethical Committee" (REC) of the Isra Post Graduate Institute of Ophthalmology was taken to report the project outcomes. Community based project "prevention and management of diabetic retinopathy" was initiated in January 15, 2006. Every three years the performance was reviewed and some changes in the strategies were made. The first phase of the project covered Jannuary 2006 to December 2008, second from Jannuary 2009 to Dec 2011 and final from Jan 2012 to March 2015.

Awareness and education material regarding diabetes and diabetic related blindness was prepared after consultation. Community was sensitized through LHWs, family physicians, religious leaders, community based organizations using electronic as well as print media. While most of the respondents were referred by LHWs, medical and paramedical staff, few patients attended on their own.

All individual ≥ 30 years age group irrespective of gender were included. Drug addicts and those with chronic diseases were excluded from this project.

Blood screening for diabetes was done in primary eye care (PEC), centers established in rural health centers (RHC) of Gaddap town. In the first phase, there were six centers reduced to three in next two phases. Post prandil (2.5 hours after breakfast) blood sugar levels was checked with Glucometer by Ophthalmic technician. Blood glucose level of ≤ 140 mg/dl was considered non diabetic, ≤ than 199 mg/dl was considered impaired glucose tolerance (IGT) diabetes and ≥ 200 mg/dl was considered as diabetetes.[10] In the first and second phases, an appointment was given for retinal screening, whereas in the third phase retinal screening was done on the same day. Diabetic patients were counselled by "Diabetic educator" during 2nd and 3rd phases.

Retinal screening was done at PEC centers. Consent was taken from respondents coming for retinal examination and the pupil was dilated with Mydriacyl 1%. The fundus was examined by resident ophthalmologist with direct ophthalmoscope in the 1st phase, by the retina specialist with direct as well indirect ophthalmoscope in the second phase and by optometrist with direct ophthalmoscopy in 3rd phase. Patients having DR were referred to tertiary center (AIEH). Diabetes counselling was provided to the patients in 2nd and 3rd phases of the project by the Diabetic educator".

At the tertiary center (AIEH) "Retina specialist" examined the patients after taking consent and dilating pupil using 90D fundal lens and slit lamp. DR was confirmed and graded according to ETDRS classification.[11] Patients with non-proliferating diabetic retinopathy without macular edema were labelled as Non Sight threatening diabetic retinopathy (NSTDR) and were given follow up at AIEH. Patients with proliferative diabetic retinopathy (PDR), clinically significant macular edema (CSME) with or without DR were labeled as Sight threatening diabetic retinopathy (STDR) and advised laser. Those with Advanced diabetic eye disease (ADED) after necessary investigations like were offered surgery. The patients were counselled by "Diabetic educator" and necessary consultation was provided by the physician. A standard Performa was used in all the phases for collecting the data.

To assess levels of knowledge, attitude and practices in the community regarding diabetes and DR two studies were designed during the project. Questionnaire based activates were conducted. First

study was done during the middle of the project (June-July 2012) and second study was undertaken after the end of the project (Jan – March 2015). In the first study, a sample of 527 individuals from all eight Union councils was drawn and interviewed. Second study (Jan to March 2015), was repeated on the same sample except 20 respondents who had either died or migrated. The data was analyzed through statistical package for social sciences version 20.0. All the continuous variables were presented in Mean ± SD. Categorical variables were shown in frequency and percentages.

RESULTS

According to 1998 census, Gaddap Town had population of 0.3 million with 100,000 (33%) people in the age group of ≥ 30 years. This was the target of our project. During all three phases covering 10 years, 42,998 individuals were screened for diabetes. The combined mean age of respondents was 36.26 ± 9.8. Male to female ratio in the beginning was found to be 3:1 and in the final phase 0.7:1 (Demographic characteristics of study population, detailed in Table 1.

Table 1: Demographic statistics of study population.

2006 – 2008	
Age, years	39.3 ± 10.2
Male	6406 (27.8%)
Female	16604 (72.1%)
Total	23008

2009 – 2011	
Age, years	36.5 ± 7.35
Male	3637 (33.4%)
Female	7222 (66.5%)
Total	10859
2012 – 2015	
Age, years	37.1 ± 6.92
Male	3950 (43.2%)
Female	5181 (56.7%)
Total	9131
Total 42998	
Total Male	13993 (32.5%)
Total Female	29005 (66.46%)
KAP 2012	
Age, years	32 ± 12.9
Male	287 (54.4%)
Female	240 (45.5%)
Total	527
Post KAP 2015	
Age, years	36.4 ± 12.6
Male	271 (53.4%)
Female	236 (46.5%)
Total	507

*Data shown in Mean ± SD and frequency and percentages (%)

Table 2: Comparative statistics for service uptake during 3 projects, spread over 9 years.

Years Target Population N = 100,000	2006 – 2008	2009 – 2011	2012 – 2015
Blood screening 43% (n = 42998)	23% (n = 23008)	14.1% (n = 10859)	13.8% (n = 9131)
Diabetes 6.86% (n = 2953)	7.5% (n = 1742)	5.5% (n = 597)	6.6% (n = 614)
Unknown Diabetes 24.6% (n = 727)	24.8% (n = 432)	24.6% (n = 146)	26.4% (n = 149)
Turn out for Retinal screening 42.6% (n = 1259)	26.4% (n = 460)	55.6% (n = 301)	81.1% (n = 498)
Diabetic Retinopathy 22.3% (n = 281)	26.5% (n = 120)	21% (n = 63)	19.6% (n = 98)
Turn out at tertiary center 28.1% (n = 79)	18.1% (n = 22)	24.0% (n = 15)	42.2% (n = 42)
Sight threatening diabetic retinopathy 44.3% (n = 35)	45 % (n = 10)	39.6% (n = 6)	45.2% (n = 19)
Intervention accepted 57.1% (n = 20)	17.3% (2 out of 10)	83.3% (5 0ut of 6)	68.4% (13 out of 19)

*Data shown in frequency and percentages (%)

Table 3: Referral pattern for past nine years of the study (n = 42998).

Period	Total Referred (Frequency)	LHWs (%)	RHC Doctors (%)	Family Physician (%)	Self (%)
1st phase	23008	50.55	31.17	7.37	10.9
2nd phase	10859	20.6	39.3%	6.4	33.5
3rd phase	9131	16.6	37.8	7.5	40.0

*Data shown in frequency and percentages

In the first phase (2006 – 08), Out of the target population 23% (23008) availed blood screening. Amongst the individuals screened, 5.02 % (1156) had Impaired Glucose Tolerance, 7.57% (1742) were diabetics amongst whom 24.8% (432) were unaware of their disease. All diabetics (1742) were given appointment for retinal screening at the same center. Turn out rate was 26.57% (460). On ophthalmoscopy, 26.5% (120) were found to have DR and were referred to AIEH for further management. Turn out at AIEH were 18.1% (22). Sight Threatening Diabetic Retinopathy (STDR) was found in 45% (10) and they all were advisedlaser, which was accepted by 17.3% (4).

In the second phase (2009 – 11) Out of remaining target population (76992), turn out for blood screening was 14.1% (10851). Out of these 6.14% (667) were found to have IGT, 5.4% (597) had diabetes with 24.6% (146) not knowing about their disease. All diabetics (597) were given appointment for retinal screening after counseling by the "Diabetic educator". Turn out rate (597) for retinal screening was 55.6% (301) amongst whom 21% (63) were found to have DR. All DR patients were referred to AIEH where 24% (15) turned up for further examination and 39.6% (6) were confirmed STDR. Patients accepting intervention were 83.3% (5).

In the final phase (Jan 2012 to March 2015), Out of remaining target population (66141), the turn out for blood screening was 13.8% (9131) with 6.44% (538) IGT, 6.6% (614) had diabetes amongst whom 26.4% (149) were unaware of their diabetes. Retinal screening was done in all the diabetics (614) on the same day. Retinal screening was accepted by 81.1% (498). DR was found in 19.6% (98), who were referred to tertiary center (AIEH) after counseling by the "Diabetic educator". Turn out rate at AIEH was 42.8% (42). On examination, 45.2% (19) were confirmed as STDR. All of these 19 patients were offered laser; but 68.4% (13) accepted laser (Comparative results Table 2).
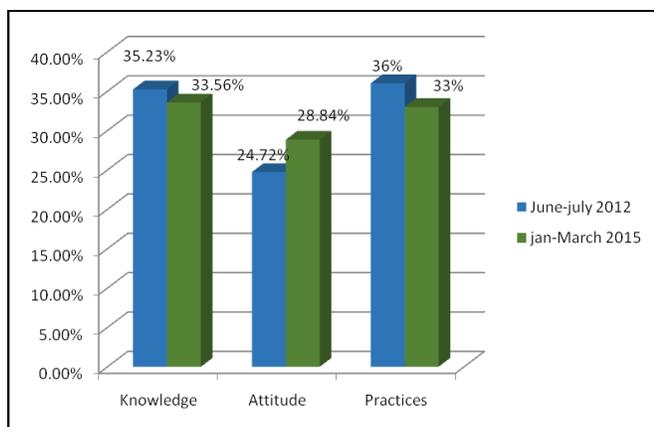
Source of referral for blood screening in initial period was 50% by LHWS and 11% on their own (self) which changed in the final phase to 16.6% by LHWs and 40% self. Referral by family physician remained 7.37% in the beginning and 7.5% in the end (Table 3).

The score for knowledge, attitude and practice regarding diabetes in the first study (Jun-July 2012) was 35.23%, 24.72% and 36%, while in the second study (Jan – March 2015) the respective figures were 33.56%, 28.84% and 33% (Fig. 1).
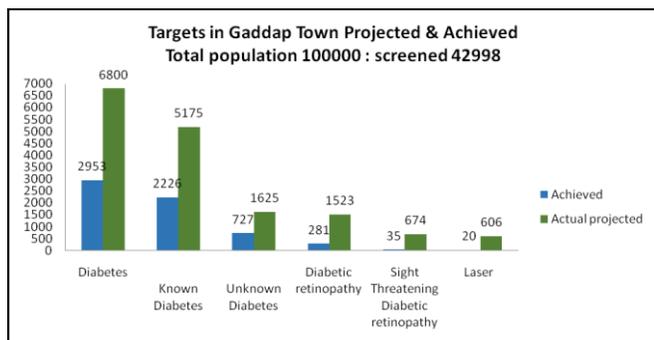
DISCUSSION

Gaddap town was selected for the project because it has a multi ethnic community and mixture of rural and urban culture. It has network of basic health units (BHU), rural health centers (RHC) and a tertiary center with well-developed vitro retina unit (Al Ibrahim Eye Hospital). It has 8 union councils and is located in district Malir. It is largest town area wise, stretching over an area of about 1800 sq. km; but smallest in terms of population with 0.3 million peoples according to 1998 census.[13] It was mostly agricultural but is fast turning into urban culture. Literacy rate is not more than 30%. It was expected to be an ideal town to develop a model for the prevention and management of blindness due to diabetic retinopathy.

Prevalence of diabetes type – 2 according to this study was 6.86% (24.6% Unware of diabetes). Impaired glucose tolerance was found in 5.6% people which is an important target for the primary prevention of diabetes mellitus. If these people continue their life style unchanged, there will be an addition of 3.24% (58% of IGT) more diabetics in the community after 3 years[9]. This study matches with national statistics of 7.6% to 11%[14]. As well as with study from UK which reports that 7.3% male and 8.6% females of Pakistani origin suffer from diabetes type 2[15].

Fig. 1: Comparison of Knowledge, attitude and practices for 2 phases of "Change of perception regarding Service utilization in patients with Diabetic retinopathy; (n = 527).

Fig. 2: Targets for Diabetic Related Blindness Projected and Achieved.

Diabetic retinopathy according to this study was 22.3% (281 from 1259) and STDR was 44.3% (35 out of 79 DR). Gaddap study reported higher DR (27.43%) and lower STDR (27.39)[16]. One study from DAP (Diabetic Association of Pakistan) reported 24.7% DR in 10768 diabetics (March 2009 – Dec. 2011)[17]. Second study (Jan 2011 to 2012) from the same center reported 21.2% DR and 39.5% STDR[18]. On the basis of these studies one can safely assumes that in 100 diabetic patients, 23 to 25 diabetics will have DR and 8 to 10 diabtics have STDR.

On the basis of the results of this project, one can highlight 6800 (5175 known and 1625 latent) diabetics, 5600 impaired glucose tolerance, 1523 DR, and 674 STDR in Gaddap town. As compared to this in actual we found 2953 diabetics (727 latent), 2411people with impaired glucose tolerance , 281 with DR and 35 with STDR (Figure 2).

These low figures as compared to projected are because of poor service uptake. At aggregate level 43% availed blood screening, 42.6% turn out for retinal screening, 28.1% turnout at tertiary center and 57.1% availed intervention (Table 4).

It is a common perception that the effectiveness of "prevention of blindness programs" is seriously hampered by the low levels of service up-take. Up till now as main focus in ophthalmology has been cataract, such studies are cataract related only. The effectiveness of prevention of blindness programs studies have been carried out in cataract uptake on the basis of which WHO states that globally only a quarter of people in need of eye care use eye services[12]. This is supported by evidence from studies conducted in India, Nepal and Pakistan which demonstrate levels of utilization of eye services, and uptake of cataract surgery ranging from 7% to 35%[18-20].

This study validates the hypothesis of "poor uptake of eye care services by community" in developing country like Pakistan in reference to diabetic retinopahthy. It has been generally argued at global and national levels that health care system unable to provide services to the people. The project findings contradicts with this common perception as service outlets established remained under-utilized as community was not willing to avail the eye care services. The project outlined some criticial challenges of the poor uptake of services.

First challenge is willingness of the community to get blood screened for diabetes. Only 43% people willingly availed the blood screening. During first three years when there were six screening centers, 23% individuals availed the service. In the second and third phases the screening centers were reduced to three which obviously reduced service uptake to 14.3% in the 2nd phase and 13.8% in the 3rd phase. This decreasing pattern inspite of awareness campaign using medical, paramedical personnels, print and electronic media to educate the community highlights the importance of easily reachable service outlets.

Solution
Gradual improvement in blood screening can be anticipated if it is carried out at Basic Health Unit (BHU) or at RHC level in addition to diabetes awarness activities at community.

Second Challenge was Devlopment of Referral Chain: Second challenge identified in the proejct was the poor turn out for retinal screening. When patients

were given date for retinal screening at same center where the blood screening was carried, only 26.4% turned out for follow up eye examination.

Introduction of Diabetic councelor was done during 2nd phase which increased turn out for retinal screening to 55.6% showing importance of diabetes counselling. Further improvement in the turn out for retinal screening was when retinal screening was offered on the same day (although optometrist did the screening instead of ophtalmologist or retina specialist). Acceptance of retinal screening in the third phase increased to 81.1%. Only those who objected to mydriasis refused screening. Non-mydriatic fundus camera (NMFC) could have improved the compliance for retinal screening still further. This was noted in a study done at "DAP" where NMFC was used, retinal screening was 100%[18].

This shows that acceptance of retinal screening is not the problem. Patient's turnout at the primary eye care center is important. Referal chain between the community and the primary eye care service outlet is to be established. This was facilitated by the diabetic educator at the time of initial diagnosis of diabetes.

Second component of the referral chain was between RHC and tertiary center. When the patients were referred to tertiary centr (AIEH) which was at a distance of 0-25KM from the community, the collective attendence was 28.1%. With persistance A&E program and councilling by the diabetic educator there was an improvement in attendance at tertiary center with the time. In the first phase the turn out was 18.1%, increasing to 24% in second phase and 42.2% in the last phase.

Solution to development of referral chain is initial awarness and education program in the community augmented awareness at the first level of contact when diabetes is diagnoseed, counselling through diabetic councelor at the time of retinal secreening and friendly, quality service at teritary center.

Third challenge noted in this study was the acceptamce of intervention. After screening of 42,998 individuals and identifying 2,953 diabetics, intervention was possible in 20 patients in ten years. In first phase (2 out of 10) 17.3% agreed for laser. In second phase laser acceptance incresase to 5 out of 6 patients (83.3%). In the final phaase intervention accpetance was 13 out of 19 (68.4%). Combined rate of intervention at the end of project was 57% in another study on laser uptake showed 70% acceptance[14]. Although six months post laser follow up was 21.2%.

These discouraging results had only one bright aspect. There was a gradual change in response of the community not only in service uptake; but in the behaviour of the respondent also (Table 2 & 3). In the period 2006 – 8, most of the respondents were referred by LHWs (50.5%) which reduced to 16.6% during 2012 – 15. Self attendence in the first phase was 10.9% which increased to 40% in the last phase. Change in the acceptance of the service was apparent in change of the gender ratio. In first phase females constituted 72.1% (16604 out of total 23008) with female to male ratio of 3:1. In the final phase females were 56.7% (5181 out of 9131) with a female to male ratio of 1:0.7. Initially members of the community were referred by LHWs with a greater influence over females. Less number of the males can also be attributed to fear of loosing income for daily wagers.

Solution to acceptance of intervention is awareness, councilling at each level of service outlet provision.

CONCLUSION

Challenges to the prevention and management of DRB are acceptance of blood screening, retinal screening and lasers. Solutions are establishing referral chain between the community and service outlets like BHUs, RHCs, tertiary centers by increasing awareness in the community through awareness program and councilling by the diabetic educator. The researchers strongly believe that quality and patient friendly services are very important solution for community mobilaization.

Collaborative efforts with government health department and the local CBOs in utilizing the health workers' network and awareness raising on DRB can bring behavioral changes and increased identification and treatment of diabetic related eye problems.

Linkages between primary and tertiary level health facilities can establish an effective referral chain, reaching people with preventive and curative treatment.

There is a dire need to train all local health professionals particularly woman health workers to create awareness about detection, prevention and control of diabetes, and encouraging them to refer the cases to health centers.

Blood screening at BHUs, retinal screening at RHC level by optometrist preferably using NMFC and strenthening of eye departments at DHQ hospitals as laser centers.

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Muhammad Faisal Fahim
Literature search, Analysis and interpretation of the data & critical review.

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