



TREATMENT SEEKING BEHAVIOUR OF DIABETIC PATIENTS WITH SPECIAL EMPHASIS ON FOLLOW-UP IN THE GOVERNMENT HEALTH FACILITIES

A case study of
Pudukottai district, Tamilnadu, India

Johns Hopkins Bloomberg School of Public Health, Baltimore, USA and
Indian Institute of Health Management Research University, Jaipur, India

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MASTER OF PUBLIC HEALTH

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TO WHOMSOEVER IT MAY CONCERN

This is to certify that Dr. Gopinath Thirugnana Sambandam, a student of Master of Public Health Program offered by Johns Hopkins Bloomberg School of Public Health, Baltimore in cooperation with Institute of Health Management Research University, Jaipur, has successfully completed his capstone project titled "Treatment seeking behavior of diabetic patients with special emphasis on follow-up in the government health facilities - A case study of Pudukottai district, Tamilnadu, India".

The student's approach to the study has been sincere, scientific and analytical. This Capstone is in fulfillment of the course requirements.

We wish him the best in all his future endeavors.



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**JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH
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CERTIFICATE BY SCHOLAR

This is to certify that the Capstone Project titled “Treatment seeking behavior of diabetic patients with special emphasis on follow-up in the government health facilities - A case study of Pudukottai district, Tamilnadu, India” under the supervision of **Prof. (Dr.) Suresh Joshi, MD** for award of Master of Public Health embodies my original work and has not formed the basis for the award of any degree, diploma associate ship, fellowship, titles in this or any other Institute or other similar institution of higher learning.



Gopinath Thirugnana Sambandam

MPH Candidate 2014-16

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15.	Dr. Subash Gandhi, MBBS	District Coordinator, Tamil Nadu Health Systems Project, Pudukottai District.	Coordinated the meeting of NCD staff nurses in Pudukottai district

LIST OF ACRONYMS

BMI – Body Mass Index

CBE – Clinical Breast Examination

CHW – Community Health Worker

ECG – Electro Cardio Gram

FBS – Fasting Blood Sugar

HPE – Histo-Pathological Examination

HT – Hypertension

DM – Diabetes Mellitus

NCD – Non Communicable Diseases

PCC – Patient Clinic Cards

PPBS – Post Prandial Blood Sugar

RBS – Random Blood Sugar

TNHSP – Tamil Nadu Health Systems Project

USG – Ultrasonography

VIA/VILI – Visual Inspection with Acetic Acid / Visual Inspection with Lugol's Iodine

VHN – Village Health Nurse

ABSTRACT

BACKGROUND

In an effort to address the Non Communicable Diseases (NCDs), the Government of Tamil Nadu has implemented NCD – Screening, Prevention and Treatment Program in 2012. Once screened positive, the patient is expected to visit that particular government health facility every month to receive drugs and every three months for lab investigations. Large number of treatment non-compliance has been reported and this study tries to find out the proportion of patients in different patterns of follow-up and further explores the possible reasons.

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RATIONALE

Regular follow-up of diabetic patients with the health care provider is of great significance in averting any long term complications. The number of patients lost to follow-up after is alarming and is a serious concern to both the implementers and funders of the program. This study tries to identify the gaps and provides valuable insights to policy makers.

OBJECTIVE

The study has the following objectives with a diagnostic approach for treatment non-compliance.

- To learn about treatment seeking behavior of patients from the perspective of key service providers – NCD staff nurses
- To identify the proportion of diabetic patients on different patterns of follow-up in the government health facility where they got enrolled during the months of Jan, Feb and Mar, 2014.
- To find out the reasons behind treatment non-compliance from the perspective of patients.

METHODOLOGY

The study has a mixed method approach with an exploratory design. The first part involves a group discussion meeting of all NCD staff nurses of Pudukottai district (Qualitative). The second part is an analysis of follow-up patterns using patient clinic cards. The third part is a cross-sectional telephonic survey of 90 conveniently chosen patients having valid contact numbers in the patient clinic cards. A semi-structured questionnaire was used in the telephonic interview.

RESULTS

Out of 4780 cases detected positive during January to March 2014, only 729 valid clinic cards were available for the study. Among those records available, nearly 70% were non-compliant to diabetes treatment. During telephonic interview, the key factors affecting treatment compliance were appearance of symptoms, insistence of doctors and other health workers, loss of daily wages, travel cost between home and health facility, awareness about disease, quality of drugs supplied, migration, travel and climatic conditions. Among those non-compliant patients, about 60% are found to be in continuous treatment either in a private clinic, or another government health facility.

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CONCLUSION

Considering the increased burden of Diabetes Mellitus and therefore increased state health expenditure, it is important to ensure that the services of screening programs are utilized to the maximum. These findings provide an opportunity for future research and policy amendments required in this area to ensure a patient centric approach.

BACKGROUND

Non Communicable Diseases (NCDs), principally Cardiovascular Diseases, Diabetes Mellitus, Chronic respiratory diseases, cancers like cervical and breast cancer, etc., have overtaken communicable diseases and become the leading cause of death and disability in India causing each year about 60% of all deaths (1). In the NCD Global Scorecard Report 2015 published in Lancet, India has a moderate performance in Governance of NCDs (57%), low performance in efforts taken to reduce risk factors (34%) and Surveillance and Research of NCDs (26%) and a very low performance in health system response (17%) (2).

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In an effort to address these NCDs, the state of Tamil Nadu implemented the NCD – Screening, Prevention and Treatment Program in all the 32 districts of the state in 2012 in two phases through the World Bank funded Tamil Nadu Health Systems Project (TNHSP).

The NCD program aims to opportunistically screen all people aged 30 years and above visiting the government health facilities in the state of Tamil Nadu for Hypertension (HT) and Diabetes Mellitus (DM). Additionally, women are screened for Cancer Cervix and Cancer Breast. A pilot project for HT was conducted in Sivaganga and Virudhunagar districts and for Cervical Cancer in Theni and Thanjavur districts in 2010. It was then up-scaled to all districts in a phased manner. The program was kick-started during June 2012 in 16 Phase I districts and during June 2013 in the next 16 Phase II districts. The screening methods for the four NCDs are shown in Table 1. Screening method for NCDs in Government Health Facilities of Tamil NaduThe total number of individuals screened and number of individuals detected positive in the program from July 2012 to March 2015 are given in Table 2.

NCD	Screening method (at 1°, 2° & 3° levels)	If normal, repeat screening after
Hypertension	Blood Pressure measurements	1 year
Diabetes Mellitus	Random, Fasting & Post-prandial Blood Sugar levels	1 year
Cancer Cervix	Visual Inspection with Acetic Acid / Visual Inspection with Lugol's Iodine (VIA/VILI) technique	2 years
Cancer Breast	Clinical Breast Examination (CBE)	2 years

Table 1. Screening method for NCDs in Government Health Facilities of Tamil Nadu

NCDs	No. of individuals screened	No. of screened positives	Positivity Rate
Hypertension	25,031,749	2,459,680	9.83%
Diabetes Mellitus	19,498,490	834,353	4.28%
Cervical cancer	8,732,828	318,175	3.64%
Breast cancer	10,781,128	133,946	1.24%

Table 2. Positivity rate of NCDs (based on data during period Jul 2012 to Mar 2015)

This capstone project focuses mainly on the NCD, Diabetes Mellitus. As part of the NCD program, TNHSP has recruited exclusive NCD staff nurses at the rate of one per Primary Health Center (PHC), two per Government Hospital (GH) and two per Medical College Hospital (MCH). They have been trained for various skills required for screening the above four diseases. For screening and follow up of Diabetes Mellitus, they are trained for performing basic examination (anthropometric measurements), laboratory procedures like testing of blood samples for glucose levels, diabetic foot care procedures, maintaining registers, drugs and stocks, counselling on Life Style Modifications (LSM) and making online entries in the NCD HMIS screens.

If confirmed for Diabetes Mellitus (RBS>200 mg/dL with symptoms or FBS>125 mg/dL or PPBS>200 mg/dL) in screening, patients are requested to visit the government health facility once in every month for drugs and during their every third month, laboratory investigations (FBS/PPBS, Serum Creatinine, Serum Cholesterol and urine albumin) will be done. During their follow-up visits, they must visit the NCD corner where the NCD staff nurse records the visit in the follow-up register and checks blood pressure and takes anthropometric readings. The NCD staff nurse also maintains a Patient Clinic Card for each confirmed hypertensive and diabetic case in her health facility. The PCC contains socio-demographic profile of the patient, LSM advices given, physical examination, follow-up visits made, lab investigations done, treatment given and referral details of the patient. A scanned copy of PCC is attached in Annexure III. In case, the patient presents with complications, they are referred to the nearest secondary and tertiary institutions for higher investigations like Electro Cardiogram, Echo Cardiogram, Ophthalmic examination, etc. Detailed screening and treatment protocols for DM are given in Annexure II: Screening and Treatment Protocols for DM.

PROBLEM STATEMENT

Currently, the phase I districts have neared the point of saturation in terms of population coverage and phase II districts will achieve the same in about 6 months' time. Though the screening efforts are quite successful, the program managers suspect that considerable number of diabetic patients are irregular or lost to follow-up in the program. This phenomenon of treatment non-compliance is seen in almost every district. There is little information available regarding the proportion and the actual reasons for non-compliance in the NCD program and there hasn't been any recent study in this area.

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PROBLEM ANALYSIS

In a broader sense, the possible reasons for patients lost to follow-up both in system's perspective and client's perspective are listed as shown in the fish bone diagram (cause and effect diagram) in Figure 1. There are certain

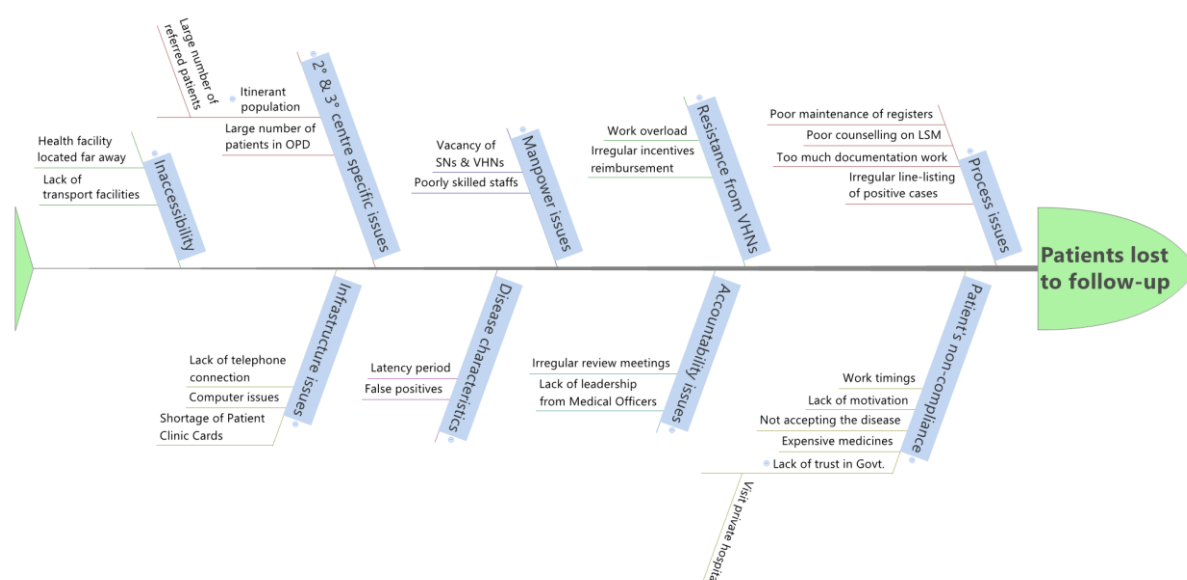


Figure 1. Fish bone diagram showing possible reasons for patients lost to follow-up

infrastructural issues, resource limitations and disease characteristics which are unavoidable in the low resource settings and increase the chances of patients becoming irregular or lost to follow up. On the other hand, some process and accountability issues and resistance from VHNs can be rectified through effective policy changes and capacity building. Patient's non-compliance is another important reason contributing to drop-out rates significantly. This study focuses on the patient's non-compliance and their perspectives of why they are irregular in follow-up or lost to follow-up for DM treatment provided free-of-charge in all government health facilities of Tamil Nadu.

OBJECTIVE

The study has the following objectives with a diagnostic approach rather than a prescriptive approach for the problem stated above.

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- To learn about treatment seeking behavior of patients from the perspective of key service providers – NCD staff nurses
- To identify the proportion of patients on regular, irregular, lost to follow up within 3 months of registration and lost to follow-up after 3 months of registration for treatment of diabetes mellitus in the particular government health facility where they got enrolled during the months of Jan, Feb and Mar, 2014.
- To find out the motivating factors for patients who are on regular follow-up for treatment of diabetes mellitus.
- To find out the major reasons of irregular follow-up or lost to follow-up during treatment of diabetes mellitus in the government health facility.

RATIONALE

The number of patients lost to follow-up after screening and diagnosing the disease is alarming and is a serious concern to both the implementers and funders of the program. There are constraints in data collection and reporting which might further magnify the problem and provide dubious figures at higher levels of data analysis. It is therefore necessary to identify the various reasons of patients lost to follow up from the perspectives of patient themselves. This study will diagnose the problems and provide valuable information for policy makers to improvise the NCD screening program.

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SELECTION OF STUDY AREA

Among the 32 districts in Tamilnadu, one of the phase I district - Pudukottai was chosen for the study due to its overall performance statistics in NCD programme close to the state average. The district has a plain terrain with a few rocky hills, rivers and coastline. It has two Health Unit Districts – Pudukottai and Aranthangi and therefore has two different administrative heads. During the study period of year 2014, there were 13 Government Hospitals (secondary care), 13 Block PHCs, 41 Additional PHCs and 1 Urban PHC. The health blocks of Pudukottai district are shown in Figure 2. Maps of Tamil Nadu state and Pudukottai district.



Figure 2. Maps of Tamil Nadu state and Pudukottai district

RESEARCH QUESTION

1. What is the proportion of diabetic patients

- on regular follow up
- on irregular follow up
- lost to follow up for treatment within 3 months of registration
- lost to follow up for treatment after 3 months of registration

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in the government health facility where they were enrolled during the period January 2014 to March 2014 in Pudukottai district of Tamil Nadu, India.

2. What are the major reasons for patients being

- on regular follow up
- on irregular follow up
- lost to follow up for treatment within 3 months of registration
- lost to follow up for treatment after 3 months of registration

in the particular government health facility where they got registered.

REVIEW OF LITERATURE

Treatment seeking behavior is closely related to the term, compliance. Therefore, it is important to understand patient compliance and related studies done around the world. Haynes defined compliance as “the extent to which a person’s behavior (in terms of taking medication, following diets, or executing life-style changes) coincides with medical or health advice” (3). But nowadays, compliance is seen more widely than behavior coinciding with medical advice. Therefore, it has been re-defined as an active, intentional, and responsible process of care, in which the individual works to maintain his or her health in close collaboration with health care personnel (4).

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Literature on treatment seeking behavior of diabetic patients were searched on PubMed database to identify a methodology for this study and to know the reasons for non-compliance among different populations. Focus group discussions and in-depth interviews (phenomenological approach) are the two most common methods used to find out the reasons for treatment non-compliance. A phenomenological research study attempts to understand people's perceptions, perspectives and understandings of a particular situation or phenomenon.

Griffin SJ, in his article has stated most research on non-attendance for health care has largely focused on characteristics of defaulters and evaluation of medical appointment systems. However, he insists that there are other factors ranging from patient health beliefs and attitudes of health professionals, the organization of the clinic and the financial costs of attendance, to the degree of patient participation within consultations (5).

Some examples for study methodologies on patient non-compliance to chronic diseases around the world are:

- **Srinivas et al** studied the treatment non-compliance in a rural PHC near Chennai in 2002. Compliance was measured through patient interviews and drug use charts. Of the 112 patients interviewed, 72% had some symptoms at the time of diagnosis, and the majority of them were diagnosed in government health centers. Noncompliance was seen in 57% of the 112 patients interviewed (6).
- **Bhojani et al** conducted in-depth interviews, using a phenomenological approach, with 16 type 2-diabetes patients from a poor urban neighborhood in South India. These patients were selected with the help of four community health workers (CHWs) and were interviewed by two trained researchers

exploring patients' experiences of living with and seeking care for diabetes. The sampling followed the principle of saturation (7).

- **Atwine et al** conducted focus group discussions of 10 female and 7 male diabetic patients in Uganda to understand reasons for using therapies offered by traditional healers (8).
- **Khanam et al** did a study to describe hypertension and factors affecting adherence to treatment among 29,960 hypertensive persons in rural Bangladesh. He collected data by a cross sectional design on diagnostic provider, initial, and current treatment. Discontinuation of medication at the time of interview was defined as non-adherence to treatment (9).
- **Jokisalo et al** conducted a cross-sectional survey of 2219 hypertensive patients to study the perceived problems and attitudes in hypertension treatment in primary health care in Finland. The study population consisted of 1561 patients currently being medically treated for hypertension and 220 patients not currently on medical treatment. Their responses were obtained through mailed questionnaires which had questions on different aspects of hypertension care and treatment (10).

METHODOLOGY

The methodology of this study has three distinct but successive parts. It follows the mixed method approach and more specifically an exploratory design. The first part involves a group discussion with all NCD staff nurses in Pudukottai district. The second part is an analysis of follow-up patterns using patient clinic cards. The third part is a telephonic interview of 90 conveniently chosen patients who have given valid contact numbers in the patient clinic cards.

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I. GROUP DISCUSSION WITH NCD STAFF NURSES

A NCD staff nurse meeting was organized in the month of June 2015 in Pudukottai under the coordination of District Project Management Unit (DPMU) – Coordinator, TNHSP. The purpose of the meeting was to learn about treatment seeking behavior of patients from the



perspective of key service provider in the program, that is, NCD staff nurses. A total of 58 NCD staff nurses attended the meeting. An introduction about the study was given followed by an interactive session where staff nurses were asked about their experiences and perspectives on the subject. All responses were recorded.

II. ANALYSIS OF FOLLOW-UP PATTERNS

During the meeting with NCD staff nurses, Patient Clinic Cards of diabetic patients who visited the government health facilities in Pudukottai district during the months of January, February and March 2014 were collected. After verification of approximately 1000 cards, 729 cards were found valid and had complete information. The pattern of follow-up visits made by the diabetic patients were categorized into 4 groups: regular, irregular, lost to follow up within 3 months of registration and lost to follow up after 3 months of registration and the proportion of each category was analyzed. The definition for the above categories are mentioned below:

REGULAR FOLLOW UP:

Patients who visited the government health facility at least once in two months to receive drugs for treatment of Diabetes Mellitus during the period Jan 2014 to Apr 2015.

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IRREGULAR FOLLOW UP:

Patients who visited the government health facility to receive drugs for treatment of Diabetes Mellitus during the period Jan 2014 to Apr 2015, but did not appear for three or more months in between the said period.

LOST TO FOLLOW UP WITHIN 3 MONTHS:

Patients who visited the government health facility to receive drugs for treatment of Diabetes Mellitus in the first 3 months from the month of registration (that is during the period Jan 2014 to Apr 2015), but did not appear after that.

LOST TO FOLLOW UP AFTER 3 MONTHS:

Patients who visited the government health facility to receive drugs for treatment of Diabetes Mellitus for more than 3 months from the month of registration (that is during the period Jan 2014 to Apr 2015), but did not appear after that.

III. TELEPHONIC SURVEY OF DIABETIC PATIENTS

From the above 729 patient clinic cards, a total of 265 cards had contact details of the patient recorded in the address section. Those having contact details were chosen conveniently and interviewed one by one till the target of 90 cases were met. The target population, source population and study population are diagrammatically shown in Figure 3. Target, Source and Study Population. These 90 cases had fixed representation from different patterns of follow-up: 30 patients on regular follow-up and 20 patients each on the other categories: irregular, lost to follow-up within 3 months and lost to follow-up after 3 months. Further, it was ensured that the samples had meaningful distribution in different types of health facilities: Government Hospital, Block PHC and Additional PHC as shown in Table 3. Distribution and Selection of samples in the study.

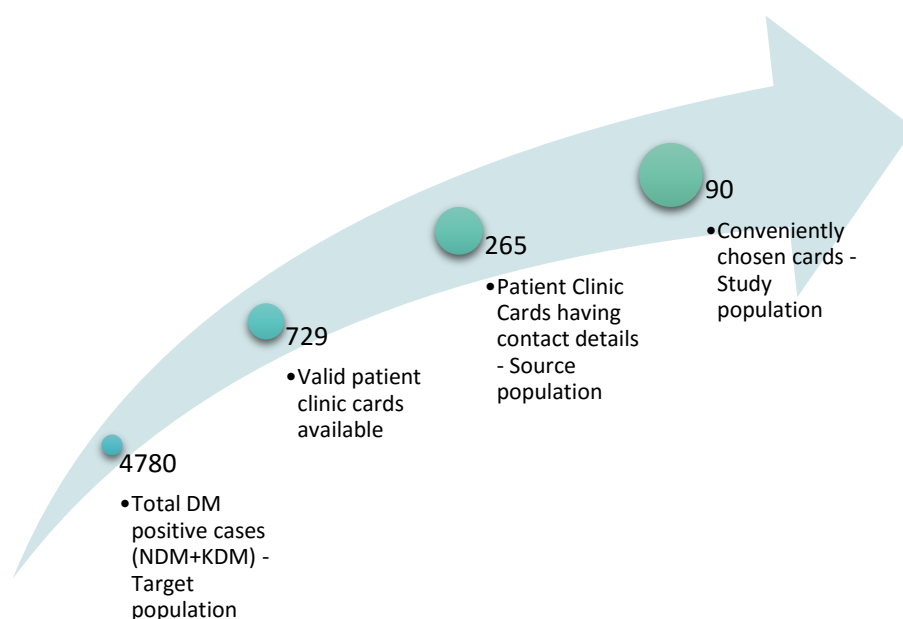


Figure 3. Target, Source and Study Population

Type of Facility	Total no. of facilities in the district	No. of facilities participating in the study	Total Cards available	No. of cards having contact details	No. of cards selected for telephonic interview
GH	13	7	216	100	36
Block PHC	13	7	148	54	19
Addl. PHC	41	24	365	111	35
Urban PHC	1	0	-	-	-
Total	68	38	729	265	90

Table 3. Distribution and Selection of samples in the study

A semi-structured questionnaire to obtain details on socio-economic status, accessibility to health facility, reasons for various patterns of follow-up, awareness of disease, level of satisfaction of services provided in govt. health facility, diabetes self-management and recommendations by the patient to improve NCD services was developed through consultation with different stakeholders for the telephonic interview (Attached in Appendix

V: Questionnaire for Telephonic Patient Survey). The questionnaire was pre-tested with 10 patients and it was revised accordingly. One interviewer was hired and trained by the principal investigator to conduct the telephone survey of 90 individuals. An oral consent was obtained before starting interview with each individual (attached in Appendix IV: Oral Consent for Telephonic Patient Survey). Those patients who did not respond and those who were not available at the time of call were called subsequently three times at different timings of the day in different days of succeeding week. The responses were recorded and later fed into a statistical software and appropriate statistical analysis was done.

RESULTS

I. GROUP DISCUSSION WITH NCD STAFF NURSES

The key service providers of NCD program - NCD staff nurses, shared their multi-dimensional perspectives of why there is drop out of patients in their district. The responses are listed in Box 1 in the order of points elicited by staff nurses. Page | 20

1. During mobile outreach services, already diabetic patients who are on regular follow-up in government health facilities are not recorded in the follow up register. So, on records the patient has not visited for the month but in reality, he is under treatment.
2. Patients worry about losing one day work salary if they have to visit health facility in the morning hours. So they appear only after their conditions worsen.
3. During outpatient hours, it is difficult for NCD staff nurses to pick up the particular patient clinic card for each patient.
4. Some patients visit two or more health facility to receive drugs. So the patient gets registered twice and becomes irregular in follow-up in both facilities.
5. Health workers are not punctual especially Lab technicians in health facility start their services late in the morning. So patients find difficulty in giving fasting blood sugar samples.
6. Old patients are not able to visit, and therefore they send proxy person to receive drugs. The proxies do not inform the NCD staff nurses about their visits.
7. When NCD staff nurse is on leave, other staff nurses do not take responsibility in updating registers.
8. Patients are afraid of diabetes as it leads to long term treatment and therefore cause financial instability.
9. The patients lost to follow-up cannot be contacted regularly due to lack of phone connections in some PHCs.
10. There is resistance from Village Health Nurses (VHNs) in effective tracking of diabetic patients in the community.
11. Lack of online tracking system.
12. Socio-cultural factors in Muslim populations, prevent them from visiting govt. health facilities regularly.
13. Combination drugs for diabetes are available in market and therefore patients prefer taking it from outside.
14. Some patients manage themselves at home using Glucometer and medications from private pharmacy.
15. Migrant population especially in coastal areas prevent them from visiting a health facility regularly.

Box 1. Reasons for high drop-out of diabetic patients

II. ANALYSIS OF FOLLOW-UP PATTERNS

The follow-up patterns of 729 new and known diabetic cases registered during the months of January, February and March 2014 in government health facilities of Pudukottai district were analyzed as shown in Table 7. The follow-up period taken into account was 1 year from the date of registration. The population (N=729) had its 29.63% share from Government Hospitals (secondary care), 20.30% share from Block PHCs (primary care) and 50.07% share from Additional PHCs (primary care). The analysis revealed that 29.63% of the cases were on regular follow-up; 32.92% were irregular; 11.52% were lost to follow-up within 3 months of registration and 25.93% were lost to follow-up after 3 months of registration as shown in **Error! Reference source not found..**

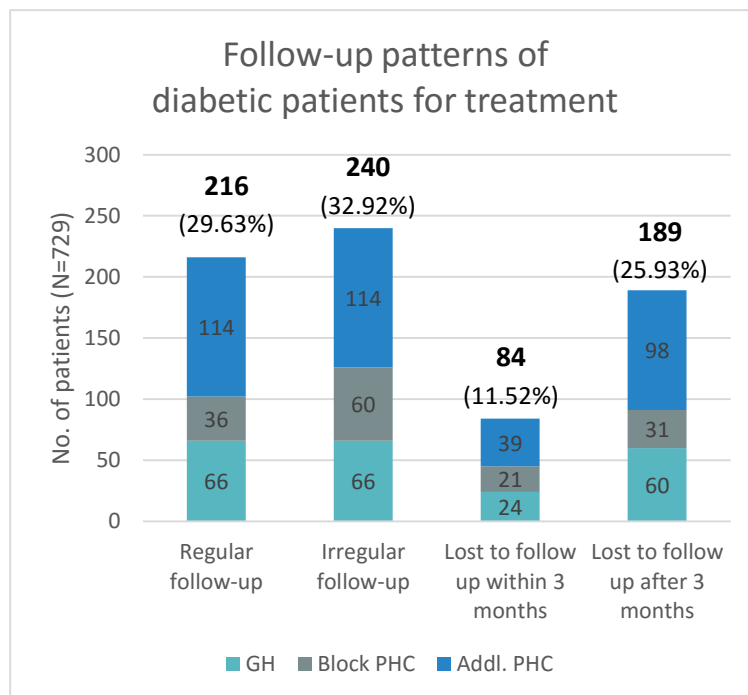


Figure 4. Follow-up patterns of diabetic patients for treatment in govt. health facilities in Pudukottai district

III. TELEPHONIC SURVEY OF DIABETIC PATIENTS

A total of 106 patients were contacted to achieve the target sample size of 90. 7 phone numbers did not exist and 9 individuals were not willing to participate in the study (Response rate = 85%). Each patient was interviewed for about 20 minutes using the semi-structured questionnaire tool shown in Appendix V: Questionnaire for Telephonic Patient Survey.

PATIENT SOCIO-DEMOGRAPHIC PROFILE

Characteristic	No. of patients (% within pattern of follow-up)
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		Regular (n=30)	Irregular (n=20)	Lost to follow up within 3 months (n=20)	Lost to follow up after 3 months (n=20)	
Age	30-39 yrs	2 (06.7%)	0 (00.0%)	3 (15.0%)	2 (10.0%)	7 (07.8%)
	40-49 yrs	10 (33.3%)	8 (40.0%)	5 (25.0%)	5 (25.5%)	28 (31.1%)
	50-59 yrs	11 (36.7%)	8 (40.0%)	7 (35.0%)	4 (20.0%)	30 (33.3%)
	> 60 yrs	7 (23.3%)	4 (20.0%)	5 (25.0%)	9 (45.0%)	25 (27.8%)
Sex	Male	21 (70.0%)	11 (55.0%)	15 (75.0%)	12 (60.0%)	59 (65.6%)
	Female	9 (30.0%)	9 (45.0%)	5 (25.0%)	8 (40.0%)	31 (34.4%)
Education	Never attended school	8 (26.7%)	5 (25.0%)	7 (35.0%)	7 (35.0%)	27 (30.0%)
	Standard (1to5)	11 (36.7%)	4 (20.0%)	6 (30.0%)	7 (35.0%)	28 (31.1%)
	Standard (6to8)	5 (16.7%)	6 (30.0%)	1 (05.0%)	3 (15.0%)	15 (16.7%)
	Standard (9to12)	3 (10.0%)	5 (25.0%)	4 (20.0%)	3 (15.0%)	15 (16.7%)
	Dip, Degree, College & others	3 (10.0%)	0 (00.0%)	2 (10.0%)	0 (00.0%)	5 (05.6%)
Religion	Hindu	26 (86.7%)	18 (90.0%)	14 (70.0%)	16 (80.0%)	74 (82.2%)
	Muslim	2 (06.7%)	2 (10.0%)	3 (15.0%)	3 (15.0%)	10 (11.1%)
	Christian	2 (06.7%)	0 (00.0%)	3 (15.0%)	1 (5.0%)	6 (6.7%)
Occupation	Retired	1 (03.3%)	1 (05.0%)	0 (00.0%)	1 (5.0%)	3 (3.3%)
	Unskilled Laborer	2 (06.7%)	1 (5.0%)	3 (15.0%)	1 (5.0%)	7 (7.8%)
	Skilled Laborer	1 (3.3%)	0 (0.0%)	5 (25.0%)	3 (15.0%)	9 (10.0%)
	Agriculture Laborer	1 (3.3%)	0 (0.0%)	2 (10.0%)	1 (5.0%)	4 (4.4%)
	Landlord	10 (33.3%)	5 (25.0%)	1 (5.0%)	4 (20.0%)	20 (22.2%)
	Self Employed	1 (3.3%)	2 (10.0%)	1 (5.0%)	0 (0.0%)	4 (4.4%)
	Government employee	1 (3.3%)	1 (5.0%)	1 (5.0%)	0 (0.0%)	3 (3.3%)
	Private employee	1 (3.3%)	1 (5.0%)	0 (0.0%)	1 (5.0%)	3 (3.3%)
	Professional/E xecutive	2 (6.7%)	1 (5.0%)	0 (0.0%)	0 (0.0%)	3 (3.3%)
	Home maker	8 (26.7%)	3 (15.0%)	4 (20.0%)	7 (35.0%)	22 (24.4%)
	Unemployed	1 (3.3%)	3 (15.0%)	0 (0.0%)	1 (5.0%)	5 (5.6%)
	Others	1 (3.3%)	2 (10.0%)	3 (15.0%)	1 (5.0%)	7 (7.8%)

Table 4 summarizes the socio-demographic characteristics of diabetic patients in the study. The samples had almost equal representation from different age groups. Nearly 66% were males and 34% were females. 30% of population were illiterates, 5.6% were diploma or degree holders and the rest attended school to varying extents. Majority of samples were Hindus (82.2%) followed by Muslims (11.1%) and Christians (6.7%). Most common occupation was home maker (24.4%) followed by landlords (22.2%) and skilled laborers (10.0%).

		No. of patients (% within pattern of follow-up)				
Characteristic		Regular (n=30)	Irregular (n=20)	Lost to follow up within 3 months (n=20)	Lost to follow up after 3 months (n=20)	Total (N=90)
Age	30-39 yrs	2 (06.7%)	0 (00.0%)	3 (15.0%)	2 (10.0%)	7 (07.8%)
	40-49 yrs	10 (33.3%)	8 (40.0%)	5 (25.0%)	5 (25.5%)	28 (31.1%)
	50-59 yrs	11 (36.7%)	8 (40.0%)	7 (35.0%)	4 (20.0%)	30 (33.3%)
	> 60 yrs	7 (23.3%)	4 (20.0%)	5 (25.0%)	9 (45.0%)	25 (27.8%)
Sex	Male	21 (70.0%)	11 (55.0%)	15 (75.0%)	12 (60.0%)	59 (65.6%)
	Female	9 (30.0%)	9 (45.0%)	5 (25.0%)	8 (40.0%)	31 (34.4%)
Education	Never attended school	8 (26.7%)	5 (25.0%)	7 (35.0%)	7 (35.0%)	27 (30.0%)
	Standard (1to5)	11 (36.7%)	4 (20.0%)	6 (30.0%)	7 (35.0%)	28 (31.1%)
	Standard (6to8)	5 (16.7%)	6 (30.0%)	1 (05.0%)	3 (15.0%)	15 (16.7%)
	Standard (9to12)	3 (10.0%)	5 (25.0%)	4 (20.0%)	3 (15.0%)	15 (16.7%)
	Dip, Degree, College & others	3 (10.0%)	0 (00.0%)	2 (10.0%)	0 (00.0%)	5 (05.6%)
Religion	Hindu	26 (86.7%)	18 (90.0%)	14 (70.0%)	16 (80.0%)	74 (82.2%)
	Muslim	2 (06.7%)	2 (10.0%)	3 (15.0%)	3 (15.0%)	10 (11.1%)
	Christian	2 (06.7%)	0 (00.0%)	3 (15.0%)	1 (5.0%)	6 (6.7%)
Occupation	Retired	1 (03.3%)	1 (05.0%)	0 (00.0%)	1 (5.0%)	3 (3.3%)
	Unskilled Laborer	2 (06.7%)	1 (5.0%)	3 (15.0%)	1 (5.0%)	7 (7.8%)
	Skilled Laborer	1 (3.3%)	0 (0.0%)	5 (25.0%)	3 (15.0%)	9 (10.0%)
	Agriculture Laborer	1 (3.3%)	0 (0.0%)	2 (10.0%)	1 (5.0%)	4 (4.4%)
	Landlord	10 (33.3%)	5 (25.0%)	1 (5.0%)	4 (20.0%)	20 (22.2%)
	Self Employed	1 (3.3%)	2 (10.0%)	1 (5.0%)	0 (0.0%)	4 (4.4%)
	Government employee	1 (3.3%)	1 (5.0%)	1 (5.0%)	0 (0.0%)	3 (3.3%)
	Private employee	1 (3.3%)	1 (5.0%)	0 (0.0%)	1 (5.0%)	3 (3.3%)
	Professional/E xecutive	2 (6.7%)	1 (5.0%)	0 (0.0%)	0 (0.0%)	3 (3.3%)
	Home maker	8 (26.7%)	3 (15.0%)	4 (20.0%)	7 (35.0%)	22 (24.4%)
	Unemployed	1 (3.3%)	3 (15.0%)	0 (0.0%)	1 (5.0%)	5 (5.6%)
	Others	1 (3.3%)	2 (10.0%)	3 (15.0%)	1 (5.0%)	7 (7.8%)

Table 4. Socio-demographic characteristics of diabetic patients in the study (telephonic survey)

ACCESSIBILITY TO HEALTH FACILITY

The most common mode of transport used by the study participants are public transport (30%), walking (28%) and motorbike (25%) as shown in Figure 55. Nearly half (48%) of those using public transport reported that it is available atleast once in an hour and the other half (48%) reported atleast once in 3 hours. Table 5 clearly tells that the average cost to travel to and fro between home and health facility for patients on regular follow-up were less (Rs. 15) compared to the rest (> Rs. 30). But, the time taken to travel by a regular patient and the rest does not show any significance.

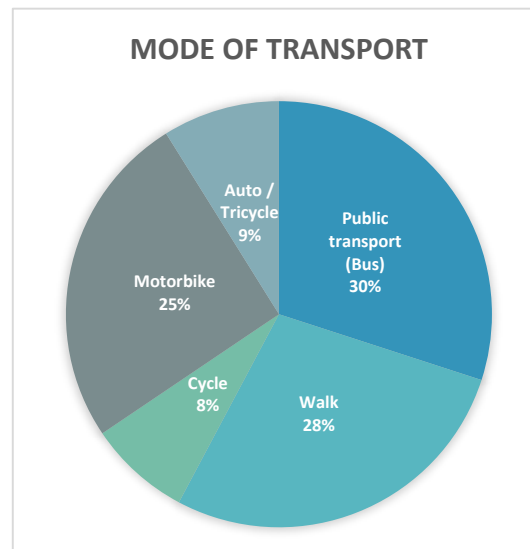


Figure 5. Mode of transport

Pattern of follow up	Regular		Irregular		Lost to follow up within 3 months		Lost to follow up after 3 months		Total	
	Mean	Std. Deviation	Mean	Std. Deviation	Mean	Std. Deviation	Mean	Std. Deviation	Mean	Std. Deviation
Average cost to travel from home to health facility and return back	14.80	22.076	31.85	46.668	32.20	47.435	35.55	39.071	27.07	38.832
Time taken to travel from home to health facility	34.67	22.550	29.25	11.271	29.00	19.642	41.50	24.339	33.72	20.616

REASONS FOR DIFFERENT PATTERNS OF FOLLOW-UP

The most common reason for a patient to be regular in follow-up for diabetes treatment was when the disease condition worsens and presents with clinical signs and symptoms. It was followed by the insistence of doctors and then staff nurses. The main reason for irregular follow-up was poor quality of drugs supplied in government health facilities followed by frequent out-of-town visits. For a patient lost to follow-up within 3 months of registration, change of residence (or frequent travelling), negligence and bad climatic conditions were the reasons. Similarly, for a patient lost to follow-up after 3 months of registration, negligence, change of residence

(or frequent travelling), fear of addiction towards medications and poor quality of drugs were the important reasons. Other reasons in order of decreasing frequency are listed in Table 6 below.

S.No.	Reasons	Frequency	Percentage of total participants in each category
I.	Regular follow-up visits (n=30)		
	Conditions worsen, if drugs are not taken regularly	18	60.0%
	By the insistence of doctors	11	36.7%
	By the insistence of staff nurses	4	13.3%
	Easy accessibility to the health facility	1	3.3%
	By the insistence of relatives	1	3.3%
II.	Irregular follow-up visits (n=20)		
	Quality of medicine is not good	6	30.0%
	Frequent out-of-town visits	4	20.0%
	If I get giddiness & headache, only then I goto health facility	3	15.0%
	Impossible to skip work	2	10.0%
	Health facility is located far from home	2	10.0%
	Due to age factor / sickness	2	10.0%
	Drugs are unavailable	2	10.0%
	Due to rain / hot sun	2	10.0%
	Expensive to travel to health facility	2	10.0%
	Over-crowding or long queues	2	10.0%
	Doctor is not good	2	10.0%
	My condition doesn't require tablet	2	10.0%
	Medicine gave me problems	1	5.0%
	Doctor told table is not necessary	1	5.0%
III.	Lost to follow-up within 3 months of registration (n=20)		
	Changed the residence / travelling	7	35.0%
	If I get giddiness & headache, only then I goto health facility	4	20.0%
	Due to rain / hot sun	4	20.0%
	I don't want to get addicted to tablets	3	15.0%
	Impossible to skip work	2	10.0%
	Quality of medicine is not good	2	10.0%
	Staff nurse and other paramedical staffs are not good	1	5.0%
	Over-crowding or long queues	1	5.0%
IV.	Lost to follow-up after 3 months of registration (n=20)		
	If I get giddiness & headache, only then I goto health facility	4	20.0%
	Changed the residence / travelling	4	20.0%
	I don't want to get addicted to tablets	3	15.0%
	Quality of medicine is not good	3	15.0%
	Due to age factor / sickness	2	10.0%
	Medicine gave me problems	2	10.0%
	Do not believe in allopathy	2	10.0%
	Doctor is giving unnecessary tablets	2	10.0%
	Impossible to skip work	1	5.0%
	Need an attender to visit health facility	1	5.0%
	Due to rain / hot sun	1	5.0%
	Doctor is not good	1	5.0%
	Staff nurse and other paramedical staffs are not good	1	5.0%

Table 6. Reasons for different patterns of follow-up

Among the irregular patients and patients lost to follow-up (n=60), 46.7% of patients informed that they took drugs for treatment of diabetes from other sources while not visiting the government health facility in the follow-up period of 2014. Out of these, 60.7% took drugs from a private health facility, 28.6% took drugs from another government health facility, 7.1% from AYUSH clinics and 3.6% from private pharmacies.

82.2% of the total sample (N=90) reported that they were informed about when to visit next. Among those informed, 26.0% were informed by Doctor, 45.2% were informed by NCD staff nurse and 56.2% were informed by Pharmacist.

11.1% of the total sample (N=90) have sent other person to get drugs for himself / herself and 13.3% of the total sample reported that they were informed by their local VHNs regarding irregularity in follow-up for diabetes treatment.

AWARENESS OF DISEASE

The awareness of patients on Diabetes Mellitus were tested by asking 3 questions on diabetes mellitus care. Regular patients were found to be more aware compared to the rest of the individuals. The percentage of correct responses for each question by patients having different patterns of follow-up are shown in Figure 6. More than 50% of the participants were not aware about the prescribed frequency of checking their blood glucose levels (that is, once in three months).

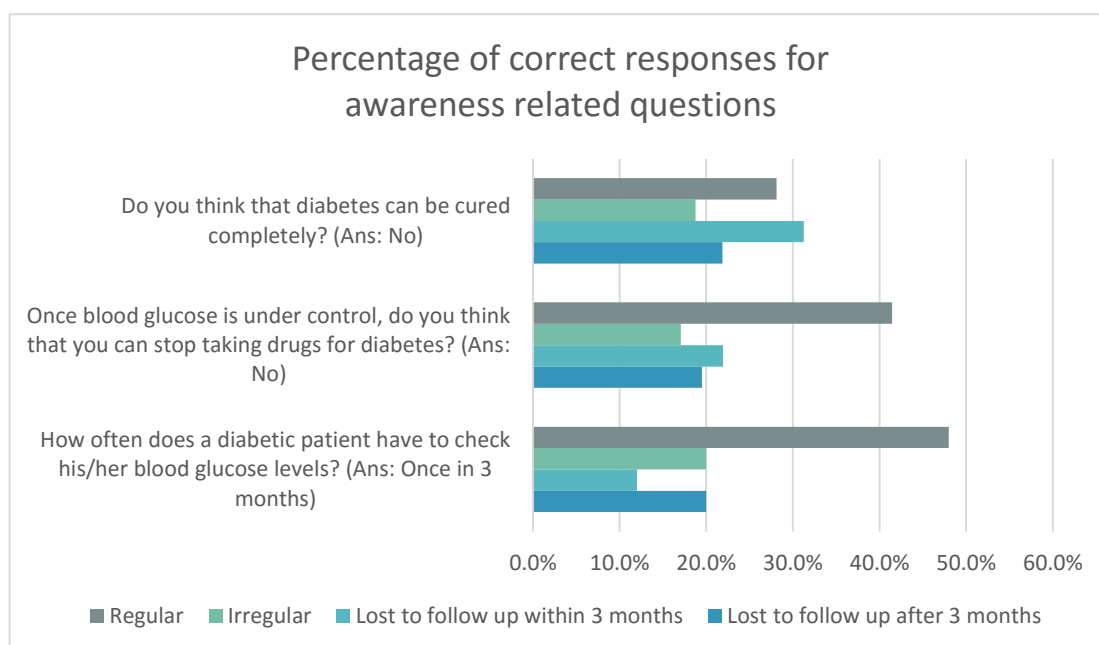
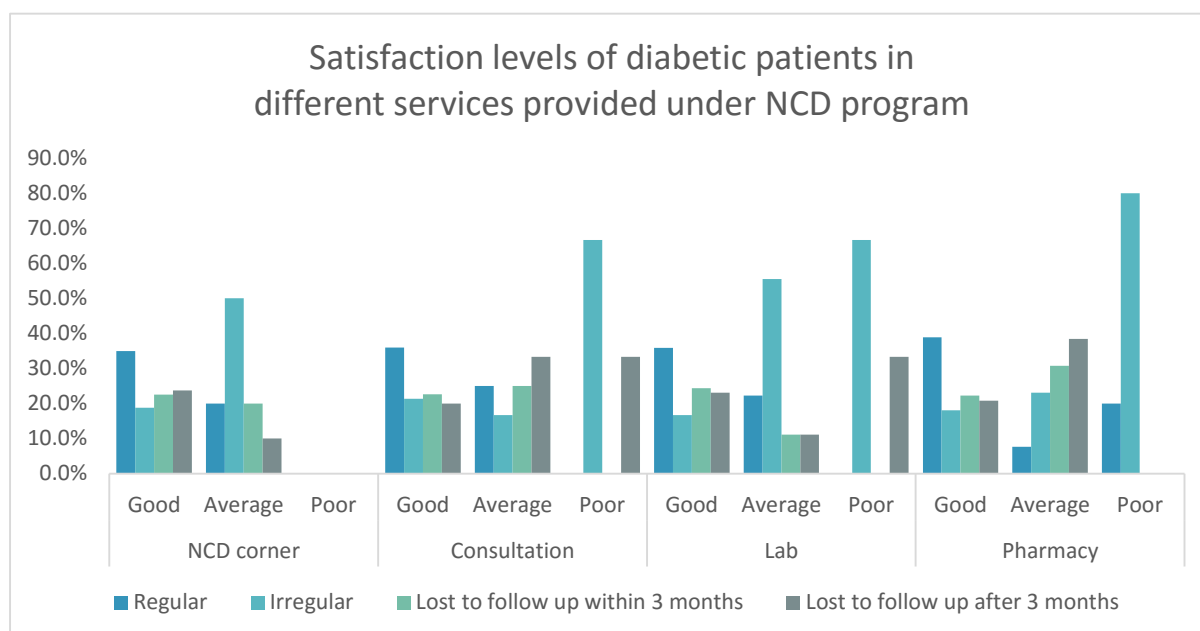


Figure 6. Percentage of correct responses for awareness related questions

LEVEL OF SATISFACTION OF SERVICES

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The average time taken for all patients to see NCD staff nurse, Doctor, Lab technician and pharmacist during his / her single visit to government health facility was 85 minutes (with a standard deviation of 37). The participants were told to rate the quality of services as good, average and poor for NCD corner, Consultation, Lab and Pharmacy services. The responses given by the 4 categories of patients are shown in Figure 7. Satisfaction levels of diabetic patients in different services.



OTHER DIABETES – CARE & TREATMENT DETAILS

In the telephonic survey, patients were asked if they were taking treatment for diabetes anywhere else before visiting the government health facility in the period January to March 2014. There were 34 positive responses (37.8%) out of which 8 patients (23.5%) had taken treatment from another government health facility and 23 patients (67.6%) from a private clinic / hospital.

18 patients reported that they have attended government medical camps during the follow-up period of one year 2014-15 and 12 of them received drugs for diabetes treatment during those camps. The mean monthly expenditure for diabetes care by patients - regular, irregular, lost to follow-up within 3 months and lost to follow-

up after 3 months were found to be Rs. 72, Rs. 226, Rs. 21 and Rs. 144 respectively. The mean monthly expenditure of all 90 samples was Rs. 110.

RECOMMENDATIONS / GRIEVANCES

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At the end of survey, patients were asked for recommendations for improving the quality of services or any grievances they encountered during their visits to government health facility. Majority of participants were highly satisfied with the quality of service and recent developments in primary care services especially the screening program for Non Communicable Diseases. They appreciated the

-
- 1. The Medical Officer does not report in time in the mornings causing delay of all services*
 - 2. The lab reports from government health facility do not match with those taken from private labs in the town*
 - 3. The pharmacist always scold while giving medicines*
 - 4. Siddha/Ayurveda medicines could be provided in PHCs for treatment of diabetes*
-

Box 2. Grievances from patients visiting Government Hospitals

counselling services and the continuous care provided by NCD staff nurses and Medical Officers in the government health facility. Some of the complaints registered by them are given in Box 2.

DISCUSSION

Following up patients for chronic diseases in a population based health program had always been a great challenge especially in developing countries. The state of Tamil Nadu was one of the state that had taken a huge risk of implementing NCD program early in the country. It was possible with the help of good leadership in the sector and funding support from the World Bank.

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Though TNHSP was successful in identifying new diabetic cases at an early stage, there are considerable number of patients lost to follow-up for treatment of NCDs like Hypertension and Diabetes Mellitus in the government health facilities of Tamil Nadu. This problem can be attributed to various system failures that are not directly linked to the patients themselves. For example, the patient might have visited the health facility regularly but the staff nurse did not update the patient clinic card regularly. The patient might have been registered twice within a health facility in which case, the first registration might be considered lost to follow-up. Cases of duplication has also been reported through usage of unique IDs and online HMIS technologies. Further, some of the newly identified cases might not require treatment immediately and the doctor might have kept him/her under observation for few months.

This study tries to analyse the magnitude of the problem and then identify the perspectives of bottom level stakeholders – NCD staff nurses and beneficiaries. After the group discussion with NCD staff nurses, some of the key problems in data management were revealed. There has been under-reporting of cases on follow-up who attend the mobile outreach services or camps in their vicinity. Some patients and proxy visitors (those who visit health facility to take drugs for their close relatives) do not actually inform the NCD staff nurse during the follow-up visits. These factors might exaggerate the problem further.

The Village Health Nurses (VHNs) are the field or community level workers who are responsible to track the irregular patients and motivate them to report to nearest health facility. Unfortunately, they are not interested with the NCD program as it does not provide them any promising benefits. Though there was a provision of special incentive (Rs. 50 per case) for bringing an irregular patient back to health facility, there was no system to monitor their activities and ensure timely disbursement of incentives. They were not recognised for the work and therefore led to poor motivation and involvement in the program.

In the second part of analysis of follow-up patterns, only 729 valid clinic cards were available out of 4780 cases screened positives as new and known DM cases in the period of Jan, Feb and Mar 2014. This might be due to both over-reporting of positive cases on one side and poor issue of patient clinic cards on the other side by NCD staff nurses. In these 729 cards, 70% of patients were either irregular or lost to follow-up.

In the telephonic survey of diabetic patients, the response rate of 85% was appreciable. Though the sample size of 90 was less for a telephonic survey, the participants had a fairly balanced distribution among the four categories (having different pattern of follow-up) in terms of age, education levels, religion and occupation.

The results of survey showed that most of the population depend on the public transport (30%) which had an acceptable frequency of service in the area that is atleast once in an hour (48%) or atleast once in 3 hours (48%). Therefore lack of public transport is no more an issue to access government health facility. There is also no relation between increased time to travel from home to health facility and irregularity in follow-up. On the other hand, increased travel costs had direct effect on irregularity of follow-up.

While analysing the responses given to the primary research question, the study revealed that advanced stages of disease presenting with clinical symptoms made patients visit more often to health facility. The other pull factor was when doctors and staff nurses insisted on the importance of subsequent diabetes care in their facility. Negative push factors making the patient non-compliant with follow-up for treatment were the perceived poor quality of drugs supply in the government health facility, frequent travel to other towns, change of residence, negligence, bad climatic conditions and fear of addiction towards medications.

The above responses had many similarities with those studies done elsewhere. In the study done by **Khonghbuh et al** in Chandigarh, India, 63.4% of diabetic patients seek follow-up care only when there was a problem (11). In the **Srinivas et al** study in a rural PHC near Chennai, irregularity in treatment was strongly associated with lack of education. It also identified that lack of a patient-friendly, flexible health care system was also a primary reason for noncompliance to diabetes treatment (7).

Challenges faced in following up hypertensive patients for treatment is very similar to that of diabetic patients. In **Jokisalo et al** study conducted in Finland, less than one third of all hypertensive patients were in good control of their illness. Traditionally, poor treatment outcomes had been blamed on patient noncompliance. But in the

cross-sectional survey, the most common perceived problem was related to lack of motivation for follow-up (72%), difficulty in accepting oneself being hypertensive (66%) and a careless attitude towards hypertension (63%) (10). Similarly, in the **Khanam et al** study in rural Bangladesh, of those who started treatment upon being diagnosed with hypertension, 26% discontinued the use of medication. Hypertensive patients of older age, least poor quintile, and higher education were less likely to be non-adherent. Patients with cardiovascular comorbidity were also less likely to be non-adherent to antihypertensive medication (OR 0.79, CI 0.640.97).

Out of the 60 irregular patients and patients lost to follow-up interviewed in our study, nearly half (46.7%) of them were concerned about their disease condition and ensured treatment either from a private hospital or another government health facility. Further, awareness levels were higher among regular patients making them more compliant to treatment compared to irregular and lost to follow-up patients.

ETHICAL CONSIDERATION

Since human subjects are involved in the telephonic patient survey, the research proposal was submitted to the Institutional Review Board (IRB) of IIHMR University, Jaipur and got approved on 20th July, 2015.

DATA CONSTRAINTS

Several data constraints occurred during the course of study. The state or district office did not have a detailed information on number of patients on follow-up for treatment of diabetes. Hence data in the form of patient clinic cards were collected from institution level. Most of the patient clinic cards were found invalid and incomplete and therefore not included in the study. Out of 4,780 patients screened positive during the months of January, February and March 2014, there were only 729 valid cards maintained by staff nurses. Some staff nurses do not update the patient clinic cards on daily or regular basis due to three reasons: difficulty in picking up the card during OP hours, increasing number of screened positive cases and lack of monitoring system to ensure the cards are up-to-date.

Though Health Management Information Systems (HMIS) has been implemented in all the primary and secondary care centers, data are not entered in real time during screening in morning hours. Instead, the staff nurses are advised to enter data during the free afternoon hours. Therefore staff nurses are not aware of the patient's previous medical records while dealing with patient directly. Secondly, follow-up details of old diabetic patient in a health facility are not recorded regularly in the HMIS.

OTHER LIMITATIONS OF THE STUDY

The results of exploratory research are not usually useful for decision-making by themselves, but they can provide significant insight into a given situation. Although the results of qualitative research can give some indication as to "why", "how" and "when" something occurs, it cannot tell us "how often" or "how many".

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Since the research was done as part of the MPH capstone project, there were both time and resource constraints in conducting the patient survey. Hence, only 90 subjects were interviewed by telephone in a single district of Tamil Nadu. This can be considered equivalent to a pilot study and might be useful if up-scaled in all districts of Tamil Nadu.

CONCLUSION

Considering the increased burden of Diabetes Mellitus and therefore increased state health expenditure, it is important to ensure that the services of screening, prevention and treatment for Diabetes are utilized to the maximum.

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This study on treatment seeking behaviour of diabetic patients in the government health facilities of Tamil Nadu reveals multidimensional perspectives of two key stakeholders – NCD staff nurses and Diabetic patients. There appears to be a huge challenge in maintaining individual patient records in the health facility which was evident through the non-availability of patient clinic cards. This has led to the exaggeration of core problem, that is, poor treatment compliance. Other factors affecting treatment compliance are: appearance of symptoms, insistence of doctors and other health workers, loss of daily wages, travel cost between home and health facility, awareness about disease, quality of drugs supplied, migration, frequent travel to other places and climatic conditions. Among those non-compliant patients in the particular government health facility where they got registered, about 60% are found to be in continuous treatment in a private clinic, or another government health facility. These findings provide an opportunity for future research and policy amendments required in this area.

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ANNEXURES

ANNEXURE I: PATIENT CLINIC CARD


Government of Tamil Nadu
Tamil Nadu Health Systems Project
Programme for Prevention, Screening & Treatment of Non Communicable Diseases
Patient Clinic Card for treatment and follow up of CVD & Diabetes Mellitus
(To be arranged in serial order as per NCD number and kept safe at the NCD clinic)

To be filled in by Staff Nurse / ANM / UHN Date of Registration:

Name of Institution:

PIN:

NCD No:

Whether enrolled under Chief Minister's Comprehensive Health Insurance Scheme (Encircle): 1. Yes 2. No

If Yes, Card No:

UID: (if applicable)

Name of the Patient:

Age: years **Sex (Encircle):** 1. Male 2. Female 3. Transgender

Community (Encircle): 1. OC 2. BC 3. MBC 4. SC 5. ST

ADDRESS: S/o/D/o/W/o:

Door No: Street:

Village: Post Office / Taluk:

Panchayat: Town / City / District:

Mobile No: Land Line / Neighbour's mobile No:

EDUCATION (Encircle): 1. Illiterate 2. 1-5th std 3. 6-8th std 4. 9-10th std
5. 11-12th std 6. Diploma 7. Degree

OCCUPATION (Encircle): 1. Farmer (Own land) 2. Farmer - unskilled Labourer
3. Skilled Worker / Employee - Govt 4. Skilled Worker / Employee - Private
5. Self Employed - Own Shop / Small Business 6. Housewife
7. Retired 8. Professional / Big business
9. Unemployed 10. Others

MONTHLY FAMILY INCOME:

HABITS: Smoking: (a) Currently Smoking: 1. Yes 2. No;
(Encircle) If Yes, (b) Frequency: 1. Daily 2. Occasionally
(c) What do you smoke?: 1. Cigarette 2. Beedi 3. Others

Smokeless Tobacco: (a) 1. Yes 2. No;
(Encircle) If Yes, (b) Frequency: 1. Daily 2. Weekly once 3. Occasionally

Alcohol Use: (a) In past one Month: 1. Yes 2. No;
(Encircle) If Yes, (b) Frequency: 1. Daily 2. Weekly once 3. Occasionally

DIET (Encircle): 1. Veg 2. Non-Veg

Edible oil used: 1. Coconut Oil 2. Sunflower oil 3. Ground nut oil 4. Soya bean oil 5. Palm oil 6. Vanaspathi 7. Mixed oil 8. Others
(Encircle)

Physical Activity: (a) During the past one week, apart from carrying out your regular work, did you perform any of the following activities which caused breathlessness or increased heart rate?
(Encircle) 1. Brisk Walking 2. Jogging 3. Cycling 4. Games / Sports 5. Gym 6. other than these 7. None

If Yes, b) Specify how many days per week did you do the above mentioned activity? days / week

PHYSICAL EXAMINATION: Height cms Weight kgs Waist cms
Systolic BP mmHg Diastolic BP mmHg Pulse / min
Body Mass Index (BMI): Please calculate BMI and tick (✓):

BMI = $\frac{\text{Wt in Kg}}{\text{Ht in meter} \times \text{Ht in meter}}$	BMI (Kg/m ²)	18.5 to 22.9	23 to 24.9	25 to 29.9	≥30
	Classification	Normal Range	Overweight	Obese	Very Obese
	Tick (✓)	☐	☐	☐	☐

HISTORY: (To tick (✓) if patient responds 'Yes' to any of the following disease condition)

Sl. No	Name of Disease condition	Past History of	Family History of	Treatment of
1.	Hypertension	☐	☐	☐
2.	Diabetes Mellitus	☐	☐	☐
3.	Dyslipidaemia	☐	☐	☐
4.	Ischaemic Heart Disease (IHD)	☐	☐	☐
5.	Chronic Kidney Disease (CKD)	☐	☐	☐
6.	Stroke / TIA	☐	☐	☐
7.	RHD / Valvular Heart Disease	☐	☐	☐
8.	Joint pain / Joint diseases	☐	☐	☐
9.	Any others (Pls. mention)	☐	☐	☐

Counseling on Life Style Modification (LSM):

Life Style Modification	Tick	Life Style Modification	Tick	Life Style Modification	Tick
Cessation of Smoking / Alcohol Abstinence	☐	Use Less Oil / Restrict Fried Foods	☐	Avoid overeating / overweight	☐
Use of Low Salt	☐	Restrict simple sugars	☐	Increase Physical activity	☐
Restrict Non Veg. (Red Meat) intake	☐	Increase Green Vegetables and Fruits intake	☐	Reduce Stress	☐

Name & Signature of Nurse

To be filled in by Medical Officer at PHC / GH / Medical College Hospital / Municipal / corporation Hospitals and ES dispensaries & Hospitals:

Presenting Complaints:

Any history of known allergy:

GENERAL EXAMINATION: Pallor (+/-) Icterus (+/-) Cyanosis (+/-) Clubbing (+/-) Pedal edema (+/-)

SYSTEMIC EXAMINATION: CVS: RS: Abdomen: CNS:

Newly Diagnosed patient at the NCD screening clinic for (Encircle):

Hypertension: 1. Yes 2. No Type 2 Diabetes Mellitus: 1. Yes 2. No

Final Diagnosis: 1. Hypertension 2. Diabetes Mellitus (NIDDM) 3. Diabetes Mellitus (IDDM) 4. Hypercholesterolaemia
(Encircle) 5. Ischaemic Heart Disease (IHD) 6. Chronic Kidney Disease (CKD) 7. Stroke 8. TIA

Note: Counseling on Life style Modification should be provided by Medical Officer / Physician during every visit.

Sl. No.	Follow Up Investigations:	Date	Value	Date	Value	Date	Value	Date	Value	Date	Value	Date	Value
1.	RBS mg / dl												
2.	FBS mg / dl												
3.	PPBS mg / dl												
4.	Sc Cholesterol mg / dl												
5.	Sc Creatinine mg / dl												
6.	Urine Protein												
7.	ECG/ ECHO findings:												
8.	Others (specify):												

Name of the Referred Institution:													
Referral details:				No	Date	Reasons for referral	No	Date	Reasons for referral	No	Date	Reasons for referral	Date
1.	Angina / IHD / Heart Failure			5.		Diabetic Neuropathy			8.			Suspicion of secondary hypertension	
2.	Dyslipidaemia			6.		Diabetic Foot / Ulcer / Foot care			9.			Lack of BP / Blood Glucose control after 3 months of treatment	
3.	CVA / Stroke / TIA			7.		Eye complications (Due to HT / DM)			10.			Claudication Pain / Peripheral Vascular Diseases	
4.	Nephropathy (Due to HT / DM)												
11.	ECG / ECHO abnormalities												
12.	Others (specify)												

Other Notes by Medical Officer:

Follow up and Treatment :

[illegible]

Amiodipine - AML, Hydrochlorothiazide - HCTZ, Enalapril - ENA, Atenolol - AT, Atorvastatin - ATOR, Metformin - MF, Isosorbitedinitrate - ISDN, Aspirin - ASA, Clopidogrel - CLOPI, Glibenzamide - GLIB, Glipizide - GLIP, Gimepride - GLIM, Insulin - INJ, JNS, Carbamazepine - CBZ, Amitriptyline - AMITRYP, Others (BCT etc.)

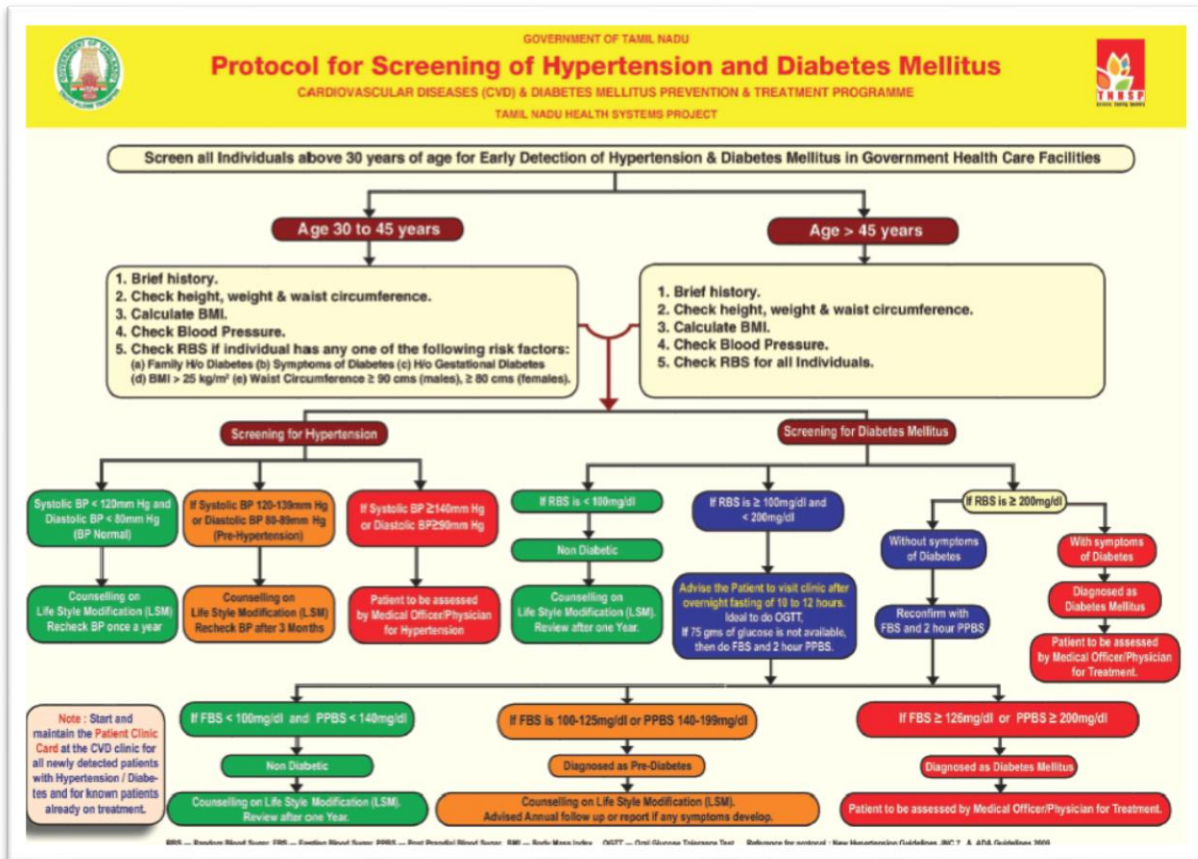
*Counseling on Life style Modification is to be reinforced during every visit by Staff Nurse and Medical Officer / Physician.

Date :

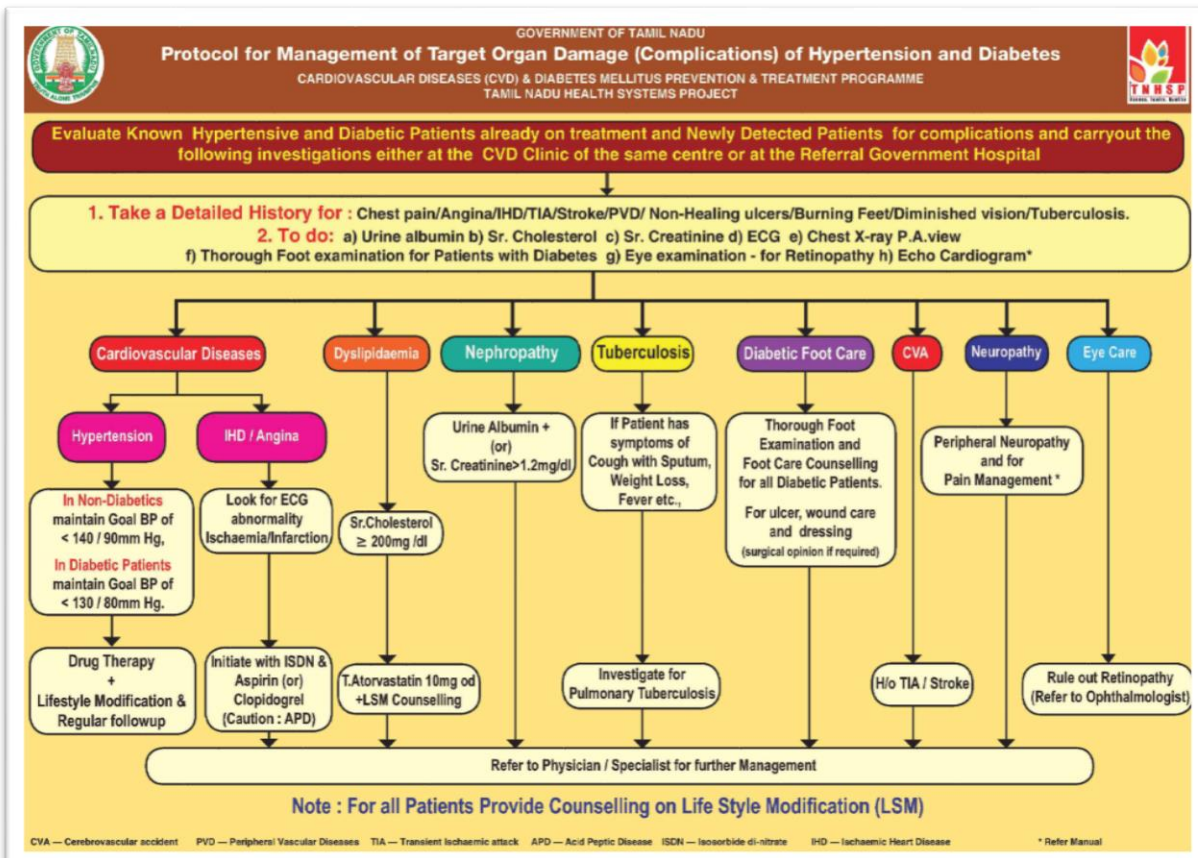
Signature of Medical Officer
(Name and Designation)

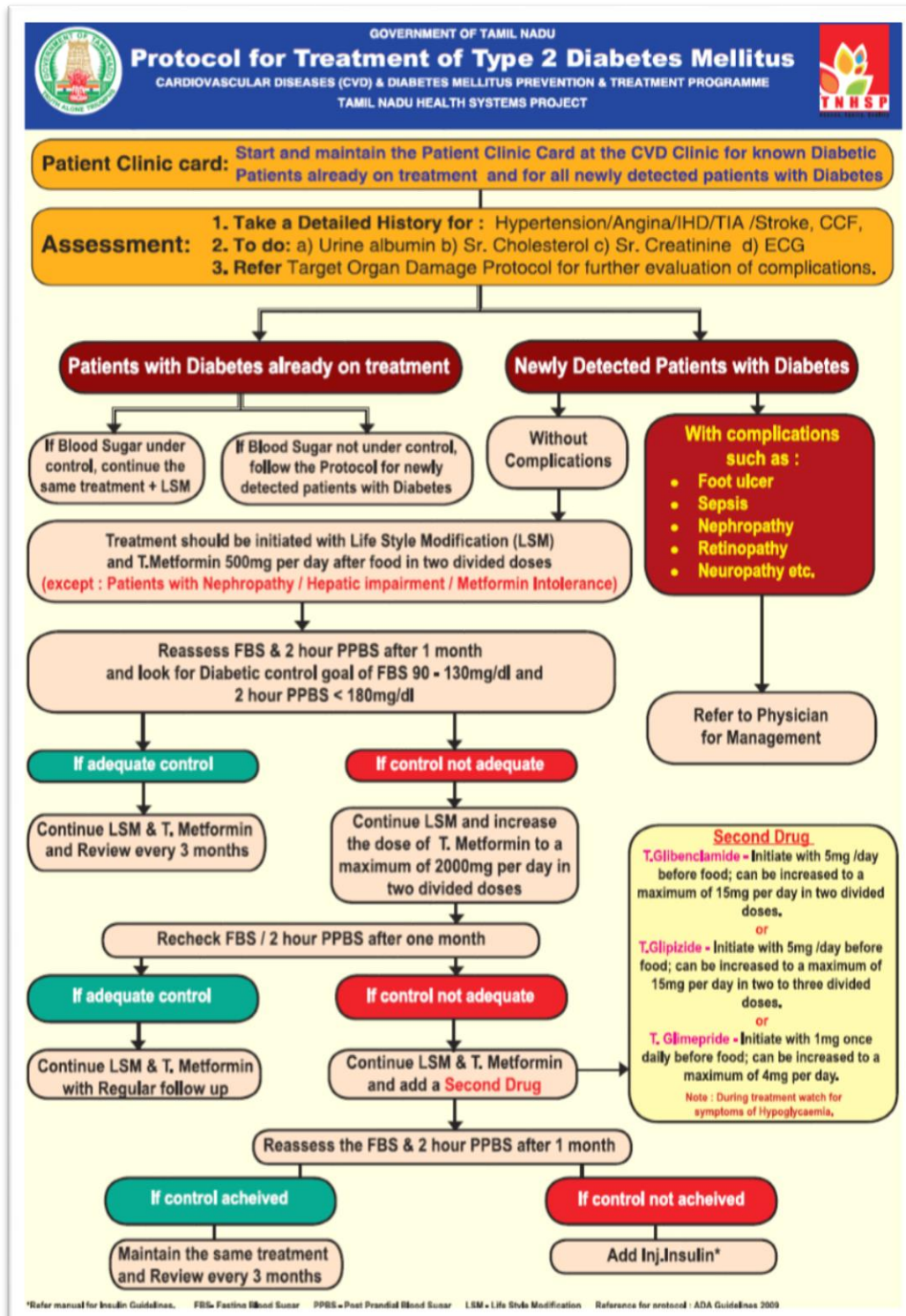
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ANNEXURE II: SCREENING AND TREATMENT PROTOCOLS FOR DM



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ANNEXURE III: TABLES

S. No.	Type of Facility	Total no. of facilities	No. of facilities participating in the study	No. of patients				TOTAL	Proportion of type of health facility
				on regular followup	on irregular follow up	lost to follow up within 3 months	lost to follow up after 3 months		
1	GH	13	7	66	66	24	60	216	29.63%
2	Block PHC	13	7	36	60	21	31	148	20.30%
3	Addl. PHC	41	24	114	114	39	98	365	50.07%
4	Urban PHC	1	0	-	-	-	-	-	0.00%
	Total	68	38	216	240	84	189	729	-
	Proportion of follow-up patterns			29.63%	32.92%	11.52%	25.93%	-	-

Table 7. Follow-up patterns of diabetic patients in different types of government health facilities in Pudukottai district

Questions		Pattern of follow up				Total
		Regular	Irregular	Lost to follow up within 3 months	Lost to follow up after 3 months	
Do you think that diabetes can be cured completely?	Yes (incorrect answer)	7	6	5	2	20
	No (correct answer)	9	6	10	7	32
	Don't know	14	8	5	11	38
Once blood glucose is under control, do you think that you can stop taking drugs for diabetes?	Yes (incorrect answer)	5	7	7	2	21
	No (correct answer)	17	7	9	8	41
	Don't know	8	6	4	10	28
How often does a diabetic patient have to check his/her blood glucose levels?	Every month	4	7	11	10	32
	Once in 3 months (correct answer)	24	10	6	10	50
	Once in 6 months	0	2	1	0	3
	Once in 12 months	2	1	2	0	5

Table 8. Responses to questions related to awareness on diabetes care

APPENDIX IV: INSTRUCTIONS GIVEN TO THE INTERVIEWER OF TELEPHONIC PATIENT SURVEY

1. Introduce yourself and get permission/consent before you start your interview
2. Have a small talk to break the ice. Be courteous and respectful at all times. Show compassion and genuine interest in what the patient has to say.
3. When the conversation is drifting in an unproductive direction, gently guide it back on course.
4. Maintain ethical standards at all times. It is not that you are interviewing through phone and not seek an informed consent or disrespect the participant's privacy.
5. Sometimes answers to some questions may emerge while the patient is responding to others. In this case, it is not necessary to ask again.
6. Do the phone interview in the afternoons or evenings in a quiet place without distractions.
7. Tell the patient that all information is confidential and his/her identity will not be shared with anyone else.
8. Be a good listener who lets people say what they want to say in the way they want to say it.
9. Record responses verbatim. Capture everything the person says.
10. If the answer is not relevant to the question, then repeat the question again without any additional words.
11. Seek clarifying information when necessary. Be alert for responses that are vague or other-wise difficult to interpret. Simple, non-leading questions like, "Can you tell me more about that?" may yield the additional information you need.
12. Keep your reactions to yourself. Avoid surprises, agreements or disapprovals of what the patient tells you.
13. Remember that you are not necessarily getting the facts. As confident and convincing as some of your participants may be, you should always treat their responses as perceptions rather than as facts.
14. If you have a mobile with an android operating system, you can record the interview using app like "Smart Voice Recorder". Further the recorded audio can be transcribed into words using transcription app like "Transcribe Player". If the interview is going to be recorded, the NCD staff nurse has to get the permission from the patient at the starting of the interview.
15. In case of any doubts, please contact the Principal Investigator immediately. Dr. Gopinath TS - 8110080693

APPENDIX IV: ORAL CONSENT FOR TELEPHONIC PATIENT SURVEY

INTRODUCTION

Greetings! I am Mr. Senthil Kumar calling from Tamil Nadu Health Systems Project.

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PURPOSE OF THE CALL

The Government of Tamil Nadu's Health Department is conducting a survey of diabetic patients to find out their views / problems / concerns on NCD program and the reasons for patients lost to follow up during treatment in the district of Pudukottai. Few diabetic patients having phone numbers are selected for interview and you are one among them.

CONSENT

The information collected in this survey is for research purposes only and will not be misused. I ensure that your identity will be kept confidential. You will be asked about 40 questions and the survey will take approximately 20 minutes. If you are taking part in this survey, I request you to provide true and frank answers as much as possible. Are you willing to take part in this survey? If yes, is this time convenient for you or do you want me to call at a different time?

APPENDIX V: QUESTIONNAIRE FOR TELEPHONIC PATIENT SURVEY

Confidential for research purposes only

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Johns Hopkins & IIMR University
MPH Capstone Project

Title: Treatment seeking behavior of diabetic patients with special emphasis on follow-up in the government health facilities – A case study of Pudukkottai district, Tamil Nadu, India

Telephonic Survey – Questionnaire

S. No.	Questions	Responses	Skip
SECTION – I : Interview Call Details (To be filled by interviewer)			
Q1.	Patient ID		
Q2.	Contact number of patient as recorded in the clinic card		
Q3.	Does the contact number exist?	Number exists and belongs to the patient..... 1 Number exists but patient could not be contacted 2 Number does not exist..... 3	End survey
Q4.	Is the participant willing to take part in the study (after reading consent on phone)?	Yes 1 No 2	End survey
Q5.	Date of Interview	 DD MM YYYY	
Q6.	Starting time of Interview	 24 hrs format	
SECTION – II: Patient Registration Details (To be filled by interviewer using clinic card)			
Q7.	Date of Registration / Date when card was issued	 DD MM YYYY	
Q8.	Type of institution	Additional PHC..... 1 Block PHC..... 2 Urban PHC..... 3 Government Hospital..... 4 Medical college..... 5	
Q9.	Name of institution		

SECTION – III: Patient Demographic Profile (To be filled by interviewer using clinic card and verified through phone if missing)				
Q10.	Age (in completed years as of 2014)			
Q11.	Sex	Male..... 1 Female..... 2 Transgender..... 3		
Q12.	Education	Never attended school..... 1 Standard (1to5)..... 2 Standard (6to8)..... 3 Standard (9to12)..... 4 Dip, Degree, College & others..... 5		
Q13.	Religion	Hindu..... 1 Muslim..... 2 Christian..... 3 Others..... 4		
Q14.	Occupation	Retired..... 1 Unskilled Labour..... 2 Skilled Labour..... 3 Agriculture Labour..... 4 Landlord..... 5 Self Employed..... 6 Government employee..... 7 Private employee..... 8 Professional/Executive..... 9 Home maker..... 10 Student..... 11 Unemployed..... 12 Others..... 13		
Q15.	Total number of people in the family (including participant)	A. Children (<18 yrs) B. Working age group (19-60 yrs) C. Old person (>60 yrs)		
Q16.	Monthly Family Income	Rs.		
SECTION – IV: Accessibility to health facility (To be filled by interviewing the patient)				
Q17.	How do you travel from your home to reach the government health facility? (Please mention the most common mode of transport)	Public transport (Bus)..... 1 Walk..... 2 Cycle..... 3 Motorbike..... 4 Auto/Tricycle..... 5 Taxi/Car..... 6 Multiple modes..... 7 Others..... 8	} → Go to Q. 19	

Q18.	How frequent is the public transport in the morning hours (7am to 1pm)?	Atleast once in an hour..... 1 Atleast once in 3 hrs..... 2 More than 3 hrs..... 3													
Q19.	How much total amount does it cost to travel from home to health facility and return back?	Rs. <table border="1" style="display: inline-table; vertical-align: middle;"><tr><td style="width: 30px; height: 20px;"></td><td style="width: 30px; height: 20px;"></td><td style="width: 30px; height: 20px;"></td></tr></table>													
Q20.	How much time does it take to travel from your home to this health facility?	Min <table border="1" style="display: inline-table; vertical-align: middle;"><tr><td style="width: 30px; height: 20px;"></td><td style="width: 30px; height: 20px;"></td><td style="width: 30px; height: 20px;"></td></tr></table>													
SECTION – V: Follow-up Pattern (Ques. 21 to be filled by interviewer using clinic card and rest all by interviewing the patient)															
Tick mark the months during which the patient has visited the health facility to receive drugs (including the first visit of screening) - To be taken from Patient Clinic Card															
2014												2015			
	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar
Q21.	Pattern of follow up (based on above question)		Regular..... 1 Irregular..... 2 Lost to follow up within 3 months..... 3 Lost to follow up after 3 months..... 4										Go to Q. 23		
Q22.	What factors motivate you to visit this govt. health facility regularly for treatment of diabetes?		Yes	No											
A. ACCESSIBILITY					} Go to Q. 24										
1)	Located close to my home														
2)	Transport available at any time														
B. GUIDANCE															
1)	Doctor insisted														
2)	Staff nurse insisted														
3)	Relatives insisted														
C. QUALITY OF CARE															
1)	Polite medical / paramedical staffs														
2)	Less crowd														
3)	Drugs are easily available at all times														
D. MISCELLANEOUS															
1)	Convenient OP timings														
2)	Free drugs														
3)	If I don't take drugs, conditions worsen														
4)	OTHERS, specify														

Q23.	For what reasons, are you irregular in follow up or lost to follow up for treatment of diabetes in this govt. health facility?	Yes	No		
A. ACCESSIBILITY ISSUES					
1)	Could not visit doctor/ PHC/ Hospital to get tablets due to distance				
2)	Clinic time inconvenient				
3)	I need an attender to visit the hospital				
4)	Often feel sick/ due to age factor unable to travel to hospital				
5)	Due to rain/hot sun, I am unable to go to hospital and get medicine				
B. COST ISSUES					
1)	Need to spend more money on transport for visiting the doctor				
2)	Medicine expensive				
3)	Impossible to skip work for going to doctor				
C. QUALITY ISSUES					
1)	Did not visit doctor to get tablets due to crowding/long waiting				
2)	Medicine not good (no improvement)				
3)	Medicine not available				
4)	Doctor is not good				
5)	Staff nurse and other paramedical staffs are not good				
D. LACK OF PROPER GUIDANCE					
1)	Doctor didn't advised me to take tablets daily				
2)	If I have giddiness & headache, then I will take tablets				
3)	I did not feel any improvement/ benefit due to treatment				
4)	Medicine gave me problems				
5)	I do not believe in English medicines				
6)	Doctor is giving me unnecessary tablet				
7)	I don't want to be addicted to tablet				
8)	My condition doesn't require tablet				
9)	Chemicals in the tablet may be harmful to me				
E. MIGRATION					
1)	Changed the residence/travelling staying away most of the time				

F. NEGLIGENCE				
1)	Forget often			
2)	Missed the Outpatient card			
3)	Had work in home			
G. UNNECESSARY CLINIC CARD FOR PATIENT				
1)	Doctor told tablet is not necessary			
2)	Not asked/continuing with the first provider			
H. I don't know/Cannot say				
I. Others, Specify				
Q24.	Did you take drugs for diabetes during the months of not visiting this health facility? If yes, from where did you get the drugs?	Yes	1	Go to Q. 26
		No	2 →	
Q25.	If yes, from where did you take drugs?	Another govt. health facility	A	Go to Q. 28
		Private clinic/hospital	B	
		Private pharmacy	C	
		AYUSH clinic	D	
		Others, specify	E	
Q26.	In the govt. health facility, were you informed about when to visit health facility again for receiving drugs?	Yes	1	Go to Q. 28
		No	2 →	
Q27.	If yes, who informed you?	Doctor.....	A	
		Staff nurse	B	
		Pharmacist	C	
		Others Specify	D	
Q28.	Have you ever sent any other person to this govt. health facility to get your drugs for diabetes?	Yes	1	
		No	2	
Q29.	Has the local Village Health Nurse (VHN) ever contacted you or met in person in regards to diabetes – treatment follow-up?	Yes	1	
		No	2	
SECTION – VI: Awareness of disease (To be filled by interviewing the patient)				
Q30.	Do you think that diabetes can be cured completely?	Yes	1	
		No	2	
		Don't know	3	
Q31.	Once blood glucose is under control, do you think that you can stop taking drugs for diabetes?	Yes	1	
		No	2	
		Don't know	3	
Q32.	How often does a diabetic patient have to check his/her blood glucose levels?	Every month.....	1	
		Once in 3 months.....	2	
		Once in 6 months.....	3	
		Once in 12 months.....	4	
		Other,	5	

SECTION – VII: Level of satisfaction of services (To be filled by interviewing the patient)				
Q33.	How much time does it take for you to see NCD staff nurse, Doctor, Lab technician and pharmacist in this health facility on an average?	Min		
Q34.	How do you rate your level of satisfaction of services provided in:	Good	Average	Poor
	a. NCD Corner			
	b. Doctor			
	c. Laboratory			
	d. Pharmacy			
SECTION – VIII: Diabetes – Care & Treatment details (To be filled by interviewing the patient)				
Q35.	Have you taken any treatment for diabetes before visiting this health facility?	Yes	1	Go to Q. 37
	No	2	→	
Q36.	Where did you take treatment for diabetes before visiting this govt. health facility?	Another govt. health facility A Private clinic/hospital B Private pharmacy C AYUSH clinic D Self-management E Others, specify F		
Q37.	Have you attended any govt. medical camp or mobile medical unit (van) in/near your village in the year 2014?	Yes	1	Go to Q. 40
	No	2	→	
Q38.	If yes, how many camps / MMUs have you attended in the year 2014?			
Q39.	Did you receive drugs for diabetes during your camp / MMU visit(s)?	Yes	1	
		No	2	
Q40.	What is the total monthly expenditure for your diabetes care?	Rs.		
SECTION – IX: Recommendations by patient (To be filled by interviewing the patient)				
Q41.	What recommendations do you want to provide for further improving the quality of services in the government hospitals?			