Need for Targeted Intervention to Tackle Type 1 Diabetes Mellitus: Case Study from Gujarat, India

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Abstract

Type 1 diabetes mellitus has increased like type 2 diabetes, with a trend of 3–5% increase/year, globally. Although in India about 50.9 million people suffer from diabetes, there are no registry at grass root level for T1DM. Therefore, this study aims to develop a Comphrensive profiling of T1DM cases and understand the coping mechanism along with the knowledge & practices in the two cities of Gujarat, India. This retrospective case study on known cases of Type 1 Diabetes was conducted in two cities of Gujarat (Ahmedabad & Kutch) during March to August 2017. Out of 56 T1DM cases documented under this study, majority of them were residing in urban area. The detailed disease history, knowledge, attitude, practices, coping mechanisms, health seeking behaviors were documented.

Keywords: T12DM; T2DM

Background

In India, about 50.9 million people suffer from diabetes, and this figure is likely to go up to 80 million by 2025, making it the 'Diabetes Capital' of the world [1]. Type 1 Diabetes Mellitus (T1DM) (β-cell destruction, usually leading to absolute insulin deficiency) accounts for only 5–10% of those with diabetes, previously encompassed by the terms insulin-dependent diabetes, type I diabetes, or juvenile-onset diabetes, results from a cellular-mediated autoimmune destruction of the -cells of the pancreas [2]. T1DM has increased like type 2 diabetes, with a trend of 3–5% increase/year [3]. The exact cause of T1DM is not known. Most likely, it is an autoimmune disorder also; it can be passed down through families [4]. The prevalence of T1DM in children is 111,500 and it's estimated that India is housing about 97,700 children with T1DM [5]. India has three new cases of T1DM per 100,000 children of 0–14 years, however; prevalence data shows 17.93 cases/100,000 children in Karnataka, 3.2 cases/100,000 children in Chennai, and 10.2 cases/100,000 children in Karnal (Haryana) [6].

The Indian Council of Medical Research funded Registry of People with diabetes, this registry is by government and called ICMR registry. It was started in the year 2006 with 10 collaborating centers across India and this registry mainly focused to provide an overview of diabetes in the young [7]. Usually an ideal disease for establishing the registry is a disease with sufficient public health importance and diabetes mellitus could be considered as an ideal disease to establish such a registry. As per the International Diabetic Federation, there is a need to revamp the preventive, promotive and appropriate curative modalities for it [8]. However, people with Diabetes with Young Age at Onset (YDR) was major focus in the registry at national or state level; there is a strong recommendation to develop a local level T1DM registry to understand the disease dynamics at different geographic level [9,10].

Therefore, this study aims to develop a Comphrensive profiling of T1DM cases and understand the coping mechanism along with the knowledge & practices in the two cities of Gujarat, India.

Materials & Methods

This retrospective case study on known cases of Type 1 Diabetes was conducted in two cities of Gujarat (Ahmedabad & Kutch) during March to August 2017. The two sites were sampled purposefully where a lead diabetic NGO was providing health care services for more than a decade. The samples included in case were enrolled with NGO for screening of complications, routine treatment and treatment of complications, counselling and dietary advice. Secondary data analysis of the line listed cases was undertaken and were contact either in person of through telephone; a camp based for further contact was also adopted as a method to seek further insights into the morbidity profile of the cases. On a specified day, the camp was conducted on both the sites; all the T1DM patients were enrolled voluntarily with a prior written consent. A total of 56 T1DM cases participated in the camps and hence are included in the this case study. A structured questionnaire was developed primarily in English and translated into vernacular language (Gujarati) and validated / pretested before being administered to the cases included in the study; to ensure uniformity in data collection, three data collectors with nursing and public health back ground were hired and trained and they administered this questionnaire and documented some of physical & biological parameters. The questionnaire focused on collecting information on socio-demographic, disease history, difficulties & coping mechanism with T1DM, knowledge, attitude & practices, health seeking behavior & treatment. Data were entered in the excel spreadsheet and descriptive analysis was conducted in SPSS version 20.

Results

Socio-demographic profile

Out of 56 T1DM cases documented under this study, majority (77%) of them were residing in urban area. More than half of participants were in the productive age group of 15-29 years. The mean age of participants was 21±10 yrs. Minimum and maximum age of participants were respectively 3 and 56 yrs (median age=23). The male and female proportion was approximately same 52% and 48%

Table 1: Socio-demographic profile of participants.

Socio-demographic variables		Frequency (N=56) (%)
Area	Rural	13 (23.2%)
	Urban	43 (76.8%)
Gender	Female	29 (51.8%)
	Male	27 (48.2%)
Age	1-14 years	15 (26.8%)
	15-29 years	31 (55.4%)
	> 29 years	10 (17.8%)
Education	Non-school going	1 (1.8%)
	Up to Higher Secondary Education	29 (51.8%)
	Graduation & more	26 (46.4%)
Occupation	Student	22 (39.3%)
	Employed	22 (39.3%)
	Unemployed	12 (21.4%)
Physical exertion related to your daily activities	Hard work	1 (1.8%)
	Moderate work	25 (44.6%)
	Sedentary work	30 (53.6%)
Religion	Hindu	53 (94.6%)
	Muslim	3 (5.4%)
Social status	OBC	20 (35.7%)
	General	34 (60.7%)
	SC	2 (3.6%)
Children in HH	No children	29 (51.8%)
	1-3 children	25 (44.6%)
	> 3 children	2 (3.6%)
Marital Status	NA	24 (42.9%)
	Married	21 (37.5%)
	Unmarried/Widow	11 (19.6%)

respectively. Almost all of them were literate up to higher secondary or more. About 39% of participants were students. Social stratification of participants show that majority of participants belonged to general class, only 3.6% was form schedule caste. Out of all, 37% participants were married (Table 1).

Disease history

Majority of participants reported age of diagnosis of T1DM between 1 to 14 years of age. Mean age at onset of T1DM found 12±8 years and median age was 10. Minimum and maximum age at onset of T1DM found respectively 3 and 36 years. On inquiring about family history of T1DM, around 18% participants had T1D family members. Further majority of participants had history of T1DM in previous generation only one respondent had history of T1DM in next generation. However, double proportion (36%) found for the history of T2DM in family member. Around 32% of participants' had family history of T2DM.

Difficulties and coping mechanism

Only 1.7% reported about post diagnosis difference in married life however, 9% of participants declined to share information on it

and rest reported no issue after diagnosed with T1DM. On the other side unmarried and participants who were eligible for marriage, only 1 out of 11 said that they were facing problem for marriage and other seven participants declined to share information on it. Further more than two third of participants (87.5%) said that their family concerned about their health. For coping up with their health, only 21% reported that they consulted doctor and 14% said that they had taken some steps towards diet change and use of insulin injection/tablets.

Knowledge, attitude & practice

Regarding knowledge, more than 80% participants had some knowledge on symptoms of T1D, which reported respectively tiredness/weakness (58.9%), polydipsia (30.6%), polyuria (30.6%), weight loss (28.6%), polyphagia (17.9%) and vertigo (5.4%). Additional knowledge on causes found poor as around 43% participants didn't have any knowledge on causes however as per participants' knowledge hormonal and autoimmune are most common cause for T1DM (Table 2). Further inquiring on knowledge regarding health complications due to T1DM, majority of them reported kidney failure (50%) followed by blindness (46.4%), heart problem (32.1%), hypertension (16.1%) and gangrene (16.1%).

Talking on T1DM is curable, 32% reported as it is curable however more than 50% participants also said T1DM is preventable. Most of them believed T1DM could prevented through regular exercise (83%) and healthy diet (80%). Almost 89% participants reported that practicing some form of exercises out of that 56% were practicing only walking as exercises however rest 44% were using combinations of exercises. Further, their attitude towards regular exercises also asked and 70% reported that they do exercise daily. Around 84% of participants had changed their diet pattern to cope up with T1DM which includes avoid sweet food (62.5%), avoid fatty/oily food (41.1%), take small and frequent meal (27%), use artificial sweeteners (8.9%) and having nutritious diet (18%). Only 16.1% participants reported that they ate fruits and veggie salads in their regular diet. Habit of tobacco consumption reported 5.4% however no one reported habit of alcohol.

More than 50% of participants had awareness on confirmatory diagnostic test of HbA1C for T1DM. Only six participants out of 21 married participants reported that they were aware and practicing about next generation planning.

Health seeking behavior & treatment

For 1st contact at onset of sign and symptoms 8.9% went to public hospital, 87.5% went to private hospital and 3.6% went to NGO/trust hospital. For diagnosis 7.1% went to public hospital, 89% went to private hospital and 3.6% went to NGO/trust hospital. However, 1st contact for treatment 3.6% went to public hospital, 94.6% went to private hospital and only 1.8% went to NGO/trust hospital. Almost all participants shared that they felt stressed after diagnosed with T1DM and stress scale shows that 40% felt its very stressful followed by stressful (38%), neither stressed nor happy (27%) and only 1% said relaxed and happy. Few participants also reported other comorbidity such as hyperthyroidism (1.7%), foot gangrene (1.7%), hypertension (3.6%) and TB (1.7%).

Participants were using different combinations of medicines also. Majority of them were on allopathic medicines such as

Table 2: Knowledge, Attitude & Practice.

Knowledge, Attitude & Practice		Frequency N=56 (%)
Knowledge on Symptoms of Diabetes	Polyphagia	10 (17.9%)
	Polydyspsea	17 (30.6%)
	Polyuria	17 (30.6%)
	Tiredness /weakness	33 (58.9%)
	Weight loss	16 (28.6%)
	Vertigo/Body Pain	3 (5.4%)
	Don't Know	10 (17.9%)
Knowledge on causes for development	Hormonal	13 (23.2%)
	Obesity	5 (8.9%)
	Heredity	9 (16.1%)
	More sweet food consumption	6 (10.7%)
	Autoimmune	12 (21.4%)
	Stress	2 (3.6%)
	Don't know	24 (42.8%)
Knowledge on Complications	Blindness	26 (46.4%)
	Heart problem	18 (32.1%)
	Kidney failure	28 (50%)
	Hypertension	9 (16.1%)
	Gangrene	9 (16.1%)
	Other health problem such as mental, thyroid & UTI	3 (5.4%)
	Don't know	23 (41.1%)
Knowledge on Diabetes curable	Yes	18 (32.1%)
	No	34 (60.7%)
	Don't know	4 (7.1%)
Knowledge on Diabetes Preventable	Yes	30 (53.6%)
	No	9 (16.1%)
	Don't know	17 (30.6%)
If yes, how could be prevented (N=30)	Regular Exercise	25 (83.3%)
	Healthy Diet	24 (80%)
Practicing any kind of exercise	Yes	50 (89.3%)
	No	6 (10.7%)
What Kind of exercises (N=50)	Only One Exercise (Walking)	28 (56%)
	Combination of Exercises	22 (44%)
How regular are you doing (N=50)	Daily	35 (70%)
	Twice in a week	4 (18%)
	Weekly	1 (12%)
Any diet change/control	Yes	47 (83.9%)
	No	9 (16.1%)
What changes kinds of changes	Avoid sweet food	35 (62.5%)
	Avoid fatty / oily food	23 (41.1%)
	Take small and frequent meal instead of heavy meals	15 (26.8%)
	Use of artificial sweeteners	5 (8.9%)
	Nutritious food	10 (17.8%)

Daily food habits	Roti-sabji	19 (33.9%)
	Rice/Rice preparation	15 (26.8%)
	Dal	11 (19.6%)
	Milk	8 (14.3%)
	Different veges/salads	9 (16.1%)
	Fruits	9 (16.1%)
Habit of tobacco consumption	Yes (Nonsmoking)	3 (5.4%)
	No	53 (94.6%)
Habit of alcohol consumption	Yes	0
	No	56 (100%)
Aware about HbA1C report done in diabetic patients	Yes	34 (60.7%)
	No	22 (39.3%)
Next generation planning (N=21)	Yes	6 (28.6%)
	No	15 (71.4%)

Heath seeking behavior & Treatment		Frequency N=56 (%)
1st contact during onset of sign & symptoms	Public Healthcare centers	5 (8.9%)
	Private Providers	49 (87.5%)
	NGO/ Trust Hospitals	2 (3.6%)
Contact during Diagnosis	Public Healthcare Centers	4 (7.1%)
	Private Providers	50 (89.3%)
	NGO/ Trust Hospitals	2 (3.6%)
1st contact of treatment after diagnosis	Private Providers	53 (94.6%)
	Public Healthcare Centers	2 (3.6%)
	NGO/ Trust Hospitals	1 (1.8%)
Your reaction/feeling being Diagnosed with Type 1 Diabetic	Very stressful	19 (33.9%)
	Stressful	21 (37.5%)
	Neither stressed nor happy	15 (26.8%)
	Relaxed & Happy	1 (1.8%)
Any other co-morbidity	Yes	5 (8.9%)
	No	51 (91.1%)
What Kind of Co-morbidity	Hyperthyroidism	1 (1.7%)
	Foot gangrene	1 (1.7%)
	Hypertension	2 (3.6%)
	TB	1 (1.7%)
Are you on medication	Yes	56 (100%)
Which type of diabetes medication	Only allopathic tablet/ Insulin	45 (80.4%)
	Allopathic & Ayurveda/ Homeopathic	9 (16%)
	Only Ayurveda/ Homeopathic	2 (3.6%)
From where do you take medicines	Private Providers	31 (55.4%)
	Public Hospital	1 (1.8%)
	NGO/ Trust Hospitals	10 (17.9%)
	Directly from medical Stores	8 (14.3%)

	Very satisfied	8 (14.3%)
Under insulin therapy what is your feeling	Satisfied	36 (64.3%)
	Neither satisfied nor dissatisfied	9 (16.1%)
	Dissatisfied	3 (5.4%)
Any changes at the site of insulin delivery	Swelling	24 (42.9%)
	Allergy/Eczema	3 (5.4%)
How regular in diabetes medications	Regular	52 (92.9%)
	Almost regular	4 (7.1%)
History of hospital admission	Yes	22 (39.3%)
	No	34 (60.7%)
Do you see yourself different from other	Yes	7 (12.5%)
Have you ever met other children with type 1 diabetes	Yes	31 (55.4%)
Does your insulin injection is painful for you	Yes	9 (16.1%)
Do you see any change of behavior/discrimination parents/ siblings/friends/school/collage	No	56 (100%)

insulin injection or tablets however, 16% of participants were also using combinations of medicines such as Allopathic & Ayurveda or Homeopath. Participants with insulin therapy reported their satisfaction respectively very satisfied (14.3%), satisfied (64.35%), neither satisfied nor dissatisfied (16.1%) and dissatisfied (5.4%). Around 16% found insulin as painful and on inquiring changes at the site of insulin delivery, 43% reported swelling and 5.4% reported allergy or eczema. In spite of all hurdle 93% said they were taking medicines regularly. Also 12.5% reported that they see themselves different from other and 55% of participants met other diabetic children. However, no one reported any behavior change/ discrimination from parents, school, job or friends.

Conclusion

About one third of T1DM cases reported in this study has family history of T2DM including difficulties in coping the condition. Knowledge level about the disease condition found to be poor, however health seeking behavior and treatment compliances were found to be satisfactory. There was possible mistrust in seeking the treatment and advice from the public health system, more so there needs to be a convergence with public and private health care providers. There is also a need for Health insurance coverage among people with Type 1 diabetes thete is also a need for undertaking studies to explore the coverage of Health insurance for people with Type 1 diabetes. Empowerment of the role of both the private sector and health insurance system is badly needed, aside from implementing proper management guidelines to deliver good services at different levels.

There is also a need of provision of adequate health treatment within the broad domain of existing RKSK and RBSK program run by Government of India. There is also an urgent need for developing a T1DM registry system, which could able to document the differential aspects of cases in near future.

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