Awareness among Diabetic (T1DM) Children and their Caregivers

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ABSTRACT: Present study was designed with an objective to assess perceptions, awareness and knowledge regarding T1 Diabetes Mellitus (T1DM) among diabetic patients and their parents/caregivers. Semi-structured interviews were conducted with T1 DM affected patients (aged 13-25 years) and their parents/care givers at Outpatient Department of Endocrinology, Postgraduate Institute of Medical Education and Research (PGIMER), Chandigarh. The study revealed a significant lack of awareness and knowledge about T1DM among respondents. Complications associated with the disease can be moderate, severe or even lethal in some cases. Lack of awareness regarding the disease poses many challenges to the individuals who are suffering from the illness and their caregivers.

INTRODUCTION

Type 1 Diabetes Mellitus (T1DM) is a serious and long-term condition that occurs due to an autoimmune reaction in which the body's immune system attacks beta cells (insulin producing cells) of the pancreas. It is the major cause of diabetes in childhood but can occur at any age (International Diabetes Federation, 2019). The typical symptoms of the T1DM include polyurea (frequent urination), polydipsia (excessive thirst), blurred vision, lack of energy/ fatigue, constant hunger and weight loss.

People with type 1 diabetes can delay or prevent many complications associated with the disease and can lead healthy lives but need daily insulin administration, education and support. (International Diabetes Federation, 2019). Onset of T1DM at any age remains challenging and troublesome for the patients as well as for their families. Children living in

countries with limited access to insulin or inadequate health care services, can face serious consequences of being diagnosed with T1DM in terms of serious complications associated with the disease and premature mortality as a result (International Diabetes Federation, 2019).

The incidence of diabetes is increasing worldwide with considerable variation across different countries. In 2019, a total of 463 million people were estimated to be living with diabetes, this number was estimated to increase to 578 million in 2030 and 700 million in 2045 (Saeedi *et al.,* 2019). According to the International Diabetes Federation Diabetes Atlas (2019) an estimated 1.1million children and adolescents have Type 1 Diabetes. Incidence of T1DM in India is also on a significant rise and requires immediate attention. India stands first for having the largest number of children and adolescents (0-14 years) with prevalent (existing) and incident (new) type 1 diabetes followed by United States of America

and Brazil (International Diabetes Federation Diabetes Atlas, 2019).

In spite of the large number of people affected with diabetes in India, India is not a diabetes-friendly society. Significant myths about diabetes exist in people with diabetes, their family members and general public about the disease, its impact on their health and their capacity to perform day-to-day activities in society (Khandelwal, 2018)

There is a need for integrated, programs of education, monitoring, and support for young people and their families who are living with diabetes. (Bobrow *et al.*, 1985). Creating more awareness among affected families and general public regarding the disease and discussion about it can resolve many queries and change the lives of many persons with T1DM. The present study is imperative to explore the knowledge pertaining to T1DM among those who are actually suffering from the disease and their parents or caregivers.

Objectives of the study: a) to assess awareness and knowledge regarding T1DM among people (aged 13-25) diagnosed with T1DM and their caregivers; b) to explore public perception and knowledge about T1DM (among non-diabetics).

RESEARCH METHODOLOGY

Self-constructed, semi-structured interviews schedule was used to conduct interviews with T1DM patients (N=35) and their parents/caregivers (N=35). Verbal consent was obtained from all the respondents to participate in the study. Self-constructed interview schedules were used separately for patients, their caregivers, and the general population. Interview questions mainly focused on awareness regarding T1DM among patients, their caregivers, and the general population. Respondents were recruited from the Endocrinology Outpatient Department PGIMER, Chandigarh. No specific criteria were followed to recruit caregivers of the patients; however, patients were recruited on the basis of the following criteria. The authors declare that there was no conflict of interest while collecting the data.

Inclusion Criteria: Patients diagnosed with T1DM for more than one year, aged 13-25 years were included in the study, who were accompanied by either parent or a caregiver for their clinical visit to the tertiary care hospital.

Exclusion Criteria: Patients who were recently diagnosed (less than one year) with T1DM, were not included in the study. Further, patients diagnosed with any other type of diabetes other than T1DM, were also not included.

RESULTS

Collectively 70 respondents were interviewed. The socio-demographic characteristics of the respondents have been displayed in table 1.

TABLE 1

Demographic details of the respondents

Characteristics	N= 70
Patients with T1DM	35
Males	20
Females	15
Mean age (SD)	20.29(4.34)
Mean age at diagnosis	12.90 (6.04)
Caregivers	35
Fathers	21
Mothers	12
Elder sibling	02

Responses from the interviews with patients came up with the concept of Knowledge, Attitude, and Practice (KAP) towards T1DM among patients.

UNDERSTANDING KAP

*Knowledge***:** For the present study this section includes knowledge about factual details of the disease, its causes, symptoms, possible risk factors, associated complications, and its management. The following questions were included in the knowledge section of the interview schedule:

1. What is T1DM?
2. What are the symptoms of T1DM?
3. What are the possible risk factors and associated complications with it?
4. Do you know how to manage and what to do in case of hyperglycemia/hypoglycemia?

*Attitude***:** It includes regular monitoring of blood glucose, insulin administration, prescribed medication, and physical activity. Questions that were asked to assess attitude regarding their condition from the patients are as follows:

1. Do you monitor your blood glucose regularly?

2. Do you administer insulin as advised or do you skip sometimes?

3. Do you take medication as prescribed?

4. Do you take care of your diet plan?

5. Do you exercise regularly?

6. Do you disclose your condition with people around you?

*Practice***:** HbA1C examination, urine examination, fundus eye examination. Questions asked to explore practices followed by the patients are as follows:

1. How many times did you get HbA1C done in the past year?

2. Did you get your eye examination done this year?

3. When did you get your eye examination done?

4. Did you get other tests done as suggested by your doctor?

KNOWLEDGE

Patients were observed to be having little knowledge about T1DM even after being diagnosed with T1DM for more than one year. Perceived causes of the disease as described by the patients have been given in Table 2.

TABLE 2

Perceived causes of T1DM among patients

Perceived cause	Respondents (%)
Don't know	45
Eating junk food	25
Stress	18
Knew it was an autoimmune disorder	12

It is evident from the table that only 12% of patients knew about what is T1DM. The majority (45%) of them had no idea about their disease even after being living with the disease for so many years.

All the patients had knowledge about its symptoms, as they all had gone through it. While talking about its treatment, almost everyone knew that insulin was the only solution currently, although some of them (N=3) asked if they could stop administering insulin and treat it with medicines and lifestyle changes. About 65 % of patients had an idea about

hyperglycemia/hypoglycemia and knew how to deal with such cases, while the other 35% did not know about it.

ATTITUDE

Patient's responses to attitude towards T1DM have been given in Table 3.

TABLE 3

Patient's responses to attitude questions

Questions	No. of patients responded
Do you monitor your blood glucose regularly?	Yes= 16, No =19
Do you administer insulin as advised or do you skip sometimes?	Yes= 19, Skip sometimes= 9, N= 7 extra doses
Do you take medication as prescribed?	Yes= 23, No= 12
Do you take care of your diet plan?	Yes= 23, No= 12
Do you exercise regularly?	Yes= 14, No= 21
Do you disclose your condition with people around you?	Yes= 8, No= 27

A considerate number of patients were observed to have a poor attitude towards T1DM, as is clear from the table.

Blood-glucose Monitoring: A sense of negligence was observed among the patients who were not doing it regularly (N=16). They mentioned that they don't feel it's necessary to check blood glucose levels all the time.

Insulin Administration: 9 out of 35 patients mentioned that they skip on insulin injections many times because of negligence that nothing would happen and at the same time some respondents (N=7) reported that they would inject extra units so that they can have their favourite food (mostly junk food as reported by them).

Medication, Diet, and Exercise: Attitude of patients towards medication, diet, and exercise also remains poor as 21 out of 35 patients reported that they were not doing any exercise or any other physical activity, despite being recommended by the doctors as they don't have time (N=16) due to schools, tuitions, etc and some (N=5) reported that they feel fatigued all the time, hence unable to perform any physical activity.

Hiding Disease from Others: When asked about disclosure of T1DM to others, patients (N=27) reported that they did not reveal their condition to others except their close relatives. Reasons were

different for everyone, not wanting to be sympathized and stigmatized were found to be the two major reasons behind not disclosing their condition to the others.

Hiding your condition from others often comes with negative consequences such as skipping insulin injections in public, not caring for a diet pretending to be non-diabetic, etc. Another disadvantage of hiding your illness from others is that instead of giving you the help you need in an emergency situation, they rather might get panicked and not be able to provide you appropriate aid at that time.

PRACTICE

Practice towards successful management of the disease was assessed in terms of regular examinations as advised by the doctors, which includes HbA1c, fundus eye examination, urine examination. Practices regarding T1DM management and care were being considered very lightly by many patients as only 14 out of 35 reported that they were adhering to regular examinations. Reason behind this remains lack of awareness regarding the possible risk factors associated with the disease. Patients were found unaware of the consequences if diabetes not checked.

KNOWLEDGE ABOUT T1DM AMONG THEIR CAREGIVERS

None among the caregivers or parents of patients were found to be aware of or having any factual knowledge about the condition before diagnosis of their own child with T1DM. All of them mentioned that they had never heard about T1DM in their lives before.

Even after many years of living with the disease, caregivers were not completely aware of the causes of the disease and its possible risk factors as many of them were found asking the interviewers about what exactly caused their child the disease, and what was the difference between T1DM and other types of diabetes.

Table 4 represents the perceived causes for the occurrence of T1DM according to parents/caregivers.

None of the parents had an exact idea about the cause of the occurrence of T1DM as it is evident from the table that majority of them (55%) thought it was due to excessive intake of sugar prior to diagnosis.

TABLE 4

Perceived causes according to parents/caregivers

Perceived cause	Parents/caregivers believed (%)
Eating a lot of sugar	55
Heredity	16
Prior illness	15
Fate, bad luck	09
Don't know	05

CONCLUSION

Findings revealed significant lack of awareness about the disease among all the respondents.

Patients and their Parents were found having little knowledge about diabetes, despite their own child being diagnosed with T1DM, many years ago. As far as general population is concerned, most of the people reported that general public would make them feel they themselves (diabetics) were responsible for their condition. Diabetes is one of the most common serious chronic conditions. Family dynamics are affected severely when a child in the family is sick. Hospital/clinic visits, surgical procedures, and frequent check-ups, administering insulin can affect everyone's schedules and take an emotional toll on the entire family. People make it more difficult for sufferers by judging or by stigmatizing the disease.

Incidents have been reported where in order to avoid being judged, or feeling embarrassed due to their disease, missing even one shot of insulin, lead to severe complications. It was found that some people living with T1DM and their caregivers, were leading miserable lives. Parents were so disturbed emotionally that disease itself is enough to go through a lot, but society sometimes makes it more challenging and burdensome, by judging them or giving demotivating remarks etc. A person with Type 1 Diabetes suffers many aspects of social stigma. Stigma can cause a considerable amount of damage for people that are already dealing with a very difficult condition. In the present study stigma was reported by all the patients. Although the term 'stigma' was not used directly by all the respondents but indirect ways in which they reported how they felt the need to hide their disease from others due to stigma associated with the disease. To our knowledge, perceiving wrong causes of the disease, need to hide insulin injections, facing stigma and discrimination, all these factors, directly or indirectly are the results of significant lack of

knowledge and awareness about the disease. It is very crucial to have awareness regarding T1DM as the sufferings of the people living with T1DM are much more than it seems to other people. It is essential to help ensure that all young people with long-term medical conditions, including type 1 diabetes, are properly supported.

Significance of the study: The research is crucial as it highlights the need for information, awareness and management of T1DM. For this purpose, the researchers took the initiative to raise awareness regarding T1DM among the participants of the study. It was a matter of surprise and concern at the same time that the information levels were low even among the affected ones. Therefore, after completion of the interviews, all the respondents were given factual details of the disease, its causes, risk factors, management, etc. Patients and parents were also explained about how to cope with the disease.

Suggestions: In order to avoid further complications, parents should be guided properly right after their child gets diagnosed with the disease. Along with parents, child care centres, doctors, schools should also be provided information about the symptoms of the disease. Awareness regarding diabetes among general population must be created at mass level through physical campaigns and social media.

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