



Perceptions, Awareness and Knowledge about Type 1 Diabetes Mellitus

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Abstract: Type 1 Diabetes Mellitus (T1DM) is a metabolic disorder where body's immune system attacks insulin producing cells (beta cells) of pancreas. Complications associated with the disease can be moderate, severe or even lethal in some cases. Although it can appear at any age, but onset of the disease is usually seen in individuals less than 30 years of age. Semi-structured interviews were conducted with T1DM affected patients (N=25), their care givers (N=20) at Department of Endocrinology, Post Graduate Institute of Medical Education and Research (PGIMER), Chandigarh. Rest of the interviews (N=25) were conducted with general population (non-diabetics) outside the Out Patient Department, within the premises of PGIMER, Chandigarh campus. Study revealed significant lack of awareness and knowledge about T1DM among respondents. It was observed that having T1DM child in a family, affects the whole family and people living with the disease go through much more, than it seems to a normal healthy individual.

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Introduction

Type 1 Diabetes Mellitus (T1DM) is an autoimmune disorder in which body's immune system attacks insulin producing cells of the pancreas. As a result, little or no insulin is produced. Insulin is a hormone responsible for regulation

of glucose into body cells (International Diabetes Federation Diabetes Atlas, 2019). Although T1DM can be diagnosed at any age but usually diagnosed in early adolescents, therefore, earlier it was also known as juvenile diabetes.

People with type 1 diabetes need daily insulin injections to maintain a glucose level in the required range and without external insulin administering, they would not survive. However, with appropriate insulin treatment, blood glucose monitoring on regular basis, education and support, people with T1DM can live healthy lives and delay or prevent many complications associated with T1DM. (International Diabetes Federation Diabetes Atlas, 2019). Onset of T1DM at early age, sometimes as early as an infant age, makes it more challenging and troublesome for the patients as well as for their caregivers including hospital visits, insulin administration and overall management.

India is home to an estimated 97,700 children with T1DM (Kumar, 2012). Incidence of T1DM in India is on a significant increase, and the situation calls for immediate attention. In 2019, a total of 463 million people were estimated to be living with diabetes, this number is expected to increase to 578 million in 2030 and 700 million in 2045 (Saeedi *et al.*, 2019).

Lack of awareness and poor knowledge about the disease possess additional challenges in its management. In people with chronic illnesses and conditions, information management is very important. They may be not sure about disclosing their condition, how much information to give, and to whom (Jochin and Acorns, 2000). There is a need of integrated, ongoing programs of education, monitoring, and support for young people and their families who are living with diabetes. (Bobrow, AvRuskin and Siller, 1985).

In the present study, an attempt has been made to explore the level of awareness and knowledge among affected (patients diagnosed with T1DM and their caregivers) and general population (non-diabetics).

Research Methodology

Semi-Structured interviews were conducted at Department of Endocrinology, Post Graduate Institute of Medical Education and Research, Chandigarh among Type 1 diabetes patients (N=25), their care givers (N=20) and for control interviews (N=25) were conducted with purposively selected respondents outside the Out Patient Department, PGIMER, Chandigarh, who were not diabetics themselves and neither did they have anyone in close relations having diabetes. 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 general population. Interview questions mainly focused on awareness and knowledge regarding T1DM among patients, their

caregivers and general population as a control sample. No specific criteria was followed to recruit caregivers of the patients, however, patients diagnosed with T1DM, falling under the age group of 13-25 years were included.

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 PGIMER, Chandigarh.

Exclusion criteria

Patients who were recently diagnosed (less than one year) with T1DM, were not included in the study.

Results and Discussion

Collectively 70 respondents (patients with T1DM N=25 (15 males 10 females); their care givers N=20; general population N=25), were interviewed. Mean age (\pm SD) of the patients at the time of interview was 20.29 (\pm 4.34) years and mean age at diagnosis (T1DM) was 12.90 (\pm 6.04) years.

The present study is imperative to explore the knowledge pertaining to T1DM among those who are actually suffering from the disease, their care givers and among general population (non-diabetic). Findings revealed significant lack of awareness about the disease. Even 30 per cent of the parents of children were found having little knowledge about diabetes, despite their own child being diagnosed with T1DM, many years ago. Thematic analysis of the interviews was done. Following themes were obtained from the interviews:

Knowledge about T1DM among 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. It was a very new thing for them before they could learn to cope up and management of the disease. Even after many years of living with the disease, patients as well as caregivers were not completely aware about the causes of the disease and its possible risk factors.

Perceived causes of the disease

According to majority (75%) of the parents or caregivers, eating a lot of sugar, sweets, sugary foods etc. in childhood was considered as prime cause of

occurrence of diabetes (T1DM). Although some (15 %) of the parents believed that it could be hereditary, while some (10 per cent) were still in a state of shock that what reason could have caused their child to be diabetic.

Hiding insulin injections

Parents narrated that there was always a fear of being judged while administering insulin. Some (25 %) of the patients with T1DM also described that it becomes very difficult sometime that how to find a secret place to inject insulin in state of emergency. One of the respondents (23-year-old male) informed us that he was once caught injecting insulin in his thigh during school, and was interrogated as if he was on some drugs. He narrated:

“Ek bar mai washroom me jaake apni thigh me insulin injection laga raha tha , achanak se mere teacher aa gaye washroom me aur unhone mujhe dekh lia. Baad me mere se kaafi sawal jawab kiye, mujhe kaafi embarrassing laga aur mere dosto ko bhi pata chal gya k mujhe diabetes hai”

(Once I went to the washroom and was injecting insulin in my thigh, suddenly my teacher came to the washroom and he saw me, later he asked a lot of questions from me, I felt it very embarrassing and my friends also came to know that I have diabetes).

Stigma perceived

A person with Type 1 Diabetes suffers many aspects of social stigma including miserable human beings, rejected marriage candidates and deprived of normal life (Abdoli *et al.*, 2013). 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 and their caregivers as well. 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. Father of 16 years old girl described due to stigmatization attached to the disease their daughter hid her condition for more than 4 years in her school days.

Mother of a 23 years old daughter said:

‘Meri beti ki abhi shadi vaali umar bhi nahi hai lekin jab bhi mai bahar nikalti hu aur kisi se milti hu toh sabka ek hi sawal hota hai, apki beti ki shadi kaise hogi? isiliye ham to jyada kisi se baat hi nahi karte is baare me’

(My daughter is not even at age to get married, but whenever I step out and meet someone, everyone has always generally one question, that how will

your daughter get married? That is why we don't talk much about it with anyone)

Discrimination

Several incidences of discrimination were reported by the patients and their caregivers. One school going child reported that he was permanently labelled as "permanently sick" and was refrained from school trips because teacher would find it risky to take 'sick child' to a trip. He narrated:

"If the teachers were educated enough to understand that this is not something abnormal, I am fit and fine and I can take care of myself, they would not have treated me as permanently 'sick child'".

Another school going girl narrated about discrimination by friends at school:

"They started maintaining distance from me, they would avoid me having in their company as they thought, they might also get diabetes because of me" further she added:

"It is not their fault, they are not aware about it, as we were also not aware before I got diagnosed with it"

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 about the disease.

Perceptions, knowledge and awareness among general population regarding T1DM

Awareness regarding T1DM among general population was scarce. Awareness was assessed in terms of the basic knowledge among non-diabetic people, how they understood T1DM, and what thought they had about T1DM affected individuals, and awareness about the sufferings of the individuals with T1DM. Out 25 non-diabetic respondents only two had heard about what is type 1 diabetes and what can be the possible risk factor for its occurrence. Rest (92 per cent) had no idea about what actually T1DM is and its causes and associated risk factors. For them it was a novel term unheard before. Some (36 per cent) people held patients with T1DM responsible for their condition. As one of them was saying:

"Log khud hi apna dhyan nahi rakhte hain, pahle se hi dhyan rakhna chahiye taki aisi pareshani aaye hi na"

(People do not take care of themselves, care should be taken beforehand so that no such problem arises)

Awareness and knowledge on the basis of educational qualification

Out of 25 respondents (Parents or caregivers), 56 per cent of them lacked formal education, 32 per cent were educated up-to Post graduation level and 12 per cent of them had completed their doctorate degree. As far as awareness or knowledge regarding disease is concerned, people with no formal education had no idea about any kind of diabetes, however, they had heard about diabetes as 'sugar' in general but they had no idea about its types, complications and what actually diabetes is.

While among respondents who were formally educated, only 2 out of 11 had paltry knowledge about T1DM and its associated complications.

Usually, one perceives that a person's knowledge may be determined by their level of education, however, that does not hold true, as was evident in case of one of the respondents among general population, who was Doctorate degree holder and by profession, a professor but he was not aware of the factual details of disease. He described T1DM as:

"I have no idea about its types, but I have heard that the one that occurs in children is different from the other"

Conclusion

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 stigmatising the disease.

Incidents have been reported where in order to avoid being judged, or feeling embarrassed due to their disease, missing on 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, giving demotivating remarks etc. Although that is not the case with everyone, some of the respondents (N=4) also reported where people around them were very supportive, and they never felt demotivated because of someone.

It is very crucial to have awareness regarding T1DM as sufferings of the people living with T1DM are much more than it seems to other people.

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.

Recommendations and 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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Declaration of Conflicting Interest

Authors declare that there is no conflict of interest.

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