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Challenges and Experiences in managing type 1 Diabetes Mellitus

Among Parents of Indian Adolescent

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Abstract: Type 1 diabetes mellitus (T1DM) effects from the autoimmune demolition of β cells of the endocrine pancreas. Pathogenesis of T1DM is diverse from that of T2DM, in which both insulin resistance and reduced excretion of insulin by the β cells show a synergistic role. Type 1 diabetes cannot be prohibited with present information. There are no easy solutions for addressing diabetes but synchronized, multi-component involvement can make a noteworthy modification. Everybody can performance a part in decreasing the influence of all forms of diabetes. Governments, health-care providers, diabetic patients, society, food manufacturers and producers and dealers of medicines and technology are all stakeholders. Communally, they can make a important support to stop the growth in diabetes and recover the lives of those individuals suffering from this disease. This paper describes the demographic profile of enrolled Patients and families and also examines socio-demographic challenges of their survival.

Keywords: T1DM, Insulin, Adolescent, Family, Hypoglycemia, Hyperglycemia.

1. Introduction

Type 1 diabetes (T1DM) is certainly not an unimportant sickness. Quite possibly the most widely recognized pediatric endocrine sickness, it influences almost 500,000 youngsters underneath the age of 15 years. Of these, over half live in agricultural countries, with India being home to an expected 97,700 youngsters with T1DM. This is more than the general weight of type 2 diabetes India needs to bear: each fifth TIDM kid on the planet is an Indian, while (just) every seventh kind 2 diabetes mellitus (T2DM) grown-up across the globe claims Indian identity [1].

Individuals with T1DM have a clinical show that is very surprising from their T2DM partners. In view of total insulin insufficiency, the ideal insulin system is a basal-bolus one or, if accessible, an insulin siphon. Immune system infection, for example, hypothyroidism and celiac illness should be

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evaluated for. A T1DM kid requires continuous checking for glycemia and ketonuria just as for musculoskeletal and rheumatologic difficulties. Accentuation on diet, calorie tallying, normal active work, infusion procedure and day off administration is fundamental. The interesting mental necessities and difficulties of developing kids should be tended to. What might be discretionary administration for a T2DM patient gets fundamental in T1DM. Every one of these and other such factors underline the requirement for an organized diabetes instruction program, for the two patients and suppliers, which centers around T1DM the board. This isn't an extravagance. It's anything but a need [2].

The occurrence of Type 1 diabetes mellitus (T1DM) is quickly expanding in explicit locales and shows a pattern toward early period of beginning. T1DM represents about 10% of diabetes, influencing 1.4 million in the United States and around 15 million on the planet. 40% of the people with T1DM are more youthful than 20 years old. The frequency of T1DM is exceptionally factor among various gatherings [3].

Diabetes mellitus coming at youthful age is quite difficult for guardians and treating clinicians. Type 1 diabetes being the commonest etiology in this age bunch [4]. Patients with type 1 diabetes are inclined to intense difficulties as diabetic ketoacidosis and hypoglycemia, if insulin is either overlooked or abused. Objectives of treatment in little youngsters are individualized relying upon their age. At early age, the principle objective of treatment is to keep youngster liberated from intense difficulties and undesired manifestations simultaneously guaranteeing a typical rest, development and advancement and a relative limitation free food propensities [5]. Constant intricacies of diabetes are less frequently seen as long as five years old or the underlying five years of beginning of diabetes in type 1 diabetes [6].

While featuring the mental necessities, we should likewise make sure to give apparatuses to progress. Ideas like patient strengthening, shared dynamic social change advising, persuasive meeting and adapting abilities preparing ought to be converted into genuine practice [7].

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2. Research Method

The subjects included 100 children and adolescents with T1D. A detailed demographic, social, family, and medical history was elicited, and examination was done in the patients. Adolescents, aged 10-20 years, and a parent/carer were recruited. Data collection occurred over a 1 year period, during which time 100 adolescents were approached.

3. Results

3.1 Challenges related to Family in managing T1DM

1. Family members who help in child treatment: The Survey results show that Majority of cases 53% both parents (mother/father) help in child treatment. Whereas 20% only mother 11% only father, 1% by Siblings, 13% by All (mother/father/siblings) and remaining 2% by others (Relatives and Neighbors). Graph 1 illustrates both mother and father plays a vital role in child treatment.



Graph 1: Graph illustrating support of Family Members in Child Treatment

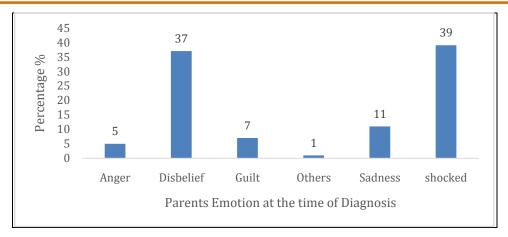
2. Parents Emotion at the Time of Diagnosis: The Survey result show that most parents 39% shocked at the time of child Type 1 Diagnosis, 37% Disbelief, 11% Sadness,7% Feeling Guilt, 5% Anger, 1% other emotion like frustration. Survey clearly indicates that majority of cases parents shocked at the time of Child Type1 Diagnosis (graph 2) followed by others negative human emotions like Disbelief, sadness, Guilt, Anger, Frustration, During survey I also find out the reason of negative human emotion to sum up in India scenario each family members are closely connected with each other that's why this kind of emotion I must say it's normal at the time of Diagnosis because they are not aware what is Type1 Diabetes is all about.

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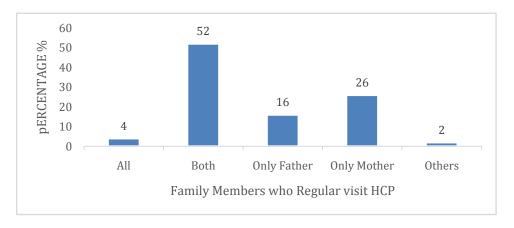
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Graph 2: Illustrates Emotional status of Parents during Diagnosis

3. Family members who regular visit HCP (Health Care Professional): The Survey results show that 52% both parents (Mother/Father) regular visit HCP with T1DM Child followed by Mother 26%, Father 16%, All (All Family Members) 4% and others (Relatives and Neighbour) 2%..

Survey and Graph 3 shows most of the parents are not left their child individually they visit HCP along with T1DM child.

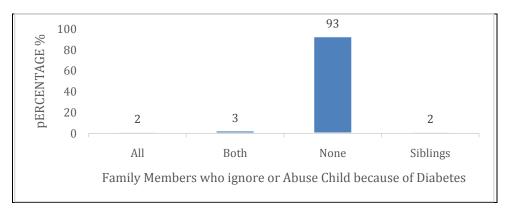


Graph 3: Graph illustrate status of regular follow-up with HCP

4. Family Members who Ignore or Abuse Child because of Diabetes : The survey results show that 93% None of the family members Ignored or Abused T1DM child, 3% Ignored or Abused by their parents, 2% by Siblings and remaining 2% by all family members.

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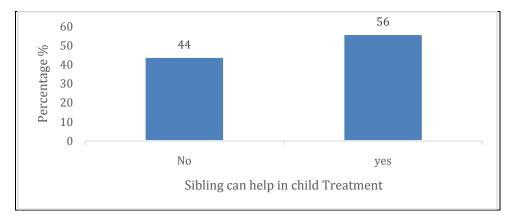
In Indian context, most of the family members are not ignored or abused their T1DM child they are ready to support throughout their journey. Very few Ignored or Abused by their parents and siblings that too found in low per capita income families because they cannot afford the insulin and monitoring strips expenses (graph 4).

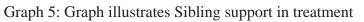


Graph 4: Ignorance of Child due to diabetes

5. Siblings can help in Child Treatment: The Survey results show that 56% Siblings help T1DM Child treatment in one way or others and remaining 44% siblings are not contributed and help in T1DM treatment (graph 5).

The result indicates that, Better glucose controlled in those families where patients and siblings both help in T1DM child treatment, that means siblings play a vital role for good over all controlled and Diet as well.





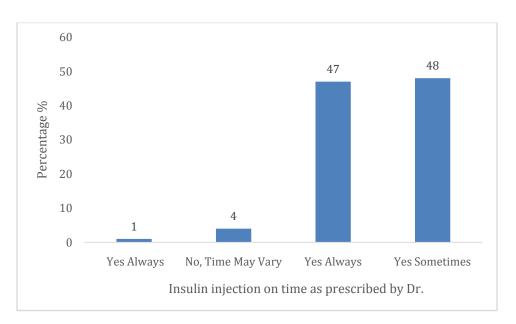


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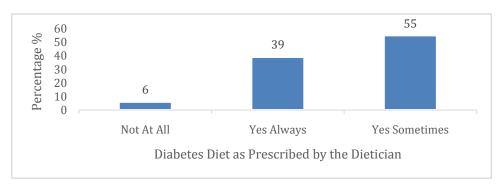
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6. Insulin Injections on Time as Prescribed by the Doctors.: The Survey results show that 48% and 47% shows yes Sometimes and yes always on time respectively followed by 4% No, time may Vary and remaining 1% said Yes, always change the Insulin time and sometimes missed it too.

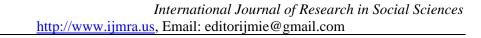


Graph 6: Graph illustrates Insulin injection on time.

7. Diabetes Diet as Prescribed by the Dietician :The survey results show that 39% said Yes always followed Diet chart as Prescribed by the Dietician, 55% followed Sometimes and remaining 6% Not at all followed.The above research results shows majority of the participants are not seriously followed dietician instruction.



Graph 7: Diabetic Diet prescribed by Dietician

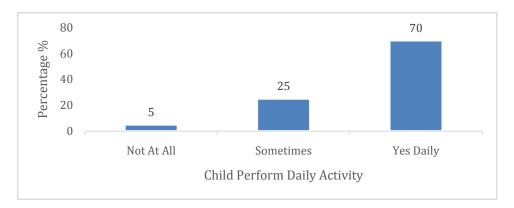


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8. Child Perform Daily PhysicalActivity :

The Survey results show that 70% children performed daily physical activities like walking, running, playing, exercise etc, 25% performed sometimes and remaining 5% not at all performed.

The study clearly indicates that most of the children performed physical activities daily some are performed weekly and very few not at all performed.



Graph 8: Child Perform daily physical activity

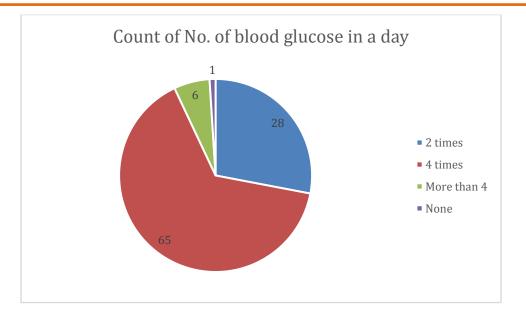
9. Child check No. of blood Glucose level in a day : The survey results show 65% T1DM child checked their blood glucose test 4 times in a day followed by 28% checked 2 times a day, 6% checked more than 4 times a day and remaining 1% checked none. The study shows most of the T1DM children checked 4 times in a day and take their insulin injection accordingly.

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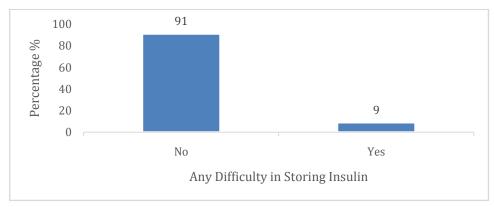
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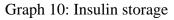
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Graph 9: Numbers of glucose monitoring in a day

10. Difficulty in Storing Insulin :The Survey results show that 91% doesn't have any difficulty in storing Insulins and 9% faced some difficulty in storing Insulin's. The Study shows that most of the participants not found any difficulty in storing insulin's they followed all cold chain guidelines in order to maintain insulin efficacy (graph 10).





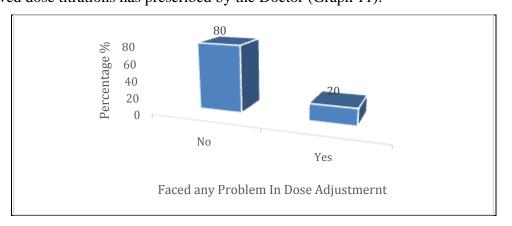
11. Faced any Problem in Dose Adjustments: The Survey results show that 80% participants doesn't have any problem in dose adjustments whereas 20% have some difficulty in dose adjustments.

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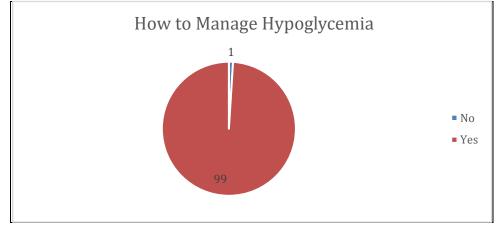
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The study clearly indicates that majority of the participants shows no difficulty in dose adjustments they followed dose titrations has prescribed by the Doctor (Graph 11).



Graph 11: Dose Adjustment Problem

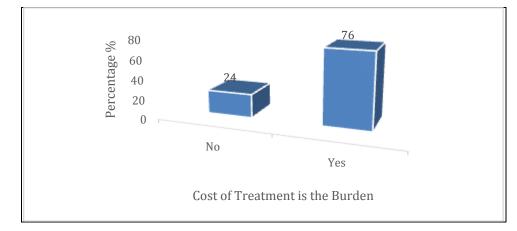
12 How to Manage Hypoglycemia: The Survey results show that 99% know how to manage Hypoglycemia only 1% don't know how to manage it. The study clearly indicates that almost all the participants have good knowledge over Hypoglycemia management, the reason behind it, Hypoglycemia is much dangerous as compare to Hyperglycemia. Severe Hypoglycemia can leads to coma or death if not treated immediately (graph 12).



Graph 12: Graph shows Family management of Hypoglycemia

13 Cost of Treatment is the Burden :The survey results show that 76% participants faced cost of treatment is a financial burden in the family whereas 24% participants considered no financial burden they said its treatment not burden.

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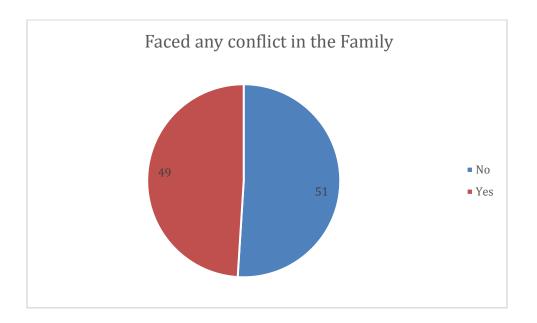


The study shows most of the families faced financial burden because of treatment cost (graph 13).

Graph 13: Graph shows family burden of treatment cost

14. Conflict faced by the Family: The study results show 51% Families doesn't faced any conflict in their families whereas 49% said yes they faced in one way or other (graph 14).

The study shows almost half of the participants faced conflict in any way and remaining half not faced any conflict within families.



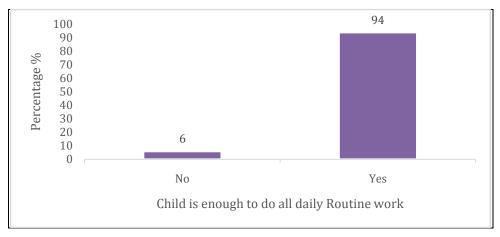
Graph 14: Conflict faced by the family.

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15. Child enough to do all Routine Activities: The study results shows that 94% T1DM are

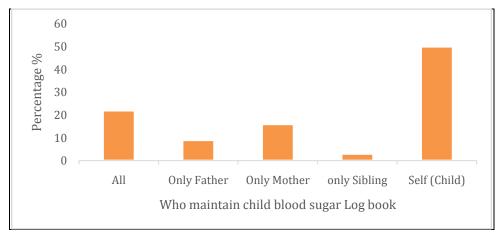
matured enough to do all routine work whereas 6% are not enough to do.

The study clearly indicates that most of T1DM children are performed daily routine work by themselves. Secondly, T1DM not impact their daily routine activities.



Graph 15: Daily routine work Habit

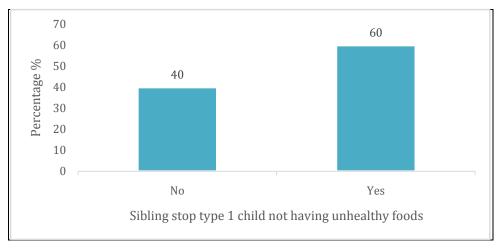
16. Who maintains child blood sugar log book: The study results show that 50% are maintained by self, 18% by their mother, 8% by father, 22% by all family members and remaining 2% by siblings. The study shows half of the participants maintained by themselves remaining half is taken care by the families members (graph 16).



Graph 16: Maintenance of child blood sugar log book

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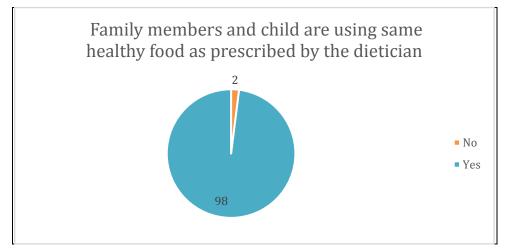
17. Siblings stop Type1 child for not having unhealthy food: The study results show that 60% siblings are stop their T1DM child not to have unhealthy food and 40% siblings are not do anything. The study shows that, in most of the families siblings are also contributed in Diabetes management.



Graph 17: Sibling role in food habit of Diabetic Child

18. Family members and child are using same healthy foods as Prescribed by the Dietician:

The survey results show that 98% are followed the same foods by their families as Prescribed by the dietician whereas 2% participants are not followed the same food (graph 18).



Graph 18: Food Habit of Family

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4. Analysis

Information on the populations' health is required for the planning of health policies and prevention programs [8]. The present study provides a database of children and adolescents with T1D in this region of India and provides an opportunity to address numerous issues of relevance to clinicians and patients. In Indian context family play an important role when it comes to Diseases/Disorder Managements, especially when it comes to T1DM because it deal with small children. The survey conducted among adolescents age group between 10 to 20 years of age with a sample size of 100 participant's .The survey is conducted in both Joint family and Nuclear family, both the families have one common objective that how to controlled T1DM. In most of the families Mother and father both help in child treatment and came across many negative human emotions at the time of Diagnosis like Disbelief, shocked, anger, sadness, guilt, blame, frustration etc. . Almost half of the participants said both mother and father visited HCP for follow up along with T1DM child and 93% family members never ever abused or ignored T1DM child because of their lifelong Disorder. In most cases, 56% siblings help in Child treatment. HbA1c better controlled when all the family members help T1DM child in one way or other. Most of the T1DM children are followed Dr and Dietician advice 48% Always, 47% Sometimes and 39% Always, 55% sometimes respectively. T1DM doesn't effect children daily physical Activities like running, walking, playing, and exercise etc. 70% T1DM children performed daily. This shows T1DM children are more pro actively performed Daily physical activities as compared with those children who does not have T1DM.In addition to, T1DM children checked their Blood Glucose level and maintain their log book by themselves, almost 65% Checked 4 times in a day and 50% maintained log book. Checking of blood Glucose level is very much important in Diabetes Management. Secondly, titration of Insulin dose is also depend upon Blood Glucose level. 80% T1DM children doesn't faced any difficulty in dose titration/adjustment and also aware about Hypoglycemia and its management because Hypoglycemia is very common with T1DM.

We all know Insulin required cold chain management if not stored properly may loose its therapeutic value. For every Insulin maybe its Short acting, Rapid Acting, Intermediate, Long

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Acting etc are stored at 2 to 8 degree, if it's opened it stored below 30 degree. Most of the patients 91% doesn't have any difficulty in storing Insulin, this shows they followed Insulin storage guidelines, but on the other hand cost of Insulin is the biggest challenge for 91% Indian T1DM Families and remaining percentage got free Insulin either from Government Hospitals or dispensary.

Most of the families are used same healthy food as prescribed by the Dietician to T1DM children because they know the importance of healthy Diet and followed the same regimen. Secondly, all family members play a vital role in T1DM treatment specially Siblings because they are the one who keep an eye on T1DM child and sometimes stop them not to have unhealthy foods that are not recommended to T1DM child.

5. Conclusion-

Firstly, Indian population not awared about Type 1 Diabetes, Secondly the cost of insulin is not affordable. The Research survey talk briefly about challenges faced by Indian Population. The present study highlights the need to mobilize more resources and improve health care of children with T1D, especially among the economically backward population. In an invited commentary on T1D in India. As we all know challenges in managing Type1 Diabetes with Indian Population is the Barriers.

References

- **1.** International Diabetes Federation Diabetes Atlas. 5th ed. Brussels: IDF; 2011
- 2. International Diabetes Federation. Diabetes Atlas. 3rd ed. Brussels: IDF; 2007
- Daga, R., Naik, S., Laway, B. A., Shakir, M., &Rafiq, W. (2015). Demographic and Clinical Characteristics of youth onset Diabetes Mellitus in Kashmir India. *International Journal of Pediatrics*, 3(4.1), 739-747.
- **4.** Zargar, A. H., Bhat, M. H., Laway, B. A., &Masoodi, S. R. (2001). Clinical and aetiological profile of early onset diabetes mellitus: data from a tertiary care centre in the Indian subcontinent. *Journal of postgraduate medicine*, *47*(1), 27.

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- Morris, A. D., Boyle, D. I., McMahon, A. D., Greene, S. A., MacDonald, T. M., Newton, R. W., & DARTS/MEMO Collaboration. (1997). Adherence to insulin treatment, glycaemic control, and ketoacidosis in insulin-dependent diabetes mellitus. *The Lancet*, 350(9090), 1505-1510.
- **6.** American Diabetes Association (ADA). Diagnosis and Classification of DM. Diabetes Care 2010;33(suppl. 1):s62-9.
- **7.** Kumar, K. P., Azad, K., Zabeen, B., &Kalra, S. (2012). Type 1 diabetes in children: Fighting for a place under the sun. *Indian journal of endocrinology and metabolism*, *16*(Suppl1), S1.
- Tolonen, H., Laatikainen, T., Helakorpi, S., Talala, K., Martelin, T., &Prättälä, R. (2010). Marital status, educational level and household income explain part of the excess mortality of survey non-respondents. *European journal of epidemiology*, 25(2), 69-76.