

Holistic Impact of Type 1 Diabetes Mellitus (T1DM) in India: An Exploratory Qualitative Study

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Abstract

Introduction: Type 1 Diabetes Mellitus is a chronic condition rooted in the pancreas deficiency of insulin production. The condition is majorly associated with juvenile population and hence impacts the overall holistic quality of life. T1DM management in India, is influenced by numerous factors. This research aims to explore these factors' impact on T1DM care by understanding the perceptions of different stakeholders involved in T1DM management.

Aims and Objectives:

1. To explore the subjective experiences and perceptions of multi-stakeholders of T1DM in India.
2. To identify the contextual factors in the management of T1DM in India and their multidimensional impact.
3. To understand how individuals with T1DM in India make sense of their condition and how contextual factors shape their management strategies.

Methodology: This qualitative research involves multi-stakeholder analysis, including T1DM individuals, caregivers, healthcare providers, insurers, technology facilitators, educational organizations, certified diabetic educators, support group members, Government and Non-governmental Organizations. Data collection spans May to August 2023, within both physical and virtual support groups. Around 30 diverse participants share experiences through In-Depth Interviews lasting 1 hour each. Thematic analysis and coding reveal patterns while upholding ethical guidelines, approval, voluntary participation, informed consent, and confidentiality. No known risks exist, with potential benefits including enhanced T1DM care. Data security respects participant autonomy. Ethical clearance was obtained from the Internal Ethics Committee of Indian Institute of Public Health-Hyderabad.

Conclusion: This study highlights various factors significantly impacting T1DM management in India, including healthcare access, socio-economic challenges, insurance coverage, insulin affordability, health literacy, cultural beliefs, healthcare disparities, stigma, and government policies. Family support, social acceptance, mental health, educational and work policies, employment, nutritional challenges, relationships and dietary preferences also affect T1DM management. Thus, this study records and reports the perceptive and subjective experiences of the stakeholders as evidence to the required changes in managing T1DM in India which is a multifaceted approach, involving healthcare system

improvements, policy changes, education, awareness, cultural sensitivity, and community support much more. Scaling and enhancing practices that positively impact T1DM can improve diabetes management and enhance individuals' quality of life in India.

Keywords: Type 1 Diabetes Mellitus (T1DM), T1DM management, Holistic Burden, Well-being.

1. Introduction

Type 1 Diabetes Mellitus (T1DM) affects various stakeholders, including individuals with the condition, their families, healthcare providers, schools, employers, and society at large [3]. Those living with T1DM face daily challenges in managing their condition, such as monitoring blood sugar levels, administering insulin, and adjusting their lifestyle to maintain health. Families of individuals with T1DM also bear significant emotional and financial burdens as they support their loved ones and manage medications. Healthcare providers play a critical role by offering medical care, education, and support to both individuals with T1DM and their families.

Schools and educational institutions are responsible for creating a safe and inclusive environment for students with T1DM. This involves training staff to handle diabetes emergencies, allowing students to manage their condition during school hours, and ensuring access to necessary resources like blood glucose monitoring equipment and insulin. Employers may need to accommodate employees with T1DM by providing flexible work schedules or permitting breaks for blood sugar management. Insurance providers and policies also impact families financially.

Research highlights the importance of engaging stakeholders in addressing disparities in T1DM technology use, improving patient-centered outcomes in pediatric diabetes studies, and identifying multidimensional healthcare transition outcomes for young adults with T1DM [4,7,13]. Involving stakeholders in translating evidence about self-management support can lead to developing acceptable care models and informing patient-centered outcomes research. This process also underscores the value of peer support and multidisciplinary care teams in diabetes care [2].

T1DM negatively affects individuals, healthcare systems, and society due to a lack of awareness, limited access to healthcare, and other barriers that hinder self-management [8]. Stakeholders generally prioritize Diabetic Ketoacidosis (DKA) prevention, education, and family preparation, but public acceptability, health anxiety, and the child's future are often concerns that lack representation [9]. Interactions between stakeholders and the community are limited [5], and policies and healthcare programs tend to prioritize Type 2 Diabetes due to its prevalence and maintenance costs, often neglecting T1DM.

T1DM significantly impacts family health-related quality of life (HRQOL), particularly for mothers, whose care is often not prioritized, leading to severe negative health outcomes [10]. Childhood-onset T1DM affects education, employment, and earnings to varying degrees [14]. It can cause frustration in the affected child, sibling jealousy, parental guilt and stress, financial burdens, social restrictions, and isolation due to body image issues, impacting the psychological well-being of the individual and their family [1].

To mitigate these negative effects and improve quality of life, the multidimensional impact of T1DM on various stakeholders should be further explored. In India, there are significant gaps in studies addressing the burden of T1DM on stakeholders beyond individuals with the condition and their families, particularly in psychosocial and emotional aspects. There are also issues in integrated care, identifying eligible beneficiaries, frontline worker capacity, and limited research on non-medical interventions [11]. Rural

youth with T1DM experience worse care quality compared to their urban counterparts, particularly in appointment adherence, patient-provider communication, and hospitalizations [15]. However, the West Bengal Model offers comprehensive healthcare for T1DM, including free insulin, glucose measuring devices, and test strips, within a structured, dedicated health system [6]. Additionally, the Diabetes Electronic Medical Record System in India helps track diabetes care and serves as a valuable research tool, with 1.4% of patients having T1DM [12].

2. Methodology

This qualitative exploratory study was conducted by a single researcher under the guidance of an expert mentor. The principal researcher was a 24-year-old female graduate student in Public Health with training in qualitative research methods. She was responsible for data collection through in-depth interviews, using specially designed semi-structured interview guides.

2.1 Research Team and Reflexivity

Personal Characteristics: The principal researcher was a 24-year-old female graduate student in Public Health.

Relationship with Participants: The researcher established contact with social groups prior to the study to build trust and encourage participation. The researcher's goals and objectives were not disclosed to participants, although the necessity and significance of the research were explained.

2.2 Study Design

Theoretical Framework: This study employed qualitative exploratory methods.

Participant Selection: Participants were selected through purposive sampling and approached either face-to-face or by telephone. Out of approximately 100 individuals contacted, 30 agreed to participate. The participants belonged to age 13 to 65 of all genders, socioeconomic strata and professional who were diagnosed with T1DM in the last 50 years and were residents of India.

Setting: Data collection occurred in isolated settings. Face-to-face interviews were conducted in a private chamber, and telephonic interviews were conducted with participants in their chosen comfortable locations. For minors, guardians provided assent and consent, and interviews were conducted by telephone, ensuring the minor was isolated from others.

Ethical Considerations: Permissions were obtained from relevant group in-charges, organization authorities, and institutes. These entities were informed about the study's aims, objectives, design, ethical permissions, mode of interview, audio recording, risks, benefits, and participants' rights. Ample time was provided for decision-making before participants signed consent forms. Ethical review was approved by Internal ethics committee of Indian Institute of Public Health- Hyderabad.

2.3 Data Collection

Interviews: A total of 30 in-depth interviews were conducted (n=30). No repeat interviews were carried out. Interviews lasted approximately 25 to 30 minutes and were conducted in Hindi, and English. The interviews were audio-recorded with participants' permission, and field notes were taken.

Data Collection Instruments: Semi-structured interview guides were used, which were pilot-tested prior to data collection.

Data Transcription: Interviews were transcribed, translated, back-translated to check accuracy, and then returned to participants for comments or corrections.

2.4 Data Analysis

Data Coding: The corrected transcripts were coded manually by the researcher.

Analysis Method: Derived thematic analysis was conducted manually to analyze the data.

3. Results

Qualitative derived thematic data analysis of 30 in-depth interviews with individuals living with T1DM and other stakeholders revealed 6 Primary themes namely Medical Management, Emotional and Psychological impact, Social and Lifestyle Impact, Economic and Financial Burden, Educational and Informational needs and Policy and Systemic factors with sub themes namely Type 1 Diabetic Adults, Type 1 Diabetic Adolescents, Caregivers (Parents and Partners), Medical Professionals. Paramedical Professional, Social support groups, non-governmental organizations, researchers, Government service providers, Insurance providers, educational institutes and policy makers.

3.1 Clinical Impact

The clinical impact of T1DM is currently significant, affecting various health aspects such as microvascular and macrovascular complications due to chronic mismanagement. These complications are including retinopathy, neuropathy, and cardiovascular diseases, emphasizing the importance of vigilant glycaemic control through insulin therapy, monitoring, and lifestyle adjustments.

“Due to lack of knowledge and prolonged uncontrolled diabetes I have all the main complications associated with T1DM I have retinopathy, I have no vision in my left eye, I have neuropathy in my left feet, can’t feel things and there is swelling and pain in my feet most of the time, and I also had my kidney transplanted” – Individual with 33 years of T1DM

Hypoglycemia is posing a concern, impacting attitudes towards treatment, especially in intensive insulin therapy, and often leading to cautious dosing.

“The only complication I have ever had due to T1DM is hypoglycemia. I have had terrible episodes of hypoglycemia all my life and especially during pregnancy, my episodes are not only traumatic to me but also to my family and in-laws.” – Individual with 30 years of T1DM.

Diabetic Ketoacidosis (DKA) is a severe complication resulting from insulin deficiency, characterized by elevated blood sugar levels, dehydration, and ketones in the bloodstream. Low general awareness in the public with regards to T1DM and its symptoms is leading to painful episodes of DKA during initial diagnosis in children.

“My child drinks tons and tons of water when her levels exceed 200, she fears the possibility of developing ketones and the complications that are associated. she is scared of the word hospital” -T1DM Caregiver.

“Most infants and Children get admitted to the hospital with severe Diabetic Ketoacidosis (DKA), because the early symptoms are generally ignored or associated with the general food habits of the child” – Clinical professional (Paediatric Endocrinologist)

Caregivers are noting associations between carbohydrate-controlled diets, insulin consumption, and long-term cognitive impacts.

“I have seen the gradual decrease in the cognitive skills of my child ever since she has been on a carbohydrate restricted diet, she often becomes blank suddenly during a conversation or activity.” - Caregiver (Mother of a T1D child).

Improper, incredible suggestions without proper medical regulations from Diabetic educators or organizations treating T1DM and advertising permanent cure currently land individuals in severe health complications, especially in children under age with T1DM. Need for continuous guidance and

interaction between the medical professional and T1DM individuals is felt and credible, age-appropriate guides for daily self-management are requested.

3.2 Psychological Impact

The Psychological Impact of T1DM is profound, influencing overall quality of life. Managing T1DM is demanding continuous monitoring and insulin administration, leading to stress, anxiety, and depression.

“I have suffered for very long; continuous monitoring is very stressful and I have given up on it now. I don’t check so frequently anymore” -T1DM individual for 15 years

“I hate checking my sugar levels before every meal, I have developed a fear of these numbers. But I also fear that I will neglect these numbers and cause harm to myself, so I push myself to do these things, it makes me feel very tired whenever I think of them” -Individual with 11 years of T1DM.

Fear of hypoglycemia is currently a significant concern, causing constant worry and avoidance of certain activities. This fear is straining relationships, increasing fear of social rejection, and eroding self-confidence, potentially leading to overcompensation in blood sugar management.

“Food is very important; however, I get irritated with the carb calculations and unit calculations, however I can’t skip it, I fear I will end up with miss management, hypoes and hypers are irritating.” - Individual with 12 years of T1D

Nocturnal hypoglycemia disrupts sleep patterns, causing fatigue during the day, impacting the quality of life and confidence of the individual in daily activities.

“Hypoglycemia is my worst fear, it is the only fear I have with T1D. I have had very bad experiences with it. The confusion and trauma of hypoglycemia makes me restrict my decisions. I also fear the possibility of over treating hypos that causes hypers” - Individual with 30 years of T1D

“I have severe nocturnal hypoglycemic seizures... my family has adjusted to it ..but I don’t think others can handle , so if I go out with others during nights or long travels generally I force myself to stay awake.” -T1DM Adult

T1DM is also impacting body image and self-esteem, particularly among adolescents and young adults, who may currently feel embarrassed or ashamed of visible devices or injection sites and certain visible changes in body due to prolonged T1DM.

“My daughter is hypo unaware and doesn’t recognize the symptoms, I used to fear sending her to school. I only started to feel safe after using sensors.” - Mother of a T1D child

Social comparison is leading exacerbate feelings of insecurity and self-consciousness.

“I used to like wearing sleeve-less cloths, but now I feel very uncomfortable, my sensor leaves marks sometimes, I don’t feel confident enough.” - T1DM Adult

Psychosocial support and open conversations can currently help individuals develop coping strategies and foster understanding among peers and family members. However, such support is lacking in the current society.

“I tried very hard and long to include and spend time with my patients and address their psychosocial aspects but it’s very difficult to make time, as clinicians we do recognise the need however our priority is the clinical aspects. Also, its very difficult to get them to open up...that’s why I suggest them to join support groups or introduce them to people with similar experiences.” -Pediatric Endocrinologist

Most T1DMs do not feel understood by their clinicians, family members and society and this leads to trust issues.

“I used to suffer from hunger due to strict diet, so I started stealing food at home and money from my father’s pocket to eat outside, I used to feel very guilty.” -T1DM Adult

“My doctor’s do not like when I say this, they do not understand... I prefer staying hyper especially during important days like exams, interviews and presentations. I intentionally stay hyper” - Individual with 17 years of T1DM

Despite the challenges, T1DM have also led to positive lifestyle changes and inspire individuals to work for the greater good, fostering support groups for social causes.

3.3 Social Impact

T1DM can lead to social isolation due to the demands of managing the condition, misconceptions about Diabetes, and stress on relationships.

“It’s irritating to explain people about my sensors and conditions. So, I generally don’t go to events.” - T1DM Teenager

Individuals with T1DM may feel reluctant to participate in social events due to concerns about diabetes management or fear of judgment.

“I have developed insulin resistance and now my neck is black ... I maintain long hair and prefer open hairstyles so that I can cover my neck.” - T1D Teenager

Family members and partners experience stress and worry about the well-being of the person with Diabetes, leading to tension and disagreements.

“I often see my parents fight over the dosages, food decisions or blame each other when something goes wrong with me due to dose.” -T1DM Teenager

“I have to handle everything about the baby, the food, the dosage, the hypo episodes everything...I don’t sleep most nights taking care of the kid, my husband knows things however he doesn’t take initiative to take care...it’s mostly just me...i can’t go anywhere, I sometimes feel like I want to run away.” - Caregiver of T1DM child

School and work environments may require special accommodations for individuals with T1DM, but a lack of understanding can result in stigma and exclusion.

“When I was in school my parents would never send me to birthday parties or functions because they feared people would get to know about my condition and it will be difficult to explain. Now I am an Introvert and can’t talk to people, they complain that If I don’t meet people, make friends and come to social gatherings then I might never find a partner. This is irreversible” - T1D Adult

Advocacy efforts in raising awareness, promoting understanding, and implementing supportive policies to create inclusive environments for individuals with T1DM, ultimately contributing to their overall well-being and success are crucially felt. Additionally, individuals with both T1DM and disabilities face unique challenges in managing their condition, requiring a holistic approach involving healthcare professionals, caregivers, and support networks to tailor diabetes care plans to their specific needs and capabilities.

“I am used to it but it troubles me and becomes troublesome when I have to handle T1DM with my visual challenge. It was very difficult to be trained because to find a guide who knows to handle a person with visual impairment along with sensitivity to T1DM is very difficult, I only came across one other child with this difficulty, but she failed to live because she didn’t have the same resources as I did.” - T1DM Adult with PwD (Visual Impairment)

Involvement with T1DM individuals has led several medical and paramedical as well as caregivers to become T1DM advocates, educating the society to create inclusion for T1DM. Initiatives such as Matrimonial sites dedicated to T1DM or Diabetic individuals, regular social gatherings for advocacy,

committees to protect the rights of T1DMs, training of school teachers for management at school have been made.

“I felt very scared when the child had to go to school, I was worried whether she will be able to handle her pump at school, it was a difficult decision for us but it was much needed. But after several sessions with the school and teachers they helped and supported us. But this is not the case with many other schools we have witnessed schools rejecting admissions due to T1DM.” – T1DM Caregiver

3.4 Economic Impact

T1DM imposes a significant economic burden on healthcare systems, individuals, families, and society overall. Healthcare systems face strains due to the continuous need for medical attention, specialized testing, and access to insulin and medications.

“I feel very pressured to meet the costs of strips and other essentials, I started working at a young age so that I can meet the requirements. However, I can’t earn much because I had to discontinue my education.” -T1DM Adult

Individuals and families bear recurring expenses for insulin, monitoring supplies, and specialized equipment, leading to financial challenges. T1DM can limit workforce participation, affecting productivity and economic output.

“I never revealed about my condition to my employer or co-workers. I am scared of losing my job if they start associating my condition to my productivity.” -T1DM Adult

Efforts to address affordability and access to insulin including calls for transparency, policy changes, and alternative distribution models are anticipated. Managing T1DM requires continuous monitoring, treatment adherence, and lifestyle adjustments, which can impact work productivity and increase healthcare costs. Diabetes-related complications further exacerbate economic challenges, resulting in higher medical expenses and reduced quality of life (QoL). Health Insurances are not customized for T1DM and are unnecessarily complicated leading to a decreased number of T1DMs taking Health Insurance, even when they take one, they hide medical facts to avoid complications.

“Insurances don’t cover conditions that can’t be prevented, so Type 1 diabetes is not covered under insurance in the sense that they do not cover the recurring costs associated with Type 1 Diabetes. But they include the costs associated with complications as a consequence of type 1 diabetes. And no, we don’t know anything about the clinical condition.” -Insurance provider

Most individuals are unaware or do not trust the government facilities.

“I am not aware of any government services provided for T1DM except for the subsidiaries for insulin, strips and financial aid which I got for my kidney transplant and dialysis.” -T1DM Adult.

“I wanted to take the insulin from the PHC however the PHC staff told me to use other sources because they are not sure of the consistency of the brand of insulin that will be available, so I had to shift to other sources.” -T1DM Adult

Government Policies, programs and initiatives majorly concentrate on the T2DM and neglect the special requirements for T1DMs making it difficult for T1DMs to benefit causing large out of pocket expenditure.

“There are several initiatives by the state and national governments that provide care, management and services for the individuals with diabetes however they are not targeted towards T1DM alone.” -NCD Program Officer

Unequal and higher investment of economic resources for one individual in families leads to compromise of the Quality of life of the entire family especially the siblings of T1DMs.

“My parents rejected my abroad plans because they were not confident about the diabetes management. I lost many opportunities and chances due to the same reason.” -T1DM Adult

The Research and development as well as manufacturing of T1DM technology is done in foreign countries majorly due to which the cost is severely high.

“The future we were waiting is already here, we have pumps that run with AI, but the cost is increasing because they are not indigenous” -Technology Provider

4 Conclusion

This Study delves into the intricate network of factors influencing the care and management of T1DM in India. It highlights the multifaceted nature of this challenge, specially highlighting the impact of the condition on the social and mental health of the directly and indirectly associated stakeholders of T1DM. It recognizes that understanding and studying the profound impact of these factors on individuals with T1DM is the first step towards a more comprehensive and effective approach to diabetes care. By addressing these complex factors T1DM management, Quality of Life and holistic wellbeing of T1DM individuals and other stakeholders can be enhanced. The study identifies that these gaps in the t1DM management are caused due to negligible or no representation of the Primary stakeholders in the decision making of the condition related care. After careful study of the responses of the stakeholders, various recommendations have been made in the study. These recommendations are as follows:

1. Endocrinologists and healthcare providers should conduct regular counselling sessions for individuals with Type 1 Diabetes (T1DM) and their families to alleviate any hidden emotional burdens. They should also strive to create a positive hospital experience for young T1DM patients to prevent them from developing a fear of medical care.
2. Other medical professionals and Diabetic Educators should offer daily support to T1D individuals while staying within their scope of expertise, avoiding potentially harmful interventions without proper training. Clear protocols should govern the role of Certified Diabetic Educators.
3. Collaborative efforts between clinicians and support groups are essential to provide ongoing care and social support to those with T1DM.
4. Insurance providers should consider covering the ongoing expenses associated with Type 1 Diabetes and educate their agents about the condition.
5. Exploring the inclusion of Type 1 Diabetes in disability legislation could benefit those primarily affected by the condition.
6. Develop standardized, user-friendly educational materials on essential T1DM topics for affected individuals, caregivers, and especially those with disabilities.
7. Educational institutions should train teachers and have trained healthcare professionals on-site to handle emergency situations related to T1DM.
8. Caregivers' needs should be addressed through frequent support group counselling sessions.
9. Encourage open communication among T1D children and teenagers, both among themselves and with their families.
10. Platforms should be made to allow the healthy representation of T1DM individuals because they are the primary stakeholders.
11. Parents should maintain constant vigilance over T1D-afflicted children while also respecting the privacy and self-esteem of unaffected siblings.
12. Continuously monitor the habits of T1D children and teenagers without negatively impacting their self-esteem.

13. Further studies should be conducted to understand the holistic burden of T1DM individuals and the other stakeholders associated with them.
14. Positive habits associated with T1DM should be encouraged to create an optimistic impact on life and promote inclusion of T1DM in the society.
15. Any promotional material regarding products or procedures claiming to cure Diabetes Mellitus should be approved from clinical bodies and specify the type of Diabetes referred.

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