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## Original research

# Awareness regarding COVID-19 and problems being faced by young adults with type 1 diabetes mellitus amid nationwide lockdown in India: A qualitative interview study

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## ARTICLE INFO

## Article history:

Received 3 June 2020

Received in revised form 30 June 2020

Accepted 3 July 2020

Available online 11 July 2020

## Keywords:

Awareness

COVID-19

Diabetes mellitus

T1DM

Young adult

## ABSTRACT

**Aims:** To assess awareness about COVID-19 and problems faced by young adults with T1DM amid nationwide lockdown in India.

**Methods:** A cross-sectional telephone-based qualitative interview study was conducted in young adults (aged 18–30 years) with T1DM amid lockdown. Following verbal consent, participants were asked 8 open-ended questions, 5 on awareness about COVID-19 and 3 catering to problems being faced concerning diet, physical activity and treatment amid lockdown. On average, 3 interviews were conducted per day with each lasting for 15–20 min. Interviews were recorded, transcribed and analyzed by qualitative content analysis.

**Results:** Thirty-two participants were interviewed; after exclusion of two poorly recorded interviews, 30 were finally analyzed. Mean age of participants was  $22.4 \pm 4.0$  years (M:F = 8:7). Only 30%, 40% and 53% of participants were aware of modes of transmission (respiratory droplets and fomites), cardinal symptoms (fever, cough and breathing difficulty) and means of prevention (staying indoors, social distancing and regular hand washing), respectively. Majority of participants were unaware of additional risks associated with COVID-19 in diabetes mellitus. Most participants could continue with their routine diet and prescribed treatment regime, however, 90% reported a reduction in physical activity and 72% experienced worsening of glycemic control post-lockdown.

**Conclusions:** Young adults with T1DM lack adequate awareness about COVID-19. Increasing awareness and imparting diabetes self-management education via digital/print media is needed.

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## 1. Introduction

The novel coronavirus disease (COVID-19) has been on the rampage ever since its outbreak in December 2019 in Wuhan, China. To date, the disease has affected over 5.3 million people, inflicting more than 342,000 casualties in over 200 nations worldwide [1]. Although the overall mortality rate of COVID-19 ranges from 1.4 to 7.2% [2,3], patients with underlying co-morbidities like diabetes mellitus (DM) tend to have severe disease, acute respiratory distress syndrome (ARDS) and increased mortality [4,5]. People with both type 1 diabetes mellitus (T1DM) and type 2 diabetes mellitus (T2DM) are at a high risk of poor outcomes with COVID-19 [6]. Thus, people with DM need to be overly cautious amid the ongoing pan-

demic and must stringently follow social distancing, ensure proper hand hygiene and maintain good glycemic control to avoid contracting the disease [5,7,8]. However, people's adherence to these control measures will be largely affected by their awareness about the disease and the means of preventing them. Proper awareness is likely to translate into effective preventive practices. However, in a cross-sectional survey conducted among 630 adults with one or more underlying chronic conditions, nearly one-third of participants could not correctly identify symptoms of COVID-19 or ways to prevent infection [9].

Nationwide lockdowns imposed by Governments all over the world have made things more difficult for people with DM. A recent study from China had shown that elderly subjects with T2DM experienced worsening of glycemic control during the ongoing COVID-19 pandemic manifesting as higher fasting blood glucose. Limitation of physical activity, altered diet, restricted availability of anti-diabetic medications, stress due to lockdown and lack of

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in-clinic follow-ups could have been the contributing factors [10]. Dietary adherence and physical activity are the cornerstones for the management of T1DM as well [11,12]. Besides, stress and frequency of clinic visits are important predictors of glucose control in people with T1DM [13,14]. Thus, the aforementioned factors that could have resulted in suboptimal glucose control in elderly individuals with T2DM might also play a role in contributing to the worsening of glycemic profile in people with T1DM amid the lockdown.

The present study was conducted with the intent to assess the awareness amongst young adults with T1DM regarding COVID-19 and the problems being faced amid the ongoing lockdown in India through telephone-based narrative interviews.

## 2. Materials and methods

The cross-sectional survey was conducted from April 20, 2020, to May 2, 2020, amid the nationwide lockdown in India. Because it was not feasible to perform a community-based face-to-face survey during this period, we conducted a telephone-based qualitative interview study in young adults with T1DM. Similar qualitative interview studies have been used in the past to assess the experiences, perceptions, behaviors and psychosocial aspects of people living with diabetes mellitus [15–21]. Although telephone-based qualitative interview has generally been considered inferior to in-person interviews [22], using telephone for qualitative interviews carries with it the logistic and practical advantages of improved access to geographically dispersed interviewees, reduced costs and increased interviewer safety [23]. Besides, the methodological strengths of telephone-based qualitative interviews include perceived anonymity, increased privacy for the respondents and reduced distraction (for interviewees) or self-consciousness (for interviewers) when interviewers take notes during interviews [24–26]. Moreover, telephone interviews may be less intrusive compared with face-to-face interviews and thereby confer greater control to the interviewees in terms of negotiating interviews to suit their schedules as well as rescheduling, interrupting, or ending the interview [26,27].

Young adults with T1DM were selected from a database maintained by ADITI (Association of Diabetes in Tricity), a North India-based social support group working for children, adolescents and young adults with T1DM in North India. Inclusion criteria were age  $\geq 18$  years and  $\leq 30$  years, residence in the Union Territory of Chandigarh in North India, diagnosis of T1DM at least 1 year back, last follow-up at least once within the prior 6 months and ability to understand and speak in English, Hindi or Punjabi (local language). ADITI has an up-to-date database comprising of 250 people with T1DM; amongst them, 134 people are young adults aged 18–30 years. Of the 52 young adults with T1DM residing in Chandigarh and fulfilling the inclusion criteria, we choose 35 patients by purposive sampling based on the chronology of enrolment in the ADITI database. Demographic characteristics and treatment-related details of the participants were retrieved from the ADITI database. Before the actual interview, all the participants were called up and explained about the details of the study. Verbal consent for participation was obtained after elucidating the fact that participation is entirely voluntary and that anonymity and confidentiality would be strictly maintained. Participants providing positive consent were asked about their availability and spare time in the upcoming 2 days and the preferred language for future communication. They were subsequently called up at that particular date and time for the final telephonic interview. Additional permission for recording the call was taken from every participant. The study was approved by the Institute Ethics Committee.

### 2.1. Data collection

Two members of the research team (UY and AV) with fluency in English, Hindi and Punjabi conducted all the interviews. Both UY and AV were trained before interviewing and received regular feedback from RP and SKB on the interview conduct during data collection based on recordings. On average, 3 interviews were conducted per day with each interview lasting for 15–20 min. The interviews were narrative and the participants were asked 8 open-ended questions; five pertaining to their awareness about COVID-19 that included knowledge about COVID-19, modes of transmission, symptoms, additional risks associated with COVID-19 in a patient with diabetes and means of protection against COVID-19. Rest 3 questions catered to problems the patients had been facing concerning dietary adherence, physical activity and ongoing treatment as a result of the prevailing lockdown. The participants were allowed to answer each question freely without any interruption from the interviewer. Only when the participant had completed answering one question, with his/her due permission the interviewer would move onto the next question. The first two interviews served as pilot interviews that reconfirmed the order in which the questions would be presented to the audience. All the interviews were recorded and initially transcribed by the interviewers (UY and AV) in the native language of the interview. The verbatim transcripts were then translated into English prior to content analysis. Throughout the process of data collection, we conducted interim analyses to gain an understanding of potential saturation of responses and thus the conclusion of data collection.

### 2.2. Data analysis

The transcripts were analyzed manually using qualitative content analysis [28,29]. Each transcript was read several times and relevant parts were extracted. We employed each primary question as an overarching category (deductive coding). These broad categories were further broken down into subcategories based on the findings that emerged from analyses of the transcripts (inductive coding). Answers to a question bearing the same meaning and content were assembled and ascribed a common code. Initially, UY analyzed all the transcripts to generate an initial series of codes for each of the 8 primary questions. Next, RP and SKB independently coded all the interviews and reviewed all the transcripts as well as all the codes assigned by UY. The analyses were discussed during consensus meetings (UY, RP, and SKB) and any differences in interpretation were discussed and resolved. Thereafter, a second round of analyses was independently undertaken by UY, RP and SKB wherein all the ascribed codes were again reviewed followed by a final discussion among the team members.

## 3. Results

We had initially selected 35 young adults with T1DM from the ADITI database. Three individuals did not provide consent. Hence, a total of 32 participants were interviewed. However, two interviews had to be excluded due to poor recording quality and thus 30 interviews were finally content-analyzed.

The characteristics of the participants have been detailed in Table 1. The mean age ( $\pm SD$ ) of the participants was  $22.8 \pm 4.0$  years (range: 18–30 years) with a male/female ratio of 8:7. All the participants were literate with most (53%) being educated up to 12th standard. The median duration of T1DM was 7 years (interquartile range: 3–10 years). The mean HbA<sub>1c</sub> ( $\pm SD$ ) of the participants (estimated at least once over the last 6 months) was  $8.4 \pm 1.6\%$ .

The mean ( $\pm SD$ ) duration of interview was  $17.2 \pm 1.1$  min. The codes ascribed to each of the 8 primary questions and the frequency

**Table 1**

Table showing characteristics of all the study participants (N = 30).

Characteristics	
Age (mean ± SD)	22.8 ± 4.0 years
Male/Female	8/7
Educational status	
● Illiterate	0 (0%)
● Educated upto 10th standard	4 (13%)
● Educated upto 12th standard	16 (53%)
● Graduate	8 (27%)
● Post-graduate	2 (7%)
Duration of T1DM [median (IQR)]	7 years (3–10)
HbA <sub>1c</sub> (mean ± SD)	8.4 ± 1.6%
Hypothyroidism	4 (13%)
Celiac disease	1 (3%)
Hypertension	2 (7%)
Insulin type	
● Premixed conventional insulin regimen	5 (17%)
● Basal-bolus regimen	
○ Long-acting insulin analogue + Regular insulin	7 (23%)
○ Long-acting insulin analogue + Rapid-acting insulin analogue	14 (47%)
○ Ultra long-acting insulin analogue + Rapid-acting insulin analogue	3 (10%)
○ Long-acting insulin analogue + Ultra rapid-acting insulin analogue	1 (3%)
Use of metformin	1 (3%)

**Table 2**

Table showing questions, relevant codes and participants' response pertaining to awareness about novel coronavirus disease (COVID-19).

Question	Code	Number (%) of participants' response matching the code
What do you know about coronavirus disease/COVID-19?	● Viral disease ● Pandemic ● Highly contagious disease ● Respiratory disease ● Fatal disease ● Via respiratory droplets ● Via fomites ● Via physical contact with infected person ● Via handshake with infected person	30 (100%) 3 (10%) 3 (10%) 3 (10%) 2 (7%) 25 (83%) 12 (40%) 10 (33%) 8 (27%)
How does coronavirus spread from one person to another?	● Fever ● Cough ● Dry cough ● Difficulty in breathing ● Cold ● Tiredness ● Body pains ● Headache ● Increased risk of infection ● Increased severity and risk of complications	24 (80%) 17 (57%) 6 (20%) 12 (40%) 17 (57%) 9 (30%) 3 (10%) 3 (10%) 20 (67%) 3 (10%)
What are the symptoms of coronavirus disease/COVID-19?		
What are the risks associated with coronavirus disease/COVID-19 in a patient with diabetes?		
How can you protect yourself from coronavirus disease/COVID-19?	● Staying indoors ● Social distancing ● Avoiding people with fever and cough ● Avoiding handshakes ● Washing and disinfecting objects brought from outside. ● Wearing masks when going outside ● Regular hand wash with soap and water ● Regular use of hand sanitizers ● Maintaining personal hygiene ● Having healthy diet	23 (77%) 16 (53%) 3 (10%) 5 (17%) 3 (10%) 21 (70%) 21 (70%) 11 (37%) 5 (17%) 5 (17%)

**Table 3**

Table showing questions, relevant codes and participants' response pertaining to problems being faced by young adults with T1DM amid the ongoing lockdown.

Question	Code	Number (%) of participants' response matching the code
How has the lockdown affected your routine diet?	● No change in routine diet ● Some change in routine diet	27 (90%) 3 (10%)
How has the lockdown affected your routine physical activity/exercise schedule?	● Physical activity/exercise reduced ● Physical activity/exercise unchanged	27 (90%) 3 (10%)
How has the lockdown affected your diabetes treatment?	● Difficulty in procuring insulin ● Reduced frequency of self-monitoring of capillary blood glucose <sup>a</sup> ● Blood glucose higher than usual <sup>a</sup> ● Documented hypoglycemic episode <sup>a</sup> ● Unable to visit physician for routine check-up	5 (17%) 10 (34%) 21 (72%) 5 (17%) 24 (80%)

<sup>a</sup> One patient had not been performing self-monitoring of capillary blood glucose even prior to lockdown.

of participants' response matching the code has been summarized in [Tables 2 and 3](#). The following findings emerged from the data.

### *3.1. What do you know about coronavirus disease/COVID-19?*

All the participants said that coronavirus disease/COVID-19 is a *viral disease*. Some of them further classified it as "a pandemic", "a respiratory disease", "a highly contagious disease" or "a fatal disease". One participant described the disease as having originated in Wuhan with the initial source of infection being bats, while another participant narrated the disease as being caused by a "laboratory-made virus".

### *3.2. How does coronavirus spread from one person to another?*

The majority of the participants (83%) said that the coronavirus spreads via inhalation of respiratory droplets. Forty percent of the participants described fomites as the mode of transmission. However, only 10 participants (30%) could recount both respiratory droplets and fomites as potential modes of transmission.

### *3.3. What are the symptoms of coronavirus disease/COVID-19?*

The most commonly encountered response was fever (80%) followed by cough, cold, difficulty in breathing and tiredness. The cough was further characterized as "dry" by 6 participants (20%). Only 12 participants (40%) did mention all the three cardinal symptoms, namely, fever, cough and difficulty in breathing. One participant did mention loss of smell and taste as a symptom as well. Two participants (7%) were not aware of the symptoms at all.

### *3.4. What are the additional risks associated with coronavirus disease/COVID-19 in a patient with diabetes?*

Seven participants (23%) were not aware of any additional risks associated with COVID-19 in patients with diabetes mellitus. Twenty participants (67%) had opined that patients with diabetes mellitus are at an increased risk of infection with coronavirus. Twelve of them believed that the weak immune system in persons with diabetes mellitus was the underlying reason. Only 3 participants had the correct knowledge; they had stated that patients with diabetes mellitus are at an increased risk of complications, respiratory problems and fatal outcomes if they get infected with the coronavirus.

### *3.5. How can you protect yourself from coronavirus disease/COVID-19?*

Participants believed that staying indoors, maintaining social distancing, wearing facemasks while going outside, regular hand washing with soap and water and regular use of hand sanitizers were the necessary precautions required to protect themselves from coronavirus infection. In total, 16 participants (53%) mentioned all the 3 major modes of protection, namely, staying indoors, maintaining social distance and regular hand wash with soap and water. The importance of not touching one's face was pointed out by only one participant. Only one participant felt the need to have a good glucose control to ward off the infection.

### *3.6. How has the lockdown affected your routine diet?*

Ninety percent of the participants recounted that their diet has remained unaltered amid the prevailing circumstances; one of who believed that her diet had improved as she was getting home-cooked food all the time. Only 3 participants believed that the ongoing lockdown had brought about some changes to their routine

diet. One of them had co-existing celiac disease and was not able to procure gluten-free oats. Another participant was worried about not being able to get his usual fruits, namely, papaya, guava and golden apple, all having low glycemic indices. However, he did feel the need to have fruits to boost his immune system and hence had to replace them with those that were more readily available, like watermelon and ripe bananas, both having high glycemic indices.

### *3.7. How has the lockdown affected your routine physical activity/exercise schedule?*

Before lockdown, all the 30 participants had been performing some form of physical activity (ranging from yoga to walk to outdoor games to resistance exercises in gym). When interviewed, most of the participants (90%) said that their routine physical activity/exercise had been reduced amid the lockdown. Amongst them, few participants (57%) had resorted to some form of physical activity (like walking in the terrace or garden or front of the house while wearing masks), however, all believed that the duration and intensity of physical activity had got reduced. Ten participants (33%) admitted that they were not performing any form of physical activity at all ever since the commencement of lockdown. Only 3 female participants (10%) were confident that they were able to perform the same extent of physical activity as they had been performing prior to lockdown. One of them had been regularly carrying out yoga at home. The second woman used to skip ropes in the morning and had recently started performing yoga "guided by YouTube videos". The third woman used to perform aerobic dance workout at home for 30 min every day.

### *3.8. How has the lockdown affected your diabetes treatment?*

Amid the lockdown, 5 participants (17%) were finding it difficult to procure the prescribed insulin preparation. One of them had voluntarily reduced the dose of insulin due to the non-availability of the same in the nearby pharmacies. Most of the participants had stocked up insulin vials/cartridges at home just prior to the commencement of lockdown. Before lockdown, all but one participant used to perform self-monitoring of capillary blood glucose (SMBG) at home. During the ongoing lockdown, 10 participants (34%) had reduced the frequency of SMBG; six of them due to limited availability of glucose strips from the pharmacies, two of them due to financial constraints while rest two believed that frequent SMBG would make them all the more anxious amid the prevailing circumstances. Seventy-two percent of the participants stated their current self-monitored blood glucose recordings were higher than those prior to lockdown. In addition, 5 participants had one or more documented episodes of hypoglycemia; one participant had an episode of severe hypoglycemia requiring hospital admission 3 days before the date of the interview. Besides, 80% of the participants were concerned that they were unable to visit their physicians for routine follow-ups. Only one participant was in touch with diabetes educators of the ADITI group via social platforms.

## **4. Discussion**

To the best of our knowledge, this is the first study examining the awareness and problems faced by people with T1DM amid the ongoing COVID-19 pandemic. In this qualitative interview study comprising of 30 young adults with T1DM, we found that there were lacunae in their knowledge and awareness about COVID-19. Most of the participants were able to continue with their routine diet and prescribed treatment, however, 72% of the individuals complained of higher blood glucose based on self-monitored capillary blood glucose recordings. This was likely because of reduced physical activity reported by the majority of the participants (90%).

Although people with diabetes mellitus (DM) are not at a higher risk of infection with COVID-19 compared to a non-diabetic population, the presence of underlying DM portends a poor prognosis in patients with COVID-19 in terms of severe disease, ARDS and increased mortality [4–6]. In a study comprising of 1590 COVID-19 patients from China, DM was found to be an independent predictor of admission to ICU or invasive ventilation or death (Hazard Ratio 1.59, 95% CI: 1.03–2.45) [30]. Hence, people with DM must realize this fact and take all necessary precautions to protect themselves. This would however be possible only if they are aware of the disease, the possible modes of transmission and measures to protect themselves. Besides, people with DM should ensure good glycemic control as it would strengthen the host innate immune response [5,7]. However, amid the nationwide lockdowns imposed by Governments all over the world, glycemic control is expected to take a backseat. Possible explanations include alteration in routine diet, limitation of physical activity, restricted availability of anti-diabetic medications, lack of follow-ups and constant stress and anxiety amid the ongoing pandemic and the prevailing lockdown [8]. The situation is expected to be worse in people with T1DM as they are on obligatory insulin therapy and any interruption in treatment or routine schedule can lead to life-threatening complications in the form of diabetic ketoacidosis or hypoglycemia.

When awareness of participants regarding COVID-19 was assessed, we found some major lacunae. Only 30% of the participants mentioned both respiratory droplets and fomites as possible modes of transmission. Similarly, while fever was stated as a common symptom of COVID-19 by 80% of the participants, only 12 (40%) participants could recount all the three cardinal symptoms, namely, fever, cough and difficulty in breathing. Besides, two participants were not aware of the symptoms at all. In addition, only 16 (53%) participants were aware of all the three principal means of protection from COVID-19, namely, staying indoors, maintaining social distance and regular hand wash with soap and water. It is very likely that only these 16 participants must be properly abiding by all the necessary precautions. Lastly, 23% of the participants were unaware of any additional risks associated with COVID-19 in people with diabetes mellitus, thereby implying that they will not feel the need to take extra precautions as is expected from people with DM. On the contrary, 67% of the participants had the misconception that people with DM are at a higher risk of infection; this is still acceptable, as they are expected to take extra precautions to protect themselves from COVID-19.

A recently conducted cross-sectional survey in the United States of America amongst 630 adults aged 23–88 years living with 1 or more chronic conditions found that nearly one-third of the participants were not able to identify the symptoms correctly or describe the ways to prevent them [9]. An online cross-sectional survey examining knowledge, attitude and practices towards COVID-19 among Chinese residents using closed-ended questions found that the overall correct rate of the knowledge questionnaire was 90%. However, the participants belonged to a relatively high socio-economic status and were well-educated and that the results could not be generalized to the entire Chinese population [31]. Socio-economic status is an important determinant of knowledge and awareness with regard to communicable and non-communicable diseases [32]. Higher socio-economic status also correlates with improved awareness and disease preventive behavior against COVID-19 [9,33]. Similarly, educational status is a well-known factor affecting disease awareness with higher educational status correlating with better disease knowledge and vice-versa [31,33–35]. The participants in our study were relatively well educated (87% being educated up to 12th standard or higher); still, we witnessed major lacunae in awareness about COVID-19. Because the overall literacy rate in India is 74% [36], it is expected that the scenario is likely to be worse in the illiterate or less educated sec-

tions of the society. The deficit has to be immediately addressed; the easiest and most effective means would be to improve awareness about COVID-19 using all types of broadcast, print and social media. In addition, non-governmental organizations should take up the responsibility to improve cognizance among high-risk groups (like people with T1DM) using various social platforms like 'WhatsApp', 'Facebook', 'Instagram', etc. As a matter of fact, soon after the results of the index study were available, ADITI had started an awareness program via 'WhatsApp' amongst all its members. We believe that this endeavor will improve the knowledge and awareness of people with T1DM.

When enquired about the problems being faced by the participants amid the lockdown, the most common response was a reduction in physical activity as reported by 90% of the individuals. In addition, 72% of the participants complained of high glucose recordings since the commencement of lockdown. The majority of the participants had no difficulty in procuring insulin or maintaining a healthy diet. Thus, the apparent worsening of blood glucose, as reported by the participants, could have resulted from a reduction in physical activity. Moreover, 5 participants had one or more episodes of hypoglycemia and 80% were concerned about the inability to physically follow-up with the physicians. Lack of in-clinic visits and subsequent modulation of insulin doses could also have been a contributory factor in the worsening of glucose control. Herein, comes the crucial role of teleconsultations in day-to-day diabetes care [37,38]. With smartphones being a norm in most households, there seems to be no dearth of scope for teleconsultations in the present era. Patients can keep in touch with their routine physicians and/or diabetes educators via teleconsultations. Aided by patient specified SMBG values, physicians can help fine-tune the insulin doses thereby avoiding prolonged periods of sustained hyperglycemia as well as recurrent episodes of hypoglycemia. In fact, the use of telemedicine in persons with T1DM has been shown to provide similar efficacy and safety outcomes as face-to-face visits [39]. In addition, teleconsultations can be a means of imparting diabetes self-management education to the people with DM amid the ongoing pandemic. Physicians could help people with T1DM choose the type and nature of the physical activity, guide them by sharing sample exercise videos and reinforce the need to remain physically active at each virtual interaction [8]. A minor recommendation would be to perform a total of 60 min of physical activity/day [40]; it could be divided between aerobic activity and muscle-strengthening activity. Simple aerobic activities that can be pursued at home include brisk walking in the terrace, lawn, balcony or treadmills (if available). Stationary cycling, stationary jogging and gardening could be performed as well. Similarly, muscle-strengthening activities that could be performed at home include bodyweight exercises (like push-ups, squats, sit-ups) and resistance exercises in the form of lifting lightweights (like buckets half-filled with water or bags filled with sand) [8].

We do respect the limitations of the study. First, we used a qualitative method of interview using open-ended questions rather than taking help of closed-ended questionnaires that are commonly employed in surveys. However, using closed-ended questions would have limited the responses of the participants and we would have missed a few responses in the absence of relevant questions. This would have been all the more relevant while enquiring about the problems being faced by the patients in the real-life setting. Using open-ended questions ensured that we were able to obtain a wide range of responses from the participants. Second, we recruited only young adults with T1DM and not children or adolescents (<18 years). This ensured that we could obtain the viewpoints of the patients *per se* and not their parents/caregivers. Third, the results of the study are based on interviews conducted in only 30 young adults with T1DM residing in a city of North India. Hence, the findings cannot be generalized to people with T1DM residing

