Introduction

Diabetes is fast becoming the epidemic of the 21st century. Both the United Kingdom Prospective Diabetes Study (UKPDS) and the Diabetes Control and Complications Trial (DCCT) have shown that aggressive glycemic control can prevent diabetic complications. The value of this approach has been shown from evidence gained in landmark clinical and epidemiological studies where the reduced incidence of micro and macrovascular complications was apparent with intensive glycemic control and has further been confirmed in a published meta-analysis of observational studies. Early initiation of insulin therapy and thereby better control of blood sugar levels has shown reduction in complications. Although insulin therapy has been demonstrated to be efficacious, its initiation is often delayed due to multiple factors including the refusal of insulin therapy by the patients. This study aims to explore the reasons for the refusal of insulin therapy in a resource-constrained primary care setting in an urban slum in India. Materials and Methods: We included 148 patients who required insulin therapy but refused. A semi-structured questionnaire was administered by a primary care physician. Chi-square test was done to test the association between demographic factors and the reasons for refusal. P < 0.05 was considered as significant. Results: The mean age of the patients was 49.53 (SD+/−9.8) years. Majority (40.5%) of the patients had diabetes for 6-10 years, and most of them were living with their families (89.9%) and 77% of them were dependent on their family for their financial and physical needs. Financial constraint was the most common reason for reason (74.3%) followed by afraid of pain (68.9%) and fear of dependency (57.4). Gender, occupation, and duration of diabetes and witnessing insulin administration were significantly associated with stigma related to insulin therapy. Conclusion: Financial constraint is one of the key factors as patients have to buy insulin out of pocket and are not covered by insurance. Government initiatives to reduce and monitor the cost of the insulin would be of great benefit to the patients in this setting.

Keywords: Diabetes, insulin refusal, primary care

Abnormal
A total of 148 patients who fulfilled the inclusion criteria were interviewed. The study population had more number of women (68.9%) than men (31.1%). The mean age of the patients was 49.53 (SD+/−9.8) years ranging from 34 to 74 years [Table 1]. Majority of them were from 41 to 50 years age group. Almost two-third (59.5%) of them belonged to Muslim community. Most of the study groups were homemakers (34.4%). The median monthly income was Rs. 4000 with a range of 0 to Rs. 25,000. Majority (40.5%) of the patients had diabetes for 6-10 years, and most of them were living with their families (89.9%) and 77% of them were dependent on their family for their financial and physical needs. More than two thirds of them were on two oral hypoglycaemic agents (62.2%), and rest (37.8%) were on more than two drugs. More than three fourths (75.7%) also had other co-morbid illnesses such as hypertension.

Financial constraint was the most common reason for the refusal of insulin therapy in our study population as 74.3% felt insulin was very expensive [Table 2]. More than two-third (68.9%) of them were afraid of pain. More than half of them (57.4%) had a fear of becoming dependent on insulin. A large proportion (42.6%) of them refused because of social stigma.

Nearly half (45.9%) of the study population had witnessed someone injecting insulin. Similarly, more than half (51.4%) of them responded that they won't be able to convince someone to give insulin. Participants who were women (82.4%), homemakers (81%), earned income less than Rs. 5000 (82.8%) were more afraid of pain compared to men (39.1%), non-home living patients (80.2%) were more afraid of becoming dependent on insulin. A large proportion (42.6%) of them refused because of fear of insufficiency.

In our primary care clinic, we manage a fair number of patients with diabetes, of which nearly half refuse to take insulin for their diabetes management. We have insufficient published studies in India on reasons for refusal to take insulin among patients from resource-constrained settings. So, this study aims to identify what could be the possible factors which hinder a patient's acceptance of insulin therapy. In majority of these studies, the common reasons for insulin refusal were the patient’s perceptions that requirement for insulin was an indicator of disease severity, needle anxiety, premature death from insulin injection, fear of hypoglycemia, weight gain, loss of independence, and reliance on others to give insulin.

### Materials and Methods

This study used a cross-sectional study design and was conducted by the Department of Family Medicine and Community Health, Bangalore Baptist Hospital in Devarajeevanahalli slum in Bangalore. This slum is served by our Urban Health Center located in the heart of the slum. This center provides primary medical care at an affordable cost with a laboratory, pharmacy, ophthalmology, and dental services. It also caters to a large number of patients with chronic diseases such as diabetes and hypertension.

Patients with poor glycemic control (HbA1C > 9%) in spite of being on maximum doses of biguanides and sulphonylureas were included for the study, and those with cognitive decline which was assessed using abbreviated mental test score were excluded. To calculate the sample size, the most common cause for the refusal of insulin therapy as found in an Iranian study fear of pain (43.7%) was used. Using the formula 4pq/d2 and an absolute precision of 8%, the sample size calculated as 148. Consecutive patients who fulfilled the inclusion criteria were included in the study. A questionnaire was administered by the principal investigator. The study tool contained socio-demographic characters and questions related to reasons for refusal. The data were coded and entered into Microsoft Excel, and the statistical software Statistical Package for Social Sciences (SPSS for Windows, Version 16.0. Chicago, SPSS Inc.) was used for the analysis. Descriptive and inferential statistical analysis was carried out. Perceived barriers and causes for the refusal of insulin were calculated in percentages. Univariate analysis was carried out to assess the association between contributing factors and refusal of insulin therapy. A P < 0.05 was considered statistically significant. Voluntary participation was ensured, and patients were assured of nondiscrimination in case if they did not wish to take part in the study. The study was approved by the Institutional Review Board of Bangalore Baptist Hospital.
makers (60%) and those earned more than Rs. 5000 (45.5%) and this difference was statistically significant \( P < 0.05 \). Similarly, those who were more than 40 years (81.4%) of age perceived insulin was more expensive than younger age group (46.7%) \( P < 0.05 \). There were no factors associated with the perception of dependence on insulin [Table 3].

### Table 2: Perceived barriers for Insulin therapy

| Barriers                                         | Frequency | %  | Frequency | %  |
|--------------------------------------------------|-----------|----|-----------|----|
| Afraid of pain                                   | 102       | 68.9 | 46        | 31.1 |
| Worried about Hypoglycemia                       | 47        | 31.8 | 101       | 68.2 |
| Think they will gain weight                      | 30        | 20.3 | 118       | 79.7 |
| Think they become dependent                      | 85        | 57.4 | 63        | 42.6 |
| Fear of social stigma                            | 63        | 42.6 | 85        | 57.4 |
| Think insulin will interfere with their work and diet | 79       | 53.4 | 69        | 46.6 |
| Think insulin is expensive                       | 110       | 74.3 | 38        | 25.7 |
| Think starting insulin is the last stage of disease process | 57       | 38.5 | 91        | 61.5 |
| Feel they are responsible for uncontrolled sugar | 53        | 35.8 | 95        | 64.2 |

### Table 3: Factors associated with perception on dependency on insulin

| Factors                      | Variables | Afraid | Yes | %  | No | Frequency | %  |
|------------------------------|-----------|--------|-----|----|----|-----------|----|
| Age                          | <40       | 20     | 66.7| 10 | 33.3| 0.76      |    |
| Gender                       | Male      | 18     | 39.1| 28 | 60.9| 0.00*     |    |
| Occupation                   | Home makers | 51   | 81.0| 12 | 19.0| 0.00*     |    |
| Income                       | < 5000    | 77     | 82.8| 16 | 17.2| 0.00*     |    |
| Years with DM                | <10 years | 52     | 67.5| 25 | 32.5| 0.70      |    |
|                             | >=10 years | 50   | 70.4| 21 | 29.6|           |    |
| Living with family           | Yes       | 90     | 67.7| 43 | 32.3| 0.32      |    |
|                             | No        | 12     | 80  | 3  | 20  |           |    |

### Table 4: Demographic and support factors associated with stigma

| Factors                             | Variables | Perception on Stigma | Chi- square value | P  |
|-------------------------------------|-----------|----------------------|-------------------|----|
| Gender                              | Male      | 6                    | 13                | 40 | 87 | 23.7 | 0.00* |
|                                     | Female    | 57                   | 55.9              | 45 | 44 | 41.1 |    |
| Age                                 | <= 40 years | 17               | 56.7              | 13 | 43.3| 3.05 | 0.80 |
|                                     | >40 years  | 46                   | 39.0              | 72 | 61.0| 50.7 | 0.15 |
| Occupation                          | Home makers | 40              | 63.5              | 23 | 36.5| 19.6 | 0.00* |
|                                     | Others     | 23                   | 27.1              | 62 | 72.9| 7.2  | 0.03* |
| Years with DM                       | <10 years | 42                   | 54.5              | 35 | 45.5| 9.4  | 0.02* |
|                                     | >=10 years | 21                  | 29.6              | 50 | 70.4| 14.2 | 0.000* |
| Income (INR)                        | <5000     | 42                   | 45.2              | 51 | 54.8| 0.68 | 0.40 |
|                                     | >=5000    | 21                   | 38.2              | 34 | 61.8| 0.3  |    |
| Living with family                  | Yes       | 54                   | 40.6              | 79 | 59.4| 2.0  | 0.15 |
|                                     | No        | 9                    | 60                | 6  | 40  | 1.6  |    |
|Witnessed insulin administration     | Yes       | 37                   | 54.4              | 31 | 45.6| 7.21 | 0.007* |
|                                     | No        | 26                   | 32.5              | 54 | 67.5| 4.2  | 0.04* |
|Confident in self administration     | Yes       | 31                   | 56.4              | 24 | 43.6| 6.81 | 0.009* |
|                                     | No        | 32                   | 34.4              | 61 | 65.6| 9.6  | 0.003* |
|Ability to convince someone to administer insulin | Yes | 42 | 58.3 | 30 | 41.7 | 14.2 | 0.00* |
|                                     | No        | 21                   | 27.6              | 55 | 72.4| 0.4  |    |
Women (55.9% vs 13%), homemakers (63.5% vs 27.1%), those who had the disease for more than 10 years (54.5% vs 29.6%), those who witnessed insulin administration by their friends and family members (54.4% vs 32.5%), felt they will more stigmatized if they start on insulin as compared to their counterparts ($P < 0.05$) [Table 4].

**Discussion**

This study was conducted in an urban slum setting where the majority of patients were from low socioeconomic strata. We had identified patients who would need insulin based on their clinical and biochemical parameters as per the guidelines.

In the study like Wong S, et al., Singapore and Wei Leong Tan, Malaysia the main reason for the patient’s refused for insulin was fear of pain and thus did not want to use it daily.[9,10] Another common cause for not accepting insulin was it might affect their day-to-day work and thus not able to fulfill their responsibilities, half of our study population also felt the same.

It was noted in our study that over two-thirds of the patients refused insulin due to financial constraints. This can be explained as patients have to buy their own insulin unlike in other studies where it was funded by government sector. This plays an important role in their decision making to buy and take insulin on a regular basis.

In a study done in East London among Bangladeshi patients, over half of them felt that their disease is in final stage if insulin is added to their medication list.[8] This is similar to our study, as nearly 40% of the study population felt that insulin should be taken only if they were in the last stage of disease, and at this point in time, their condition was not that serious as to warrant insulin injections. Similar observation was noted in a prospective study conducted in Korea, where nearly one-third of the patients felt that their disease is in last stage if insulin is suggested by their physicians.[11]

In DAWN study (Diabetes Attitudes, Wishes, and Needs study), there was detailed discussion among the patients and providers.[9] Patients felt that the progression of disease is because of their poor control of sugars and there was an element of self-blame. In our study, around 35% of the study population felt that they were responsible for their illness, henceforth take in lot of self-blame which in turn affected their future sugar control and appropriate decision making.

In a study conducted at Iran among type-2 diabetes patients, multiple factors were identified such as financial implications, fear of injection, literacy of the population.[12] In our study also, similar factors were the hindrance for starting insulin therapy.

In Wong S, et al. study, one of the key reasons along with the pain after injection is fear of hypoglycaemia which was also noted in Wei Leong Tan study, but in our study population, more than 70% of the group were not worried about hypoglycaemia.[9,10] This could be explained in two ways, first, as majority had witnessed someone using insulin, their fear for pain could have been reduced and, second, they might be ignorant about the signs of hypoglycaemia and either do not recognize it or not be able to inform the healthcare providers.

Nearly half of our study population were not confident about injecting themselves though they had witnessed someone injecting insulin. This finding is similar to Khan S study, where more than 40% of the study group was not confident administering on their own.[8] This could be due to multiple reasons like fear of dependency and inability to read the correct unit and name of the drug.

In our study, majority of the patients who needed insulin were above 40 years of age and are homemakers. They were financially dependent on their spouses and, henceforth, were not the decision-makers in their household. One of the key reasons for refusing insulin was due to financial constraints.

As a community, patients are very apprehensive about starting insulin, one of the important factors identified in our study along with financial constraints is their knowledge about insulin. It is a common belief that a patient’s feel that insulin is used only in the last stage of disease and their death is imminent in the near future. Also, there is plenty of social stigma in using insulin, especially among women. This particular finding mirrors similar findings in the study conducted among Bangladeshi population in East London.[9]

**Limitation**

Delay in starting insulin is not only from a patient’s perspective, it can also be from providers’ end. One of the limitations of our study is that we have not looked into the providers’ side. Once we outline the reasons for refusal from both sides, we would be able to make a structured format to enhance the insulin utilization and, henceforth, reduce complications in our primary care clinics.

**Conclusion**

Insulin is a key for effective blood sugar control in patients with type 2 diabetes. We have standard guidelines both locally and internationally on when to start insulin in type 2 diabetes mellitus. There have been various reasons for the refusal of insulin from a patient’s perspective. In our study, financial constraint is one of the key factors as patients buy insulin out of pocket and are not covered by insurance. During the study, we also noted patients’ knowledge on insulin was inadequate as they felt their disease is in the end-stage if they start using insulin along with various other myths about insulin.

To improve the glycemic level and avoid complications secondary to high sugar level, educating our patients about the advantages of insulin and quashing the myths associated with insulin are
important. Healthcare professionals, doctors, nurse educators play an important role in educating patients and thereby reduce the complications of diabetes.

**Ethical approval**

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Declaration of patient consent**

All Informed consent was obtained from all individual participants included in the study.

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Nil.

**Conflicts of interest**

There are no conflicts of interest.

**References**

1. Wright A, Burden AC, Paisey RB, Cull CA, Holman RR; U.K. Prospective Diabetes Study Group. Sulfonylurea inadequacy: Efficacy of addition of insulin over 6 years in patients with type 2 diabetes in the U.K. Prospective Diabetes Study (UKPDS 57). Diabetes Care 2002;25:330-6.

2. Diabetes Control and Complications Trial Research Group. The effect of intensive treatment of diabetes on the development and progression of long term complications in insulin-dependent diabetes mellitus. N Engl J Med 1993;329:977-86.

3. UK Prospective Diabetes Study (UKPDS) Group. Intensive blood-glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with type 2 diabetes (UKPDS 33). Lancet 1998;352:837-53.

4. ADVANCE Collaborative Group, Patel A, MacMahon S, Chalmers J, Neil B, Billot L, Woodward M, et al. Intensive blood glucose control and vascular outcomes in patients with type 2 diabetes. N Engl J Med 2008;358:2560-72.

5. Selvin E, Marinopoulos S, Berkenblit G, Rami T, Brancati FL, Powe NR, et al. Meta-analysis. glycosylated hemoglobin and cardiovascular disease in diabetes mellitus. Ann Intern Med 2004;141:421-31.

6. Peyrot M, Rubin RR, Lauritzen T, Skovlund SE, Snoek FJ, Matthews DR, et al. Resistance to insulin therapy among patients and provides results of the cross-national diabetes attitudes, wishes and needs study. Diabetes Care 2005;28:2673-9.

7. Larkin ME, Capasso VA, Chen CL, Mahoney EK, Hazard B, Cagliero E, et al. Measuring psychological insulin resistance: Barriers to insulin use. Diabetes Educ 2008;34:511-7.

8. Khan H, Lasker SS, Chowdhury TA. Prevalence and reasons for insulin refusal in Bangladeshi patients with poorly controlled type 2 diabetes in East London. Diabetic Med 2008;25:1108-11.

9. Wong S, Lee J, Ko Y, Chong MF, Lam CK, Tang WE. Perceptions of insulin therapy amongst Asian patients with diabetes in Singapore. Diabetic Med 2011;28:206-11.

10. Tan WL, Asahar SF, Harun NL. Insulin therapy refusal among type II diabetes mellitus patients in Kubang Pasu District, Kedah, Malaysia. Singap Med J 2015;56:224.

11. Kim SG, Kim NH, Ku BJ, Shon HS, Kim DM, Park TS, et al. Delay of insulin initiation in patients with type 2 diabetes mellitus inadequately controlled with oral hypoglycemic agents (analysis of patient- and physician-related factors): A prospective observational DIPP-FACTOR study in Korea. J Diabetes Investig 2017;8:346-53.

12. Torabian F, Mostafavian Z, Gharesh S, Yazdi MS, Khazaei MR. Data on insulin therapy refusal among type II diabetes mellitus patients in Mashhad, Iran. Data Brief 2018;18:2047-50.