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#### Correspondence

Dr. Ujjawal Paudel, Medical Officer, Jibjibe Primary Health Care Center, Rasuwa, Nepal  
Email: paudelujjawal@gmail.com

#### Peer Reviewers

Prof. Dr. Jay N Shah  
Patan Academy of Health Sciences, Nepal

Asst. Prof. Dr. Yagya Pokharel  
Patan Academy of Health Sciences, Nepal

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## Clinical characteristics and perspectives of children and youths with type 1 diabetes attending Patan Hospital, Nepal

Ujjawal Paudel\*<sup>1</sup>, Buddhi Prasad Paudyal<sup>2</sup>, Prerana Kansakar<sup>3</sup>, Mila Shakya<sup>4</sup>

<sup>1</sup>Medical Officer, Jibjibe Primary Health Care Center, Rasuwa, Nepal; <sup>2</sup>Prof., Dept. of Internal Medicine, <sup>3</sup>Asst. Prof., Dept. of Paediatrics, <sup>4</sup>Clinical Researcher, Oxford University Clinical Research Unit, Patan Hospital, Patan Academy of Health Sciences, Lalitpur, Kathmandu, Nepal

\*Y1 Postgraduate Resident, School of Med., Patan Academy of Health Sciences

### Abstract

**Introduction:** Type 1 Diabetes Mellitus (DM1) has reportedly a high proportion of initial presentation as diabetic ketoacidosis, more in resource-poor settings. This study was designed to assess the demographics and clinical characteristics of DM1 patients as well as their perception of diabetes management in local scenario.

**Method:** This is a cross-sectional study of data collected prospectively by a questionnaire survey among young patients with DM1 presenting to Medical and Paediatric Referral Clinics of Patan Hospital, Nepal during April 2016 to June 2016. Ethical approval was obtained. Demographics, and disease process- initial presentation of diabetic ketoacidosis, HbA1c target, and common problems were analyzed by SPSS using chi-square and Fisher exact tests,  $p < 0.05$  considered statistically significant.

**Result:** Fifty-eight patients were enrolled in the study. Diabetic ketoacidosis was the initial presentation in 27(46.55%). A 15(27.78%) of surveyed patients had achieved age-specific goals of the HbA1c target. Financial issues and difficulty to come for regular follow-ups were the common problems in diabetes management.

**Conclusion:** Diabetic ketoacidosis was a common initial presentation in nearly half of the DM1 patients. Three quarter of them didn't have adequate control of the disease with age-specific goals of the HbA1c target.

**Keywords:** diabetic ketoacidosis, perception, type 1 diabetes mellitus

## Introduction

Type 1 Diabetes Mellitus (DM1), associated with immune-associated destruction of the insulin-producing beta cells, is one of the most common chronic diseases of childhood.<sup>1</sup> Ten to 70% of the patients present with diabetes ketoacidosis, a potentially life-threatening acute complication of DM1, at the initial presentation.<sup>2</sup>

Patients with DM1 have to rely on daily subcutaneous injections of insulin or insulin infusions; and the treatment regimen includes daily blood glucose monitoring, carbohydrate counting, dietary plan, and physical activity.<sup>3</sup> The complexity of treatment can be overwhelming even for the most competent patient.<sup>4</sup> In a resource-poor setting like ours, where organized care of diabetes management is virtually non-existent<sup>5</sup>; accessibility, availability, and costs associated with insulin and monitoring supplies, and access to proper clinical care can directly impact the patient outcome. There are no known reported studies in Nepal regarding clinical presentations of DM1 patients and their perspectives on clinical management.

Thus, this study was designed to assess the basic demographic and clinical characteristics of DM1 patients and their perception of diabetes management.

## Method

This is a cross-sectional prospective study comprising of a questionnaire-based survey on young patients with DM1 presenting to Medical and Paediatric Referral Clinics of Patan Hospital. Fifty-eight patients and/or parents attending the clinics from April 2016 to June 2016 were included in the study.

Written informed consent was taken from the patients who were 18y of age or older and from the parent(s) / guardians for participants <18y. The study was approved by the Institutional Review Committee (IRC) of Patan

Academy of Health Sciences, Patan Hospital, Lalitpur, Nepal.

A questionnaire comprising of three sections was used for data collection. It was pretested among five patients before data collection. Section A comprised of patient demographic information such as date of birth, sex, current residence district (inside Kathmandu valley vs. outside), mother and father's education level, and occupation. Section B comprised of information about the disease process which included age at first diagnosis, amount of insulin usage, mean HbA1C, number of injections per day, and past hospitalizations. Section C Comprised of patient perspective on diabetes management, which included difficulties in managing diabetes, effects of diabetes in education, treatment satisfaction, and confidence in self-management of diabetes.

For statistical analysis, the data were entered on Microsoft Excel 2013 and analyzed using Statistical Package for Social Sciences program (SPSS, Version 20, IBM, Chicago, Illinois, USA) software. The mean, or median (interquartile range, IQR) were calculated for data as appropriate. A p-value of <0.05 was used as a cut-off for all tests of statistical significance.

## Result

Fifty-eight patients were included in the study. Among them 33(56.90%) were female and 25 (43.10%) were male. The mean age  $\pm$  SD at the time of the interview was 19.6 $\pm$ 6.7y (Range 3y to 34y). The mean age $\pm$ SD at the time of diagnosis was 13.5 $\pm$ 6.9y (range 3mo to 31y). Among 58 patients, 32(55.17%) were currently residing in Kathmandu valley (includes three districts: Kathmandu, Lalitpur, and Bhaktapur) while the remaining 26(44.83%) were residing outside the valley.

Diabetic ketoacidosis (DKA) was the initial presentation in 27(46.55%) patients. There was no significant difference between gender, residence (within Kathmandu valley vs. outside) mean age at diagnosis, and parental

education in the DKA as a presentation of DM, Table 1.

The mean dose of insulin was  $50 \pm 21$  units per day, with a range of 8-108 units. Fifty six (96.55%) patients were taking insulin injections twice a day, 1(1.72%) was taking 3 times a day while another 1(1.72%) was taking 4 times a day. Forty-nine (84.48%) patients were doing blood sugar tests twice a day while 3(5.17%) of them doing it 3-4 times a day and the remaining 6(10.34%) were not doing daily blood sugar tests.

The mean  $\pm$  SD of HbA1c at the last visit was  $8.9 \pm 2.5$  % and the range was 5.3% to 14%. Among 54 patients, 15(27.78%) had achieved age-specific goals of the HbA1c target. No significant difference was observed between patients who had their HbA1c within the target or above target and age group, gender, residence, and parental literacy, Table 2.

Primary hypothyroidism was seen in 3(5.17%) patients, hypertension in 1(1.72%), and Grave's disease in 1(1.72%). Seventeen (29.31%) patients had required hospitalization during last year. Among those who required hospitalization, 6(35.29%) were due to DKA, 5 (29.41%) due to hypoglycemia, and 3(17.65%) due to hyperglycemia. The remaining 3(17.65%) were hospitalized for indications unrelated to diabetes. All of them improved

after the hospitalization and were on regular follow-up.

Thirty-three (56.90%) patients were pursuing their education while 25(43.10%) have left their studies. Among all participants, 24(41.38%) of them said diabetes had affected their education in some ways. Among them, the most commonly cited effect was: they couldn't attend school/college because of illness 10(41.66%), 7(29.16%) of them left school soon after they fell ill with diabetes, 3(12.50%) couldn't afford both the treatment and education. Other reasons cited were such as fatigue/lack of concentration, stress during the examination, poor performance, teachers not favouring, the school doesn't accept them because of illness and one child was having difficulty learning because of Down syndrome.

All patients were satisfied with the diabetes management at Patan Hospital except 2(3.45%); who cited the reason being a long queue at the outpatient clinic of Patan Hospital. Nineteen patients (32.76%) didn't complain of any difficulty in their diabetes management. Fifteen patients (25.86%) had financial problems, 14(24.14%) had difficulty coming for regular follow-ups. Nine (15.52%) patients reported trouble with injection use and the remaining 1(1.72%) perceived difficulty due to different doctors at different visits.

**Table 1. Demographics and clinical profile of type 1 diabetic children and youths with and without diabetic ketoacidosis (DKA) as an initial presentation (N=58)**

Profile	DKA		No-DKA		p-value*
	N	%	N	%	
<b>Gender</b>					
Female	14	42.42	19	57.58	0.67
Male	12	48	13	52	
<b>Residence</b>					
Inside valley	17	53.13	15	46.87	0.15
Outside valley	9	34.62	17	65.38	
<b>Parental Literacy</b>					
Both parent illiterate	10	50	10	50	0.31
One parent illiterate	5	29.41	12	70.59	
Both parent literate	11	52.38	10	47.62	

\*Pearson Chi-square Test

**Table 2. HbA1c target achievement of children and youths with type 1 diabetes (N=54)**

Profile	HbA1C Within Target		HbA1c Above target		p-value <sup>#</sup>
	N	%	N	%	
<b>Gender</b>					
Female	7	21.21	26	78.79	0.35
Male	8	32	17	68	
<b>Age y</b>					
<6	0	0	1	100	0.81*
6-12	1	20	4	80	
13-19	5	22.73	17	77.27	
>19	9	34.62	17	65.38	
<b>Residence</b>					
Inside valley	7	21.88	25	78.13	0.44
Outside valley	8	30.77	18	69.23	
<b>Parental Literacy</b>					
Both parent illiterate	4	20	16	80	0.5
One parent illiterate	6	35.29	11	64.71	
Both parent literate	5	23.81	16	76.19	

# Pearson chi square test \* Fisher's exact test

When patients were asked what bothers them most as a diabetic patient, 6(10.34%) of them said there are no bothering factors. Most commonly reported bothering factors were worries about their future career 23(39.66%), dietary restrictions 15(25.86%), insulin injections 11(18.97%), frequent blood sugar testing 10(17.24%), and fear of social stigma 9(15.52%). Other factors reported are difficulties with travel to come to the hospital, time management, worries about their children, the possibility of children getting DM, and complications of diabetes in the future.

Fifty (86.21%) patients were confident in injection technique, 48 (82.76%) in self-monitoring of home glucose, 46(79.31%) in diabetic diet and lifestyle modification, 45(77.59%) in hypoglycemia identification and management, and 45(77.59%) in the overall disease process. Only 33(56.90%) of respondents were confident to identify and seek medical help for complications.

## Discussion

In this study, nearly half (46.55%) of children and youths with type 1 diabetes had DKA as initial presentation, which is quite high as compared to other regions/countries such as

18% in Kashmir (India), 19 % in Finland, 25% in Kuwait, 26% in Germany, and 31% in the USA.<sup>6-10</sup> However a study from Malaysia reported a higher percentage of DM1 patients (65%) having DKA as the initial presentation.<sup>11</sup> The disparity in prevalence due to the differences in the case of definitions (varying cut-off age used for inclusion in different studies) and delay in seeking health care.

This study didn't show any significant difference between gender, residence (within Kathmandu valley vs. outside) mean age at diagnosis, and parental education in the DKA as an initial presentation of diabetes mellitus. However, a systematic review of factors associated with the presence of diabetic ketoacidosis at diagnosis of diabetes in children and young adult showed that younger age, ethnic minority, lower body mass index, preceding infection, and delayed treatment are associated with increased risk while having a first degree relative with DM1 at the time of diagnosis and higher parental education are associated with decreased risk.<sup>2</sup>

The American Diabetes Association (ADA) recommends multiple tests daily, for example, testing of blood glucose before meals and snacks, at bedtime, occasionally postprandially, before exercise, when they suspect low blood glucose, after treating low

blood glucose until they are normoglycemic, and before critical tasks such as driving.<sup>12</sup> In the study almost all of the patients were doing blood tests twice a day. The 'Life for a Child program' provides only two strips per day and they might have difficulties buying extra strips for strict monitoring as many of them reported financial difficulties in this study. All of them were on multiple daily insulin regimens, 96.55% taking insulin injections twice a day. A similar study from Oman showed most of the patients were taking multiple daily injections (76%) while only 16% taking twice daily insulin and remaining on insulin pump therapy.<sup>13</sup> Most of them take insulin only twice a day because they can't afford extra strips to test blood glucose after each meal and they are given only 2 strips/d by 'Life for a Child Program'. Insulin pump therapy is costly and is not yet available easily in Nepal.

Five percent of the patients had primary hypothyroidism which is similar to studies that have shown that 2 to 5% of patients with DM1 develop autoimmune hypothyroidism. Though studies have shown that about 5% of patients with DM1 develop celiac disease, it was not assessed in this study.<sup>14-16</sup>

Hospitalizations subject the patients to psychological stress as well as a financial burden. The DKA, a life-threatening condition was the most common indication for hospitalization. A systematic review showed that DKA and diabetes-related comorbidities are common indications for hospitalization and people with DM1 are three times more likely to be hospitalized than non-diabetic and stay in the hospital twice as long.<sup>17</sup>

About forty-one percent of the respondents in our study said diabetes affected their education in some ways. They were having difficulties in attending school, coping with the stress, and lack of support from teachers. A study from the UK showed children whose parents reported that school personnel who received diabetes training showed significantly better diabetes control than

those who reported untrained school personnel, and children who reported their classmates received diabetes training had a significantly better quality of life than those who reported untrained classmates.<sup>3</sup> However, there is a lack of training for teachers/classmates about childhood diabetes in Nepal.

One-third of the respondents didn't perceive any difficulties while managing diabetes. However, the most reported difficulty was financial, followed by the difficulty to come for regular follow-up and injection use. Worries about a future career were frequent; dietary restriction, having to take insulin injections, frequent blood sugar testing and social stigma were other cited difficulties. A qualitative study among diabetic patients (both type 1 and type 2) from the UK also showed that challenges surrounding diet management and social stigma attached to having diabetes were the two predominant barriers to effective diabetes management among south Asians in the UK.<sup>18</sup> A similar study from Ireland showed that Diabetes distress was triggered by multiple factors, the most common of which were: self-consciousness/stigma, day-to-day diabetes management difficulties, having to fight the healthcare system, concerns about the future, and apprehension about pregnancy.<sup>19</sup>

Respondents demonstrated a high level of confidence (approximately 8 out of 10) in key areas of management. They showed high confidence in injection use (86.21%), but some still fear it. Taking insulin injections is a fearful experience for many patients and caregivers which was also shown by an American study.<sup>20</sup> A lower level of confidence was only observed in detecting/managing complications of diabetes mellitus. Respondents in this study showed high confidence in hypoglycemia symptom detection (77.59%). However, a Finnish study showed more than half of DM1 patient have fear of hypoglycemia.<sup>21</sup>

## Conclusion

Diabetic ketoacidosis was the most common initial presentation in type 1 Diabetes Mellitus patients and it was high in nearly half of the study population compared to other countries, demonstrating a lack of early diagnosis and management. Many patients had HbA1C above the target level suggesting they need better control measures.

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## Conflict of Interest

None

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None

## Author Contribution

BP, PK, and MS designed the study, collected data, and reviewed the manuscript. UP analyzed the data and prepared the manuscript. All authors read and approved the final manuscript.

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Supplements

Diabetes in the Young (Type 1) Questionnaire

Case No: \_\_\_\_\_

Section A: General Information

Date of Birth	Sex
Place of Residence	District
Mother's Education Level	Mother's Occupation
Father's Education Level	Father's Occupation

Section B: Diabetes

Type of Diabetes	Type 1	Type 2	Other (Specify) _____
Family History of DM	Yes	No	

Reason for current visit

Routine	Hypoglycemia	Ketoacidosis
Uncontrolled Diabetes	Infection	Other
Other (Specify) _____		

Age at first presentation \_\_\_\_\_

Date of Diagnosis \_\_\_\_\_

Residing area when diagnosis was made: \_\_\_\_\_

No of Medical consultations before diagnosis: \_\_\_\_\_

Initial diagnosis as DKA	Yes	No
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Mean daily insulin dose \_\_\_\_\_

No. of injections/day

No. of blood tests/day	None	1 – 2	3 – 4	> 4
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Admissions in the previous year	Yes	No
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Total No of Admissions: \_\_\_\_\_

Diabetes Related (Specify)	Hypoglycemia		Outcome		
	Yes	No	Regular f/u	Death	Lost to f/u
1.	<input type="checkbox"/>				
2.	<input type="checkbox"/>				
3.	<input type="checkbox"/>				

Diabetes unrelated (Specify)

- 1.
- 2.
- 3.

HbA1c level at last visit:

**Section C: Patient perspective**

1. What difficulty are you facing while managing your diabetes?
  - a. None
  - b. Financial
  - c. Injection use
  - d. Difficult to come for regular follow ups
  - e. Different doctors at different visits
  - f. Others (Specify): \_\_\_\_\_
2. Are you pursuing your education?    Yes            No
3. Is diabetes affecting your education?    Yes            No
4. If yes, in what way?
  - a. Left school soon after I fell ill with diabetes
  - b. Can't attend school/college because of the illness
  - c. Schools/colleges do not accept me because of my illness
  - d. Family cannot afford both treatment and education
  - e. Other (specify): \_\_\_\_\_
5. How satisfied are you with your diabetes management at Patan Hospital?    Satisfied            Unsatisfied
6. If unsatisfied, what is the reason?
  - a. Long waiting time/queue
  - b. Doctor's behavior
  - c. Long queue in pharmacy
  - d. Problems with supply of insulin and other stuffs like strips
  - e. Others (specify)
7. What do you find difficult about having diabetes?
  - a. Insulin injections
  - b. Frequent blood sugar testing
  - c. Dietary restriction
  - d. Maintaining blood sugar level
  - e. Fear of social stigma
  - f. Withdrawal from social activities
  - g. Worry about future career
  - h. Others (specify)
8. Education about diabetes: In which areas you are confident?
  - a. About disease itself
  - b. Diet and lifestyle changes
  - c. Injection technique
  - d. Home glycemic monitoring
  - e. Hypoglycemia
  - f. Complications
  - g. Others (specify)