

ISSN: 2476-8642 (Print) ISSN: 2536-6149 (Online) www.annalsofhealthresearch.com African Index Medicus, Crossref, African Journals Online, Scopus, C.O.P.E & Directory of Open Access Journals

# Annals of HEALTH RESEARCH (The Journal of the Medical and Dental Consultants' Association of Nigeria, OOUTH, Sagamu, Nigeria) Volume 10 No. 3 July – Sept., 2024

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PUBLISHED BY THE MEDICAL AND DENTAL CONSULTANTS ASSOCIATION OF NIGERIA, OOUTH, SAGAMU, NIGERIA. www.mdcan.oouth.org.ng

# **Annals of Health Research**

(The Journal of the Medical and Dental Consultants Association of Nigeria, OOUTH, Sagamu, Nigeria) CC BY-NC Volume 10, Issue 3: 276-284

Volume 10, Issue 3: 276-284 September 2024 doi:10.30442/ahr.1003-06-246

# ORIGINAL RESEARCH

# Adherence to Recommended Care in Type-1 Diabetes Mellitus Among Adolescents and Youths Attending the Diabetes Camp in Ogun State, Nigeria Adekoya AO<sup>\*1</sup>, Adesina OF<sup>3</sup>, Abolurin OO<sup>1</sup>, Oyewole OA<sup>4</sup>, Oguntade IO<sup>4</sup>, Sodeinde KJ<sup>2</sup>, Ale AO<sup>5</sup>

<sup>1</sup>Department of Paediatrics, <sup>2</sup>Department of Community Medicine, Benjamin S. Carson College of Health and Medical Sciences, Babcock University/Teaching Hospital, Ogun State, Nigeria <sup>3</sup>Talabi Diabetes Centre, Isara-Remo, Ogun State, Nigeria

<sup>4</sup>Department of Paediatrics, Federal Medical Centre, Abeokuta, Ogun State, Nigeria

<sup>5</sup>Department of Medicine, Obafemi Awolowo College of Health Sciences, Olabisi Onabanjo University/Teaching Hospital, Ogun State, Nigeria

\*Correspondence: Dr AO Adekoya, Department of Paediatrics, Benjamin S. Carson College of Health and Medical Sciences, Babcock University/Teaching Hospital, Ogun State, Nigeria. E-mail: doctornator2@gamil.com ; ORCID - 0000-0002-0515-7002.

#### Abstract

**Background:** Adolescents and youths living with Type 1 diabetes mellitus (T1DM) are known to have challenges in managing the condition and may be prone to poor glycaemic control and complications.

**Objectives:** To assess the level and adequacy of care for adolescents and youths living with T1DM.

**Methods:** A cross-sectional, descriptive study was conducted among adolescents and youths living with T1DM who attended the 2023 Ogun Youth Diabetes Camp. An interviewer-administered questionnaire was used to obtain information.

**Results:** Twenty-five participants with a mean age of  $18.0\pm3.9$  years (range 13-24 years) were recruited, with 80% being females. The mean HbA1c was  $7.1\pm1.8\%$ , and in-camp postprandial glucose values were mostly high (76%). The mean age at diagnosis of T1DM was  $11.7\pm4.8$  years. One participant had T1DM for < 2 years, 11 for 2-5 years, and 13 for > 5 years. Among those who had lived with T1DM for more than 5 years, ten had been referred to a dietitian, nine to an ophthalmologist, and two to a neurologist. One participant had been screened for thyroid disorder.

**Conclusion:** The adolescents and youths living with T1DM in this survey had suboptimal glycaemic control, and evaluation by their care providers during clinic visits was also suboptimal. Therefore, they may be at increased risk of developing complications. It is recommended that all stakeholders lend timely and aggressive support to these individuals to ensure adequate management and prevent complications.

Keywords: Adolescents, Complications, Glycaemic control, Type 1 Diabetes mellitus, Youths.

#### Introduction

Type 1 Diabetes mellitus (T1DM) is one of the most common chronic metabolic conditions in the paediatric age group.<sup>[1]</sup> It is characterised by immune-mediated destruction of the  $\beta$  cells of the pancreas, leading to insulin deficiency.<sup>[1,2]</sup> Insulin deficiency, especially if prolonged, leads to hyperglycaemia, which may result in acute and chronic complications.<sup>[3]</sup> T1DM presently accounts for about 5-10% of all cases of diabetes mellitus and is the predominant type in children and adolescents.<sup>[3]</sup> Globally, the prevalence of T1DM has been increasing over the years and about 19 - 38 million people presently live with T1DM.<sup>[4]</sup> The prevalence is noted to be on the rise in African children.<sup>[5]</sup>

According to the World Health Organisation, adolescents and youths are between 10 to 19 years and 15 to 24 years, respectively.<sup>[6]</sup> Adolescents and youths living with T1DM are faced with many challenges, including hormonal, psychological and social factors, which may negatively affect the overall management of the condition. This may make them prone to developing complications.<sup>[7,8]</sup> The most dreaded acute complication of T1DM is diabetic ketoacidosis, a potentially fatal condition.<sup>[9]</sup> Chronic complications of T1DM may affect virtually every organ in the body, causing nephropathy, neuropathy, retinopathy, cardiac diseases, cerebrovascular disease, peripheral arterial disease, and others.<sup>[10]</sup> The cost of insulin and other related expenses of care may be challenging in affected Nigerian children and may worsen glycaemic control.[11]

Preventing the complications of T1DM is hinged mainly on achieving good glycaemic control, which is affected by multiple factors, including the type, adequate dosing and correct administration of insulin, blood glucose monitoring, diet, exercise, and early and routine screening for complications. Attending a diabetes camp has also been observed to help achieve good glycaemic control [12] and improve the quality of life.<sup>[13]</sup> According to the 2022 Clinical Practice Consensus Guidelines of the International Society for Paediatric and Adolescent Diabetes (ISPAD), people living with diabetes must be screened for microvascular and macrovascular complications at specified periods from the time of diagnosis. In addition, affected persons must be periodically screened for other autoimmune conditions.[14] These are targeted at early detection of complications. This study aimed to document the level of self-care and adequacy of medical care received by adolescents and youths with T1DM. The findings may help identify the gaps in medical care and proffer solutions for improvement, with the prospect of delaying or avoiding complications from T1DM.

#### Methods

#### Study design/study population

This cross-sectional, descriptive study was conducted among adolescents and youths aged 10 - 24 years with T1DM who attended the 2023 Annual Ogun State Youth Diabetes Camp. The Diabetes Camp is held annually at the Youth Development Centre, Olusegun Obasanjo Presidential Library, Abeokuta, Ogun State. The Diabetes Camp is the initiative of the Talabi Diabetes Centre in conjunction with the Ogun State Government, Dr Abi Afonja Trust, Diabetes Association of Nigeria (Ogun Chapter), Olusegun Obasanjo Presidential Library, and the Society for Paediatric and Adolescent Endocrinology of Nigeria (Ogun Chapter). It was commenced in 2020 and receives interested participants aged 10 - 25 years. Paediatric and endocrinologists, adult diabetic nurses, dietitians, psychologists, persons living with diabetes, and other stakeholders are part of the resource persons for the Diabetes Camp.

The camp activities included talks and discussions on glucose monitoring, insulin types,

storage and administration, diet and carbohydrate counting, exercise and other aspects of care. There were physical exercise sessions, and tours to the Presidential Library, museum, and zoo. There were also boat rides and visits to the cinema to watch films. The camp was entirely free for the participants.

#### Inclusion criteria/Exclusion criteria

All consenting participants aged 10 - 24 were included in the study. The exclusion criteria included multiple chronic morbidities and a diagnosis of T1DM made less than one year at the time of the survey.

#### Sample Size

All consenting participants who attended the camp were recruited for the study using convenient sampling.

#### Data collection

An interviewer-administered questionnaire was used to obtain the participants' sociodemographic data, including age, religion, level of education, occupation, and family setting. Clinical details such as insulin doses, frequency and duration of insulin use, diet, physical exercise, and care during clinic visits were also obtained. Using a Likert scale, the participant's perception of the adequacy of glucose monitoring, insulin doses, exercise routine, compliance with diet and diary-keeping habits were rated from 'very poor' to 'very good'. The last HbA1c done within three months of the camp was obtained. In-camp fasting blood glucose (FBG) and 2-hour postprandial blood glucose (2HrPP) values were also obtained. The HbA1c value of <7.0%, fasting blood glucose within 70 -144 mg/dl, and 2-hour postprandial glucose within 70 - 180 mg/dl were taken as targets for good glycaemic control.<sup>[15]</sup>

#### Data analysis

All data were analysed using the Statistical Package for the Social Sciences Version 23.0.

Continuous variables were expressed in means and standard deviations, while percentages were determined for categorical variables. Pearson's Chi-Square test was used to test the association between categorical variables. Likelihood-Ratio test was applied to Chi-square analysis when over 20% of the cells had expected counts less than five. Analysis of variance was used to analyse the difference between the means of more than two groups. Statistical significance was set at p values <0.05.

#### Ethical considerations

Ethical approval was obtained from the Health Research Ethics Committee of the Ministry of Health, Abeokuta, Ogun State (OGHREC/467/259/APP). Detailed information about the study was provided, and informed consent was obtained from every participant aged 18 years or older and the parents of those younger. Assent was taken from participants younger than 18.

#### Results

Twenty-five participants attended the 2023 Diabetes Camp with ages ranging from 13 to 24 years and a mean age of 18.0±3.9 years. There were more females (20, 80%) than males. Twenty-three (92%) participants had endocrinologists as their primary care providers, while two (8%) were unsure if their doctors were endocrinologists. Twelve (48%) participants were managed in a tertiary hospital, while 10, 1, and 2 were managed at a Federal Medical Centre (nonteaching tertiary hospital), General Hospital and Private Hospital, respectively. The mean age at diagnosis of T1DM was 11.7±4.8 years, with the earliest being one year and the oldest 22 years at the time of diagnosis. One participant (4.0%) had T1DM for less than two years, 11 (44.0%) for 2-5 years, and 13 (52.0%) for more than 5 years. Five (20.0%) of them were first-timers at the camp, while 14 (56.0%) were attending for the third

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time. Only 10 participants remembered their last HbA1c, ranging from 4.2 to 10.8 %, with a mean value of 7.1 $\pm$ 1.8%. Five of these had HbA1c values >7.0%. One of the participants had never checked HbA1c. There was no significant relationship between the duration of illness and HbA1c levels (F = 3.91, p = 0.073).

Almost all the participants (24; 96.0%) had a personal glucometer. The in-camp fasting blood glucose ranged between 30 and 524 mg/dl with a mean of 179.2±126.3 mg/dl. Four participants (16%) had FBG <70mg/dl, seven (32%) had values between 70 and 144 mg/dl, and 13 (52%)

had values >144 mg/dl. The 2-hour postbreakfast glucose ranged between 64 and 500 mg/dl with a mean of 265.3±132.7 mg/dl. Two participants (8%) had 2HrPP <70 mg/dl, four (16%) had values between 70 – 180 mg/dl, and 19 (76%) had values >180 mg/dl. Thirteen campers (52.0%) were on premixed insulin, while 12 (48.0%) were on basal-bolus combination. On the regularity of taking their insulin injections, 15 (60.0%) participants had never missed their insulin doses, while 2 (8.0%) participants admitted to missing it daily, as shown in Figure 1. None of them was on continuous glucose monitoring, and none had used an insulin pump.



Figure 1: Regularity of insulin injections

More than half (52.0%) of the participants rated their blood glucose monitoring as good. Also, 64.0% rated their regularity with insulin doses as good, and 68.0% rated their diary-keeping habit as good. About half rated their exercise routine (52.0%) and compliance with dietary advice (40.0%) fairly, as depicted in Table I. On the awareness of body parts affected by the complications of T1DM, the eyes (20), kidneys (20), and feet (11) were most listed by the participants. On their clinic experiences, 17 (68%), 11 (44%), 7 (28%), and 18 (72%) participants, respectively, said that the doctors checked their blood pressure, insulin injection sites, feet and diaries at every clinic visit, respectively. Other details on their clinic experiences are shown in Table II.

Table III shows that about two-thirds (68.0%) of the participants had been referred to a dietitian, 16.0% to a neurologist and 1.0% to a nephrologist.

#### Adherence to Recommended Care in Type-1 Diabetes Mellitus

One participant reported ever being screened for thyroid disorder but none for coeliac disease.

	Very poor	Poor	Fair	Good	Very good	
Blood glucose monitoring	2 (8.0)	2 (2.0)	7 (28.0)	11 (44.0)	3 (12.0)	
Insulin doses	0 (0.0)	1 (4.0)	8 (32.0)	10 (40.0)	6 (24.0)	
Exercise routine	0 (0.0)	3 (12.0)	14 (52.0)	4 (16.0)	4 (16.0)	
Compliance with dietary advice	1 (4.0)	3 (12.0)	10 (40.0)	7 (28.0)	4 (16.0)	
Keeping diary	1 (4.0)	3 (12.0)	4 (16.0)	11 (44.0)	6 (24.0)	

#### Table I: Self-rating of glucose monitoring, insulin doses, exercise, diet and diary-keeping

Figures in parentheses are percentages of the total in each row

#### Table II: Patient-doctor clinic interactions

	Frequently	Sometimes	Rarely	Never
Blood pressure check	17 (68.0)	4 (16.0)	2 (8.0)	2 (8.0)
Insulin injection sites check	11 (44.0)	9 (36.0)	1 (4.0)	4 (16.0)
Feet check	7 (28.0)	5 (20.0)	5 (20.0)	8 (32.0)
Diary check	18 (72.0)	5 (20.0)	1 (4.0)	1 (4.0)

Figures in parentheses are percentages of the total in each row

Among those who had lived with T1DM for more than 5 years, ten had been referred to a dietitian, 9 to an ophthalmologist, and 2 to a neurologist. Among those who had lived with T1DM for 2-5 years, six had been referred to a dietitian, 7 to an ophthalmologist, and 2 to a neurologist (Table IV). There was no statistical significance in the relationship between the duration of T1DM and referral to a specialist. Regarding developing complications from T1DM, 19 campers were concerned, while six were neutral. Concerning their preparedness in preventing complications of T1DM, 19 campers affirmed preparedness, while four were neutral and two were unprepared. Sixteen (64.0%) campers had enough support from home, while 20 (80.0%) had enough support from their doctors in managing T1DM.

#### Table III: Pattern of referral to other specialists

	Yes	No	I don't know
Dietitian	17 (68.0)	8 (32.0)	0 (0.0)
Ophthalmologist	16 (64.0)	8 (32.0)	1 (4.0)
Psychologist/psychiatrist	4 (16.0)	19 (76.0)	2 (8.0)
Neurologist	4 (16.0)	16 (64.0)	5 (20.0)
Dermatologist	2 (8.0)	17 (68.0)	6 (24.0)
Nephrologist	1 (4.0)	18 (72.0)	6 (24.0)

Figures in parentheses are percentages of the total in each row.

#### Discussion

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This study showed that most participants had high blood glucose levels, and many had not been referred to the appropriate specialists to be screened for complications. Living with T1DM is demanding and can be burdensome to affected individuals and their parents. All efforts and strategies in preventing the complications of T1DM are targeted at achieving good glycaemic control. Complications from T1DM may be debilitating and could lead to avoidable deaths, especially in adolescents and youths.<sup>[16]</sup>

	Duration of T	Duration of T1DM			
	<2 years	2-5 years	>5 years	p-value	
Dietitian	1 (100.0)	6 (54.5)	10 (76.9)	0.343	
Ophthalmologist	0 (0.0)	7 (63.6)	9 (69.2)	0.333	
Psychologist/psychiatrist	0 (0.0)	2 (18.2)	2 (15.4)	0.823	
Neurologist	0 (0.0)	2 (18.2)	2 (15.4)	0.823	
Dermatologist	0 (0.0)	1 (9.1)	1 (7.7)	0.911	
Nephrologist	0 (0.0)	0 (0.0)	1 (7.7)	0.510	

Table IV: Relationship between the duration of T1DM and	nd referral to a specialist
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Figures in parentheses are percentages of the total in each row.

The mean HbA1c among the participants in this survey was above <7%, as recommended by the American Diabetes Association.<sup>[17]</sup> It was slightly higher than the 7.02% observed among 20 campers in Italy.<sup>[18]</sup> Although the mean age in this survey was higher than the Italian report, the mean HbA1c might also have been much higher, considering that the results were from ten campers. The camper who had never checked HbA1c was managed at a teaching hospital and had financial difficulties, which might explain why the laboratory test was not done. The camper without a personal glucometer shared the device with a family member who also had diabetes mellitus. The markedly elevated blood glucose values among most of the participants in this survey further strengthen the possibility of higher HbA1c values. These connote poor glycaemic control and an increased risk of developing complications from T1DM.

While we are positive that the knowledge and skills acquired at the camp will enhance better T1DM management, sadly, there are divergent observations on the effect of camp attendance on blood glucose control. Some studies showed improvement in glycaemic control after camp attendance, <sup>[12]</sup> while others did not.<sup>[18]</sup> This emphasises the importance of quality care by the care providers, the parents/guardians and the affected adolescents/youths, beyond the periodic support from the camp.

Insulin is critical to the management of T1DM. Nearly half of the participants in this study are on premixed insulin, which has some challenges with dose adjustment and is against the recommended basal and prandial combinations in children of all ages.<sup>[19]</sup> Premixed insulin is associated with a rigid administration schedule, night-time hypoglycaemia, and a high variability in glucose-lowering action.<sup>[19]</sup> Unfortunately, missing insulin doses seems to be a universal occurrence. It is particularly discomforting that 40% of them miss their doses at various times within a month owing to rationing. Missing insulin may trigger diabetic ketoacidosis, a lifethreatening acute complication of T1DM. [20] The need for compliance with recommended insulin regimen must be emphasised to persons living with T1DM, and the dangers of insulin rationing must be clearly explained to them.

In addition to blood glucose monitoring and insulin therapy, exercise and appropriate diet are important in managing T1DM. Exercise has been recommended as an adjunct therapy to glycaemic control in adolescents and youths.[21] Although the types of exercise were not explored in this study, more than half rated their exercise routine as fair or poor, which is suboptimal. Adherence to a healthy diet is a documented challenge in young people.<sup>[22]</sup> More than half of the participants rated their compliance with dietary advice as fair, poor or very poor. These observations portend a risk of diabetic complications. A consistent exercise routine and complying with dietary advice are major reflections of home and societal support.

The ISPAD recommends screening for nephropathy, retinopathy, neuropathy, and macrovascular complications of T1DM within 2-5 years of diabetes duration.<sup>[14]</sup> The Society also recommends a blood pressure check at every clinic visit and an annual comprehensive foot examination.<sup>[23]</sup> Furthermore, thyroid screening should be done every 1-2 years, or more frequently if symptoms are present, and screening for celiac disease should be performed during the initial year of diabetes diagnosis and at 2-5 years intervals.<sup>[24]</sup> Considering that the youngest camper was 13 years old and only one camper had lived with T1DM for less than two years, it implies that practically all of them should have been screened or commenced screening for these complications. Having endocrinologists, especially in tertiary health facilities, take care of them should aid in early screening. However, just a few of them had been referred for such screening. While the study could not verify the reasons for the low screening rate, a future survey of endocrinologists is essential to know how often they screen adolescents living with T1DM for complications.

The participants in this study enjoyed more support from their doctors than parents/guardians in managing T1DM. While it is commendable on the part of the doctors, it is an expected finding in the parents as some might have physical, psychological and financial challenges coping with the diagnosis and managing the condition in their children.<sup>[25]</sup> This shows that parents and guardians need more support in understanding and managing T1DM to prevent or delay its complications. Without adequate support from home, the efforts of the doctors may be futile. The limitations of this study include the small number of participants and the non-availability of HbA1c results for some of the participants.

#### Conclusion

Adolescents and youths living with T1DM may be at increased risk of having complications due to suboptimal glycaemic control and delayed or infrequent screening for complications. Patient evaluation by care providers during clinic visits could have been more suboptimal. It is therefore recommended that all doctors/endocrinologists and parents/guardians involved in managing adolescents and youths living with T1DM in Nigeria lend timely and aggressive support to individuals ensure these to adequate management. This will help prevent or delay the complications of the condition.

Authors' Contributions: AAO1, AOF, AOO, OOA, OIO, and AAO2 contributed to the conception and design of the study. AAO1 and AOF did the literature review. AAO1, AOO and SKJ analysed and interpreted the data. AAO1, AOO and SKJ drafted the manuscript, while AOF, OOA, OIO and SKJ revised the manuscript for sound intellectual content. All the authors approved the final version of the manuscript. Conflicts of Interest: None.

Funding: Self-funded.

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**Publication History:** Submitted 31 August 2024; Accepted 28 September 2024.

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