DOI: 10.4274/jcrpe.galenos.2024.2024-4-7

Research Article

The Effect of Parental Collaboration on Diabetes Self-Efficacy, Quality of Life and HbA1c Level in Adolescents Diagnosed with Type 1 Diabetes

Özgüven Öztornacı B et al. Parental Collaboration, Diabetes Self-Efficacy, Quality of Life and HbA1c Level in Adolescents with T1D

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What is already known on this topic?

Adolescence is a period when the child's autonomy comes to the fore and wants to be independent. T1D is a chronic disease for which the **adolescent** and parent must manage care and treatment together. Parental participation in disease management in T1D is effective on compliance, that is, QoL and metabolic control.

What this study adds?

Parental collaboration does not affect the adolescent's diabetes management HbA1c level. However, the QoL increases when the adolescent does diabetes follow-up himself/herself with the support of his/her parents.

Abstract

Objective: Type 1 diabetes mellitus (T1D) is a chronic disease that is common in childhood and adolescence, where care and metabolic control are difficult for both adolescents and their parents. Parental participation in the care and treatment process, especially during adolescence when adolescents develop autonomy and take responsibility for self-care, affects both the adolescent's perception of autonomy and may cause difficulties in self-management. This study was conducted to determine the effect of parental support on adolescents' self-efficacy, quality of life (QoL) and glycaemic control in adolescents with T1D.

Methods: This study was descriptive and cross-sectional. Descriptive questionnaires, The Collaborative Parental Involvement Scale for Adolescents with T1D, Diabetes Management Self-Efficacy Scale for Adolescents with T1D and QoL Scale in Children with Diabetes Mellitus (PedsQL 3.0) were administered to 79 adolescents with T1D. Adolescents were also asked about their HbA1c levels measured in the last 3 months.

Results: There was no relationship between parental collaboration and adolescent's HbA1c levels. However, it was concluded that there was a positive and moderate relationship between parental collaboration and adolescent's QoL (p=0.043) and a positive and strong relationship between parental collaboration and adolescent's QoL (p=0.043) and a positive and strong relationship between parental collaboration and adolescent's QoL (p=0.000).

Conclusion: It was found that adolescents who followed up diabetes with the support of themselves and both parents especially their fathers, who were not school absenteeism and had regular blood glucose measurements had better QoL, there was no relationship between HbA1c levels and QoL, and there was a strong relationship between parental cooperation and adolescent self-efficacy in the same direction. **Keywords:** Adolescent, diabetes, parental collaboration, self-efficacy, quality of life, HbA1c level

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Introduction

Type 1 diabetes (T1D) is one of the most common chronic diseases in childhood and adolescence. Adolescence is a period when care and metabolic control of T1D is difficult for both parents and adolescents (1,2,3). T1D requires a multidisciplinary approach of a team such as endocrinologist, diabetes murse, dietician, psychologist and the participation of the family in a holistic manner since it requires adjustments in lifestyle due to the nature of the disease as well as insulin treatment, blood glucose monitoring and diet. Failure to maintain metabolic control and blood glucose levels at the desired level leads to complications, and the risk of microvascular complications accelerates throughout adolescence. HbA1c alone is not an indicator of diabetes self-management, but it is one of the most important markers of metabolic control (4). When the HbA1e value is below 5.7%, it is classified as normal or non-diabetic, and when it is between 5.7% and 6.4%, it is classified as prediabetes. In cases where the HbA1c value is 6.5% and above, diabetes is diagnosed. The Diabetes Control and Complications Trial reported that a higher mean HbA1c level was the dominant predictor of diabetic retinopathy progression. Achieving HbA1c levels of 7% or lower with tighter control in patients with type 1 diabetes has been associated with a 35-76% reduction in microvascular complications such as retinopathy, nephropathy, and neuropathy (5). Management of blood glucose and prevention of complications are very important for a healthy and long life in adolescents with T1D (6).

While adolescence is a period when autonomy develops and the adolescent takes responsibility for self-care, the diagnosis of T1D both affects the adolescent's perception of autonomy due to parental involvement and leads to additional complex difficulties in self-management (6). Adolescents with T1D have difficulty in achieving metabolic control and dietary compliance due to their efforts to be accepted by their peers, to be independent from their parents, and psychosocial problems (7). Besides to the perception of the disease and its effect on life domains, parents' emotional responses, their perspective on treatment and level of knowledge may also play a role in the behaviour of adolescents (8).

It is known that mothers whose adolescents are diagnosed with T1D experience emotions such as shock, denial, anxiety, anger and guilt with the diagnosis, just like other mothers with adolescents with chronic diseases. Mothers may experience an intense sense of loss including the loss of normality and healthy adolescent (3). With the effect of anxiety and loss, parents intervene in the life of the adolescent diagnosed with diabetes and conflicts may occur between the adolescent and his/her family. Conflict may cause deterioration in the relationship between parents and adolescents. Adolescents with T1D and some of their parents spend this period with fewer problems (9).

Factors affecting the adaptation of adolescents to T1D can be explained according to the Roy Adaptation model. According to this model, age, gender, duration of diabetes diagnosis, pubertal development, family environment and treatment method are individual and familial characteristics that affect adaptation. Individual and family characteristics lead to psychological responses such as various levels of stress, anxiety, depressive symptoms, eating disorders and behavioural disorders. Individual and family characteristics and psychological responses lead to the development of coping, self-efficacy, social competence, and self-management in the adolescent and family, and ultimately, QoL and metabolic control are indicators of adaptation. When harmony is achieved between the patient and the family, QoL and metabolic control are realised at a good level (10). Self-efficacy, which is defined as the individual's judgement of the ability to organise and execute action plans (11), determines the disease-specific behaviours of patients with chronic diseases and is important in the realisation of adaptation. Adolescents with a sense of self-efficacy are more likely to achieve the targeted metabolic control as they are more confident and take an active role in disease management (12). As parental monitoring increases, disease management and metabolic control may result in poor glycaemic control. It is argued that diabetes self-management will be achieved by preventing parental conflict and supporting parental involvement in the adolescent period (14).

Based on all this information, the aim of this study was to determine the effect of parental support on self-efficacy, QoL and glycaemic control in adolescents with T1D.

Method

This descriptive and cross-sectional study was conducted in the pediatric endocrinology outpatient clinic of a university hospital in western Turkey between March 2023 and September 2023. The number of patients between 11-18 years of age followed up in the centre during these dates was 198.

Participants

The study sample included 79 adolescents with T1D who were followed up in the pediatric endocrinology outpatient clinic of the hospital and met the inclusion criteria. Adolescents who were diagnosed at least 6 months ago were included in the study. Since having another chronic disease besides diabetes may affect self-efficacy, QoL and glycaemic control, adolescents with a chronic disease other than diabetes were not included in the sample.

Instruments

In data collection; Descriptive questionnaire, Collaborative Parental Involvement Scale for Adolescents with T1D, Diabetes Management Self-Efficacy Scale for Adolescents with T1D and Quality of Life Scale in Children with Diabetes Mellitus (PedsQL 3.0) were introduced to the adolescents and their parents, how to fill them out was explained and applied to the adolescents. The data collection process was conducted online. It took an average of 15-20 minutes to complete the forms.

Descriptive questionnaire: This form consists of 17 questions in total. Nine of the questions included sociodemographic information such as age, gender and education level of the adolescent and parents. Eigth of the questions were related to the adolescent's diabetes, including the number of years the adolescent has had diabetes, the last measured HbA1c level of the adolescent, who does diabetes follow-up at home, the effect of diabetes on school attendance, regular diabetes follow-up, regular insulin use and regular blood glucose measurements. Collaborative Parental Involvement Scale for Youth with T1D: The parental involvement scale was developed by Nansel et al. (2009), and

its Turkish validity and reliability was performed by Ayar et al. The scale consists of 12 items and a single sub-dimension and is scored on a 1-5 scale: 1 = almost never; 2 = sometimes; 3 = often; 4 almost always; 5 = always. The scale does not have a cut-off point and the higher the score, the closer the parental involvement (15,16).

Diabetes Management Self-Efficacy Scale in Adolescents with TID: The scale was developed by Moens (1998), and the Turkish validity and reliability study was conducted by Ozturk, Ayar, and Bektas (2017). The scale is used to determine the educational needs of adolescents or to evaluate the effectiveness of diabetes education programmes. The scale consists of 26 items ranging from 1 (strongly agree) to 5 (strongly disagree). The scale score is calculated by dividing the total self-efficacy scores by the number of items to show the strength of perceived self-efficacy for different performance levels. The lowest total score that can be obtained from the scale is 26 and the highest is 130. Higher score indicates less self-efficacy. The scale has four sub-dimensions including medical treatment and nutrition (items 1, 2, 4, 5, 7, 9, 10, 11, 14, 18, 22 and 26), assessment of glycaemia, adjustment of nutrition and insulin dose (items 6, 8, 12, 13, 17, 19, 21 and 25), talking about diabetes (items 23 and 24), honesty towards oneself and others (items 3, 15, 16 and 20). The total scores that can be obtained from the sub-dimensions of the scale are minimum 12, 8, 2, 4; maximum 60, 40, 10 and 20, respectively. Cronbach's alpha coefficient was found to be 0.85 (17,18).

Quality of Life Scale in Children with Diabetes Mellitus (PedsQL 3.0): The scale was developed by Varni et al. (2003) and its Turkish validity and reliability was performed by Ayar (2012). This scale measures both general domains of QoL and disease-specific domains. The scale is a comprehensive, multidimensional scale with both diabetic children and proxy (parent/caregiver) reports. The PedsQL 3.0 Diabetes Scale (28 items) includes five subscalest diabetes symptoms (11 items), treatment barriers (4 items), treatment compliance (7 items), anxiety (3 items), and communication (3 items). In the scale prepared according to the five-point Likert system, 0= never creates a problem, 1= almost never creates a problem, 2= sometimes creates a problem, 3= often creates a problem and 4= always creates a problem. In the total score calculation of the scale, a linear conversion is applied and it is converted into 0-100 points. If the answer to the question is marked as never, it receives 100 points; if it is marked as ararely, it receives 75 points; if it is marked as sometimes, it receives 50 points; and if it is marked as almost always, it receives 0 points. The higher the total score, the better the health-related QoL is perceived. The reliability coefficients of the subscales in the child form of the scale were found to be diabetes symptoms; 0.81, treatment barriers; 0.66, treatment compliance; 0.66, anxiety; 0.63, communication; 0.77, respectively; and the reliability coefficients of the subscales symptoms; 0.81, treatment barriers; 0.68, treatment compliance; 0.73, anxiety; 0.81, and communication; 0.84, respectively (19,20).

Independent Variables of the Study: Adolescent's gender, age, duration of diabetes diagnosis, parental education level and Collaborative Parental Involvement Scale Score for Youth with T1D.

Dependent Variables of the Study: Quality of Life Scale in Children with Diabetes Mellitus (PedsQL 3.0) and Diabetes Management Self-Efficacy Scale Score in Adolescents with T1D, adolescent's HbA1c level.

Statistical Analysis

SPSS 26.0 programme was used for statistical analyses. Descriptive data of adolescents and parents were given as numbers and percentages. The Student-t test and Anova test were used to analyse the variables that conformed to the normal distribution rule. Mann-Whitney U and Kruskal Wallis tests were used to analyse variables that did not fit the normal distribution. Correlation analysis was used in the relationship between continuous variables.

Results

The mean age of the adolescents who participated in this study was 14.29 years and their HbA1c level was 8.43. Of the adolescents, 27.8% followed up diabetes themselves, 45.6% were absent from school due to diabetes, 88.6% went for regular check-ups, 97.5% used regular insulin and 94.9% had regular blood glucose measurements (Table 1).

When Table 2 was analysed, it was observed that the gender of the adolescent (p=0.282), education of the mother (p=0.521) and father (p=0.481), education of the adolescent and family about diabetes before p=(0.926) or regular insulin use (p=0.541) had no effect on QoL. However, the person who monitores of diabetes (p=0.001), school absenteeism (0.000) and regular blood glucose measurement (p=0.045)

were found to have an effect on QoL. It was concluded that the QoL of adolescents who monitored diabetes themselves without the help of their mothers, adolescents who were not absent from school and adolescents who had regular blood glucose measurements had a better QoL. Gender of the adolescent (p=0.813), mother's (p=0.543) and father's education (p=0.478), the person who monitores of diabetes (p=0.478), school absenteeism (p=0.148), regular insulin use (p=0.818) or regular blood glucose measurement (p=0.086) had no effect on the self-efficacy of the adolescent. The self-efficacy scores of adolescents who monitored diabetes themselves without the help of their mothers were significantly higher than the self-efficacy scores of adolescents who monitored diabetes with the help of their mothers (p=0.036) (Table 2). Gender of the adolescent (p=0.322), mother's (p=0.441) and father's education (p=0.161), the person who monitores of diabetes (p=0.457), school absenteeism (p=0.172), regular insulin use (p=0.644) or regular blood glucose measurement (p=0.690) had no effect on the colloboration of parents (Table 2).

There was no relationship between parental collaboration and adolescent's HbA1c levels. However, it was concluded that there was a positive and moderate relationship between parental collaboration and adolescent's QoL (p=0.043) and a positive and strong relationship between parental collaboration and adolescent's QoL (p=0.003) (Table 3).

Discussion

Diabetes management of adolescents with T1D is controlled by measuring HbA1c levels, which are defined as glycosylated haemoglobin levels in 2-3 months. HbA1c level, which is considered normal below 5.7%, brings about microvascular complications such as retinopathy when it exceeds 7%. Regular blood glucose monitoring and HbA1c levels of adolescents with T1D are indicators of adolescent selfmanagement (4,5,21,22,23). In this article, self-efficacy is evaluated by including adolescents with HbA1c level above 6.5% among the descriptive characteristics of adolescents. Similarly, Harrington et al. (2021) conducted a study on adolescents with HbA1c values of 6.5-11% in order to evaluate the relationship between diabetes self-management of adolescents get 13-17 years with T1D_x-HbA1c and depression among psychosocial outcomes (24). The mean final HbA1c level of adolescents. However, the use of a single measurement of HbA1c level, which is also among the limitations of this study, is not sufficient for generalizability.

Parental involvement in adolescents with T1D is considered necessary for improved glycaemic control, better compliance with the T1D management regime and self-management (6). It was determined that parental involvement in adolescents with T1D contributed to the adaptation and self-efficacy of the adolescent (8), and parental adaptation had an effect on HbA1c control (13). QoL and self-efficacy levels of adolescents who followed up diabetes without the help of their mothers were found to be high in this study. The group without maternal involvement includes the adolescents themselves and adolescents with paternal involvement. It is desirable for the adolescent to take responsibility in diabetes management, and the positive effect of father involvement on self-management and hie capacity may be a reflection of the patriarchal family structure and the position of the father in the family. With a cultural approach, the participation of fathers in the diabetes management of adolescents with diabetes can be further supported.

While the quality of self-care in adolescents with T1D is associated with glycaemic control, reduction in complications and increase in QoL; the management of factors that inhibit self-care results in the integration of the disease into the individual's identity level in adolescents with T1D (25). According to the results of the study, regular insulin use had no significant effect on the increase in QoL, while the relationship between regular blood glucose measurement and QoL was significant.

In adolescents diagnosed with T1D, there is a significant relationship between the development of disease-specific self-management skills with a decrease in complications and HbA1c level in the process of regular health care services, trainings and controls carried out with various supportive practices (26). Regular blood glucose monitoring stands out as an important factor for individual health management in adolescents and is associated with an increase in QoL while it is considered as self-management of adolescents (27). This study was determined that regular blood glucose measurement of adolescents had an effect on QoL.

The QoL of adolescents who monitored diabetes only by themselves was found to be significantly higher than that of adolescents who monitored diabetes only by their mothers. The QoL was found to be higher in the group in which the mother and father monitored diabetes with the adolescent, but there was no significant difference between the other groups. Factors such as family, peer and health care team interaction, pain, understanding care are suggested as self-management barriers and have an impact on the QoL of adolescents with T1D. QoL is significantly associated with self-management, which is considered as self-management behaviours of adolescents (28). Families of children with chronic diseases may develop overprotective and controlling behaviour patterns compared to families of children without chronic diseases. This situation may negatively affect personality development in children and lead to the development of an externally directed, dependent personality structure, deterioration in social relations and loss of self-esteem in adolescence. Therefore, the adolescent may show angry and aggressive behaviours (29-33). In a study examining the relationship between parental attitudes and diabetes selfmanagement in adolescents diagnosed with type 1 DM, it was found that as the protective parental attitude increased, the fasting blood glucose values of the adolescents increased (32). Increased self-management of adolescents in this study in diabetes management leads to an increase in QoL. The QoL of the adolescent decreases as family members, especially the mother, play a more active role in diabetes management. This may be attributed to the fact that families, especially mothers, have protective and controlling behaviour patterns. In a global study conducted with young people with T1D, the decrease in HbA1c level is accepted as one of the self-management indicators and it is emphasised that the lower the HbA1c level, the higher the QoL (27). In addition, no significant relationship was found between glycaemic control and QoL in studies conducted with adolescents (34,35). There was no relationship between HbA1c and QoL in this study. This may be due to analysing only a single recently measured HbA1c level. In adolescents with T1D, stigmatisation, social problems, problems experienced in school life due to factors that complicate diabetes management at school (difficulty in diabetic nutrition, inability to manage regular insulin use, inadequate physical activity) prevent diabetes management of the adolescent (36,37). Accordingly, QoL decreases with difficulty in the management of health in adolescents (34,37). Adolescents may hide the fact that they have diabetes with the desire to adapt to the environment of friends they are in and to avoid the prejudiced behaviours of others. For this reason, glucose monitoring and insulin injections may not be performed regularly (38). They may deliberately restrict and neglect insulin in combination with irregular eating behaviour for weight control (39). Therefore, adolescents should be questioned about whether they regularly monitor their blood glucose levels and whether they regularly administer insulin. In this study, four adolescents did not measure blood glucose regularly and two adolescents did not apply insulin regularly.

The study was determined that adolescents without school absenteeism had a better QoL than those with school absenteeism. However, there is no significant relationship between school absenteeism and self-efficacy.

There was no significant relationship between regular blood glucose measurement and self-management. Contrary to the findings, in a qualitative study conducted with adolescents with T1D, the negative impact of not taking regular blood glucose measurements due to fear of injections, laziness and forgetfulness on health management is highlighted among the barriers to self-management (37). It has been determined that regular blood glucose measurement is associated with high glycaemic control in adolescents with T1D (20). Similarly, the importance of regular blood glucose measurement for self-management is emphasised (40).

Parents are an important factor on the QoL of adolescents with T1D (39). Parent-adolescent collaboration has a critical importance on adolescent's self-management (42) and increased adolescent self-management is associated with positive parental attitude and increased QoL of adolescents with T1D (21). Similarly, this study was concluded that there was a positive and moderate relationship between parental collaboration and adolescent's QoL.

Strengths and limitations

Conducting this study in a single hospital constitutes the limitation of the study. Since this study was conducted in a single centre and simple sampling method was used, the representativeness and generalisability of our results may be limited. In this study, children were evaluated with a single HbA1c level. This is one of the limitations of our study. However, the results of the study are important and similar studies should be conducted.

Conclusion

The study was determined that the QoL of adolescents who followed up their diabetes with the support of themselves, and adolescents who were not absent from school and had regular blood glucose measurements had a better quality of life, there was an inverse relationship between HbA1c levels measured at the last control and QoL. It was determined that there was a positive and moderate relationship between parental collaboration and adolescent's QoL, and a positive and strong relationship between parental collaboration and adolescent's diabetes management self-efficacy. As a result of the study, it was observed that the mean HbA1c levels of the adolescents were high. It is thought that it would be useful to continue planning for the development of self-efficacy and self-management in adolescents and adolescents and to plan approaches to support father participation.

Acknowledgements

We would like to thank the adolescents participating in the study.

Ethics

Ethics Committee Approval: The study was approved by the İzmir Katip Celebi University Non-interventional Clinical Studies Institutional Review Board (Protocol number: 0101, Date: 03/23/2023).

Informed Consent: Consent form was filled out by all participants.

Financial Disclosure: The authors declared that this study received no financial support.

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Table 1. Descriptive Characteristics of the Child and the Fam	nily (n=79)

Characteristic	Number (n)	Percentage (%)		
Age (year)	14,29±2,86 (min:11 max	::18)		
Mother Age (year)	40,75±6,08 (min:28 max	::62)		
Father Age (year)	45,71±6,79 (min:35 max:67)			
Duration of Diabetes	5,22±3,51 (min:1 max:1	2)		
HbA1c Level	8,43±1,81 (min:5,30 ma	x:13)		
Gender				
Female	44	55,7		
ſale	35	44,3		
Mother Education Level				
Primary Education	32	40,5		
Secondary Education	15	19		
High School Education	20	25,3		
Jniversity Education and Above	12	15,2		
Father Education Level				
rimary Education	28	35,4		
Secondary Education	13	16,5		
High School Education	23	29,1		
Jniversity Education and Above	15	19		
Diabetes Monitoring Person				
elf monitoring	22	27,8		
Only Mother	21	26,6		
With mother	19	24,1		
With Mother-Father- Themselves *	17	21,5		
School Absence Due to Diabetes				
Yes	36	45,6		
No	43	54,4		
Regular Insulin Use Status		07.5		
Yes	77	97,5		
No Regular Blood Glucose Measurement Status	2	2,5		
	75	94,9		
Yes No	4	5,1		
		5,1		

min-max: minimum-maximum, HbA1c: hemoglobin A1c *The group in which only the father performed diabetes follow-up and the group in which adolescents, mothers and fathers performed diabetes follow-up together were combined.

Characteristic	QoL Scale in Children with Diabetes Mellitus (PedsQL 3.0)		Diabetes Management Self- Efficacy Scale in Adolescents with T1D		Collaborative Parental Involveme Scale	
	⊼±SD	р	⊼±SD	р	<u>x</u> ±SD	p
Gender						
Female	63.31±17.18		101.15±19.68		51.77±11.55	
Male	58.82±19.59	-0.282*	100.85±20.59		54.14±9.91	<u>−−0.322^β</u>
Mother Education Level						
Primary Education	60.99±18.30		77.62±18.13		51.28±9.76	
Secondary Education	55.89±16.70		73.06±20.83		49.53±15.47	
High School Education	65.31±18.11	0.521 [¥]	78.95±23.32	0.543 ^Ω	55.52±10.57	0.441 ^Ω
University Education and Above	62.56±20.78		74.66±19.97		56.82±5.17	
Father Education Level						
Primary Education	57.65±19.27		73.53±22.21		49.75±12.42	
Secondary Education	65.52±14.46		82.46±11.13		56.46±5.73	
High School Education	60.86±18.70	0.481 [¥]	77.65±21.95	0.478 ^Ω	51.47±12.77	0.161 ^Ω
University Education and Above	65.23±19.03		75.86±19.30		57.46±4,10	
Diabetes Monitoring Person		X		•		
Self Monitoring	70.04±16.03		107.54±16.53		50.95±10.23	
Only Mother	49.91±20.52		95.95±22.33		54.80±10.12	
With Mother	59.49±13.66	0.001 ¥	96.36±22.75	0.478 ^Ω	49.05±14.18	0.170 ^Ω
With Mother-Father-Themselves	66.17±16.00		104.05±15.78		57.00±6.10	
School Absence Due to Diabetes				I		
Yes	53.47±16.40		98.00±19.17		50.72±12.17	
No	67.89±17.35	0.000*	103.55±20.47	0,148 ^β	54.58±9.40	0.172 ^β
No	60.90±18.94		102.78±15.26		56.57±5.16	
Regular Insulin Use Status	ļ 1		1	I	1	I
Yes	61.12±18.28		100.46±19.87		52.75±10.98	
	69.19±24.62	-0.541*	122.50±10.60	0.818 ^β	55.50±3.53	0.644 ^β
No	09.19±24.02		1	1	1	I
No Regular Blood Glucose Measureme						
			1.56±20.21		52.76±11.08	

Table 2. The relationship between OoL and self-efficacy and sociodemographic variables in adolescents (n=79)

Table 3. The relationship between parental collaboration and QoL, diabetes management self-efficacy and HbA1c level in adolescents (n=79)

	QoL Scale in Children with Diabetes Mellitus (PedsQL 3.0)		Diabetes Management Self- Efficacy Scale in Adolescents with T1D		HbA1c Level		
	r	р	r	р	r	р	
Collaborative Parental Involvement Scale	0.228	0.043	0.614	0.000	-0.091	0.442	

T1D: Type 1 Diabetes Mellitus, HbA1c: Hemoglobin A1c, r: Correlation Value, p: Statistical Significance Value