Factors Affecting Adherence toward Therapeutic Regimen among Children with Type 1 Diabetes Mellitus

Rahma Elsayed Abdel Aziz, Safy Salah Eldin Alrafay, Randa Mohamed. Matter, Salma El Sayed Hassan
Department of Pediatric Nursing, Faculty of Nursing, Ain Shams University

Abstract

Background: Although medication adherence is important for diabetic children to prevent disease-related complications and improve quality of life, the rate of children adherence to therapeutic regimen is somewhat disturbing. Hence, this study **aime**d to assess factors affecting adherence toward therapeutic regimen among children with type 1 Diabetes Mellitus. **Design:** Descriptive exploratory design. **Setting:** This study was conducted at Diabetic Outpatient Clinic in Children's Hospital affiliated to Ain Shams University Hospitals. **Sampling:** A purposive sample comprised of 175 children with type 1 Diabetes Mellitus. **Tools:I-** Interviewing questionnaire; it was used to assess factors affecting adherence toward therapeutic regimen **II-** Morisky Scale: it was used to assess children' adherence to medication. **Results:** This study revealed that the mean age of studied children was 13.01±2.4yearsand slightly more than half of them were female. Most of studied children were adhered toward medication regimen and had agreement with beliefs toward therapeutic regimen. In addition, more than half of studied children had positive attitude factors toward adherence to therapeutic regimen, had social support factors to therapeutic regimen and did not have sufficient health care system factors. **Conclusions:** Attitude factors, social support factors, therapy factors, health care system factors and disease factors positively affected studied children' adherence towards therapeutic regimens. Meanwhile, beliefs factors and motivation factors did not have a significant effect on studied children' adherence towards therapeutic regimen. **Recommendation:** Continuous health teaching to children with type 1 diabetes to improve their adherence**.**

Key words: Children – Adherence -Therapeutic Regimen – T1DM.

Introduction

Type 1 diabetes, is one of the most common chronic diseases in childhood worldwide, is caused by insulin deficiency following destruction of the insulin-producing pancreatic beta cells. It most commonly presents in childhood, but one-fourth of cases are diagnosed in adults. Type 1 diabetes remains the most common form of diabetes in childhood, accounting for approximately two-thirds of new diagnoses of diabetes in children's ≤19 years of age in the United States, despite the increasing rate of type 2 diabetes ***(Mayer-Davis et al., 2017).***

Adherence to medication is important especially in children with chronic illness to prevent disease-related complications, improve quality of life, and extend life expectancy. Although

medication adherence is important, the rate of Childs' adherence to medication is somewhat disturbing ***(Jaser et al., 2014).***

Pediatric nurse plays an important role in diabetes management. Thus, facilitating the children diabetes care. Pediatric nurse for the children with diabetes must have a basic understanding of the disease,blood glucose goals, management tasks, and symptoms of hypoglycemia and hyperglycemia which may require intervention ***(Griffey et al., 2014).***

Significance of the Study

Type 1 diabetes is the most common endocrine metabolic disorder of childhood and adolescent there are reported small studies from Cairo, the prevalence of type 1 diabetes in children and adolescent is 0.38/1000 in Egypt ***(Salem et al., 2010).*** Additionally, in Egypt the incidence variance between 8/100000 per year ***(El-Ziny et al., 2014).***

Moreover, many factors are important to be studied in relation to adherence toward therapeutic regimen such as parents and children related factors.

The aim of the study

This study aimed to assess factors affecting adherence toward therapeutic regimens among children with type 1 diabetes mellitus.

Design:

A descriptive exploratory design was used.

Setting:

This study was conducted at Diabetic Outpatient Clinics in Children's Hospital affiliated to Ain Shams University Hospitals.

Subjects:

A purposive sample consisted of 175 children with type 1 diabetes and their accompying caregivers who attended to the previously mentioned setting, equal 550-570 in 2013-2014 and 2014-2015 respectively and under the following criteria.

1. Children with Type 1 Diabetes mellitus age group (9≤18) years.
2. Diagnosis at least one month before the study.

Exclusion criteria: Children suffering from other chronic diseases, mental or psychiatric illness.

Tools of data collection:

The data was collected using the following Tools:

I-Interview questionnaire sheet.

It was written in a simple Arabic language by the researcher after reviewing the related literature and reviewed by supervisors. It consists of 3 parts:

Part I: Characteristics of children including; age, gender, level of education, ranking and residence.

Part II: Characteristics of caregivers including; age, level of education and working.

Part III: Past & present history of children regarding diabetes as duration of diabetes, previous hospitalization, number, duration and causes of hospitalization.

Part IV: Adherence of children to therapeutic regimen which composed of: (a) Adherence to diet regimen, (b) Adherence to exercise regimen and (c) Adherence to follow-up in outpatient clinic.

Part V: Factors affecting children adherence toward therapeutic regimen which include the following: Caregivers knowledge factors, Children beliefs factors, Children attitude factors, Children motivation factors, Social support factors, Therapy factors, Disease factors and Health care system factors

II- Morisky Medication Adherence Scale (MMAS) - Revised.

It was adopted from ***Morisky et al. (2010),*** to assess the children adherence toward medication regimen it consisted of 8 questions.

III-Observation checklist:

It consisted of 3 checklists which namely: (a) Insulin syringe, (b) Insulin pen injection and (c) Analysis of sugar in the blood (haemotest), to observe the extent of children's adherence.

Operational design:

The operational design includes preparatory phase, content validity & reliability, and Pilot study.

Preparatory:

It included reviewing of related literature was done to develop the study tools and to get acquainted with the various aspects of the research problem.

Content validity and reliability:

It was be done based on result of pilot study and ascertained by a jury of three expertise from Pediatric Medical and Nursing staff, to review the tools for clarity, relevance, comprehensiveness, understandable and applicability. For reliability test-retest was done (0.87).

Exploratory Phase:

A pilot study was carried out during November 2016 involving 10% (18 children with type 1 diabetes). The result of the data obtained from the pilot study helped in removing of some repeated questions have the same meaning related to caregiver's knowledge factors and motivation factors. All children involved in the pilot study were included of the study sample.

Field of work:

The actual field work of the study was carried out from the first of October 2016 up to March 2017 (6 months) the researcher was available in the study setting 2 days/week (Tuesday and Wednesday) to collect data. From 9 am to 2 pm. The children and their caregivers were interviewed (for 45-60 minutes). The researcher started the interview by introducing herself to both the child and his/her caregivers, giving them clear and brief idea about the aim of the study and its expectation to each child before starting the interview questionnaire. Then

each child with diabetes was interviewed individuals to answer the questions and to be assessed during his/her actual practice of self-injection and preparation, self-blood testing for glucose by observational check lists. Children were noticed to have their haemotest and insulin brought with them in thermos.

Administrative Design:

An official approval was obtained to carry out the study that issued from the Dean of the Faculty of Nursing, Ain Shams University to the Directors of the Children's Hospitals of Ain Shams University.

Ethical Considerations:

Ethical approval was obtained from the Scientific Ethical Committee of Faculty of Nursing Ain-Shams University In addition, written informed consent was obtained from children and their caregivers prior to data collection. They were assured that anonymity and confidentiality would be guaranteed and the right to withdraw from the study at any time. Ethics, values, culture and beliefs were respected.

4-Statistical Design:

The data obtained was categorized, analyzed, and presented in the form of tables and figures using the Statistical Package for Social Sciences (SPSS) version 20. Qualitative variables was presented in the form of frequencies and percentages; quantitative variables was presented in the form mean and SD. Qui square and fishers tests were used to test the significance of results obtained. Statistical significant difference was considered at $P < 0.05$.

Results:

This study was designed to identify the factors affecting adherence of children with type 1 diabetes mellitus to the therapeutic regimen.

Table (1): Number and percentage distribution of the studied children according to their sociodemographic characteristics (n=175).

Items	N	%
Age (years)		
9 <12	72	41.1
12 <15	57	32.6
15≤18	46	26.3
Mean ± SD	13.01±2.4	
Sex		
Male	86	49.1
Female	89	50.9
Residence		
Urban	102	58.3
Rural	73	41.7
Level of education		
Primary	42	24
Preparatory	88	50.3
Secondary	45	25.7
Ranking		
First	30	17.1
Second	50	28.6
Third	35	20
Other remember	60	34.3

Table (1): As regards characteristics of studied children, this table showed that 41.1% of them aged less than12 years with a mean age 13.01±2.4 years and more than half of them were females , their level of education were preparatory and from urban area (50.9%, 50.3% & 58.3%) respectively.

Table (2): Number and percentage distribution of studied children according to total factors affecting children adherence toward their therapeutic regimen (n=175).

Total factors score	N	%
Caregivers' knowledge factors		
Satisfactory	87	49.7
Unsatisfactory	88	50.3
Beliefs factors		
Agree	163	93.1
Disagree	12	6.9
Attitude factors		
Positive	95	54.3
Negative	80	45.7
Motivation factors		
Positive	102	58.3
Negative	73	41.7
Social support factors		
Support	100	57.1
Not support	75	42.9
Therapy factors		
Affect	84	48
Not affect	91	52
Disease factors		
Affect	29	16.6
Not affect	146	83.4
Health care system factors		
Sufficient	85	48.6
Not sufficient	90	51.4

Table (2): showed that most (93.1%) of studied children had agree with beliefs toward therapeutic regimen, while, more than half (54.29 %) of them had positive attitude factors toward adherence to therapeutic regimen. Also, this table revealed that more than half (57.14% & 51.43%) of studied children had social support factors always support therapeutic regimen and had not sufficient health care system factors respectively.

Figure (1): Percentage distribution of the studied children according to their total adherence level regarding to medication regimen (n=175).

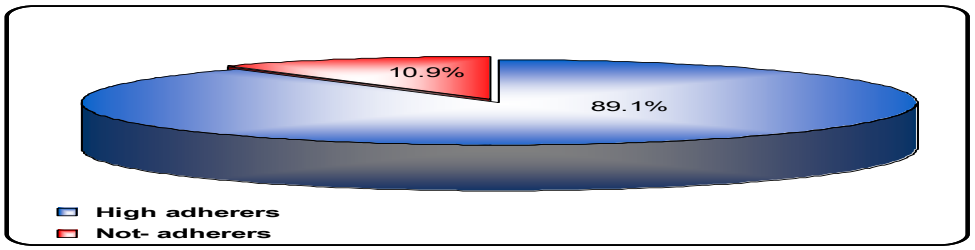

Figure (1): Showed that, most of the studied children (89.1%) had adhered toward medication regimen.

Figure (2): Percentage distribution of studied children according to their practice of insulin syringe injection, insulin pen injection and blood glucosetest (haemotest) (n=175).

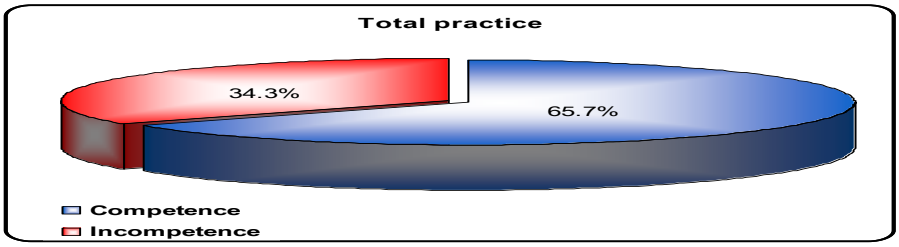

Figure (2): This figure showed that, about two thirds (65.7%) of studied children had incompetence to total practice.

Table (3): Relation between characteristics of studied children and their adherent to therapeutic regimen (n=175).

Item	Children adherence					
	Adhered		Not adhered		Chi-square	
	N	%	N	%	X^2	P value
Age groups						
9->12	67	93.1	5	6.9		
12->15	51	89.5	6	10.5	3.175	0.204
15 or more	38	82.6	8	17.4		
Sex						
Male	73	84.9	13	15.1	3.169	0.075
Female	83	93.3	6	6.7		
Residence						
Urban	89	87.3	13	12.7	0.901	0.343
Rural	67	91.8	6	8.2		
Level of education						
Primary	38	90.5	4	9.5		
Preparatory	81	92	7	8	3.070	0.215
Secondary	37	82.2	8	17.8		
Ranking						
First	27	80	6	20		
Second	47	94	3	6	fisher's	0.925
Third	35	100	0	0.0		
Last mentions	50	83.3	10	16.7		

Table (3): illustrated that, there were no statistical significance difference between studied children characteristics and their total adherence to therapeutic regimen. Moreover, 93.1% of children aged less than12 years and 90.5% their level of education is primary level.

Table (4): Relation between total practice of studied children and their adherence to therapeutic regimen (n=175).

Practice	Children adherence					
	Adhered		Not adhered		Chi-square	
	N	%	N	%	X^2	P value
Competence	60	100.0	0	0.0		
Incompetence	96	83.5	19	16.5	Fisher's	0.000*
Total	**156**	**89.1**	**19**	**10.9**		

* Highly Statistical significance difference.

Table (4): showed that, there were a highly statistical significant difference between total practice of studied children and their adherence to therapeutic regimen**.** All of children (100%) were competent in their practices and they were adhered to the therapeutic regimen.

Discussion

Diabetes Mellitus (DM) is a major health problem worldwide; which needs more attention a way for applying basis of proper interventions, and thus prevention of early and late problems of children having type 1 diabetes mellitus have incorporated a set of regimens into their daily lives to prevent diabetic complications ***(International Diabetes Federation [IDF], 2015).*** Adherence to treatment is a key link between process and outcome in medical care. More health benefits worldwide would result from improving adherence to existing treatments than by devolving new medical treatments ***(Faria et al., 2013).***

Adherence to any treatment regimen is particularly difficult if children do not come to clinic regularly. Increased adherence to diabetes management favorably impacts glycemic control and, in turn, lower hemoglobin A1c (HbA1c) levels reduce the risk for diabetes complications. The impact of non-adherence varies across chronic illnesses as diabetes mellitus and ranges from minimal to very significant. In addition to increased morbidity and mortality have been observed amongthose non-adherents ***(Borus&Laffel, 2010).***

Regarding to characteristics of the study subjects the finding of the present study showed that the mean of the studied children with type 1 diabetes was 13.01±2.4 years. This finding is in agreement with ***Ziegler and Bonifacio (2012)*** who carried out a study entitled "Age-related Islet Autoantibody Incidence in Offspring of Children's with Type 1 Diabetes in Germany" and found that the incidence of type 1 diabetes has its peak around puberty. Moreover, this finding supported with***Patterson et al. (2014)***who carried out a study entitled "Diabetes in the young - A global view and worldwide estimates of numbers of children with type 1 diabetes in Europe" and found that the incidence of type 1 diabetes has its peak <15 years. In the same context,***Maahs et al. (2010)*** had a study entitled "Epidemiology of Type 1 Diabetes in US" and found that a peak incidence of type 1 diabetes mellitus increased between ten and –fourteen years ago.

The finding of the present study showed that slightly more than half of the studied children with type 1 diabetes were

females. This finding was supported by ***Omar et al. (2015)***who carried out a study entitled "Microalbuminuria and Glycated Hemoglobin in Children, with Type 1 Diabetes Mellitus at the Alexandria University Children's Hospital" and found that the incidence of diabetes was females more than males.

The result of the present study revealed that more than half of the studied children with type 1 diabetes lived in urban area. This result was supported by ***Miller et al. (2011)*** had a study entitled "Urban–rural variation in childhood Type 1 Diabetes Incidence in Canterbury, New Zealand 1980-2004" they found that, there was significantly higher incidence of childhood type 1 diabetes in urban communities. This could not be explained by population density or household overcrowding in these areas. Moreover, this finding supported by***Demirbilek, Ozbek, & Baran (2013)*** who carried out a study entitled "Incidence of Type 1 Diabetes Mellitus in Turkish Children from the Southeastern Region of the Country: A Regional Report" and reported that a higher incidence in urban compared to rural areas of residence. While these findings were contrary to those of***Borchers, Uibo& Gershwin (2010)***who carried out a study entitled "The Geoepidemiology of Type 1 Diabetes in Italy" and reported that rural residence increased the risk of type 1 diabetes compared to urban residence. Moreover, ***Rytkonen, et al. (2003)*** studied "The Incidence of Type 1 diabetes among Children in Finland—Rural–Urban Difference" and found that, an association between high risk of type 1 diabetes and rural residence. In the same context, ***Pundziute et al. (2003)*** stated in a study entitled "Incidence of Type 1 Diabetes in Lithuanians Aged 0–39 Years Varies by the Urban– Rural Setting" that the differences in socioeconomic deprivation between the rural areas of various countries may provide at least a partial explanation for the observed discrepancies in the association of type 1 diabetes incidence with urban–rural status.

Concerning children beliefs factors regarding therapeutic regimen, the finding of the current study showed that, more than two thirds of the studied children with type 1 diabetes agreed that the family has an important role in their adherence to the therapeutic regimen. It could be due to that families are considered strongly supportive members. This findings was in accordance with***Ellis et al. (2007)***who mentioned in a study entitled "The Role of Parental Monitoring in Adolescent Health Outcomes: Impact on Regimen Adherence in Youth with Type 1 Diabetes in a Large Midwestern Metropolitan Area" and clarified that parental support for diabetes care and diabetes-specific parental monitoring were significantly related to one another. Moreover,this findingwas supported by ***Griffin et al. (2000),*** who carried out a study entitled "Parenting Practices as Predictors of Substance Use, Delinquency, and Aggression among Urban Minority Youth : Moderating Effects of Family Structure and Gender in United States" and reported that parental support was a significant predictor of adherence when parental support and parental monitoring were considered simultaneously.

The findings of the present study pointed outthat the majority of the studied children with type 1 diabetes agree with total beliefs toward therapeutic regimen.

It could be due to that child and family believed that those therapeutic regimens are important for health enhancement. This finding was in disagreement with ***Patino et al. (2005),*** who carried out a study entitled "Health Beliefs and Regimen Adherence in Minority Adolescents with Type 1 Diabetes at University of Miami " and clarified that health beliefs of minority youths with Type 1 Diabetes did not predict regimen adherence or glycemic control, their perceived risk of short-term diabetes-related complications was significantly greater than perceived risk of long-term complications and their perceived risk of complications occurring to others was significantly greater than perceived risk to self.

Concerning study of children attitude factors regarding therapeutic regimen, the result of the present study showed that less than half of studied children with type 1 diabetes always feel sad about having diabetes mellitus. It could be due to feeling powerless and family restriction due to an overprotective parenting style, which can delay the teen's ability to take responsibility for his or her treatment or cause frustration for the adolescent, subsequently; low adherence can be a way of confronting the authority of parents and professionals. This finding was contrary with ***Pilacinsk&Ziołkiewicz (2014),*** who had a study entitled "Influence of Lifestyle on the Course of Type 1 Diabetes Mellitus" and found that majority of children included feel sad about having diabetes mellitus and may be associated with poor glycemic control.

Moreover, slightly less than two thirds of studied children with type 1 diabetes never feel frustrated and don't want to continue therapeutic regimen. This finding was in accordance with ***Memon et al. (2015)*** who found out in a study entitled "An Assessment of Knowledge, Attitude and Practices (KAP) towards Diabetes and Diabetic Retinopathy in a Suburban Town of Karachi" that less than two thirds of studied subjects had positive attitudes toward their diabetes and its treatment.

Concerning study of children social support factors regarding therapeutic regimen, the result of the present study illustrated that less than half of studied children with type 1 diabetes had a financial burden due to transportation costs. This finding was in agreement with ***Helgeson & Palladino (2012)*** who reported in a study entitled "Implications of Psychosocial Factors for Diabetes Outcomes among Children with Type 1 Diabetes", that poor diabetes-outcomes resulting from poor follow up which due to low family socioeconomic status.

Concerning study of children health care systems factors regarding therapeutic regimen, it was found that, most of studied children with type 1 diabetes reported that the places of health care has not sufficient resources. It could be due to most of care providers system are governmental that had high flow with no sufficient recourses. This result was supported by ***Gandhi et al. (2016),***who carried out a study entitled "Psychosocial aspects of type 1 diabetes in Latino- and Asian-American Youth in the United States" and found that the majority of children had poor access to care due to inadequate health care system which is associated with poor glycemic control. However, the current study results were agreed with ***Jin et al. (2008)*** who carried out a study entitled "Factors Affecting Therapeutic Compliance: a Review from

the Patient's perspective in the Canada" and found that healthcare system problems were significantly related to adherence. In addition, accessibility and satisfaction with the healthcare facilities are important contributors to adherence because children satisfaction with healthcare is crucial for their adherence. Long waiting time for clinic visits and unhappy experience during clinic visits.

Regarding medication regimen, this study revealed that, the majority of studied children with type 1 diabetes were adherence with insulin in the past two weeks. It could be due to the child recognizing the dangerous complications of insulin dose forgetting. This result was in accordance with ***Holl et al. (2003),*** who carried out a study entitled "Insulin Injection Regimens and Metabolic Control in an International Survey of Adolescents with Type 1 Diabetes over 3 Years in Germany" and reported that majority of children with type 1 diabetes adherence to medication regimen.

The current study indicated that, there were no statistical significance difference between study children gender and their total adherence to therapeutic regimen. This result was in line with ***Mohammad et al. (2012),*** who found that gender was not associated with glycemic control.

Concerning of studied children with type 1 diabetes regarding relation between total practices and their adherence to therapeutic regimen there were statistically significance difference between total practice of studied children with type 1 diabetes and their adherence to therapeutic regimen. It could be due to that children with type 1 diabetes had malpractices technique toward insulin syringe injection, insulin pen injection and blood glucose tests (haemotest), while these children adhered to medication regimen due to their knowledge about the importance of insulin to maintain their life.

Conclusion

Upon the findings of the current study, it was concluded that caregivers' knowledge factors, attitude factors, social support factors, therapy factors, health care system factors and disease factors positively affecting studied children' adherence toward therapeutic regimens. Meanwhile, beliefs factors and motivation factors did not affect studied children adherence toward therapeutic regimen.

Recommendation

In view of the study findings, the following recommendations are suggested: Continuous health teaching to children with type 1 diabetes and their caregivers regarding diabetes, its complication and management. Designing an educational handout about type 1 diabetes mellitus and its management plan and allocated for diabetic children and their caregivers. Periodical assessment and regular monitoring of children adherence toward therapeutic regimen. Continuous health education to children and their caregiver's to improve their adherence. Psychological support, since emotional well-being is strongly associated with positive diabetes out comes.Periodical assessment and regular monitoring of factors affecting children adherence toward therapeutic regimen. More researchers are needed to explore the benefits of the adherence of the children with 1 type diabetes to

generalize the results and be evident to other studies.

Summary

This study conducted to assess This study aims to assess the factors affecting adherence of children with type 1 diabetes mellitus, using descriptive design, on (175) children with type 1 diabetes mellitus and their care givers were attended in the previously mentioned setting over a 6 months period regardless duration of disorder. From both sex, their age from 9-18 years and had no previous history of medical or psychiatric problem. The highest frequency of age group among type 1 diabetes children (41%) ranged between 9 <12 years and the majority of children (50.9%) were females.

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