

## Effect of Caregiver's Health Education on Patterns of Self-Management and Glycemic Control in Pediatric Type 1 Diabetes

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### Abstract

**Background:** Type I diabetes mellitus (T1DM) is a lifelong disease that affects all aspects of diseased children's life and thus can negatively affect their mental, physical health and their health-related quality of life. Effective self-management of type 1 diabetes in pre-adolescent and adolescent years is important to prevent diabetes-related complications later in life. **Objectives:** to assess self-management patterns among caregivers of type 1 diabetic children pre and post health education about management of pediatric Type 1 diabetes mellitus and to assess glycemic control pre and post health education among children attending Zagazig university diabetes clinic. **Method:** An educational intervention (pre-test/post-test) study was carried out from the first of August 2019 to the end of March 2020 for Caregivers of Type 1 Diabetes children who attend Zagazig diabetes clinic for receiving periodic insulin therapy and regular checkup. **Results:** Self-Management patterns had significantly changed throughout the study as adaptive pattern increased from 22.4% pre-intervention to 36.8% and 44.3% post-intervention at 3 and 6 months respectively. On other hand, maladaptive pattern decreased from 20.8% pre-intervention to 7.9% and 6.6% post-intervention at 3 and 6 months respectively. Glycemic control had significantly improved throughout the study. Percentage with good glycemic control increased from 57.6% pre-intervention to 62.3% and 70.8% post-intervention at 3 and 6 months respectively. **Conclusion:** The study illustrated that self-management among caregivers of Type 1 Diabetes children as well as the children's glycemic control improved after health education. Adaptive Self-Management pattern was significantly associated with good glycemic control.

**Keywords:** caregiver, health education, Self-Management, Glycemic Control, Type 1 Diabetes

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### Introduction

Type 1 diabetes mellitus (T1DM) is one of most common chronic pediatric diseases in which pancreatic islets are gradually destroyed in genetically susceptible individuals<sup>1</sup>; leading to loss of insulin secretion.<sup>2</sup>

Various studies have shown a rising incidence of type 1 diabetes in children around the world.<sup>3-5</sup> A study carried out in three Egyptian governorates (Fayoum, North Sinai, and Suez) showed that the

prevalence rate of T1DM among children and adolescents 0.7/1000 and the incidence rate was 4.01/100 000.<sup>6</sup> Another study which carried out in Menoufia governorate showed that the prevalence rate of juvenile DM among school age children was 3.75/1000.<sup>7</sup>

Type I diabetes mellitus (T1DM) is lifelong disease that affects all aspects of diseased children's life and thus can negatively affect their mental, physical

health and their health-related quality of life (HRQOL).<sup>8</sup>

Management of T1DM requires lifelong insulin replacement therapy via an insulin pump or subcutaneous injection multiple times a day. If not managed correctly, long-term complications include retinopathy, neuropathy, cardiovascular disease, foot damage, and kidney difficulties.<sup>9</sup> So, it requires changes in the behavior of the whole family and the responsibility falls mainly upon the mother.<sup>10</sup>

Achieving and sustaining a good glycemic control in a child with type 1 diabetes (T1DM) is a big challenge. As the child with diabetes grows, he undergoes a variety of physical, psychological and life style changes. Empowering the child and his family to take the reins of diabetes management in their hands is the single most important intervention to improve glycemic control and quality of life.<sup>11</sup>

Many studies showed that diabetes education program carried out at many Centers to the children with T1DM and their caregivers is feasible and very successful.<sup>12</sup>

Daily self-management requires planning and correct and timely execution of tasks, which are difficult in general and demands higher-order cognitive skills with a prominent role for executive functioning (EF).<sup>13</sup> Therefore, parents of type 1 diabetic children have the responsibility of Effective self-management at first then the children become responsible when they grow up.<sup>14</sup> Effective self-management of type 1 diabetes in pre- adolescent and adolescent years is important to prevent diabetes-related complications later in life.<sup>15</sup>

The increased prevalence of type 1 diabetes mellitus in children with its complications, that affect the expectancy of their lives and adversely affecting their

quality of life that lead to worsening of their compliance and adherence to the treatment with subsequent hazards. Implementation of an educational program to the newly diagnosed T1DM children and their caregivers is very important for improving the diabetes self-management patterns and glycemic control as well as the long term clinical outcome among this target group. Few studies had investigated the role of caregiver in self-management of type 1 diabetes.

The aim of this study was to assess self-management patterns among caregivers of type 1 diabetic children pre and post health education about management of pediatric Type 1 diabetes mellitus and to assess glycemic control pre and post health education among children attending Zagazig diabetes clinic.

## Method

An educational intervention (pre-test/post-test) study was carried out from the first of August 2019 to the end of March 2020 for Caregivers of Type 1 Diabetes children who attend for receiving periodic insulin therapy and regular checkup in Zagazig diabetes clinic, Egypt. This clinic provides free curative services for diabetic patients who are residing in Sharkia governorate. These services include health insurance curative services of school children with chronic diseases.

Sample size was calculated by EPI INFO TM<sup>16</sup> assuming that percentage of adaptive Pattern of Self-Management in Pediatric Type 1 Diabetes was (18%) before intervention versus (41.8%) after intervention.<sup>17</sup> Sample size was (114) with 95% confidence level and 80% study power. We increased the sample by 10% to mitigate risk of dropout throughout the study.

Inclusion criteria: caregivers having a child or more than one child with diabetes,

his age 6 – 12 years old, diabetic for at least 1 year. Exclusion criteria: monogenic diabetes of the young (MODY), presence of potential causes of Type 1 Diabetes e.g. corticosteroid therapy, cystic fibrosis.

Eligible participants were randomly selected from the daily clinic list and contacted by clinic personnel to ask about their interest in the study and then were approached by research staff during a regularly scheduled outpatient clinic visits. The study was carried out through three phases:

*1<sup>st</sup> phase:* Baseline data were collected: socio-demographic data, Diabetes Self-Care Inventory (SCI), last Hemoglobin A1c (HbA1c) and contact information.

Fahmy et al., 2015<sup>18</sup> questionnaire was used to assess the socio-demographic characteristics.

Self-Care Inventory (SCI)<sup>19</sup> is defined as the daily regimen tasks that the individual performs to manage diabetes. It consists of a 13-item self-report measure which was developed to assess patients' perceptions of the degree to which they adhere to treatment recommendations for their diabetes self-care. The SCI has been used with children and adolescents with Type 1 diabetes; for preadolescent children, parents are the informants for their child's level of self-care. It consists of four subscales (blood glucose testing and monitoring, insulin and food regulation, exercise, and emergency precautions). It contained items of five points likert scale. A total self-management score (maximum score was 65) was determined by summing all products. Regarding Self-Care Inventory, cut off points were: less than 50% (means maladaptive self-management), from 50%- 75% (consider Moderate adaptive self-management) and more than 75 % ( consider Adaptive self-management').<sup>20</sup>

Self-management patterns were classified into three types<sup>21</sup>: (1) "Maladaptive self-management" Defined as having difficulties in nearly all diabetes management areas as measured by SCI. (2) "Moderate adaptive self-management" It was defined as having difficulties in managing one or more diabetes management areas but not necessarily difficulties in all diabetes management areas. (3) 'Adaptive self-management' has been described as having little to no diabetes management deficits.

The questionnaire was translated to Arabic and back translated to English by language experts. The reliability of the scales was tested through measuring their internal consistency. It demonstrated a good level of reliability (Cronbach alpha = 0.82)

Hemoglobin A1c (HbA1c) was measured at baseline and after 3 and 6 months at the diabetes clinic laboratory. Hemoglobin A1c below 6.4% was considered as good glycemic control.<sup>22</sup>

*2<sup>nd</sup> phases:* Health education sessions were introduced after data collection. The first session was face to face in diabetic clinic took about 20 minutes in which we explained main items and gave caregivers health education booklet and how we will communicate with them online. The frequent sessions were through face book group containing all participants of care givers, where we did live videos and provided them with different health education message methods like photos, videos, small quiz and finally, we asked them for any questions or explanations

Health education message was designed according to American Diabetes Association (ADA) "Standards of Medical Care in Diabetes" for management of type 1 diabetes in children.<sup>23</sup> The message included: blood glucose monitoring and management (how and importance), Blood/Urinary Ketone Monitoring (how

and importance), Comprehensive nutrition education ( healthy eating , Monitoring carbohydrate intake, whether by carbohydrate counting.....), Approaches for Physical Activity and Exercise( types of Exercise suitable for them, importance of Physical Activity and how to prevent hypoglycemia during exercise ), child behavior and mental health, development and diabetes demands and priorities across childhood, Management of complications.

**Table (1): Socio-Demographic Characteristics of Study Participants**

Caregivers (n=117)	N (%)
<b>Type of caregiver:</b>	
Mother	99 (84.6)
Father	12 (10.3)
Other family member	6 (5.1)
<b>Educational level:</b>	
Illiterate / Read & Write	0 (0.0)
Primary / Secondary	50 (42.7)
University	67 (57.3)
<b>Socio-economic level of family:</b>	
Low	15 (12.8)
Middle	47 (40.2)
High	55 (47.0)
<b>Diabetic children (n=125)</b>	
<b>Age (years):</b>	
Mean ± SD	8.7 ± 1.9
<b>Gender:</b>	
Male	65 (52.0)
Female	60 (48.0)
<b>Education stage:</b>	
Primary	111 (88.8)
Preparatory	14 (11.2)
<b>Age at diagnosis of DM (years):</b>	
Mean ± SD	6.6 ± 1.2
<b>Duration of DM:</b>	
Less than 1 year	41 (32.8)
From 1 to 2 years	39 (31.2)
More than 2 years	45 (36.0)
<b>Other diabetic brother/sister:</b>	
Yes	16 (12.8)
No	109 (87.2)
<b>BMI (kg/m<sup>2</sup>):</b>	

Mean ± SD	22.2 ± 2.7
<b>Other comorbidities:</b>	
None	85 (68.0)
Hypothyroidism	27 (21.6)
Celiac disease	13 (10.4)
<b>Regimen of insulin therapy:</b>	
Multiple daily injection	125 (100)

Continuous diabetes self-management education and support were established through Facebook group led by research staff.

*3<sup>rd</sup> phase:* Further assessment of diabetes self-management and glycemic control were done after 3 and 6 months.

Pilot study was done one month before data collection to detect any difficulties and to test content validity and reliability of the questionnaire after translation. It also helped to estimate time needed for data collection and expected frequency. The sample included in the pilot study was excluded from the main sample because of the changes that were done in the final version of the questionnaire.

An official permission from General Authority for Health Insurance was taken to Zagazig diabetes clinic. General Authority for Health Insurance was informed about the nature and steps of the study and written consent was taken from institutional managers.

**Ethical approval**

Approval of Institutional Review Board (IRB) of Zagazig University, Faculty of medicine was taken after revision of study protocol (ZU-IRB #6348). The study participants were informed about the nature and the purpose of the study and verbal consent was taken before interview. All caregivers' and patient's data were confidential.

**Statistical analysis:**

The collected data were entered to and analyzed by computer using Statistical Package of Social Services, version 25

(SPSS).<sup>24</sup> Data were presented in table as frequencies, proportions, mean and standard deviation. Friedman and Cochran Q tests were used to analyze dependent data of Self-Management patterns and glycemic control respectively. Pearson Chi square test, Chi Square for linear trend and

fisher's exact were used to analyze qualitative independent data. Odds ratio and 95% confidence interval were used for risk assessment. Binary logistic regression analysis was used for prediction of improvement in Self-Management patterns.

**Table (2): Self-Management Patterns and Glycemic Control of The Study Participants:**

Outcome	Pre-intervention (n=125) N (%)	Post-intervention		Test of sig.	P
		At 3 months (n=114) N (%)	At 6 months (n=106) N (%)		
<b>Self-Management patterns:</b>					
Adaptive	28 (22.4)	42 (36.8)	47 (44.3)	F	<0.001 HS
Mixed	71 (56.8)	63 (55.3)	52 (49.1)	51.1	
Maladaptive	26 (20.8)	9 (7.9)	7 (6.6)		
<b>Hemoglobin A1c (%):</b>					
Median	6.3	6.0	5.9	F	0.01 S
IQ-Range	5.8 – 11.5	5.5 – 9.3	5.5 – 7.9	4.8	
<b>Glycemic control:</b>					
Good	72 (57.6)	71 (62.3)	75 (70.8)	Q	<0.001 HS
Bad	53 (42.4)	43 (37.7)	31 (29.2)	33.1	
<b>Dropout</b>	-	11 (8.8)	8 (6.4)	-	-

F: Friedman test, Q: Cochran Q test, HS: High statistical significance

The Hosmer-Lemeshow test is used to determine the goodness of fit of the model.

**Results**

Most of caregivers were mothers (84.6%), only 6.8% of the studied caregivers had more than one diabetic sibling, more than half had high educational level and 47.0% had high Socio-economic level (Table 1).

Mean age of diabetic children was 8.7 years old, male to female ratio was almost 1:1, most of them (88.8%) were primary stage students, mean age at diagnosis was 6.6 years old, mean BMI was 22.2 kg/m<sup>2</sup>. Some of children had other comorbidities, mainly Hypothyroidism (21.6%) and Celiac disease (10.4%). All of them had multiple daily insulin injection regimens (Table 1).

Self-Management patterns had significantly changed throughout the study as adaptive pattern increased from 22.4%

pre-intervention to 36.8% and 44.3% post-intervention at 3 and 6 months respectively. On other hand, maladaptive pattern decreased from 20.8% pre-intervention to 7.9% and 6.6% post-intervention at 3 and 6 months respectively. Mixed pattern was the most prevalent Self-Management pattern at pre- and post-intervention phases (Table 2).

Also, Glycemic control had significantly improved throughout the study. Percentage with good glycemic control increased from 57.6% pre-intervention to 62.3% and 70.8% post-intervention at 3 and 6 months respectively (Table 2).

Dropout rate was 15.2% (8.8% and 6.4% at 3- and 6-months post-intervention).

There were high statistical significant association between Self-Management patterns and Glycemic control throughout the study. Maladaptive pattern was associated with bad glycemic control

before and at 3 months and 6 months after intervention (OR= 18.8, 59.2 & ∞) respectively (Table 3).

There were statistical significant associations between improvement in Self-Management patterns at end of study and some socio-demographic characteristics of the studied children. Younger children (< 8 years old) had more improvement compared with older children (48.9% versus 27.3%, OR=2.6). Presence of Other

diabetic brother/sister was associated with improvement in Self-Management patterns (OR=3.8) (Table 4).

Caregivers with Primary and Secondary education had more improvement compared with higher education (59.0% versus 20.5%, OR=5.6) (Table 4).

Families with low and middle Socio-economic level had more improvement than

**Table (3): Association between Self-Management Patterns and Glycemic Control**

Self-Management patterns	Glycemic control				OR (95% CI)	χ <sup>2</sup>	p
	Good		Bad				
	No.	%	No.	%			
<b>Pre-intervention:</b>							
Adaptive (n=28)	25	89.3	3	10.7	Reference	19.4	<0.001 HS
Mixed (n=71)	39	54.9	32	45.1	6.8 (1.9 – 24.7)		
Maladaptive (n=26)	8	30.8	18	69.2	18.8 (4.4 – 80.6)		
<b>At 3 months post-intervention:</b>							
Adaptive (n=42)	37	88.1	5	11.9	Reference	24.6	<0.001 HS
Mixed (n=63)	33	52.4	30	47.6	6.7 (2.3 - 19.4)		
Maladaptive (n=9)	1	11.1	8	88.9	59.2 (6.1 – 578.2)		
<b>At 6 months post-intervention:</b>							
Adaptive (n=47)	43	91.5	4	8.5	Reference	28.8	<0.001 HS
Mixed (n=52)	32	61.5	20	38.5	6.7 (2.1 – 21.6)		
Maladaptive (n=7)	0	0.0	7	100	Undefined		

χ<sup>2</sup>: Pearson’s chi-square test, HS: High statistical significance

high Socio-economic families (OR=7.2 & 5.1) (Table 4).

In regression analysis Educational level of caregiver and Socio-economic level of family were significant predictors of improvement. Non-significant Hosmer-Lemeshow test indicates a good fit model. (Table 5).

**Discussion**

Effective self-management in pediatric T1DM involves the collection of advanced techniques and is best achieved by engaging in high-quality structured education.<sup>25</sup>

The results of the study revealed that Self-Management patterns had significantly

improved throughout the study as adaptive pattern increased from 22.4% pre-intervention to 36.8% and 44.3% post-intervention at 3 and 6 months respectively. It is consistent with the results of a previous Egyptian study,<sup>26</sup> reported a significant improvement in diabetes knowledge and the self-management practices associated with educational program. Also it comes in concordance with the results of a study conducted in United States stated an association between the implementation of educational program to the newly diagnosed T1DM children and their caregivers and the great improvement in diabetes self-management patterns as well

as the long term clinical outcome among this target group.<sup>27</sup>

Glycemic control had significantly improved throughout the study, as percentage of participants with good glycemic control increased from 57.6% pre-intervention to 62.3% and 70.8% post-intervention at 3 and 6 months respectively. These results support the findings of previous studies, which strongly correlated glycemic control improvement to the development of a formalized diabetes education program and made it available to children with T1DM

and their caregivers.<sup>28, 29</sup> It also agrees with the results of a study conducted in Saudi Arabia<sup>30</sup>, which concluded that control of the level of HbA1c among the children studied was linked to the knowledge of their mothers.

Moreover, the results of the current study showed a high statistical significant association between Self-Management patterns and glycemic control as adaptive Self-Management pattern is linked to good glycemic control. This observation is consistent with the results of a previous

**Table (4): Association between Improvement in Self-Management Patterns at End of Study and Socio-Demographic Characteristics of The Studied Children**

Socio-demographic characteristics	Improved (n=31)		Not improved (n=47)		OR (95% CI)	$\chi^2$	p
	No.	%	No.	%			
<b>Age (years):</b>							
< 8 years	22	48.9	23	51.1	2.6 (1.0 – 6.7)	3.7	<b>0.05 S</b>
≥ 8 years	9	27.3	24	72.7			
<b>Gender:</b>							
Male	17	44.7	21	55.3	1.5 (0.6 – 3.7)	0.7	0.4
Female	14	35.0	26	65.0			
<b>Education stage:</b>							
Primary	30	40.0	45	60.0	1.3 (0.1 – 15.4)	fisher	0.99
Secondary	1	33.3	2	66.7			
<b>Age at diagnosis of DM (years):</b>							
< 6 years	18	50.0	18	50.0	2.2 (0.9 – 5.6)	2.9	0.08
≥ 6 years	13	31.0	29	69.0			
<b>Duration of DM:</b>							
Less than 1 year	15	40.5	22	59.5	Reference	0.7	0.7
From 1 to 2 years	11	44.0	14	56.0	1.2 (0.4 – 3.2)		
More than 2 years	5	31.3	11	68.8	0.7 (0.2 – 2.3)		
<b>Other diabetic brother/sister:</b>							
Yes	7	70.0	3	30.0	3.8 (1.0 – 16.0)	4.4	<b>0.03 S</b>
No	24	35.3	44	64.7			
<b>BMI (kg/m<sup>2</sup>):</b>							
Normal	7	35.0	13	65.0	0.8 (0.3 – 2.2)	0.3	0.6
Underweight	24	41.4	34	58.6			
<b>Other comorbidities:</b>							
None	25	47.2	28	52.8	Reference	3.9	0.1
Hypothyroidism	3	21.4	11	78.6	0.3 (0.1 – 1.2)		
Celiac disease	3	27.3	8	72.7	0.4 (0.1 – 1.8)		
<b>Type of caregiver:</b>							

Mother	29	42.6	39	57.4	Reference	5.8	0.06
Father	0	0.0	7	100	Undefined		
Other family member	2	66.7	1	33.3	2.7 (0.2 – 31.1)		
<b>Educational level of caregiver:</b>							
Primary / Secondary	23	59.0	16	41.0		12.0	<b>0.001</b>
University	8	20.5	31	79.5	5.6 (2.0 – 15.2)		<b>S</b>
<b>Socio-economic level of family:</b>							
Low	8	61.5	5	38.5	7.2 (1.7 – 29.9)		<b>0.003</b>
Middle	17	53.1	15	46.9	5.1 (1.7 – 15.7)	11.4	<b>S</b>
High	6	18.2	27	81.8	Reference		

$\chi^2$ : Pearson's chi-square test, S: Statistical significance

N.B. Participants with adaptive pattern at the start of the study (Pre-intervention) and dropout participants (19 participants) were excluded from this table.

Improved Self-Management pattern: Shift to a higher level pattern (change of mixed to adaptive and change of maladaptive to mixed or adaptive)

**Table (5): Binary Logistic Regression Analysis for Prediction of Improvement in Self-Management Patterns**

Predictors	OR (95% CI)	P
Age (< 8 years)	1.0 (0.4 – 17.3)	0.3
Presence of another diabetic brother/sister	0.6 (0.1 – 4.6)	0.6
Educational level of caregiver (Primary & Secondary)	3.7 (1.3 – 10.6)	<b>0.002</b>
Socio-economic level of family (low & middle)	2.6 (1.0 – 11.1)	<b>0.01</b>

Hosmer and Lemeshow test = 3.3, p-value = 0.6

study in India, which reported that the most essential strategy to improve glycemic control is to motivate the child and his or her family to take control of diabetes in their hands through an effective health education.<sup>31</sup>

Being a caregiver for a diabetic child of type 1 is a major challenge.<sup>32</sup> Mothers identify a need for close monitoring and attention to the child's diabetes especially for those at very young age.<sup>33</sup> As for the age of the children included in the study, the caregivers of younger children (< 8

years of age) were approximately 3 times more likely to improve their self-management patterns compared to older children. In addition, the improvement in Self-Management patterns was 4 times higher among caregivers with more than one diabetic child. One possible explanation of this may be due to the full burden of the complex daily management such as giving the insulin injections, finger bricks for blood glucose measurement and the difficulty of the young children in clearly describing and communicating their symptoms; being on the shoulders of the caregivers and doubling the burden on those with more than one diabetic child to be more responsive for the self-management education. Also, in parallel with the results of the previous Norwegian study among diabetic children and their caregivers, improved blood glucose monitoring and improved glycemic control among children in the youngest age group were identified.<sup>34</sup>

This study reported that families with low and middle socio-economic status had a 7 and 5 times respectively greater likelihood of positive response to the health education program in the form of an improved self-management patterns as compared to those with a high socio-economic status, As well as education as part of socio-economic measurement, the improvement in self-management patterns among the less



educated caregivers was about 6 times higher.

This finding is in line with the results of a previous study, which reported that people with low socio-economic status are motivated to change their lifestyle when they have experienced health complaints; health education interventions consider potential cost concerns when targeting individuals with low socio-economic status find good response and better adherence to health advice.<sup>35</sup>

On the contrary, a German study<sup>36</sup>, showed a significant association between socio-economic status and diabetes self-management patterns and glycemic control given that, low socio-economic status is linked to poor diabetes management and glycemic control with higher complications and bad outcomes.

Patients with low socio-economic status have a high hospital admission rate, reflecting the importance of individual education not only to the routine health education of this vulnerable group.<sup>37</sup>

## Conclusion

The study illustrated that self-management among caregivers of Type 1 Diabetes children as well as the children's glycemic control improved after health education. Adaptive Self-Management pattern was significantly associated with good glycemic control. The self-management improvement was significantly more prevalent among caregivers who had younger children (<8 years of age), had more than one child diagnosed as diabetic, less educated and with low socio-economic status.

**Recommendation:** The study sheds light on the importance of diabetes management education for caregivers. More efforts are required to support and maintain continuous training and education for the families of Type 1 Diabetes children for

good glycemic control, improved quality of life and fewer hospital admissions.

**Study limitations:** Lack of cooperation by some child caregivers, but the researchers persuaded them to participate in the study after explaining the importance, objectives and methodology of the study. The Egyptian Diabetes Association guidelines were not used because we found that the American Diabetes Association guidelines were more recent, comprehensive, and conclusive and cited by majority of studies. It also was acknowledged by pediatric endocrinologists. Besides, The Egyptian Diabetes Association guidelines are adopted from ADA.

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