# Barriers and Facilitators that Affect Self-Care Practices among Children with Type 1 Diabetes

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## ABSTRACT

**Background:** Type 1 Diabetes Mellitus (T1DM) is a more common disease in children. Self-care is critical for disease management and lowering the risk of diabetes-related complications. **Design:** cross-sectional study was used. **Sample:** A purposive sample of 193children was included. **Instruments:** Part I: Socio-demographic characteristics of children; Part II: Diabetes Self-Care Ability Questionnaire; Part III: Barriers that hinder self-care; Part IV: Perception of studied children about potential facilitators to self-care: **Results:** The highest barriers which hinder self-care practices were poor adherence to medications, difficulty in following recommended dietary plans and lack of knowledge about the health condition, additionally, anxious about the health condition as actually barriers that hinder self-care. The top most facilitators as emotional support and allow clinic follow-up at the school, motivate the students to adequate self-care and training program about disease as ways to facilitate self-care. **Conclusion**: More than half of studied children had unsatisfactory total self-care, while more than one third of them had satisfactory total self-care. Also, there was high negative correlation between total barriers and total self-care practices. **Recommendations:** Design implications for technologies to support collaborative care by improving children's transition to independent illness management. Supplementing therapeutic education with strategies designed to raise levels of motivation, discussion of beliefs about the disease

**Key words:**

Barriers, facilitators, self-care practices, children, type 1 diabetes

## Introduction

Type 1 Diabetes Mellitus (T1DM) is a chronic illness caused by an autoimmune reaction that destroys pancreatic beta cells that produce insulin; it is not preventable and cannot be cured at this time. T1DM is a more common disease in children. Self-care is critical for disease management and reducing the risk of diabetes-related complications (**International Diabetes Federation, 2019).** T1DM is becoming more common in pre-school and school-aged children, and they enter the educational system with unique assistance needs for best managing their insulin and blood glucose regimen (**Montali et al., 2022).**

This chronic disease necessitates the patient's active participation in treatment, including self-management of symptoms, lifestyle changes, coping with physical and psychosocial consequences, and managing tasks related to insulin self-administration, blood glucose self-monitoring, and nutritional and exercise management. (**Caruso et al., 2019).** These tasks are deemed too difficult and time-consuming for young children to complete without the assistance of parents/caregivers (**Goethals et al., 2020).**

However, as children mature emotionally and develop new motor skills and cognitive abilities, they are encouraged to gradually acquire the skills needed to manage their diabetes on their own. (**Bratina et al., 2018).** Early childhood diabetes education is thought to be critical for achieving optimal Glycemic control and reducing the likelihood of long-term complications (**Rankin et al., 2018).**

Diabetes self-care education is critical because it improves patients' knowledge and skills, ultimately improving patient outcomes and health-related quality of life. (**El Masri et al., 2020**). A high level of self-care can improve health outcomes such as illness stability, health, and well-being significantly. For example, better self-care in diabetes has been associated with better Glycemic control, fewer complications, and better quality of life (**Fabrizi et al., 2020**).

The studies on diabetes self-care practices draw attention to various factors that are barriers to or facilitators of diabetes self-management (**Adu et al., 2019).** There are several barriers to adequate self-care, including a lack of knowledge, skills, or motivation, ineffective interactions with healthcare providers, family conflict, and a lack of peer support (**Saoji et al., 2018).** Additionally, diabetes self-care facilitators were acceptance of diabetes diagnosis; availability of counseling classes on Type 1 diabetes and support from family and health

care providers (**Adhikari et al., 2021**). A better understanding of patient barriers and facilitators to self- care behavior is needed to guide the design of interventions to improve self- care and quality of diabetic care (**Mogre et al., 2019**).

## Significance of the study

Diabetes mellitus, a "silent disease," progresses quickly until target organ damage and, because of its terrible side effects, has emerged as a significant public health issue. Diabetic patients require effective self-care management to reach and maintain an ideal blood glucose level (**Baral&Baral, 2021**). There were 542 000 children throughout the world aged 0 to 14 years old who were diagnosed with type 1 diabetes in 2015, as reported by the International Diabetes Federation (**IDF-2015).** In Egypt, there is a lack of information regarding the prevalence of type 1 diabetes in adolescents; since the latest incidence of type 1 diabetes in children aged 0 to 14 was 8/100,000 according to the IDF-2011, while in adults there were 8.222. 600 cases of diabetes with a prevalence rate of 15.1%. In Egypt, there is a lack of information regarding the prevalence of type 1 diabetes in adolescents (**Atlas, 2019**). Therefore; the study aims to explore barriers and facilitators that affect self-care practices among children with type 1 diabetes.

## Methods

**Purpose of the study:** to explore barriers and facilitators that affect self-care practices among children with type 1 diabetes, through:

-Assess self-care practices level among children with type 1 diabetes

-Assess barriers that hinder self-care practices level among children with type 1 diabetes

-Assess perception of children about facilitators that improve self-care practices.

-Assess relation between barriers and self-care practices among children with type 1 diabetes.

## Research questions

To fulfill the purpose of the study the following research questions are formulated:

**Q1:** What is the level of self-care practices level among children with T1DM?

**Q2**: What are barriers that hinder self-care practices level among children with T1DM?

**Q3:** What are the facilitators that improve self-care practices among children with T1DM?

**Q4:** Is there relation between barriers and self-care practices among children with T1DM?

## Research design:

A cross-sectional study design was utilized to accomplish the purpose of the study.

**Setting:**

The present study was conducted in the Diabetic Center in the comprehensive medical complex, Abu Baker AL- Siddiq clinics for health insurance in Menoufia at Shebin El-Kom that serves Menoufia Governorate and The Comprehensive health insurance clinics in Timor Queessna.

## Sample:

This study was carried out on a multistage cluster sampling method (193children) through Purposive sample, the sample size was calculated using the MedCalc software program (www.medcalc.org/index.php) at 5% α error (95% significance) and 20% β error (80% power of the study), Inclusion criteria: Age:10-16 years, Sex: male and female and type one diabetes.

**The instruments of data collection:**

Four instruments were used to collect data for the study.

**Part I**: **Socio-demographic characteristics of children**: this part developed the researcher included age, gender, education level, residence, family income, BMI, years of diagnosis, other chronic disease.

**Part II:** Diabetes Self-Care Ability Questionnaire—The Diabetes Self-Care Ability Questionnaire (DSCAQ)—developed in Thailand (Mekwiwatanawong et al., 2013; Partiprajak et al., 2011)—incorporated 36 items covering 6 domains: diet, exercise, Self-monitoring of blood glucose level, information, and follow-up,

Personal hygiene & foot care, and Insulin Regimen & medication taking. Answers are graded on a 4-point Likert-type scale ranging from 0 (rarely to never done) to 3 (always). Total scores categorized as unsatisfactory (0 to 65), and satisfactory (66 to 108).

**Partiprajak et al., 2011**).

**Part III: Barriers that hinder self-care;** it was developed by researcher after reviewing literature review**Mogre et al., 2019 & Letta et al., 2021**. It included 17 items that hinder self-care practices among diabetic children as difficulty in following recommended exercise, financial constraints, anxious about the health condition, disabling bad emotional state…etc. Responses are graded on two-points as yes "1" or no "0". A higher total score indicates a higher barrier, categorized as high (10 to 17), and low (0 to 9).

**Part IV: Perception of studied children about potential facilitators to self-care:** it was developed by researcher after reviewing literature review **Mogre et al., 2019 & Letta et al., 2021**. It included 12 items as Training program about management, allow clinic follow-up at the school, and provide financial support….etc. Allow to each child to select more answers from the potential facilitators.

## Validity & Reliability:

The adapted tools were tested for their reliability by using Cronbach's alpha coefficient test in SPSS program version 24 by a statistician. It was carried out on 20 children and the results were as the following: Internal consistency reliability (Cronbach's α) for diabetes self-care ability questionnaire merged as excellent (.0915), Barriers emerged as good (.0.803facilitators emerged as good (.0.813). A group of five experts in the pediatric nursing ascertained the content's validity; their opinions were elicited regarding the format, layout, consistency, accuracy, and relevancy of the tools.

## Pilot study

It was carried out on 10% of the sample (20children) who were included in the main study sample. It was carried out to evaluate the applicability and clarity of the content, as well as the feasibility and time required to fill in the tools. There were no changes to the question based on the results of the pilot study.

## Data collection procedure

The researchers explain to the children the study's purpose, goal, data collection instruments, and process. A review of recent national and international related literature using journals, periodicals, textbooks, the internet, and theoretical knowledge of the study's various aspects. The development of data collection instruments took three months, from June 1st , 2021 to August 30th , 2021. The researchers prepared the tools and translated them into Arabic so that they could be used. The researchers distributed the data collection instruments with instructions about how to fill them. The questionnaires sheet took between 20 and 25 minutes to complete. The completed forms were collected on time and revised to ensure completeness in order to avoid missing data.

## Ethical Considerations

The study proposal revised by the ethical committee at faculty of nursing Menoufia University. The questionnaire was filled in anonymously and the data were kept confidential and used for research purposes only. Participants were informed about the study's purpose, the duration of the questionnaire, the identity of researchers, and how the data would be stored in a section at the beginning of the form. Written informed consent was obtained online before the respondents completed the questionnaire.

## Statistical Analysis

Data was sorted, classified, and the results were shown in tables. The Statistical Package for the Social Sciences was used to analyze the data on a suitable personal computer (SPSS Inc; version 21; IBM Corp., Armonk, NY, USA). The one-sample Kolmogorov–Smirnov test was used to determine the data's normality. Numbers and percentages were used to describe qualitative data. Continuous variables were presented as means ± standard deviation. Pearson correlation coefficient was used to measure of linear correlation between two sets of data. A linear regression model is a linear approach to modeling the relationship between a scalar response and

one or more explanatory variables. The results were considered significant when the probability of error is less than 5% ($p< 0.05$) and highly significant when the probability of error is less than 0.1% ($p< 0.01$).

## Results

**Table (1)** revealed that mean age of studied children was 12.84(3.89) years, 54.9% of studied children were female and 39.9% of them were at preparatory school. According to residence, 60.6% of them from urban areas and 67.4% of them reported that their family had not enough income. Also, 69.9% of studied children was normal weight and mean of years diagnosis was 4.12(1.86) years. In addition, 92.7% of studied children suffered from other chronic disease.

**Table (2)** showed that 58.1% of studied children had unsatisfactory practice related insulin regimen and 58.4% of them had unsatisfactory practice related follow-up. Also, 55.9% of them had satisfactory practice related Personal hygiene & foot care and 46.1% of them had satisfactory practice related Self-monitoring of blood glucose level. According to total self-care practices, 59.6% of studied children had unsatisfactory total self-care, while 40.4% of them had satisfactory total self-care.

**Table (3)** presented that 89.1% of studied children reported that poor adherence to medications, 88.6% of studied children reported that difficulty in following

recommended dietary plans and 77.7% of them reported that lack of knowledge about the health condition, Additionally, 77.2% of them reported that anxious about the health condition as actually barriers that hinder self-care. Meanwhile, 10.9% of studied children reported that physical limitation and compound effect of other health condition/disease.

**Table (4)** displayed that 83.9% and 80.8% of studied children selected that emotional support and allow clinic follow-up at the school as ways to facilitate self-care, respectively. Also, 77.7% and 77.2% of studied children selected that motivate the students to adequate self-care and training program about disease as ways to facilitate self-care, respectively.

**Figure (1)** stated that 78.8% of studied children had high barriers, while 21.2% of them had low barriers related self-care.

**Table (5)** found that there was high negative correlation between total barriers and total self-care practices at p value $<0.01**$.

**Table (6)** declared that high significant model discovered by F test value was (9.552) with p value. 000. This model accounts for 58% of the variation in self-care practice discovered by $R^2$ value 0.58. furthermore, explained that increasing child age, enough income, and years of diagnosis had slight frequency positive effect on self-care practice at p value $<0.05*$. On other hand, increasing BMI and present other chronic disease

had high frequency negative effect on self-care

practice at p value <0.01**

**Table (1): Socio-demographic characteristics of studied diabetic children (N=193).**

| Items | No | % |
|---|---|---|
| Age: | | |
| 10 - <12 | 65 | 33.7 |
| 12- <14 | 78 | 40.4 |
| 14 – 16 | 50 | 25.9 |
| Mean (SD)                12.84(3.89) | | |
| Gender: | | |
| Male | 87 | 45.1 |
| Female | 106 | 54.9 |
| Education level: | | |
| Primary school | 67 | 34.7 |
| Preparatory school | 77 | 39.9 |
| Secondary school | 49 | 25.4 |
| Residence: | | |
| Rural | 76 | 39.4 |
| Urban | 117 | 60.6 |
| Family income: | | |
| Enough | 63 | 32.6 |
| Not enough | 130 | 67.4 |
| BMI: | | |
| Underweight | 12 | 6.2 |
| Normal | 135 | 69.9 |
| Overweight | 29 | 15.1 |
| Obese | 17 | 8.8 |
| Year of diagnosis: | | |
| Since < 1 year | 37 | 19.2 |
| Since 1 to 3 years | 45 | 23.3 |
| Since >3 years | 111 | 57.5 |
| Mean (SD).                4.12(1.86) | | |
| Other chronic disease: | | |
| Yes | 14 | 7.3 |
| No | 179 | 92.7 |

**Table(2): Self-care practices' scores of the studied diabetic children (N=193)**

| | Satisfactory | | Unsatisfactory | |
|---|---|---|---|---|
| | N | % | n | % |
| Insulin Regimen & medication taking | 81 | 41.9 | 112 | 58.1 |
| Self-monitoring of blood glucose level | 89 | 46.1 | 104 | 53.9 |
| Dietary regimen | 76 | 39.4 | 117 | 60.6 |
| Physical exercise | 84 | 43.5 | 109 | 56.5 |

| | | | | |
|---|---|---|---|---|
| Information and Follow-up | 80 | 41.4 | 113 | 58.5 |
| Personal hygiene & foot care | 108 | 55.9 | 85 | 44.1 |
| Total self-care practices | 78 | 40.4 | 115 | 59.6 |

**Table (3) Frequencies of barriers to self-care among studied children (N=193)**

| Items | No | % |
|---|---|---|
| Difficulty in following recommended exercise | 76 | 39.4 |
| Financial constraints | 84 | 43.5 |
| Anxious about the health condition | 149 | 77.2 |
| Disabling bad emotional state | 98 | 50.8 |
| Difficulty in following recommended dietary plans | 171 | 88.6 |
| Exhausting frequency of visits | 121 | 62.7 |
| Frustration from delayed response to treatment | 105 | 54.4 |
| Physical limitation | 21 | 10.9 |
| Time management constraints | 103 | 53.4 |
| Lack of knowledge about the health condition | 150 | 77.7 |
| Poor communication with healthcare provider | 22 | 11.4 |
| Target level to be achieved by the management plan was not identified | 64 | 33.2 |
| Poor adherence to medications (Schedule and coordination of Medication | 172 | 89.1 |
| Lack of Social support | 41 | 21.2 |
| Poor compliance with management plan | 79 | 40.9 |
| Compound effect of other health condition/disease | 21 | 10.9 |
| Low self-efficacy/ sense of loss of control | 77 | 39.9 |

**Table (4): Perception of studied children about potential facilitators to self-care (N=193)**

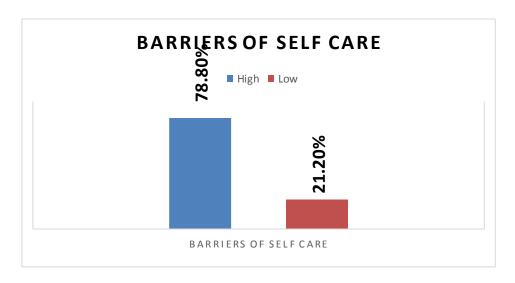| Items | No | % |
|---|---|---|
| Training program about disease | 149 | 77.2 |
| Training program about management | 139 | 72 |
| Allow clinic follow-up at the school | 156 | 80.8 |
| Provide financial support | 74 | 38.3 |
| Provide family support | 102 | 52.8 |
| Provide peer support | 82 | 42.5 |
| Applications for calculate calories intake | 112 | 58 |
| Applications as reminder for insulin dose | 54 | 27.9 |
| Improving their skills related insulin injection | 142 | 73.6 |
| Provide emotional support | 162 | 83.9 |
| Motivate the students to adequate self-care | 150 | 77.7 |
| Encourage students for continuing follow-up | 64 | 33.2 |



**Figure ( 1): Frequencies of total barriers to self-care among studied children (N=193)**

**Table (5) Correlation between total barriers and self-care practice**

| Item | | Total self-care practice |
|---|---|---|
| Total Barriers | r. | -0.589 |
| | p. | <0.01** |

**Table(6):** Multiple Linear regression model for self-care practice (N=193).

| | Unstandardized Coefficients | Standardized Coefficients | | |
|---|---|---|---|---|
| | *B* | B | **T** | **P. value** |
| **Gender (Female)** | .110 | .065 | 1.032 | .074 |
| **Age** | .204 | .153 | 3.141 | .025* |
| **Family income (Enough)** | .201 | .136 | 2.897 | .032* |
| **Chronic disease (Yes)** | -.286 | .214 | 5.677 | .003** |
| **BMI** | -.261 | .199 | 4.712 | .005** |
| **Years of diagnosis** | .198 | .103 | 2.910 | .030* |

| **Model** | **R²** | **Df.** | **F** | **P. value** |
|---|---|---|---|---|
| **Regression** | **0.581** | 5 | 9.552 | .000** |

a. Dependent Variable: self-care practice

b. Predictors: (constant): Gender (Female), Age, Family income (Enough), Chronic disease (Yes), BMI, Years of diagnosis

## Discussion:

Children with T1DM are expected to take more responsibility in self-care, but this is difficult to incorporate in daily life and not all of them possess the necessary skills. Inadequate diabetes self-care promotes insecurity among children concerning treatment based on the triad of diet, physical exercise and insulin therapy. The complex regimen become overwhelming and time consuming, so the current study aimed to explore barriers and facilitators that affect self-care practices among children with T1DM (**Letta et al., 2021**).

According to the characteristics of studied children, our study revealed that mean age of studied children was 12.84(3.89) years, more than one half of studied children were female and more than one third of them were at preparatory school. According to residence, less than two thirds of them from urban areas and more than two thirds of them reported that their family had not enough income. These results in cohort with the study conducted by(**MolalignTakele et al., 2021**)who stated that more than half were male and about half of them had enough income. While, consistent with the study by (**Hajinia et al., 2021**) who reported that the majority of studied children were female.

Also, more than two thirds of studied children were normal weight and mean of years diagnosis was 4.12(1.86) years. In addition, the most of studied children suffered from other chronic disease. These results supported with the study by (**MolalignTakele et al., 2021**) who found thatmore than two thirds of studied children had normal bodyweight. Likewise, regular with (**Hussein et al., 2018**) who reported that one third of the studied diabetic students discovered the disease from four to less than six years with a mean of $3.52 \pm 0.983$years.

Concerning self-care practice of children, more than half of studied children had unsatisfactory practice related insulin regimen and unsatisfactory practice related follow-up. While, more than half of them had satisfactory practice related Personal hygiene & foot care and less than half of them had satisfactory practice related Self-monitoring of blood glucose level. According to total self-care practices, more than half of studied children had unsatisfactory total self-care, while more than one third of them had satisfactory total self-care. These results may be attributed to more than three quarters of them had high barriers related self-care, insufficient school training for children about self-care practice and lack of a rehabilitation and educational center. These results similar with the study by (**Baral&Baral, 2021**) who reported that, less than half had desirable self-care practice for diabetes management. Of the total, 89.9% had adequate

exercise and 74.8% and had foot care management practices.

Likewise, **(Bogale et al., 2022)** found that patients with diabetes had trouble taking their medications and taking care of themselves. They didn't take care of their feet, didn't follow the diabetes-recommended diet plan, and didn't exercise regularly. Also, **(Mansour et al., 2014**) reported that Eighty-four percent (n= 192) of the patients did not follow their selfcare program in an accepted manner, taking treatment of diabetes regularly was the most followed domain in the program of the self-care by 85.5% (n= 195).

Concerning to barriers that hinder self-care, more than three quarters of studied children had high barriers, while one fifth of them had low barriers related self-care.Also, there was high negative correlation between total barriers and total self-care practices. These results supported with the study by **Sarpooshi et al., 2020**who reported that patients' self-care behavior was influenced by different factors and conditions. Also, **(Letta et al., 2021)** who found that more than half of studied patients had high barriers which negatively effect on self-care practices.

The highest barriers which hinder self-care practices were poor adherence to medications, difficulty in following recommended dietary plans and lack of knowledge about the health condition, Additionally, anxious about the health condition

as actually barriers that hinder self-care. The highest facilitators as emotional support and allow clinic follow-up at the school, motivate the students to adequate self-care and training program about disease as ways to facilitate self-care. These results cohort with **(Mogre et al., 2019)** who reported that Self-care support was easier to give when patients were motivated, and healthcare professionals worked as a team.Poor inter-professional teamwork and language problems were obstacles to self-care support.

Furthermore, (**Montaliet al., 2022**) mentioned that technology, such as apps and insulin infusion systems, acts as both barriers and facilitators of self-care. People with T1DM are subjected to stigma both towards the disease and the injections, which can impact their self-care. Transition from pediatric to adults'services is a challenge due to a perceived lack of global assessment and treatment. In addition, **(Elosbky et al., 2022**) who stated that the majority of the youngsters in the study engaged in poor self-care practices and had a negative attitude. Moreover, (**Cha et al., 2022)** who showed that children's drive for self-care and understanding of sickness management were essential for their transition to independence. Furthermore, **(Alvarado-Martelet al., 2019)** stated that the factors that most significantly influenced whether people engaged in self-care activities were motivation, diabetes management training, views about the illness, and self-efficacy. In contrast, anxiety and despair were quite common and linked to reduced adherence. Also, (**Datyeet al., 2019)** detected that

Facilitators of self-care behaviors, like the health system and diabetes education, were found. Situational influences, facilitators, and self-care behaviors all worked together to affect how well people with diabetes stuck with their treatment.

Moreover, the present study stated that increasing child age, enough income, and years of diagnosis had slight frequency positive effect on self-care practice. On other hand, increasing BMI and present other chronic disease had high frequency negative effect on self-care practice. These results consistent with the study by **(Baral&Baral, 2021)**who found that poor self-care practice was likely to occur among patients with co-morbidities (AOR=2.801; 95% CI=1.121-7.002; p <0.05).While **(Thomas et al., 2021)** stated that stress level had negative effect on their self-care activity.

## Conclusion

Based on the current study's findings, it was concluded that more than half of studied children had unsatisfactory total self-care, while more than one third of them had satisfactory total self-care. The highest barriers which hinder self-care practices were poor adherence to medications, difficulty in following recommended dietary plans and lack of knowledge about the health condition, additionally, anxious about the health condition as actually barriers that hinder self-care. The topmost facilitators as emotional support and allow clinic follow-up at the school, motivate the students to adequate self-care and training program about disease as ways to facilitate self-care. Also, there was high negative correlation between total barriers and total self-care practices.

## Recommendations:

Based on the finding of the current study, the following recommendations are recommended:

1- Design implications for collaborative care technologies that improve children's transition to independent illness management.
2- Diabetes self-management education video game for children on adherence to a self-care regimen.
3- Supplementing therapeutic education with strategies designed to raise levels of motivation, discussion of beliefs about the disease

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