

**Problems of Children
with type 1 Diabetes
and their caregivers' burdens**

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Abstract:

The aim of this study was to assess problems facing children with type 1 diabetes and their caregivers' burdens.

Methodology:

This cross-sectional descriptive study was carried out on a sample of 300 children with diabetes and their accompanying caregivers coming to Out-Patient Clinic of pediatric hospital, Ain Shams University.

Results:

Data collection tools included an interview questionnaire to assess problems of children with diabetes and an interview questionnaire to assess burdens facing their caregivers. The results revealed that age of children between 10-12 years, 62% were boys and 38% were girls. The duration of disease constitutes 61% more than 3 years. The highest percentage of physical problems as hypoglycemic coma, visual weakness, underweight, teeth problems, easily fatigue, and previous hyperglycemic coma were 97%, 89%, 75%, 69%, 67% and 66%, consecutively. While mental problems, the highest percentage were 77% for poor ability to recall, 70% for distractibility & 68% for poor attention. But psychosocial problems of children were moderate self-esteem which estimates 70%, moderate social withdrawal in a percentage of 68%, high anxiety level in 57%, and moderate depression represent 50% of the study subject. According to parents caregivers, their physical and economical burden: the result demonstrate that general health exhaustion, fatigue, low back pain, insufficient rest and sleep, and headache represent 85%, 83%, 76%, 69%, and 30%, consecutively of physical burden of the study subject while elevation in medication cost, routine investigation cost, restrictions to special types of food, nutritional regimens cost, emergency and continuous hospitalization, and difficult in reaching to health centers and hospitals where 92%, 88%, 79%, 78, and 62%, consecutively of economical burden of the study subject. About psychosocial burden

of parents caregivers, sadness related to child's problems, fear from complications, worry about child school achievements, lack of positive coping, upset related lack of medication, frustration due to child psychological problems, anxiety related to insufficient knowledge, guilty feeling toward child disease, nervousness from handling child problems, and frustration from child non obedience (related to disease instruction) where in ratios 98%, 97%, 69%, 92%, 85%, 83%, 68%, 73%, 60%, and 45% consecutively of caregivers psychosocial burden.

Conclusions:

The study concluded that children suffering from physical, social, psychological and mental problems related to their disease Most of their caregivers facing multiple burdens regarding caring of their children. The study recommended implementation of counseling sessions to all out patient clinic attendants' family care givers having children with diabetes. A hotline must be available to solve immediate problems of caregivers and their children.

Keywords:

Type 1 diabetes, children Problems, Caregivers' Burdens.

Introduction:

Diabetes is a chronic disease in which the body does not make or properly use insulin. Insulin is a hormone needed to convert sugar, starches, and other food into energy. People with diabetes have increased blood glucose (sugar) levels because they lack insulin, have insufficient insulin, or are resistant to insulin's effects. High levels of glucose build up in the blood and spill into the urine; as a result, the body loses its main source of fuel. (National Diabetes Education Program, 2009).

Type 1 diabetes is the common form of diabetes in children and occurs when the pancreas is unable to make enough insulin. The result of this insulin shortage is potentially extensive: heart and blood

vessel disease, nerve damage, kidney damage, eye damage, foot damage, skin and mouth conditions, osteoporosis, pregnancy complications, and hearing problems Type 1 diabetes always requires insulin treatment. (Mayo Clinic, 2009). When a person has diabetes, they become unwell with the symptoms of diabetes which may include excessive thirst, extreme hunger, excessive urination, weight loss Blurred vision, Feeling tired, Nausea, dry, itchy skin, fruity or sweet odor on the breath heavy, labored breathing and dehydration. (Ambler et al 2010).

The management of diabetes in Children (6-12) years old is particularly challenging, because many 6 to 12 year olds require insulin with lunch or at other times when they are away from home. Many require insulin administration while at school, which demands flexibility and close communications between the parents, the healthcare team, and school personnel. The lack of abstract thinking in most children of this age limits management choices and dictates that parents or other adults make most of the treatment decisions. While children in this age-group may be more able to recognize and self-treat hypoglycemia, close adult supervision is still required. On the other hand, the ability of most children of this age to recognize, report, and seek treatment for hypoglycemia, combined with an absence of insulin resistance and psychological issues associated with puberty, makes this age-group perhaps the most amenable to intensive glucose control. (Verstein et al 2005).

Sixty percent of Egypt's population of 70 million in 2004 census is under the age of 20. It's estimated that 7 million Egyptians have diabetes, with 700,000 having type 1 diabetes, expected to increase rapidly. Psychosocial issues are especially relevant, because despite the high number of people with diabetes, the culture has a very negative outlook on the disease, or illness of any kind. In a country

where poverty is also an issue, families can even come to resent the fact that one member takes an unfair share of time and money for health issues. Traditionally, there's also been an unwillingness to invest in the education or careers of people with diabetes, as their futures are seen as uncertain. (Felton, 2005).

Children's problems can also include temperament, physical, or mental problems, children may face psychological problems such as temporary adjustment disorder with somatic complaints, social withdrawal, anxiety or depression. (Dantzer et al., 2003. Soltész, 2007. Greening et al., 2007). Rebelliousness, insecurity, and denial among children, mild impairment of cognition such as visuospatial or verbal defects may also occur. Factors in the family, such as cohesiveness and conflicts in the family, which can influence the psychological and self-care behavior of the child. (Dharmalingam & Kumar, 2001)

Caregiver burden in families raising a child with Type I diabetes stress, is defined as the state of changed or disturbed equilibrium. When the change in equilibrium, or stress, becomes overwhelming it can become a crisis. These stresses including the weight of responsibility as a result of parental obligations, the perceived level of emotional strain, and the imposition of care giving activities on an individual's life (Mitchell et al., 2009). This perception possibly stems from the child's social inhibition (Rubin et al., 2009).

Parents raising children with diabetes are at risk for depressive symptoms and other emotional stress (Raina et al., 2004). A chronic disease, such as diabetes, may also increase the child's externalizing and internalizing behavior problems, such as aggression or depression, which may disrupt the parents' depression and burden. This depression is an issue for the family in that it may result in a

further disruption of the parents' ability to work or manage the family (Lewin et al., 2005). Children's characteristics can also include temperament, physical, or mental problems, and be connected to the caregiver burden of a parent as well. The child's conduct or behaviors have a specific impact on parents' feelings of caregiver burden. For example, the temperament of a child, such as inhibition or shyness, affects the amount of time a parent spends with the child, increasing or decreasing the stress on the parent (Mitchell, et al 2009). In addition, if the child has behavioral issues or conduct problems such as aggression, parents are more likely to have higher levels of caregiver burden (Ambler et al., 2010).

Significance Of The Study:

Diabetes is a life threatening disease caused by the inability of the body to process food. Children with diabetes suffer from physical, psychological, and social problems. They add to the burden of a condition and increase the risk of long-term mental health problems and poor quality of life for the children and their families. In addition, psychological problems are likely to be associated with a higher risk of sub-optimal diabetes management, complications and poor health outcomes in the short and longer term, leading to increasing caregiver burden that result in an increase in poor family and child functioning. Due to these and other negative effects, it is important to continue investigating these factors that contribute to familial stress and decreased child well-being.

Aim Of The Study:

It aimed to assess problems facing children with type I diabetes and their caregivers' burdens.

The Research Questions:

1. What are types of problems facing children with type 1 diabetes?
2. What are burdens facing caregivers of children with type 1 diabetes?

Hypothesis:

The research hypothesis was that children with type 1 diabetes suffer from physical, mental, psychological, and social problems, leading to poor child functioning. Caregivers of children with type 1 diabetes complain of burdens that result in an increase in poor family functioning.

Subject And Methods:

The methodology used in carrying out the study is described under four designs, namely technical, operational, administrative, and statistical designs.

Technical Design:

- ⊠ Research Design: An exploratory cross-sectional descriptive research design was adopted to fulfill the purpose of the study. It helps the researchers to describe and document aspects of a situation as it naturally occurs. As well, this design helps to establish a database for future research.
- ⊠ Study Setting: The study was carried out at Out-Patient Clinic of pediatric hospital, Ain Shams University.

Subjects And Sample:

A convenient sample of 300 children with type 1 diabetes and their accompanying caregivers coming to the above mentioned setting were recruited for the study, the children of the study were choosing according to the following criteria:

- ⊠ Male and females children suffering from diabetes alone.
- ⊠ School age children (6-12) years.
- ⊠ Caregivers have no other chronic ill child to avoid overlapping with other burden related to any family circumstances or illness.

Tools:

The tools used in the study were:

1. An interviewing questionnaire, designed by the researchers after reviewing the related literature, it consists of:
 - a. Demographic data about children and their

parents.

- b. Statements to assess physical, mental, psychological and social, problems of children with type 1 diabetes.
 - c. Statements to assess physical, psychological, social, and economical burden facing caregivers of children with type 1 diabetes.
2. Scale to assess anxiety developed by Castaneda, Mc Candless and translated by El Beblawy (1985), It was used to assess anxiety. It consists of 53 items (Physiological symptoms, social anxiety and negativity). Each sentence has a score ranging from (0-1), (0 for No and 1 for Yes).
 - ⊠ 18 score was considered mild
 - ⊠ 19-28 score was considered moderate
 - ⊠ 29 score was considered severe.
 3. Introverted behavior scale developed by Moss (1989) translated by Abd El-Hamid (1995), It composed of 30 sentences to assess introverted behavior among school age children (shyness, social isolation, and negativity). Scoring was done by each sentence has a score ranging from (0-1-2) (0= no, 1= sometimes, and 2= yes).
 - ⊠ 29 Score Was Considered Low
 - ⊠ 30-39 score was considered moderate
 - ⊠ 40 Score Was Considered High
 4. Self-Esteem inventory sheet developed by Coopersmith and translated by Mosa and El-Doske (1987), It consists of 24 statements to measure self-esteem of school age children, evaluate attitudes toward the self in social academic, family and personal areas of experience. Scoring was done by each sentence has a score ranging from (0-1) (0= no apply, 1= apply)
 - ⊠ 7 Score Was Considered Low
 - ⊠ 8-15 score was considered moderate

- ✧ 16- 24 score was considered severe
- 5. Children depression inventory developed by Kavas and translated by Ghareeb (1988), It included 27 statements (Sadness, optimism, post failure, change in sleep, change in appetite, suicidal in thoughts, guilty feeling, and loss of interest) to assess level of depression in children. Scoring was done by each statement has score ranging from (0-1-2) (0= no, 1= sometimes, and 2= yes)
 - ✧ 0-14 was considered none
 - ✧ 15-22 was considered mild
 - ✧ 23-29 was considered moderate
 - ✧ 30 Was Considered Severe

The reliability of the developed tools used was assessed through the internal consistency method. The tool reliability proved to be very good, with Cronbach alpha coefficient 0.86.

Also, the developed tools were reviewed by experts in nursing pediatrics, psychiatry, as well as experts in community-health sciences. Validation was through majority agreement.

Operational Design:

- ✧ Pilot Study: A pilot study was carried out a sample of 30 diabetic children of both sexes and their accompanying caregivers to judge the feasibility of conducting the study. It also served to check the clarity and applicability of the study tools and test their ability to elicit the desired information. As well, the tools were tested for appropriateness, content, wording and order. The pilot also helped to measure the time needed for filling out the forms, According to the results of the pilot, necessary changes were done and the tools finalized.
- ✧ Fieldwork: Once official permission was granted from the research committee, and from the director of the selected hospital to proceed with the study, the researchers initiated data

collection. Children and their caregivers who met the eligibility criteria were identified. The researchers met with each potential subject, and informed him/her about the purpose and the nature of the study and its procedures. The researchers explained to caregivers how to fill out the forms. Then, the assessment by the researchers was done by individually interviewing each child. The time required filling in the questionnaire varied from one child to the other depending on educational status, past experience, and psychological and social status; the average time was between 50 and 70 minutes. The researchers visited the hospital three times every week during day time, 9 am to 2 pm. Data collection was carried out over a period of six months, from January 2008 to January 2009.

Administrative Design:

Oral consent along with written permission was obtained from the responsible authority. Approval for the study was obtained; the objectives of the study were illustrated, as well as, the main data items to be covered. Prior to the initial interview, each child and caregiver were fully informed about the purpose of the study. The researcher emphasized that participation in the study was entirely voluntary and anonymity of the child was assured through coding the data. They were informed about their right to refuse or withdraw at any time. The study maneuvers could not cause any harmful effect to participants.

Statistical Design:

Data entry and statistical analysis were done using SPSS 14.0 statistical software package. The statistical analysis of data were revised, coded, analyzed, and tabulated using number and percentage distribution in order to determine whether there were significant differences or not,

comparisons were done using the arithmetic mean, standard deviations, and correlation coefficient test. Pearson correlation analysis was used for assessment of the inter-relationships among quantitative variables, and Spearman rank correlation for ranked ones. Statistical significance was considered at p-value <0.05.

Results:

Table (1) shows the distribution of socio-demographic characteristics of parents of diabetic children: It reveals that the highest number (42%) of the study subject less than 30 years and the majority of them were females (87%) regarding their level of education, about 42% of the study subject were in moderate level of education and about 5% were post graduate level of education. And about marital status 70% were married, 18% were widowed and 12% were divorced. Also 74% of the total study subject not working.

Table (2) illustrates the distribution of socio-demographic characteristics of diabetic children: It shows that 49% of diabetic children between 10-12 years and 62% were boys and 38% were girls, their level of education in primary stages and 46% in preparatory stage. The rank of the child in the study subject 31% of them were the second and 28% of them were the first. In this respect the period of disease constitutes 61% more than 3 years.

Table (3) demonstrates the distribution of diabetic children according to their physical and mental problems: It is obvious that the highest percentage of physical problems as previous hypoglycemic coma, visual weakness, underweight, teeth problems, easily fatigue, and previous hyperglycemic coma were 97%, 89%, 75%, 69%, 67% and 66% consecutively. while mental problems, the highest percentage were 77% for poor ability to recall, 70% for distractibility & 68% for poor attention.

Regarding to psychosocial problems of children table (4) illustrates that, these children have moderate self-esteem which estimates 70%, moderate social withdrawal in a percentage of 68%, high anxiety level in 57%, and moderate depression they represent 50% of the study subject.

Table (5) shows distribution of parents caregivers according to their physical and economical burden: The table demonstrate that general health exhaustion, fatigue, low back pain, insufficient rest and sleep, and headache represent 85%, 83%, 76%, 69%, and 30% consecutively of physical burden of the study subject while elevation in medication cost, routine investigation cost, restrictions to special types of food, nutritional regimens cost, emergency and continuous hospitalization, and difficult in reaching to health centers and hospitals where 92%, 88%, 79%, 78, and 62%, consecutively of economical burden of the study subject.

About psychosocial burden of parents caregivers table (6) clears that, sadness related to child's problems, fear from complications, worry about child school achievements, lack of positive coping, upset related lack of medication, frustration due to child psychological problems, anxiety related to insufficient knowledge, guilty feeling toward child disease, nervousness from handling child problems, and frustration from child non obedience (related to disease instruction) where in ratios 98%, 97%, 69%, 92%, 85%, 83%, 68%, 73%, 60%, and 45% consecutively of caregivers psychosocial burden. But lack of social visits and recreation, increase parents quarrelsome, lack of family cooperation, poor friends relationships, and low work performance and repeated absenteeism where 92%, 73%, 47%, 45%, and 30%, consecutively of caregivers social burden.

Table (7) reveals the relation between levels of social withdrawal of diabetic children and their ages

and periods of disease: demonstrates that there are a significant positive relation between the degree of social withdrawal of diabetic children and their ages and also their periods of disease ($r= +0.75$, $r= +0.79$ & $P < 0.05$).

In relation between levels of depression of diabetic children and their ages and periods of disease table (8) demonstrates that there are a significant positive relation between the level of depression of diabetic children and their ages and also their periods of disease ($r= +0.71$, $r= +0.73$ & $P < 0.05$).

Table (1): Distribution of socio-demographic characteristics of parents of diabetic children (n=300)

Item	No.	%
Age (Years)		
20-	66	22
30-	126	42
40-	108	36
Mean± SD	36.4±7.5	
Sex		
Male	39	13
Female	261	87
Level Of Education		
Read& Write	84	28
Moderate	126	42
University	75	25
Post-Graduate	15	5
Marital Status		
Married	210	70
Divorced	36	12
Widowed	54	18
Occupation		
Working	78	26
Not Working	222	74

Table (2): Distribution of socio-demographic characteristics of diabetic children (n=300)

Item	No.	%
Age (Years)		
6-	72	24
8-	81	27
10-12	147	49
Mean± SD	9.5± 1.6	

Item	No.	%
Sex		
Boys	186	62
Girls	114	38
Level Of Education		
Read& Write/Primary	162	54
Preparatory	138	46
Rank Of Child		
First	84	28
Second	93	31
Third	54	18
Fourth/Fifth	69	23
Duration of disease (years)		
< 3 Years	117	39
> 3 Years	183	61
Mean± Sd	3.2 ±0.8	

Table (3): Distribution of diabetic children according to their physical and mental problems (n=300)

Item	No.	%
Physical Problems		
Under Weight	225	75
Over Weight	45	15
Visual Weakness	267	89
Recurrent Dermatitis And Urticaria	81	27
Extremities Numbness	168	56
Easily Fatigue	201	67
Delay Wound Healing	99	33
Vascular Affection	177	59
Foot Sore	123	41
Renal Problems	60	20
Teeth Problems	207	69
Previous Hypoglycemic Coma	291	97
Previous Hyperglycemic Coma	198	66
Pneumonia	105	35
Cerebral Infraction	54	18
Cardiac Infraction	87	29
Mental Problems		
Poor School Achievement	153	51
Out School Related To Diabetes	85	28
Distractibility	210	70
Confusion	54	18
Low Concentration	183	61
Poor Attention	204	68
Poor Ability To Recall	231	77

Table (4): Distribution of diabetic children according to their psychosocial problems (n=300)

Item	No.	%
Self-Esteem		
High	30	10
Moderate	210	70
Low	60	20
Mean± SD	1.9±0.5	
Social Withdrawal		
High	57	19
Moderate	204	68
Low	39	13
Mean± SD	2.1±0.6	
Anxiety		
High	171	57
Moderate	84	28
Low	45	15
Mean± SD	2.4±0.7	
Depression		
High	30	10
Moderate	150	50
Low	84	28
None	36	12
Mean± SD	1.6±0.8	

Table (5): Distribution of parents caregivers according to their physical and economical burden (n=300)

Item	No.	%
Physical Burden		
Fatigue	249	83
Low Back Pain	228	76
Headache	90	30
Insufficient Rest And Sleep	207	69
General Health Exhaustion	255	85
Difficult to reaching to health centers and hospital	186	62
Restriction to special types of food	240	80
Economical Burden		
Elevate The Medication Costs	276	92
Emergency And Continuous Hospitalization	234	78
Routine Investigation Costs	264	88
Nutritional Regimen Costs	237	79

Table (6): Distribution of parents caregivers according to their psychosocial burden (n=300)

Item	No.	%
Psychological Burden		
Sadness Related To Child's Problems	294	98
Guilty Feeling Toward Child Disease	219	73
Fear From Complications	291	97
Worry About Child School Achievements	288	96
Frustration Due To Child Psychological Problems	249	83
Lack Of Positive Coping	276	92
Upset Related Lack Of Medication	255	85
Anxiety Related To Insufficient Knowledge	234	78
Nervousness From Handling Child Problems	180	60
Frustration From Child Non Obedience (Related To Disease Instruction)	135	45
Fear From Emergency Circumstances	207	69
Neglect Personal Appearances	210	70
Loss Of Warm, Love, And Security Within Family	90	30
Loss Of Appetite	180	60
Social Burden		
Lack Of Social Visits And Recreation	276	92
Increase Parents Quarrelsome	219	73
Poor Friends Relationships	135	45
Low Work Performance And Repeated Absenteeism	90	30
Lack Of Family Cooperation	141	47

Table (7): Correlation between levels of social withdrawal of diabetic children and their ages and periods of disease (n=300)

Item	Social Withdrawal						r	P-Value
	High		Moderate		Low			
	No	%	No	%	No	%		
Age (Years):								
6-	2	6.6	50	16.6	20	6.6	+0.75	P<0.05 Sign
8-	18	6	54	18	9	3.3		
10-12	37	12.3	100	33.3	10	3		
Period Of Disease (Years):								
< 3 Years	21	7	86	3.3	10		+0.79	P<0.05 Sign
> 3 Years	36	11.6	118	39.3	29	9.6		

Table (8): Correlation between levels of depression of diabetic children and their ages and duration of disease (n=300)

Item	depression								r	P-Value
	High		Moderate		Mild		None			
	No	%	No	%	No	%	No	%		
Age (Years):										
6-	6	2	26	8.6	22	73	18	6	+0.71	P<0.05 Sign
8-	16	5.3	34	11.3	24	8	13	4.3		
10-12	14	4.6	90	30	38	12.6	5	1.6		
Duration Of Disease (Years):										
< 3	10	3.33	60	20	16	53	31	10.3	+0.73	P<0.05 Sign
> 3	20	6.6	90	30	86	22.6	5	1.6		

Discussion:

Diabetes is a serious chronic disease in which blood glucose (sugar) levels are above normal due to defects in insulin production, insulin action, or both. Diabetes must be managed 24 hours a day, 7 days a week. (National Diabetes Education Program, 2009). Diabetes requires the patient to take responsibility of managing their health with daily injections, careful monitoring of diet, exercise and blood glucose levels for the rest of their lives. Chronic illness marks the children as different from their peers. It also burdens the family with demanding healthcare responsibilities that they may be unwilling to meet. It is therefore not surprising that many children with diabetes have many problems both emotional and behavioral. (Dharmalingam,& Kumar 2001)& (Greening et al 2007).

Caregiver burden results from the stress that parents feel due to their responsibilities as a caregiver. Caregiver Burden in Families Raising a Child with Type I Diabetes Stress, These stresses including the weight of responsibility as a result of parental obligations, the perceived level of emotional strain, and the imposition of care giving activities on an individual's life (Ambler et al 2010).

Concerning socio-demographic data related to diabetic children as regards age, the finding of

present study showed that, half of diabetic children between 10-12 years. This is consistent with Ambler et al (2010) who found that Type 1 diabetes, which formerly called juvenile diabetes, is usually first diagnosed in children, teenagers, or young adults, the greatest increase in the incidence of type 1 diabetes mainly occurred in children aged, <14 years, In this form of diabetes, the beta cells of the pancreas no longer make insulin because the body's immune system has attacked and destroyed them.

As regards gender, the finding of present study revealed that, 62% of studied children were boys and 38% were girls. this result is contradicting with that of Fontaine (2005), who found the incidence of juvenile diabetes was similar in boys and girls. Male and female children are equally likely to develop diabetes

Concerning the physical problems affecting diabetic children the finding of present study revealed that the highest percentage of physical problems were hypoglycemic coma, visual weakness, underweight, teeth problems and easily fatigue similar to Ambler et al. (2010) Symptoms of type 1 diabetes often develop over a short period of time. Keep in mind that the most common diabetes symptoms in younger children are polydipsia (drinking a lot), polyuria (urinating a lot), frequent urination (in children, a recurrence of bed-wetting after toilet training has been completed), unusual thirst, especially for sweet, cold drinks. Extreme hunger, sudden, weakness, extreme fatigue, blurred vision or other changes eyesight, Irritability, pain in the joints, tiredness and/ or generalized body ache. and Nausea, vomiting (acute symptoms) loss of appetite, sometimes dramatic weight loss, delayed healing of wound and Low blood sugar (hypoglycemia) can develop when child takes more insulin than needed, eats too little food, or is more active than usual. Low blood sugar usually develops

within 10 to 15 minutes. Early symptoms include sweating, weakness, shakiness, and hunger; however, if not treated, low blood sugar can get worse and lead to confusion, slurred speech, and loss of consciousness. Diabetes can lapse into a life-threatening diabetic coma, known as diabetic ketoacidosis or DKA, (Vanelli, 2007) which may be the first sign in severe cases of type 1 diabetes. (Michael et al, 2009)& (National Diabetes Education Program, 2009).

Regarding mental problems affecting diabetic children, the present study revealed that the highest percentage were poor ability to recall, distractibility& poor attention. This is agree with Sultana et al.(2007), who found that children with type 1 diabetes may also be restless, apathetic, and have trouble functioning at school. Such as poor school attendance, learning disabilities, It may be due to The results of a recent meta-analysis indicate that children with type 1 diabetes have a variety of mild cognitive impairments and slightly reduced overall intellectual functioning (Daines,2005). While psychosocial problems affecting diabetic children the present study Illustrates that, these children suffering from moderate level of self-Esteem, moderate social withdrawal, high anxiety level and moderate level of depression (Jaser et al., 2007). Similarly other study by Romer,(2005).reported that chronically ill children are at an increased risk for psychological difficulties. Polonsky& Guzman (2009) found that children with chronic illnesses experience a twofold increase in psychiatric disorders compared to healthy unaffected peers, such as emotional and behavioral disorders, including risk-taking behaviors resulting in delinquent behavior and depression.

It may be due to that chronic illness considering a direct threat to child which he /she cannot deal easily with it and always facing it with behavioral changing and difficulties, children with type 1

diabetes feel that life is never the same again& the pain never end, they live under a constant shadow, there is no care or treatment and there is uncertainty about the future which considered a constant challenge to attainment of normal life.

The present study showed that, the highest number of the parents less than 30 years and the majority of them were the mothers; this finding could be due to that most of those children's mothers were not working. This finding also reflects the strong emotional ties between mothers and their children, besides mothers react more patiently with children's behavior and caring issues than fathers.

The present study demonstrate that parents of children with type 1 were suffering from many physical burden including general health exhaustion, fatigue, low back pain, insufficient rest and sleep, and headache while economical burden were highest medication cost, routine investigation cost, restrictions to special types of food, nutritional regimens cost, emergency and continuous hospitalization, and difficult in reaching to health centers and hospitals.

Similarly finding with Bolyai et al. (2003)& Berg et al. (2007). Mothers (especially those with limited resources) the ongoing responsibility affected their parental sleep, with reports of chronic sleep deprivation. The burden of care also resulted in some of the mothers experiencing personal health problems, such as weight gain or loss, migraines, and being hospitalized, they attributed these problems to the burden and responsibility of care with limited support or respite. Parents of children with high technology needs reported that the constancy of the demands was exhausting and contributed to a sense of care giving burden, beside those daily tasks such as frequent glucose monitoring and insulin injections may become more complicated for the parents to manage and handle their exhausted coasts.

The burden of the physical care often overrode attention to child development and other family-related activities reported personal caregiver burden issues included not getting enough sleep, poor managed their other daily responsibilities, the day-to-day concerns and stressors they experienced, and kinds of internal and external resources they can used, the responsibility of ongoing monitoring for hypoglycemia and giving injections over time. Harris (2006) found that the bulk of the burden of care rests on the mothers of school-aged children with diabetes frequently reported that the lack of cooperation and social support from the school system placed more burdens on them. On the same line, Diabetes Prevention and Control Program (2010) added that the cost of hospitalization, medical consultation, paramedical services, routine laboratory and diagnostic tests and medications, placed a strain on the parent caregiver's financial resources, thereby contributing to stress or low morale.

As regard the parental psychosocial burden this study revealed that, Sadness related to child's problems, fear from complications, worry about child school achievements, lack of positive coping, upset related lack of medication, frustration due to child psychological problems, anxiety related to insufficient knowledge, guilty feeling toward child disease, nervousness from handling child problems, and frustration from child non obedience (related to disease instruction) were the main caregivers psychosocial burden. But lack of social visits and recreation, increase parents quarrelsome, lack of family cooperation, poor friends relationships, and low work performance and repeated absenteeism were the caregivers' social burden that parents surfing from. Choi & Marks (2008) reflected that parenting a child with type 1 diabetes is challenging, particularly when the child is very young. In addition to the normal challenges of promoting

physical, cognitive, and socio emotional growth and development, parents must face the complex management of the disease, including blood glucose monitoring, insulin administration, and meal planning. The complex caretaking responsibilities can create tremendous stress experiencing of fears, frustrations, feelings of helplessness, remorse, guilt and anger. (Lucyna et al., 2009). In addition to Parents may become so burdened with concerns related to the day-to-day illness management, especially preventing episodes of hypoglycemia, that they lose sight of normal development and psychosocial interaction, as well as other family-related needs, fewer opportunities for socialization, or personal time, Similarly, other studies reported that It is critical to understand the day to day experiences of parents in order to provide appropriate guidance and support to their children which with time leading to feeling of concerned, stressed, and frustrated.

Also Parental fears include fear of hypoglycemia and associated seizures, anxiety associated with frequent blood glucose monitoring, fear of 'not being there, general anxiety associated with the burden of caring for a child with Type 1 diabetes, frustrations, feelings of helplessness, remorse, guilt and anger. Besides fear that others, such as, teachers and others will be unable to provide appropriate care for their child. Nocturnal hypoglycaemia in particular poses particular stressors to mothers. (Landolt et al., 2005)

Conclusion:

The study concluded that children suffering from physical, social, psychological and mental problems related to their disease Most of their caregivers facing multiple burdens regarding caring of their children.

Recommendations:

1. The study recommended replication of the study by using larger probability sample from different

geographical areas, with equal sample size from male and female and different demographic varieties to achieve generalizability.

2. A hotline must be available to solve immediate problems of caregivers and their children.
3. There should be adequate financial support to enable them to meet the extra-costs of caring for diabetes.
4. Workshop training programs for Psychiatric Mental/ Health Nurses on how to help caregivers to relieve their burden and cope appropriately with their children with type 1 diabetes. Implementing counseling sessions to all out patient clinic attendants' family care givers having children with diabetes.

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كانوا الأمهات وأن ٤٢% كانت أعمارهم أقل من ٣٠ سنة وكان مستوى تعليمهم متوسط وحوالي ٥% منهم تعليمهم عالي و ٧٠% منهم متزوجات و ١٨% أرامل و ١٢% مطلقات.

٢. تبين أن ما يقرب من نصف العينة من الأطفال المصابين بمرض السكر تتراوح أعمارهم ما بين ١٠ إلى ١٢ عام وأن عدد الذكور يفوق عدد الإناث وأن ٤٦% من الأطفال كانوا في المرحلة الإعدادية وأن أكثر الأطفال المصابين بمرض السكر هو الطفل الثاني في الترتيب داخل الأسرة وأن ٦١% من الأطفال فترة تعرضهم لمرض السكر تجاوزت الثلاث سنوات فأكثر. ٣. وجد أن أكثر المشاكل الجسدية التي يتعرض إليها الأطفال المصابين بمرض السكر كانت على النحو الآتي غيبوبة نقص السكر، اضطراب وضعف في الإبصار ونقصان الوزن ومشاكل بالأسنان والإنهاك الجسدي ومن المشاكل العقلية عدم القدرة على استرجاع المعلومة والتشتت وضعف الانتباه ٤. أما بالنسبة للمشاكل النفسية والاجتماعية وجد أن ثلث العينة يعانون من درجة متوسطة من تقدير الذات و ٦٨% يعانون من السلوك الأنطوائي بدرجة متوسطة ونصف العينة يعانون من الاكتئاب بدرجة متوسطة كما أن أكثر من نصف العينة يعانون من درجة عالية من القلق.

٥. أظهرت الدراسة أن الأعباء الجسدية التي يعاني منها اغلب الأهالي القائمين على رعاية الأطفال المصابين بمرض السكر كانت تتمثل في الإرهاق الجسدي العام والام بالظهر وعدم كفاية فترات الراحة والنوم والتعرض المستمر للصداع، إما الأعباء المادية التي ترهقهم اشتملت على ارتفاع سعر الدواء المعالج والتحليل المعملية الخاصة بالمتابعة والنظام الغذائي الخاص بالطفل والتعرض للمكوث بالمستشفى والحجز للعلاج في كثير من الأحيان وفي حالات الطوارئ. وجد أيضا أنه من الأعباء النفسية والاجتماعية التي يتعرض لها الوالدين هي الحزن على حالة الطفل المرضية والخوف من المضاعفات التي ممكن أن تحدث نتيجة المرض إلى جانب العصبية والتوتر والشعور بالذنب تجاه الطفل وصعوبة التعامل مع مشاكله وصعوبة السيطرة عليه للالتزام بالنظام الغذائي الخاص بمرضى السكر.

الملخص

مشاكل الأطفال المصابين بمرض السكر نوع ١ وأعباء القائمين على رعايتهم

تهدف هذه الدراسة إلى تقييم مشاكل الأطفال المصابين بمرض السكرى نوع ١ وأعباء القائمين على رعايتهم.

افتراضية البحث:

مرض السكر لدى الأطفال يصاحبه العديد من المشاكل الجسدية والعقلية والنفسية والاجتماعية التي يعاني منها هؤلاء الأطفال، إلى جانب معاناة الأهالي القائمين على رعايتهم بالكثير من الأعباء منها المادى، الجسدى، النفسى وأيضا الاجتماعى التي تؤثر بالسلب على الأسرة.

منهجية البحث:

٢ التصميم البحثي: استخدم تصميم استكشافى مقطعى وصفى لتنفيذ هذه الدراسة.

٢ مكان البحث: أجريت هذه الدراسة في عيادة الأطفال بمستشفى الأطفال التابعة لجامعه عين شمس

٢ عينة البحث: شملت الدراسة ٣٠٠ طفلا مصابا بمرض السكر ذكور وإناث في سن ٦-١٢ سنة وبمرافقة عضو الأسرة القائم على رعايتهم، كما تم تجنب الأسر التي بها أطفالا مصابين بأى أمراض أخرى.

الأدوات:

تم استخدام الأدوات التالية:

١. استمارة استبيان مصممة بواسطة الباحثين لجمع بيانات عن الطفل والأسرة مثل (السن والنوع ودرجة التعليم والحالة الاجتماعية والوظيفة ترتيب الطفل داخل الأسرة وفترة الإصابة بالمرض) إلى جانب أسئلة خاصة عن المشاكل النفسية والاجتماعية والعقلية والجسدية التي يتعرض لها ويعانى منها الأطفال المصابين بمرض السكر.
٢. أسئلة خاصة عن الأعباء الجسدية والمادية والنفسية والاجتماعية التي يتعرض لها ويعانى منها الأسر القائمة على رعاية الأطفال المصابون بمرض السكر
٣. مقياس القلق المترجم بواسطة البيلوى ١٩٨٥.
٤. مقياس تقدير الذات ترجمة موسى والدسوقى ١٩٨٧.
٥. مقياس السلوك الأنطوائى ترجمة عبدالحميد ١٩٩٥.
٦. مقياس الاكتئاب ترجمة عبدالفتاح غريب ١٩٨٨.

النتائج:

١. كانت أهم نتائج الدراسة:

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