

## **Depression, Stress, Health Effects and caregiver burden experienced by caregivers of children with diabetes**

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### **Abstract**

**Background:** Most children relish healthy childhoods with little need for specialized health care assistance. However, some children experience complications in early childhood and require considerable health care resources access and utilization over time. Although caregiving is a natural part of being a young child's parent, this role depends on an entirely different significance when a child undergoes functional limitations and possible long-term dependence. One of the primary parental challenges is to handle their child's chronic health problems effectively and juggle this role with the everyday living requirements. Consequently, the caring task for a child with a complex health problem at home might be somewhat daunting for caregivers. Such care provision may prove detrimental to both the physical health and the psychological well-being of parents of children with chronic diseases. During this intense and unpredictable course, the caregiver's burden is difficult and

complicated by multiple competing priorities. Because caregivers are often faced with multiple stressful concurrent events and extended unrelenting stress, they may undergo adverse health effects, mediated in part by immune and autonomic dysregulation. **Objective:** An investigation Study on predictors of caregiver burden, focusing on mothers and fathers who are raising a child with diabetes; include child characteristics, such as child behaviors; parent characteristics, such as maternal or paternal depression; and the marital relationships aspects, such as marital dispute or marital satisfaction, as predictors of parents' caregiver burden. **Methodology:** A cross-sectional study using questionnaires with a systemic random sample of 100 subjects; parents of children with diabetes aged 5–12 years were selected in Riyadh, Saudi Arabia. A questionnaire was used for collecting information about socio-demographic data and clinical characteristics. Depression, Self-care management behaviors and the barrier to adherence were collected. **Findings:** Results of the correlation analysis for parents showed that marital conflict ratings, depression, and child externalizing behaviors were all correlated significantly with Parents' ratings of caregiver burden, with correlations of 0.38 or higher. There is a statistically significant correlation between the degree of depression and age which is that the degree of depression increases with age ( $p = 0.001$ ). As for gender, there

was a statistically significant correlation indicating that the incidence of depression among females was higher than that of males ( $p = 0.001$ ).

**Conclusion:** Caregivers of patients with cancer are essential partners in the quality of care we strive to deliver to our patients. The prevalence of depression among subjects (parents of diabetic children) is high compared with that of Parents with healthy children. This was associated with gender, educational level, insulin treatment, low self-management behaviors and increased barriers to adherence. Psychosocial treatments are also valid for mild depression. Antidepressants can be a valid treatment form for moderate-severe depression but are not the first treatment line for mild depression cases. **Recommendations:** Urgent early detection and management of depression. Conduct training sessions for diabetic caregivers to better adapt to care conditions and pressures, further study of the factors affecting depression among caregivers.

**Keywords:** Diabetic Children – Caregiver – Depression – Stress – Health Problems

## Introduction

The profession of nursing is considered a high and human profession because of its association with human health, preserving his life, alleviating his suffering and sense of pain, and all those who work in this profession are called Mercy angels for the humanitarian role they perform in different therapeutic stages. In the medical aspect, this profession achieves generalization in the provided medical services and seeks its perfection. The doctor is the first person to determine the nature of the disease and decide the form and type of treatment; while it is the responsibility of the nurse to follow the health of patients, and follow all possible means to ease their pain and their condolences.

Diabetes is one of the world's most pressing health challenges in the 21st century, with an epidemic of human and material resources threatening both developed and developing countries. Complications are such as cardiovascular disease, diabetic neuropathy, and renal failure, blindness, varying degrees of disability and low standard of living, and increasing economic burdens on the individual, the family, and society as a whole.

The increase in the number of people with diabetes in developing countries, in particular, calls for attention and concern. This chronic condition is a significant risk factor for heart disease and cerebrovascular disease and is often associated with high blood pressure, which is also a

significant risk factor that causes chronic problems. Developing countries contribute with three-quarters of the global burden of diabetes. However, the number of those diagnosed as diabetic patients will increase from 135 million in 1995 to 300 million by 2025.

Diabetes is a threatening disease caused by the body inability to process food; when the body does not produce insulin—the needed hormone to properly convert food into energy (American Diabetes Association, 2007). The insulin shortage result is potentially extensive: heart and blood vessel disease, nerve damage, renal damage, eye blindness, foot injury, skin and mouth conditions, osteoporosis, pregnancy complications, and hearing problems (Mayo Clinic, 2009). The stress brought about from raising children, and other circumstances of the family contribute to the burden on the caregiver (Robinson, 1983).

These stresses include the responsibility burden as a result of parental obligations (Vitaliano, Russo, Young, Becker, & Maiuro, 1991), the perceived emotional strain level, and the caregiving activities imposition on an individual's life (Savundranayagam, Hummert, & Montgomery, 2005). The caregiver burden experienced by parents raising a child with diabetes has also been called pediatric parenting stress and refers to the child's health and the psychological and behavioral responses and

adaptations to the illness (Mitchell, Hillard, Mednick, Henderson, Cogen, & Streisand, 2009).

### **Diabetes in Children**

Diabetes usually appears suddenly in children. If it is not early diagnosed, it can lead to coma and death. Insulin is a lifesaver for children, and reliance on it is imperative and inevitable, so early detection of the disease and providing treatment are of the basic requirements. The primary objective is to secure the child's physical and emotional development. The first aspect is based on adequate nutrition, with insulin given with the appropriate extent, to meet the changing requirements and the different activity patterns.

Emotional growth may be threatened by parents' fears and excesses of child protection, as well as child resistance to treatment and disaffection with the life system imposed on him. Parents are entrusted with the responsibility of injecting, measuring insulin and making decisions about the nutrition system as well as monitoring the child until he can perform these tasks safely, the child should be discussed with awareness and provide the child and his parents with relevant publications. Parents seek to make adaptation and transition to the school environment easy, help the child form a close friendship with children of the same gender, work

on developing intellectual and sports skills, and form a definite sense of self.

The problem of the study

Depression is a widespread psychological problem around the world, with about 340 million people suffering from depression around the world and affecting the way they think and act. The incidence of depression among health care providers (parents) of diabetic children in Riyadh, Saudi Arabia is associated with a lack of awareness about self-management and treatment, an increase in medical burdens and expenses, which affects the health, psychological and social aspects and is a burden on parents which may negatively affect public health and quality of life.

Quality of life assessment is of vital importance, as both chronic disease and treatment strategies can lead to negative symptoms and difficulties in the lifestyle of patients and their families. The assessment of mental health and quality of life for caregivers from parents includes attention to those who develop symptoms of depression or anxiety and evaluation of new therapeutic techniques taking into account psychosocial damage and awareness of dissatisfaction with care.

Study Questions

- What is the relationship between parental depression and the caregiver burden?
- What are the associations between the child and parents characteristics with each other and with the caregiver burden?
- How does the identification of significant predictors of caregiver burden help the parents with providing better care for children with diabetes?

### Study Objectives

The Study focused on mothers and fathers who are raising a child with diabetes in Riyadh, Saudi Arabia; include child characteristics, such as child behaviors; parent characteristics, such as parental depression; and the marital relationships aspects, such as marital struggle or marital satisfaction, as predictors of mothers' and fathers' caregiver burden.

### Specific Objectives

- Evaluate the prevalence of depression among caregivers for diabetic children in the kingdom of Saudi Arabia.
- Evaluate the quality of life of caregivers for diabetic children in the kingdom of Saudi Arabia.



- Assess the relationship between depression and quality of life of caregivers for diabetic children in the kingdom of Saudi Arabia.

### Importance of the study

Family caregivers in the kingdom of Saudi Arabia are vital partners in sophisticated health care services delivery, and this case exemplifies the associated caregiver burden and stress during diabetes treatment. Unlike professional caregivers such as nurses, informal caregivers, typically members of family or friends, provide care to individuals with a variety of conditions. As more evidence recommends that caregiving is unhealthy to one's health, increased awareness is being paid to the caregivers' day to day well-being.

Caregivers often experience psychological, behavioral, and physiological effects that can contribute to impaired immune system function and coronary heart disease, and early death. Good public health and social care are essential for promoting caregivers' health, preventing disease and treating chronic illness, and training all health providers to deal with psychological issues and disorders is essential. Primary mental health care at the community level for caregivers is critical; focusing on the

long-term care of psychological disorders, as well as providing education, training, and support to caregivers.

An appropriate and supportive legislative environment, based on internationally accepted human rights standards, is needed to ensure that the highest quality of services is provided to caregivers with psychological illness.

### Materials and Methodology

A cross-sectional design was used with a systemic random sample of 100 subjects; parents of children with diabetes aged 5–12 years were selected. A questionnaire was used for collecting information about socio-demographic data and clinical characteristics. Depression, Self-care management behaviors and the barrier to adherence were collected.

### Sample and Setting

Using the WHO guidebook for Sample Size Determination in Health Studies, at confidence interval 95% with a conservative estimate of the 15% anticipated population proportion and with an absolute precision of 2%, the minimal sample size needed for the study was calculated to be 100 caregiver; Participants included families with diabetic children who were between aged 5–12 years in Riyadh, Saudi Arabia. Families were

randomly recruited as volunteer participants from the diabetes management clinic at a Saudi medical center at the time of their visit to the clinic. Information on those patients was collected as part of a clinical trial. Parents (study subjects) gave informed written consent for inclusion before the participation in the study. The study was conducted under the Declaration of Helsinki.

### Data Collection and Analysis

Data was collected using the following tools:

#### **First Tool- Biometric Demographic Data Form:**

It was amplified by the researcher and included specific information about the patient and caregivers about age, gender, educational level, marital status, date of diagnosis, number of hospital admissions, etc.

#### **The second tool- II Scale Inventory Beck:**

The second Beck Depression Scale is the second version of the Beck Inventory and released in 1996. The scale consists of 20 set of items to measure the severity of depression starting at the age of 25 years; each group consists of four terms arranged gradually from no depression to more severe, and grades were given according to (0-3), and therefore depression degree is determined by total grades of items.

### **Third Tool- World Health Organization Quality Of Life (WHO QOL – BREF) 2004**

The Standard Life Quality Scale was developed as a shortened version of the World Health Organization (WHO) Quality of Life Scale (100) for use in time-limited cases. The Scale contains 24 items covering four areas: Physical Health (7 items) and Mental Health (6 items), Social relationships (3 items) and environmental health (8 items). It also contains one item for measuring public health and another for measuring the quality of life. Each item records a result from (1 to 5) on the answer scale.

#### **Data Analysis**

Data were checked for completeness and consistency. As for data analysis, SPSS software will be used. The confidence interval of 95% and the odds ratio are utilized as a measure of risk.

#### **Research Limitation**

Assessment of the caregiver and caregiving situation is particularly complex because it involves:

- Assessing individual psychological symptoms of caregivers (often below clinically-significant levels) and sometimes also assessing symptoms or psychopathology in care recipients
- Understanding the demands which illness or disability impose on the family
- Determining the circumstances which predispose the caregivers to have positive or negative experiences during the period of caregiving

## Results and Discussion

Informal caregivers – people who afford regular care to closely related persons in need of help for an extended period and who did not choose caregiving as an occupation – represent a large population proportion. Current estimates reveal that in Europe, with a population of about 750 million, about 125 million people are informal caregivers.

The emergence of a subjective burden is a complex multivariate process. The development of the framework of the Burden Scale for Family Caregivers was based on two conceptual models. The Caregivers' Stress Model by Pearlin and colleagues describes five interacting components mediated by coping and social support: background and context (e.g. socio-economic status characteristics); primary stressors (e.g. relational

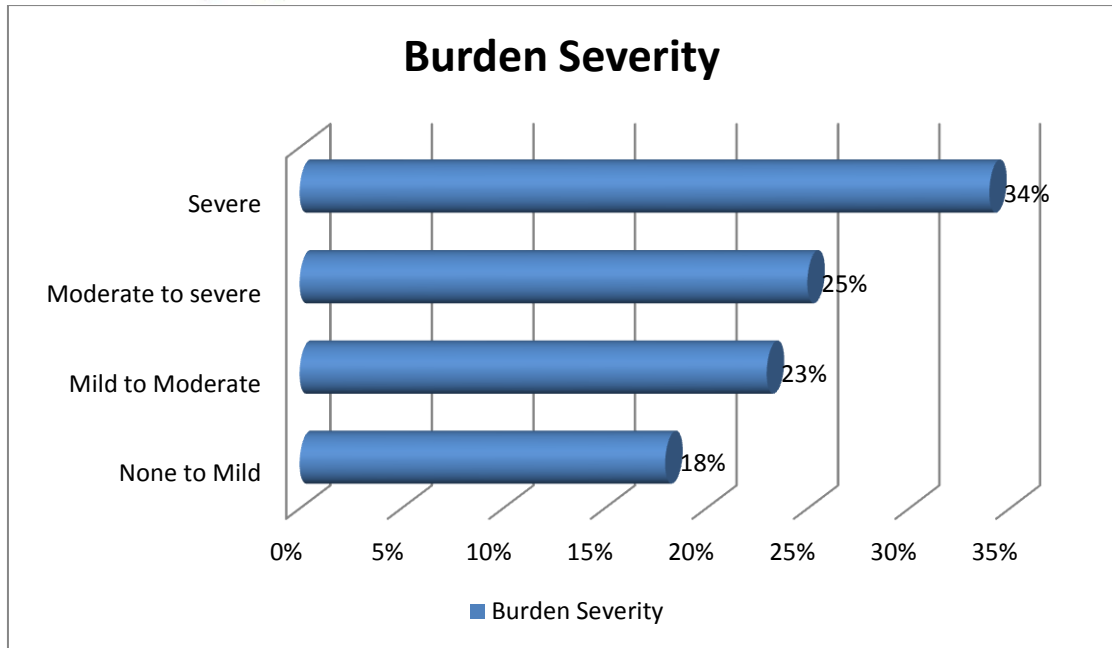
deprivation); secondary role strains (e.g. job-caregiving conflict); secondary strains (e.g. loss of self); outcomes (e.g. physical health).

The practical value of the "subjective burden among family caregivers" theoretical concept has been demonstrated by the predictive subjective burden power, which has been empirically well confirmed: At the social level of health services research, the subjective family caregivers' burden is a powerful predictor of institutionalization and, hence, of the termination of home care

- The prevalence of depression in the sample was 32%
- 74% of those caregivers have an above average extent of physical symptoms.

Score	Burden Category	Risk symptoms	Sample percentage
0-20	None to Mild	Not at risk	18%
21-40	Mild to Moderate	Moderate risk	23%
41-60	Moderate to Severe	Increased risk	25%
61-80	Severe	Very high risk	34%

Table (1) illustrate the burden severity of care



- There is a statistically significant relationship between the degree of depression and age which is that the degree of depression increases with age ( $p = 0.001$ )
- As for gender, there was a statistically significant correlation indicating that the incidence of depression among females was higher than that of males ( $p = 0.001$ ).

This may be explained by research that focuses on family and work roles of parents and the relationship those roles have on parents' depression (Aneshensel, Frerichs, & Clark, 1981).

- Regarding the level of education, there was a statistically significant relationship between the educational level and the degree of depression. The lower the educational status, the higher the degree of depression ( $p = 0.002$ )

- There were no statistically significant differences between work and the degree of depression among caregivers of children with diabetes.
- In the case of marital relationships and caregiver burden, Erel and Burman (1995) also found that there was a significant and positive direct relationship between a marriage relationship and the caregiver burden felt by the parent, providing additional evidence for the spillover theory. Therefore, the marital relationship can be viewed as a source of negative or positive influence, with the feelings produced from the marital relationship contributing to caregiver burden (Fincham & Hall, 2005).

Variable		Mean (SD)	Median	Number	Percentage
Age (Years)		42.82 (5.38)	51		
Years of Education		15.70 (2.81)	12		
Gender	Male			24	24%
	Female			76	76%
Marital Status	Married			65	65%
	Single			15	15%
	Widow			12	12%
	Divorced			8	8%

Table (2). Distribution of sex, age, marital, educational and socio-economic status of participants (n=100)

Subjective burden affects family caregivers at the individual level, particularly concerning health. Self-assessment reports have shown that family caregivers reveal, on average, a higher number of depressive signs



than non-caregivers, but do not proclaim significantly more physical problems. Thus, the same age caregivers and non-caregivers do not oppose in a related clinically manner in subjective physical health. The higher the family caregivers subjective burden, the more physical symptoms were reported, e.g., in samples with more than 1,000 participants. Examination of the objective mortality criterion showed that only caregivers who experience subjective burden are at a higher risk of mortality. The caregivers' mortality of those who do not experience subjective burden is not significantly higher than that of non-caregivers of the same age.

## Conclusion

The burden endured by family caregivers is the essential caregiver-related variable in care at home of a chronically-ill person. The extent of subjective burden has a significant impact on the family caregiver's emotional and physical health, and even affects the spouse caregivers' mortality. It influences the way the family caregiver deals with the care-receiver and determines the time of institutionalization.

The caregivers' psychological and physical health, who in this study were mothers and fathers, was strongly influenced by caregiving demands. Child health problems were a significant predictor of caregiver psychological well-being, both directly and indirectly, through their

impact on self-perception and family function. Caregiving requirements contributed directly to both the caregivers' psychological and physical health. The practical child's day-to-day needs generated difficulties for parents. The social support influence provided by extended family, friends, and neighbors on health outcomes was secondary to that of the direct family working closely together. Family function induced health directly and also mediated the self-perception, social support, and stress management effects. In families of children with diabetes, strategies for optimizing caregiver physical and psychological health include behavioral support management and daily functional activities as well as stress management and self-efficacy techniques. Regarding prevention, providing parents with cognitive and behavioral strategies to manage their child's health status may have the potential to improve caregiver health outcomes.

### Recommendations

- That family support in the care of diabetics has a significant impact on improving the health outcomes of diabetics. It is therefore essential that diabetes self-management education and support are available to all people with diabetes and their families to overcome the emotional impact of the disease that can lead to a negative quality of life; World Health

Organization says diabetes will become the seventh leading cause of death in 2030.

- The burden of diabetes can be prevented or reduced by maintaining the effectiveness of simple lifestyle measures in preventing type II diabetes.

To help prevent type II diabetes and its complications, people should:

- Work to attain and maintain a healthful weight;
  - Physical activity - at least 30 minutes of regular moderate physical activity on most days of the week, weight control requires more physical activity;
  - A healthy diet includes 3 to 5 daily servings of fruits and vegetables, reducing intake of sugar and saturated fat; And
  - Avoid smoking tobacco, as smoking increases the brain and Cardiovascular diseases.
- Work on early detection of depressive symptoms in caregivers for people with diabetes.
  - Conduct training sessions for diabetes care providers to better adapt to the conditions and pressures of care.
  - Conduct a study on the factors affecting the incidence of depression in caregivers for people with diabetes.

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Name: \_\_\_\_\_

Date: \_\_\_\_\_

Gender: \_\_\_\_\_ Age: \_\_\_\_\_

We are asking you for detailed information about your current situation. The present situation comprises your caregiving deduced from the illness of your family member.

The following statements often point to the type of your assistance. This may be any guide up to treating care.

Please put an "X" for the best classification of your current situation.

**Please answer every question!**

	strongly agree	agree	disagree	strongly disagree
1. I feel fresh and rested in the morning.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My life satisfaction has suffered because of the care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I often feel physically exhausted.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. From time to time I wish I could "run away" from the situation I am in.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I miss being able to talk with others about the care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I have enough time for my own needs and interests.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Sometimes I feel that the person I am caring for is using me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Away from the caring situation I can switch off.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	strongly agree	agree	disagree	strongly disagree
9. It's easy for me providing the necessary nursing care (washing, feeding etc).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Sometimes I don't really feel like "myself" as before.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. The care I give is acknowledged by others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Since I have been a caregiver my financial situation has decreased.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I feel like being forced into this caregiving situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. The wishes of the person I am caring for are reasonable in my opinion.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I feel I have a handle on the care situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. My health is affected by the care situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I am still capable of feeling really joyful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I have had to give up future plans because of the care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Caregiver Burden Scale

Caregiver's name: \_\_\_\_\_ Age: \_\_\_\_\_ Gender: \_\_\_\_\_  
 \_\_\_\_\_ Education Degree: \_\_\_\_\_ Marital  
 Status: \_\_\_\_\_

Topic	Never	Rarely	Frequent ly	Always
1. Do you feel stressed due to balancing between caring for your diabetic child and trying to meet other family or work responsibilities?	0	1	2	3
2. Do you feel embarrassed over your diabetic child's behavior?	0	1	2	3
3. Do you feel angry when you are besides your diabetic child?	0	1	2	3
4. Do you feel that your diabetic child currently affects your relationship with other family members or friends in a negative way?	0	1	2	3
5. Are you concerned about what the future holds for your diabetic child?	0	1	2	3
6. Do you feel your diabetic child is dependent on you?	0	1	2	3
7. Do you feel tense when you are around your diabetic child?	0	1	2	3
8. Do you observe that your health has suffered because of your involvement with caregiving?	0	1	2	3
9. Do you think that you don't have sufficient privacy?	0	1	2	3
10. Do you believe that your social life has endured too much because you are caring for a child with diabetes?	0	1	2	3
11. Do you feel uneasy about having friends over, because of your diabetic child?	0	1	2	3
12. Do you consider that you do not have enough money to care for your diabetic child, in addition to the balance of your expenses?	0	1	2	3
13. Do you feel that you will be incapable of taking care of your diabetic child much longer?	0	1	2	3



14. Do you feel you can not control your life since your diabetic child's illness?	0	1	2	3
15. Do you crave you could leave the care of your diabetic child to someone else?	0	1	2	3
16. Do you feel unsure about what to do about your diabetic child?	0	1	2	3
17. Do you think you can be doing more for your diabetic child?	0	1	2	3
18. Do you think you can do a high-grade job in caring for your diabetic child?	0	1	2	3
19. How often was your diabetic child admitted to the hospital?	0	1	2	3
20. Overall, how often do you feel burdened in caring for your diabetic child?	0	1	2	3
<p>Scoring Key            0 to 20 = little or no burden, 21 to 40 = mild to moderate burden, 41 to 60 = moderate to severe burden,            61 to 80 = severe burden.</p>				

Source: Zarit et al. (1980), Gerontologist, 20(6), 649-55