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# Parenting Stress among Parents of Children with Type 1 Diabetes Mellitus

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## Abstract

**Type 1 Diabetes Mellitus is a common and widely spreading chronic disease among children. Affected children's parents are prone to psychological illness. Services of nurse are required to measure the stress level among parents of children having T1DM. The purpose of this study is to extract the parenting stress among parents of children with Type 1 Diabetes Mellitus (T1DM). The study aims to find the factors creating stress among parents, the differential level of stress in between father and mother, a descriptive correlational design by recruiting 98 parents through network purposive sampling and they completed the Parenting Stress Index-Short Form questionnaire. The results revealed that parents reported significant level of stress, with a mean score of 111. Moreover, the results indicated that mothers stress level is significantly higher than fathers (t=2.6; P=0.01). Greater parental stress was associated with increasing age of parents (β = .56, P<.000). Nurses can play a vital role in sustainability and empowerment of parents from time of diagnosis till the cure. The nurses required special trainings to cater parents according to their needs and demands. Providing parents psychological support and educational awareness.**

**Keywords**: Type 1 Diabetes Mellitus; Parental Stress; Parenting Stress Index; Psychological Support

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## Introduction

Type 1 diabetes is a major global health problem. It is common among young ones (Nwaokoro et al., 2014; World Health Organization, 2019). Globally 371 million people suffer from this disease (Juvenile Diabetes Research Foundation, 2012). The highest incidence of disease is among European children and is expected to be doubled by 2020 (Boogerd et al., 2014). Rapidly increasing urbanization and significant changes in living patterns is increasing disease prevalence in Middle Eastern region (Alghadir et al., 2016). Jordan has the highest prevalence of diabetes around the world (Ajlouni, Jaddou and Batieha, 1998). The prevalence of diabetes has increased from 6.3% to 7.4% in 2004 among Jordanian population (Centers for Disease Control Prevention, 2006). There is 31.5% increase in the prevalence of diabetes in Jordanians aged 25 years or older compared with a similar survey conducted in 1994 (Ajlouni et al., 2008). Population growth rate and disease prevalence estimated that by 2050, approximately 1 to 3 million people in Jordan will have diabetes, hypertension, or increased blood cholesterol (Brown et al., 2009).

The disease is characterized by cell destruction and insulin deficiency. The deficiencies may cause hyperglycemia and altered metabolism. The symptoms commonly started in childhood or early adulthood. (Boogerd et al., 2014). T1DM with ketoacidosis (DKA) is the leading cause of mortality and morbidity in children and affects 1-10 cases per 100 patients (Roche, Menon, Gill and Hoey, 2005). High disease prevalence creates economic burden (Moucheraud et al., 2019). The healthcare costs of T1DM in the United States are estimated to be $174 billion annually (Juvenile Diabetes Research Foundation, 2012). The prevalence of T1DM among children can be controlled by self-care program encompassing adherence to insulin injection process, blood sugar monitoring, diet restriction and physical activity (Soltesz, Patterson and Dahlquist, 2010). The complications of the disease result in low quality of life (Malerbi et al., 2012).

Parents usually show emotional and physical stress after the diagnosis of disease. Emotionally, the parents express feel of anger, fear, grief, and helplessness. Physical reactions are weight loss or gain, headaches, sleep loss and fatigue (Streisand et al., 2010).

Parental support is required to enhance children adherence to diabetes self-care (Nabors et al., 2011). Therefore, caring for a child with T1DM can be emotionally and physically exhausting for parents (Johnson, 2013; Pateraki et al., 2015) This stress can cause mental illness and depression among parents (Flynn, 2013)

The disease is described as a family disease since; the whole family is focused on providing health care toT1DM patient (Williams et al., 2009). The family suffers greatly and collectively from the diseases. This creates strong physical and psychological impacts on parents. Investigating the factors associated with stress can be essential in providing education to parents for the better cure and management of T1DM children.

The parents of children with T1DM experience high level of

stress at the time of initial diagnosis of disease (Oskouie et al., 2013). Parental stress is expressed as negative feelings, these feelings are due to the fear and impact of disease on family lifestyle (Streisand et al., 2008). Behaviorally problematic children are unable to perform diabetes management efficiently being a reason of stress on parents (Delamater et al., 2018).

Haugstvedt (2011) reported that T1DM is managed through a complex treatment regimen and parental involvement is essential. It involves parental efforts for the maintenance of dietary plan and physical routine. Along with basic medical education (Melboume, 2010). Altering adverse effect of hypoglycaemia, seizures and amputation parental involvement and assistance is necessary (Williams and Pickup, 2007).

Malerbi et al. (2012) found out that both parents reported high level of parental stress due to their children's conditions. Nevertheless, mothers experienced higher level of discomfort, anxiety and depression than fathers. Generally, mothers are the primary care taker of the effected child. Streisand et al. (2010) illustrates that single mothers have higher level of stress and single parenting reduces the efficiency of care taking child. Lack of medical education among parents' aids in stress level (Abolhassani et al., 2013).

Family functioning and upbringing of child is adversely affected due to the disease. The family functioning cycle is disrupted (Williams et al., 2009). Parental conflict created negative impact on disease curing. Whereas, positive parental attitude and relations aids in recovery of child (Young et al., 2014; Williams et al., 2009).

To improve self-care, health behaviour of children and families have to be understood by prescribed therapist (Marshall et al., 2009). Therefore, it is essential to understand the social, physical, financial, and psychological aspects that are vital in parents and their child's adjustment to T1DM (Streisand, Mackey and Herge, 2010). The psychosocial aspects have a strong impact on the well-being of children with diabetes, it also increases the family's capacity of catering their child (Moreira et al., 2014). Low family income increases the stress level of parents (Oskouie, Mehrdad and Ebrahimi, 2013; Monaghan et al., 2009).

## Methods

Study Design

A descriptive correlational design was used to describe the level of stress among parents of children with T1DM and its correlates. The study was conducted in city of Aman, the capital of Jordan. The researchers have collected the data in a naturalistic setting, participant's homes and workplaces. The target population was the Jordanian parents of children T1DM who are living in Amman. Snowball sampling technique was used to identify suitable participants through the researcher's social network.

Study Participants

The participants were purposively selected from the target population and those who met the eligibility criteria were invited to participate. As it was recommended by (Johnston et al., 2010), the initial participants were asked about other potential participants.

The inclusion criteria were Jordanian parents who had a four to eleven years old child with T1DM and minimal duration of time since diagnosis was three months. Also, parents who were involved in this study had the ability to read and write Arabic. The exclusion criteria were parents whose child had other chronic or critical illnesses.

The total sample consisted from 98 parent, 53 mothers and 45 fathers. The researcher recruited into the sample those who were available and willing to participate, that is some participants were part of a couple parenting the same child, others were not. The sample size was calculated using the G power software for sample size estimation, the sample size was calculated at a medium effect size; 6 predictors; power of 0.80 and $\alpha < 0.05$).

## Ethical Consideration

The study protocol was approvedby Mutah University ethical committee. All subjects gave written informed consent in accordance with the Declaration of Helsinki.

## Study Instruments

The data collection was conducted by using a questionnaire consisting of two sections that were distributed face to face by the researcher to parents of children with T1DM.The first part of the questionnaire include information of the participants' socio-demographic characteristics. It also included questions determining the parent relation to the child (mother or father), parent age, and age of the child, time of diagnosis, monthly income, and number of children who have T1DM in the family.

The second part of the questionnaire was the original Parenting Stress Index- Short Form (PSI – SF) (Abidin, 1995). This self-report instrument consists from 36 items. The scale is divided into three subscales: parental distress (PD) (emotional distress in the parenting role) which includes the items from 1-12, Parent-Child Dysfunctional Interaction (P-CDI) problematic parent – child interactions which includes the items from 13-24 and Difficulty of Child (DC) problematic child behaviour or demands which includes the items 25-36 (Abidin, 1995). The PSI-SF is rated on a 5-point Likert scale, ranging from 1 (strongly agree) to 5 (strongly disagree). The scale was scored by reordering the items so that 5 = 1, 4 = 2, 3= 3, 2 = 4, and 1 = 5. Possible scale scores range from 36 to 180, indicating the overall level of stress experienced by the parents as a function of the three subscales. The higher the total score, the higher the level of stress.

On the PSI-SF, scores above 33 on the PD and DC subscales and above 27 on the PCDI subscale are considered clinically elevated. Raw total scores above 90 indicates clinically significant high level of stress (Abidin, 1995).

According to Abidin (1995), the result of the Cronbach's alpha test indicated that the scale had a strong reliability. The $\alpha$ coefficients of the PSI-SF was 0.91 for total scale, with 0.87 for PD, 0.80 for P-CDI and 0.85 for DC (Abidin, 1995). Construct validity and predictive validity have been demonstrated for this instrument.

A translated Arabic version for PSI–SF was obtained from

Psychological Assessment Recourses publisher of psychological assessment materials. According to Dardas and Ahmad, (2014) the Arabic version of the PSI-SF has high over all internal consistency (Cronbach's alpha= 0.91). Internal consistency of the three Arabic subscales was also high with the following Cronbach's alpha: PD= .91, P-CDI =0.85 and DC=0 .82.

## Data collection

Before the study was conducted, the approval from the Dean of Princess Muna College of Nursing was obtained, since the research was conducted through the researcher's social network, the approval from the Institutional Review Board was not required.

Names and addresses of parents of T1DM children were obtained through snowball sampling. Parents were contacted either by telephone if it was available or by visiting their homes to get their agreement to participate in the study. A total of 98 parents who met the inclusion criteria agreed to participate in this study. Parents were provided with a detailed description of the purpose of the study, benefits, duration, procedure, confidentiality and participant's rights. Data were collected at parents' homes where privacy and comfort were maintained.

Self-report questionnaire (demographic and PSI –SF) were used to collect data from parents who agreed to participate in the study in the presence of the data collector. Instruction was given to the participants before obtaining their responses and they were assured that the result would be used for research purposes only. It took 10-20 minutes for each participant to the complete questionnaire. Participants were informed that they can withdraw at any time. Confidentiality was assured to all parents and the questionnaires were coded numerically. The questions of the Arabic version of the PSI-SF instrument had no harmful effect on parents feeling with no questions asking about sensitive issues. Completed questionnaires had no identification data and were kept by the researcher safely to ensure confidentiality.

Data Analysis

Analysis of data was carried out by using the Statistical Package for Social Science (SPSS) version 17 with the significance level of 0.05. The mean, standard deviation, and frequency were used to describe the sociodemographic variables and parental stress level among parents of children with T1DM. Inferential statistics (independent sample t test) was used to find out the difference in parental stress between mothers and fathers. Also, Linear multiple regression was used to identify the predictors of parental stress. Stepwise linear multiple regression analysis was used which combined forward and backward entering of the predictors to the model to evaluate their contribution to the dependent variable and the other independent variables were controlled through the computer-based technique rather than the researcher (Leech, Barrett and Morgan, 2008). The Zero-order part and partial correlation of each predictor with scores of each expected control subscales were requested in addition to set of 0.05 P value as a default level of significance. Partial correlation was requested in order to identify any suppression effect of some predictors on others which might affect the slope of regression.

The demographical data that were entered as predictors include; parent's age, child's age, gender, monthly income, time since diagnosis. Since the numerical variables have just two categories, there was no need for dummy coding of variables.

## Results

A total of 98 parents of children with T1DM were included in this study, 53 (54.1%) were mothers (mean age = 35.0 ±5.8 years) and 45 (45.9 %) were fathers (mean age= 32.0 ±4.6years). The overall mean age of parents was (33.68 ±5.48). Regarding the parent's monthly income, the mean was 429.39 JD (±116.399). The mean age for the affected children was 7.07 years (±1.81), their age ranged from 4 to 11 years. The mean time since diagnosis with T1DM was (10.66 ±3.6 years) (Table 1).

## Parental Stress Level

The total scores of PSI-SF ranged from 55-152 (mean = 111.3±19.7). Difficult Child (DC) subscale revealed the highest mean (38.2 ±7.4), Parental Distress (PD) subscale total score mean was 37.5 ±8.9. The lowest parents mean score was for the Parent–Child Dysfunctional Interaction (PCDI) subscale, with mean of 35.6 (± 7.7).

More than half of parents 82.7% (n= 81) reported high stress level, where 79.6% (n=78) on PD level, 92.9% (n=91) PCI and 67.3% (n=63) for DC subscale. For mothers, 81.1% (n=43) reported high stress level, while 84.4% (n=38) of fathers reported high stress level.

Chi square test was conducted to identify the differences among high versus low parental stress level between mothers and fathers. The results showed no significant differences between high versus low stress level either at total stress level as well as PD and PCDI subscales. However, there was a significant difference between high and low stress level in DC subscale ($X^2$ 12.89, $p < 0.05$). Table (2) presents the percentage of high versus low stress level of total scale as well as subscale for mothers and fathers.

Differences of Parental Stress Level between Fathers and Mothers

Independent sample t- test was used to identify the significant difference of Parental stress between fathers and mothers. The result showed that, there was significant differences in parental stress between fathers and mothers (t= -2.6, p= < .05), where mothers reported higher mean stress score (115.9± 21.1) than fathers (mean= 105.8 ±16.3). Also, there was significant difference on the PD subscale (t= -2.4, p= < .05) as well as the DC subscale (t= -2.7, p= < .05) in both subscales' mothers had higher mean scores than fathers (Table 3).

## Predictors of Parental Stress Level

Stepwise Linear multiple regression was used to identify the predictors of the parental stress among the entire study sample. The demographical data that were entered as predictors include; parent's age, child's age, gender, monthly income, time since diagnosis. The results showed that only parental age and child age have predicted the parental stress significantly. The overall regression was statistically significant, (R=0.59, r2= 0.35, P

=.03). These results indicated that the parent's age and child's age accounted for approximately 35% of variance in the study participant's parental stress. For the parental age (β =0.56, P = .000) and the child age (β = - 0.18, p = 0.03), the negative β slope mean the parental stress of study sample increase when the child age decreased. Table 4 shows the results of stepwise multiple regressions.

| **Demographics characteristics** | | **Mean** | **(SD)** |
|---|---|---|---|
| | Father | 32 | 4.6 |
| Parent age in years | Mother | 35 | 5.8 |
| Child age in years | | 7.0714 | 1.8177 |
| Time since diagnosis | | 10.663 | 3.64 |
| Monthly income in Jordanian Dinar | | 429.398 | 116.399 |

**Table 1:** Demographic Characteristics of participant in this study (N = 98)

| Stress level | Whole sample | Mother | Father | $X^2$ | P |
|---|---|---|---|---|---|
| Total stress | | | | | |
| High | 82.7% (n=81) | 81.1% (n=43) | 84.4% (n=38) | 0.19 | 0.79 |
| Low | 17.3% (n=17) | 18.9% (n=10) | 15.6% (n=7) | | |
| PD | | | | | |
| High | 79.6% (n=78) | 79.2% (n=42) | 80% (n=36) | 0.009 | 1 |
| Low | 20.4% (n=20) | 20.8% (n=11) | 20% (n=9) | | |
| PCDI | | | | | |
| High | 92.9% (n=91) | 94.3% (n=50) | 91.1% (n=41) | 0.38 | 0.7 |
| Low | 7.1% (n=7) | 5.7% (n=3) | 8.9% (n=4) | | |
| DC | | | | | |
| High | 67.3% (n=63) | 83% (n=44) | 48.9 % (n=22) | 12.89 | 0.000* |
| Low | 32.7% (n=32) | 17% (n=9) | 51.1% (n=23) | | |
| * significant p< 0.05 | | | | | |

**Table 2:** Percentage of high versus low stress level among mothers and fathers

| **Parental Stress** | **Fathers (n=45)** | | **Mothers (n=53)** | | **t** | **p** |
|---|---|---|---|---|---|---|
| **PSI-SF** | **Mean** | **SD** | **Mean** | **SD** | | |
| Total | 105.8 | 16.3 | 115.9 | 21.1 | -2.6 | .01* |
| PD | 35.28 | 7.77 | 39.43 | 9.41 | -2.4 | .02* |
| PCDI | 34.53 | 6.71 | 36.49 | 8.4 | -1.3 | 0.2 |
| DC | 36.02 | 7.78 | 39.98 | 6.68 | -2.7 | .008* |

**Table 3:** Differences of parental stress level between mothers and fathers

| Model | β | t | Sig | R | r2 | Sig |
|---|---|---|---|---|---|---|
| Parent age | 0.56 | 6.6 | 0 | | | |
| Child age | -0.18 | -2.1 | 0.03 | 0.59 | 0.35 | 0.03 |

**Table 4:** Parental stress predictors among whole study sample (n= 98)

## Discussion

Parenting child with T1DM is a difficult task. Parental stress is outburst in a form of psychological illness. Higher level of stress and disruption in mental health may create negative impact on family cycle. Majority of respondents have faced significant level of stress elaborated in research. The previous literature about parental stress and T1DM (Nwaokoro et al., 2014) corresponds with the findings of this paper. In the current study, complex parental role requirements and the needs of children might have combined together and were reflected as parental stress. Children with behavioral problems aids in parent's stress level.

Mary et al. (2006) explains the behaviour of a child might predict the mother's behaviour. The findings were consistent with the findings of Streisand et al., (2008) who argued that caring of child with T1DM is stressful task as parenting. It was supported by similar study which states that; particularly child with difficult behaviour can be very stressful for both parents (Hilliard, Harris, and Weissberg-Benchell, 2012).

The parents have reported relatively high mean score on PD subscale (37.5). PD describes the experience of parent distress that is determined by personal factors, which is usually demonstrated as dysfunctional parenting. The findings of the current study were consistent with the findings of other studies (Nightingale et al., 2019; Nwaokoro et al., 2014; Nordfeldt et al., 2013; Streisand et al., 2010). Notably the option in questionnaire "I feel trapped by my responsibilities as a parent" scored the highest mean in PD subscale which corresponds with the previous studies.

Mean score of P-CDI subscale was 35.5 indicating high stress level related to parent's perception of their child survival in society and parent's role in their life. This finding corresponded with the findings of Emily (2016) study according to which, parental stress of children with T1DM has a negative effect on parent communications with their child and causes family conflict.

The factors of high stress level among parents is supported by previous studies, according to Whittemore et al., (2010) stress appraisal and coping model to T1DM, the experience of rearing a child with T1DM elicits parental stress which is characterized by several psychosocial responses. The study of Elissa (2019) illustrates that being stigmatized is the core factor to influence parenting relationship. The negative perception of society about their parenting ability increases stress level. However, further studies with qualitative approach are requiring eliciting the specific causes that underlies the parent experience of stress.

Results of the current study revealed a significant difference in parental stress level between mothers and fathers. Mothers reported higher mean PSI-SF scores than fathers. The current study results support the findings of (Elahi et al., 2019). Who examined the difference in the level of stress between mothers and fathers of children with T1DM .Previous research findings indicated that the mothers of children with TIDM showed negative response, denial and decrease in self-esteem as a result of stress they experienced (Nwaokoro et al., 2014; Streisand, Mackey and Herge, 2010). In addition to other home duties, the mothers usually endure the responsibility for caring of children with T1DM and this explains the higher level of maternal stress. Moreover, coping with difficult behaviors of the child adds additional stress.

In the current study, negative correlation was found between the child's age and the level of parental stress among mothers. Mothers are usually the primary caregiver who provide the daily care for their child with physical illness (Streisand, Mackey and Herge, 2010). The lower the child ages the higher the mother's stress level. Parents of younger children face greater challenges in helping their child to gain an understanding of their illness and treatment (Whittemore et al., 2009) the results were supported by similar study of Malerbi et al. (2012) children's age was a significant source of parental stress in relation to complications of disease.

Parent's age is also found to be evident in increasing stress level. Older parents face more stress in comparison of younger parents. However, this conclusion is not evident in previous literature. This can may be because of Jordanian cultural context in which younger parents receive support from family. A previous study evident it that parent's stress is increased due to previous lifestyle of parents. The living standard, late parenthood and less exposure to children (Hansen et al., 2012).

The parental stress is corelated with their lack of awareness and inefficiency. Soon after the diagnosis of disease professional nurse helps can aids in normalizing the life pattern of parents. The nurses special training to deal with stress full parents and handling behaviourally challenged children with proper care and satisfaction of parents. Engagement of parents in educational events regarding the disease management and cure increase satisfaction level. Nurses proper communication with parents and addressing their concerns can make situation better.

Conclusion

It seems that the unexpected diagnosis of T1DM and parenting a child with such chronic illness impose an enormous amount of parental stress. Diabetes is a lifelong illness and parents usually face many challenges throughout the journey of child care. Therefore, it is essential for parents to educate themselves about the management and cure of the disease. The child's and parent's age are related in creating stress level. Mothers as being primary caretaker of house face greater stress levels. Parents previous life style is one of the reasons for rapidly increasing stress level. Professional nurses can create an ambiance of physical and psychological support for parents.

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Conflict of Interest

The author declares no conflict of interest.

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