

## REVIEW ARTICLE

# Parental Stress among Parents of Children with Type 1 Diabetes Mellitus: A Review

Ola Hassouneh<sup>1</sup>, Mona Nsour<sup>2</sup>, Lee Khuan<sup>3</sup>, Haytham Mohammad Al-Oran<sup>3</sup>

<sup>1</sup> Department of Child Health Nursing, Princess Muna College of Nursing, Mu'tah University, Jordan.

<sup>2</sup> Royal Medical Services, Amman, Jordan.

<sup>3</sup> Department of Nursing & Rehabilitation, Faculty of Medicine and Health Science, Universiti Putra Malaysia, 43400 Serdang, Selangor, Malaysia

## ABSTRACT

This review provides an overview of the evidence which concerns the parental stress of children with type 1 diabetes mellitus. Articles for this review were collected using the Science Direct, CINAHL, PsycINFO, Medline, Scopus, EBSCO, Springer, Ovid, PubMed, Google Scholar, and Cochrane Library. In total, 38 articles were relevant to this review. The findings of the reviewed studies provide an exciting opportunity to advance our knowledge for a different aspect of parental stress which is related to the disease and predictor's factor contributes to parental stress. This review sheds new light on developing the educational programs to reduce the level of parental stress and to help them to cope positively with this disease.

**Keywords:** Diabetes mellitus, Type I diabetes mellitus, Diabetic children, Parental stress, Predictors of parental stress

## Corresponding Author:

Lee Khuan, PhD

Email: leekhuan@upm.edu.my

Tel: +603-97692438

## INTRODUCTION

Diabetes Mellitus (DM) is one of the most common chronic endocrine illnesses of youth and forms a major worldwide health problem (1-2). A marked variation in diabetes prevalence is noted among different countries and there is an extraordinarily high incidence of diabetes, mainly type 1 diabetes mellitus (T1DM) in children (3). T1DM is one of the most common endocrine metabolic and chronic conditions of childhood and is characterized by absence or deficiency in insulin secretion and action, which leads to hyperglycemia and produces alteration in fat, carbohydrates and protein metabolism (3-4). The importance of DM along with hypertension as major cardiovascular risk factors that causes significant morbidity and mortality is undoubted (5-7).

T1DM is a common condition that is particularly challenging to control and manage during adolescence (8). Besides, T1DM is a chronic condition requiring long-term management behaviors and parent's support; therefore, it is not surprising that T1DM have a direct negative impact on the mental status of parents (9-10). Furthermore, the dilemma among parents of children

with T1DM is serious and considered as the main source of parental stress due to social and emotional adaptation, in addition to the loss of regular and routine life they lived before DM diagnosed (11).

Parental stress is expressed as negative feelings of anger, fear, grief, helplessness, and worries due to treatment (12-13). As well as, parent stress linked with many issues concerning lifestyle, such as compliance with treatment and resistance to the process of injection, that may result physically in pictures of weight loss or gain, headaches, sleep loss, fatigue and may lead to failure of metabolic control (14-15). The overall aim of this review was to provide an overview of the evidence for parental stress among parents of children with T1DM.

## METHODOLOGY

### Search Strategy

A searched electronic medical database was conducted including Science Direct, CINAHL, PsycINFO, Medline, Scopus, EBSCO, Springer, Ovid, PubMed, Google Scholar, and Cochrane Library. This review included studies that were published from 2001 till 2019. The following keyword search terms were used "diabetes mellitus", "type I diabetes mellitus", "diabetic children", "parental stress", "predictors of parental stress". The advanced search terms were a combination of "diabetes mellitus", OR "type I diabetes mellitus", OR "parenting

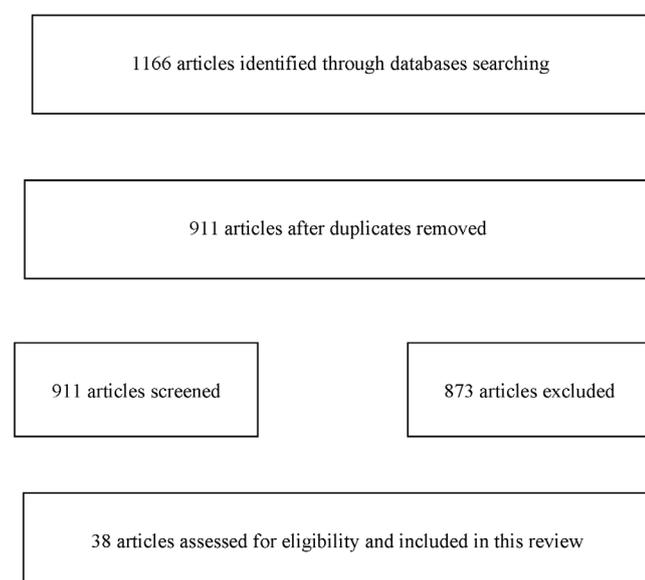
stress”, OR “predictors of parental stress”.

### Inclusion and Exclusion Criteria

For inclusion criteria in this review, all articles must fulfil the following criteria: (1) they were published in the English language; (2) they examined the parental stress as a study outcome; and (3) quantitative and qualitative studies were included. Previous reviews, letters and case reports were excluded.

### Included and Excluded Studies

The search strategy yielded a total of 1166. All articles were found in the English language with full text/methodology section in accordance with the inclusion and exclusion criteria of the review. However, 873 were excluded due to they weren't to be relevant in focus to the current review. Meanwhile, 255 articles were found to be duplicates. As a result, 38 articles were included in the review (Fig.1).



**Figure 1: Flowchart for the studies selection process**

## RESULTS

Three themes were identified: parental stress of children with T1DM, the different stress between mothers and fathers of children with T1DM, and socio-demographic variables and parental stress.

### Parental Stress of Children with T1DM

Parents' experience an array of emotional and physical responses which are expressed through feelings of being overwhelmed and out of control, in consequence of an unexpected diagnosis of diabetes in their children (15). Besides, stress can lead to the cause of decreased parents' mental health outcomes as a result of depression (16).

A number of the researchers, in trying to identify parental stress among parents of children with T1DM, Hullmann (17) pointed out that an increase in stress level among

parents due to chronic disease treatment that involved a daily care aspect. Similarly, Carpenter (18) notably that the complexity of diabetes treatment may clarify a higher possibility for parental stress. The parents of a diabetic child live with high levels of stress due to the treatment protocol, complications and many issues to lifestyle (2,15).

The parents of T1DM children experience a high level of stress due to initial shock from diagnosis and a basic role as caregivers affected by psychological, emotional, and social aspects (19). Moreover, parental stress comes from the inability of the parent to manage effectively their child. This finding corroborated by a study by Streisand and colleagues (20), they found that the caring of a diabetic child with difficult behaviors particularly with relation to tasks relevant to diabetes management can be incredibly stressful for both parents.

Hilliard and colleagues (21) described that the psychological stress among parents of T1DM children with treatment has an effect on family communication, may lead to family conflict, shrink and restrict the ability of parent's role effectively, in addition to a negative impact on child health. Other sources of parental stress resulted from fear of having another sibling with DM which was confirmed by frequent check of mothers and fathers the level of blood sugar for non affected children in the same family (22). Overall, in the previous studies reviewed above, there is evidence emphasized that parents of children with T1DM experience a high level of stress.

### The Different Stress between Mothers and Fathers of Children with T1DM

Numerous studies have found that there are differences in the stress levels between mothers and fathers of children with T1DM. Mitchell and colleagues (23) reported that both mothers and fathers of children with T1DM live with feelings of being overwhelmed in addition to significant stress due to their child's diagnosis. Whereas, Hilliard and colleagues' (21) reported that the parents perceived their children's misbehavior as challenging, particularly with relation to tasks related to diabetes treatment such as sleeping time and mealtimes.

Parents, and especially mothers, have a major responsibility in the administration of daily care for their child, so they experience significant emotional distress in response to their child's diagnosis, treatment and health outcomes (2,15). In particular, Mitchell and colleagues in (23) revealed that child disease characteristics may have stronger associations with mothers' stress than fathers'. Similarly, Malerbi and colleagues (22) found that the parents reported a high level of stress due to their children's conditions. Also, the results revealed that mothers experienced a higher level of discomfort and stress than fathers. Haugstvedt and colleagues (24) reported that both mothers and fathers showed that

their burden was related to lifelong health concerns but mothers reported a greater burden related to medical treatment, lack of information and lack of attention to their needs at the time of diagnosis and significantly more emotional distress than the fathers. Regarding marital status, Streisand and colleagues (15) revealed that single mothers reported a high level of stress than mothers with partners.

On the other hand, Oskouie and colleagues (19) conducted a qualitative study to explore parental stress. The result revealed that parents role in providing the care for children with T1DM and knowledge deficit about the disease and the interventions have greater responsibilities for parents and the main source of stress. Overall, according to previous studies burdens of children with diabetes for mothers is more than for father and reported that mothers experience a relatively higher level of stress rather than fathers.

### **Socio-Demographic Variables and Parental Stress**

The literature review explored numerous socio-demographic variables and parental stress of children with T1DM (i.e. child age, duration of diagnosis, and economic status).

#### **Child age and parental stress**

There is a paucity study examining the association of child age and high level of stress among parents of children with T1DM. Malerbi and colleagues (22) revealed that the child's age was a significant source of parental stress with complications of disease, hypoglycemia and diabetes care in young children if compared to parents of an adolescent age group. Halverson et al. (25) described that the young children's age, the age of rapid growth, irregular eating habits, and changing insulin demands, impose additional efforts and level of worries to maintain an optimum level of treatment for their children.

Jaser and colleagues (26) emphasized that parent of younger children and adolescents show a significant fear and worries from hypoglycemia, and how to balance their involvement in disease management. The American Diabetes Association (27) reported that caring for young children with T1DM provokes the feelings of being overwhelmed and worries due to their being disoriented to hypoglycemic episodes.

The age of the child with T1DM with developmental stages increases the challenges that the parent faces in becoming involved in diabetic care as in younger children (16). The age of the child with T1DM to developmental stages increases the challenges faced by the parent in becoming involved in diabetic care as in younger children, as well as the need for continuous monitoring and the need to cooperate with teachers add to parental responsibilities. However, no investigators have been able to draw on any research into the

relationship between the gender of the diabetic child and parental stress. The research to date has tended to focus on child age rather than child gender. As a conclusion, there are distinctive challenges that the parents face in parenting a child with T1DM at different developmental stages, whether younger or older. This suggests that parents of young children with T1DM may be at higher risk to have additional stress than the parent of older children.

#### **Time since diagnosis and parental stress**

The most stressful period for a parent who has a child with T1DM is immediately after the diagnosis, and present as symptoms of depression and emotional disruption which are resolved in the first few months to one year with emotional resiliency (16). When examining the effect of duration from initial diagnosis, Bowes and colleagues (28) found that long term periods of having a child with T1DM (after 7-10 years of diagnosis), the parent shows an adaptation level with diagnosis and daily diabetic care for their child, but the feeling of sorrow and anger come back from time to time as a result of critical situations such as hospitalization and child's development. Moreover, stress is likely to be highest through the first weeks instantly after a child's diagnosis, then decreases but does not diminish completely over the years (23). Also, families expressed their first year of lived experience as living a different and difficult lifestyle regarding the normal life they lived before their children diagnosed with diabetes and that described to the feeling of acceptance yet frustration, worry, and insecurity (29-30).

Researchers found that 17% to 22% of mothers reported high levels of stress in pictures of moderate to severe depression after their school-age children (8-16 years old) were newly diagnosed with T1DM (26). Landolt and colleagues (31) examined the prevalence and predictors of posttraumatic stress disorder (PTSD) in mothers and fathers of children with newly diagnosed T1DM. The study results revealed that the mothers of children aged 6 to 15 showed a significant level of stress until one-year post-diagnosis. Besides, they reported clinical symptoms of PTSD in 22.4% of mothers at 6 weeks, 16.3% at 6 months and 20.4% at 12 months. Related to previous studies, there was no such literature to describe the effect of parent age and the presence of other affected siblings in the family on parental stress with T1DM child.

#### **Economic status and parental stress**

Economic condition plays a significant role on the level of parents' stress and is considered as one of the barriers due to expensive treatment which is needed to maintain stability and metabolic control of the children, such as buying glucose test strips to check blood sugar and the laboratory examinations, in addition to the shortage of support from insurance companies (19).

The American Diabetes Association (27) estimated that

total cost of diagnosed diabetes in 2012 was 245 billion dollars, which highlights the significant burden that diabetes imposes on families and society including pain and suffering, resources from care provided by nonpaid caregivers. Furthermore, the Texas Pediatric Diabetes Research Advisory Committee (33) supposes that direct medical care costs for T1DM children with an average age of 12 years require hospitalization at diagnosis and each one imposes \$27,000 for additional care and revealed that the cost of diabetes increase in relation to its complication such as a diabetic child with kidney dialysis cost \$59,000 per year, if compared to \$31,000 for a child without diabetes.

Families with low monthly incomes live with more parental stress and worries concerning their children's metabolic control as a result of the cost of treatment, which added another stressor and symptoms of depression (19, 34). In particular, Jaser and colleagues (26) found that lower family income was the strongest predictor of parents stress. Overall, diabetes management inflicts a severe economic burden on the family of a child with T1DM and includes both direct and indirect costs, which result in increasing the level of parental stress in relation to low income.

In terms of other factors associated with parental stress, research on the subject has been mostly restricted to the limited study of the relationship between children's school performance and parental stress. Meo and colleagues (35) conducted a cross-sectional study to examine the effect of Type 1 diabetes on academic performance in Saudi children compared to non-diabetic children. The authors found that academic performance in children with Type 1 diabetes is significantly lower compared to their non-diabetic peers, and this drop in academic performance may result in the association between diabetes and cognitive function. In addition, the results revealed that parental stress strongly associated with a poor school performance of diabetic children. Conversely, a study was conducted by cooper and colleagues (36) to examine the school performance of Australian children with type 1 diabetes in comparison to their peers and they conclude that no significant variation between two chosen groups of diabetic and non-diabetic.

## DISCUSSION

This review attempts to highlight the importance of the evidence regarding parental stress among parents of children with T1DM. The literature review identified three main themes: parental stress of children with T1DM, the different stress between mothers and fathers of children with T1DM, and socio-demographic variables and parental stress. Based on the literature review of parental stress level; it is clear that there have been consistencies in the findings regarding emphasize that parents of children with T1DM experiences a high

level of parental stress (2,17-18,15,20-22). Moreover, the literature review has highlighted on the different stress levels between mothers and fathers of children with T1DM, it is clear that there have been consistencies in the results emphasize that mothers showed a significantly high level of stress than fathers (22-24).

As for the socio-demographic variables with a high level of parental stress, there were consistencies with studies finding regarding the association between parental stress and child age (16, 22, 25-26), time since diagnosis (16,23,26,28,31) and economic status (19,26,34).For the association child age and parental stress level, the findings indicated that younger child was significantly associated with a high level of parental stress (16), which is an agreement with other studies (22, 25-26). Regarding the association between duration of diagnosis and parental stress, there is only a small body of studies focused on whether the parents experience a high level of stress when their children diagnosis of T1DM. There are converses findings regarding the relationship between duration of diagnosis and parental stress, whether recently duration of diagnosis (16,26) or lately (28,31). This review also revealed that parents with lower monthly income reported a higher level of stress (19), this result is congruent with those reported by other studies (26, 34). On the other hand, what is not yet clear is the association between school performance and parental stress (35-36). Also, little is known about child gender and it is not clear whether associated with parental stress.

It is important to emphasize that nurses play a pivotal role in building a close relationship with parents. Nurses should be well prepared to provide comprehensive information about the disease and its sequence to the parents of diabetic children (especially parents of behaviorally problematic children) with more emphasis on parents and their children to empower them to instill routines in their child's daily activities and increase the likelihood of adherence to treatment.

## CONCLUSION

The current review provides a picture of the research literature on parental stress among parents of children with T1DM. This review focus on identifying the level of parental stress, the different stress level between mothers and fathers of children with T1DM and socio-demographic variables and parental stress. The parents of children with T1DM reported a high level of stress, and the mother reported a high-level than father. As well as, the younger child, the recent duration of diagnosis and low monthly income strongly associated with a high level of parental stress. Much uncertainty still exists about the relationship between school performance, child gender and parental stress. This review makes a major contribution to research as a key to developing an educational support program. Also, the findings should

make an important contribution to the field of assisting parents in improving adaptation to a stressful situation.

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