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Stress and Posttraumatic Stress in Mothers of Children With Type 1 Diabetes

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Abstract

The onset of acute and chronic illness in children frequently triggers episodes of stress and posttraumatic stress symptoms (PTSS) in mothers. Mothers of children with type 1 diabetes (T1D) consistently report high levels of stress and PTSS. The purpose of this integrative review was to review and synthesize the published empirical research. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were used to conduct this integrative literature review. A total of 19 studies were identified from a sample of 128. Stress and PTSS were prevalent in mothers of youth with T1D. While PTSS was most severe at disease onset, symptoms often persisted 1 to 5 years after diagnosis. The diagnosis of T1D in a child was traumatic for mothers. Stress and PTSS in mothers adversely affected children's health. Management of stress symptoms in mothers may lead to improved behavioral and metabolic outcomes in children.

Keywords

stress; posttraumatic stress; chronic illness; maternal attachment; type 1 diabetes

Type 1 diabetes (T1D) is one of the most prevalent chronic illnesses in childhood, affecting more than 200,000 youth in the United States (American Diabetes Association [ADA], Chiang et al., 2014). The overall prevalence of T1D continues to increase worldwide (Chiang et al., 2014; Liese et al., 2006; Maahs, West, Lawrence, & Mayer-Davis, 2010). Management of T1D in youth requires an intensive and complex daily regimen that includes continuous monitoring and constant attention from caregivers (ADA, 2012). Caregivers report high levels of stress related to both the diagnosis of T1D in their children, as well as the burden of daily management (Whittemore, Jaser, Chao, Jang, & Grey, 2012).

The onset of acute and chronic illness in children frequently triggers episodes of stress, posttraumatic stress symptoms (PTSS), or posttraumatic stress disorder (PTSD) in mothers. Stress is defined as a state of mental or emotional strain or tension and PTSS is defined as a

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subclinical state of mental or emotional strain that develops after a shocking, frightening, or dangerous event. PTSD occurs when PTSS becomes a diagnostic, clinically significant distress that impairs functioning (Horsch, McManus, Kennedy, & Edge, 2007). Mothers of children with T1D consistently report higher levels of stress and PTSS than fathers, as well as lower self-esteem and satisfaction related to caring for their child (Helgeson, Becker, Escobar, & Siminerio, 2012; Lewin et al., 2005). While fathers play an important role in disease management, mothers are most often responsible for carrying out the majority of daily disease-related tasks (Streisand et al., 2008; Wysocki & Gavin, 2006). This discrepancy may help to account for the differences in reported stress and PTSS in mothers compared with fathers (Landolt, Vollrath, Laimbacher, Gnehm, & Sennhauser, 2005; Mitchell et al., 2009).

T1D is unique because it is both an acute and a chronic illness (Horsch et al., 2007). The diagnosis is often experienced as an acute, life-threatening event, and episodes of hypoglycemia or hyperglycemia can occur at any time and can be severe, requiring hospitalization (Wood et al., 2013). Daily management of T1D has been reported as being intensive, stressful, and never ending (Horsch et al., 2007). Any error in daily management can lead to an acute event, and ongoing proper daily treatment vigilance and management is essential to reducing the risk of complications (Wood et al., 2013).

Mothers have reported both chronic and acute stressors related to disease management and complications in their children with T1D (Sullivan-Bolyai et al., 2016). These stressors are especially pertinent for mothers of young children, where disease management is even more complex due to administration of frequent, small doses of insulin, inconsistent eating patterns, and the inability of the child to recognize and communicate early symptoms of hypoglycemia (Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2003). These mothers must adapt their disease management tasks repeatedly to align with the child's growth and development. Mothers reported common daily stressors associated with T1D, including dietary management, diabetes-related family conflict, insulin administration, frequent daily blood glucose monitoring, fear of acute episodes, fear of long-term complications, constant worry associated with nighttime symptoms—"sleeping with your eyes open"—and mastering the treatment regimen (Beveridge, Berg, Wiebe, & Palmer, 2006; Sullivan-Bolyai et al., 2003, p. 24).

Women in general are at a 50% higher risk for developing a PTSD diagnosis than men (Levine & Land, 2014). The *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*; American Psychiatric Association [APA], 2013) criteria for PTSD include more than one month of (a) persist reexperiencing of a traumatic event, flashbacks, and nightmares; (b) persistent avoidance of stimuli associated with the event; and (c) persistent symptoms of increased arousal for more than a month (APA, 2013). An individual can experience symptoms of PTSS without meeting the criteria for PTSD. In addition, individuals with PTSS can develop PTSD over time.

The *DSM* criteria for PTSD diagnosis includes learning that one's child has a life-threatening disease as a precipitating event for PTSD (APA, 2013). Mothers of children newly diagnosed with T1D are not only at a heightened risk of experiencing PTSS, but also

of developing a diagnosis of PTSD. Heightened general caregiver stress has been associated with an increased risk of anxiety disorders and depressive disorders in the caregiver (Whittemore et al., 2012). Mothers of children with chronic illnesses are at risk for developing a variety of mental health disorders related to the chronic and acute stressors that they face as a result of their children's illness. For example, nearly 30% of mothers of adolescents who survived childhood cancers met diagnostic criteria for PTSD at some point after their child's remission had already occurred (Kazak et al., 2004). These mothers reported PTSD symptoms to an even greater extent than the adolescent cancer survivors themselves (Kazak et al., 2004).

Models of maternal-child dyadic coping suggest that successful emotional adjustment of both the ill person and the caregiver is enhanced when each member of the dyad perceives emotional support and positive coping from the other member (Berg et al., 2007; Bodenmann, Kayser, & Revenson, 2005). If one member of the dyad experiences unmanageable stress, both members are more likely to display poorer adjustment. For example, stress symptoms in mothers have been linked to poorer diabetes outcomes in youth, including poorer adherence, deteriorating glycemic control, poorer quality of life, and greater depression (Cameron, Northam, Ambler, & Daneman, 2007; Jaser, Whittemore, Ambrosino, Lindemann, & Grey, 2008; Whittemore et al., 2012). Adolescents who perceived that their mothers were unable to cope with their own psychological issues were more depressed than those who perceived that their mothers were able to manage (Butler, Skinner, Gelfand, Berg, & Wiebe, 2007). Collectively, researchers support the conclusion that maternal mental health is a critical component of mental health and adjustment in youth.

Mental health disorders in youth are associated with poorer T1D outcomes, including poorer glycemic control (Herzer & Hood, 2009; Hood et al., 2006). Poorer glycemic control is associated with poorer quality of life and increased risk for short- and long-term disease-related complications (Herzer & Hood, 2009). As maternal mental health is linked with mental health in youth, and as poorer mental health in youth is associated with poorer diabetes outcomes, it is important to identify mothers struggling with the acute and chronic stress associated with caring for a child with T1D. Screening for mental health disorders in mothers may be as important as screening for mental health disorders in children.

Detection and treatment of mental health disorders in mothers may not only improve their ability to accurately manage their children's diabetes treatment regimen, but also may prevent the development of mental health disorders in youth. Limited research has been devoted to understanding this phenomenon in mothers with chronically ill children. A better understanding of the stressors that are most common in mothers of children with T1D has the potential to inform the development of screening measures and interventions. Thus, the aims of this integrative review were to (a) review and synthesize the current published empirical research concerning stress and PTSS in mothers of preadolescent children with T1D; (b) identify emerging themes; and (c) suggest directions for future research, with a focus on future interventions that may serve to assist mothers in coping with stress and PTSS.

Method

An integrative review of the literature was performed following Whittemore and Knafl's (2005) framework for data collection, analysis, and synthesis and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, Altman, & the PRISMA Group, 2009). The steps of the analysis were (a) a well-defined literature search strategy was established with guidance from a medical librarian; (b) two reviewers (K.R., L.S.S.) screened the search results; (c) primary sources that met eligibility criteria were organized into groups according to study design; (d) data were categorized into groups based on study findings; (e) validated quality measures were used to assess quality of the sample; (f) data within subgroups were organized and grouped appropriately, and then reduced for display in a table format; (g) conclusions were drawn to capture both the breadth and depth of the available literature.

Search Methods

During October 2015, we searched the electronic databases Medline, EMBASE, PsycINFO, and CINAHL. Relevant keywords and subheadings within the electronic databases were identified and combined resulting in the following search terms: "Diabetes Mellitus," "Diabetes Mellitus, Type 1," "Diabetes," "Insulin Dependent Diabetes Mellitus," "Stress Disorders, Posttraumatic," "Posttraumatic Stress Disorder," "Psychological Stress," "Stress, Psychological," "Mothers," "Mother-Child Relations," "Maternal Behavior," "Maternal Role," and "Maternal Stress." Each of these terms was searched in every database and all matched terms were utilized. For example, the search for Medline was as follows: (a) exp Diabetes Mellitus, Type 1; (b) exp Stress Disorders, Posttraumatic; (c) exp Stress, Psychological; (d) exp Mother-Child Relations; (e) exp Mothers; (f) exp Maternal Behavior; (g) 2 or 3; (h) 4 or 5 or 6; (i) 1 and 7 and 8. Keywords from all articles included were reviewed to ensure that all appropriate terms were included. Bibliographic searches of all included articles were conducted. Detailed search strings are available upon request.

Studies were included if (a) they were published within the last 25 years to include as much breadth and depth of evidence as possible; (b) they represented primary research; (c) stress or PTSS in mothers of children under the age of 18 with T1D was measured; (d) in quantitative studies, the measurement of stress or PTSS was explicit; (e) in qualitative studies, aims included exploration of disease-related stress or coping in mothers caring for children with T1D; (f) they were written in English or translated into English for publication. Studies were excluded if they were unpublished manuscripts, not topical, or did not include a measure of stress or PTSS in mothers.

Review Process

The full citations, including bibliographic details, keywords, abstract, and Web addresses (when available), of all titles identified through the searches were imported into the online bibliographic management program *RefWorks*TM and combined into a database. Duplicate papers were removed. Two authors (K.R., L.S.S.) read the titles and abstracts of each article independently, and the sample was established based on eligibility criteria; differences were reviewed jointly, and eligible studies were combined into a final sample.

Quality Appraisal

The National Institutes of Health (NIH) “Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies” was used to determine relative quality of cross-sectional data (NIH & National Heart, Lung, and Blood Institute, 2014). The “Cochrane Collaboration’s tool for assessing risk of bias” was utilized to determine relative quality of the experimental studies (Higgins et al., 2011). The U.K. Centre for Evidence Based Medicine’s “Critical Appraisal Skills Program” Qualitative Checklist was utilized to determine relative quality of qualitative studies (Critical Appraisal Skills Program [CASP], 2004). Each paper was scored based on the criteria of each measure.

Data Abstraction and Synthesis

The final articles in the sample were read and relevant information was summarized systematically using a data extraction form (Table 4). This data reduction technique allowed for iterative analyses across sources. Data were then organized into categories according to study design. Studies were then synthesized within and across categories.

Results

There were 168 papers obtained through searches, and after removal of duplicates, a sample of 128 papers was reviewed. A total of 109 papers were excluded based on the above criteria. The remaining 19 papers met all inclusion/exclusion criteria (see Figure 1). Quality assessments were completed for each article and results are displayed in Tables 1, 2, and 3. The quality of the included studies was moderate to high.

The final sample included 15 correlational studies, three qualitative studies, and one intervention study. Data abstraction and synthesis are displayed in Table 4. Four distinct themes emerged from the analysis: (a) diagnosis of T1D in children was a traumatic event for many mothers and PTSS/PTSD were prevalent in this population; (b) PTSS in mothers adversely affected mental health outcomes in their children; (c) trusted social networks were an important factor in alleviating PTSS in mothers and may be protective; (d) management of maternal PTSS and PTSD may improve behavioral and physiologic outcomes in children with T1D, but additional evidence is required.

PTSS at Disease Onset and Beyond

Mothers experienced significant emotional stress and distress at the onset of their child’s diabetes (Kokkonen, Taanla, & Kokkonen, 1997). They described shock and increased anxiety as a result of their child’s diagnosis (Koizumi, 1992). The majority of mothers reported considerable emotional turmoil at disease onset as well as depressive symptoms, weight loss, pain, and fatigue as common symptoms that occurred throughout the first year of the child’s illness (Kokkonen et al., 1997). Mothers’ perception of the severity of T1D was associated with coping; the more serious that mothers perceived the disease to be, the less able they were to cope with activities of daily diabetes management (Athasari et al., 2010).

Psychological distress was most acute at the time of diagnosis and throughout the first year after diagnosis (Kokkonen et al., 1997). In one study, within 6 weeks of a child's diagnosis, approximately 51% of mothers met diagnostic criteria for partial PTSD and 24% of mothers met diagnostic criteria for full PTSD based on the Posttraumatic Stress Diagnostic Scale (PDS; Landolt et al., 2002). In another study, 29.3% of mothers met full diagnostic criteria for PTSD based on PDS within 6 weeks of diagnosis, and mothers were significantly more vulnerable to PTSS than fathers (Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012). Within 6 months of diagnosis, 22.4% of mothers met full diagnostic criteria for PTSD based on the PDS; 1 year after diagnosis, 20.4% met full diagnostic criteria for PTSD based on the PDS (Landolt et al., 2005).

While psychological distress was most acute within the first year after diagnosis, for many mothers, PTSS and PTSD persisted beyond the first year. Within 5 years of diagnosis, 15% of mothers met criteria for partial PTSD and 10% met criteria for full PTSD based on the Structured Clinical Interview for *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; *DSM-IV*; APA, 1994; SCID) PTSD module and PDS criteria; of these, 45% identified their child's diagnosis as the traumatic stressor (Horsch et al., 2007). In addition, 40% of mothers endorsed continuous emotional distress associated to their child's disease 5 years after diagnosis (Kokkonen et al., 1997). Mothers of children with T1D were much more likely to experience child-related stress than mothers of children without diabetes (Hannonen et al., 2015). Mothers of children with T1D experienced poorer overall well-being related to behavioral problems in their children compared with mothers of children without diabetes (Hannonen et al., 2015).

PTSS in Mothers and Mental Health in Children

Mental health in mothers was associated with mental health in their children. Mothers with PTSS at the time of diabetes diagnosis were more likely to have children with PTSS (Landolt et al., 2012). In addition, mothers with PTSS were more likely to have children who demonstrated poorer recovery from PTSS (Landolt et al., 2012). PTSS in children were not found to be associated with PTSS in mothers (Landolt et al., 2012). Thus, maternal mental health likely has a stronger impact on her child than a child's mental health has on a mother. Mothers with higher stress levels had poorer coping skills and greater depressive symptoms. Maternal stress, as measured by a four-item survey designed by the authors, was also associated with poorer maternal psychological well-being and poorer maternal coping skills (Streisand, Mackey, & Herge, 2010).

Maternal coping style, as measured by the Coping Inventory for Stressful Situations, predicted the coping style of their children (Pisula & Czaplinska 2010). Maternal coping style, as measured by the Coping Health Inventory for Parents, and child coping style, as measured by the Child Perceived Coping Questionnaire, were correlated (Kager & Holden, 1992). Mothers who scored lower on the Coping Health Inventory for Parents had children with poorer self-worth and lower self-perception of competence (Kager & Holden 1992). Poorer maternal coping, as measured by a single survey item asking mothers how well they felt they were coping, was associated with poorer metabolic and psychological outcomes in children (Streisand et al., 2010). When mothers and their children with diabetes reported that

they did not help each other to cope with regard to their stress symptoms, both experienced greater symptoms of depression (Berg et al., 2007).

Maternal PTSS was associated with self-management behaviors, adherence to T1D management regimens, and overall adjustment in children. Children of mothers with PTSS or PTSD displayed overall poorer adherence to their treatment regimen than did children of mothers without PTSS or PTSD (Horsch & McManus, 2014). As younger children need to rely on their caregivers for diabetes care, this result may portend even more problems, but this study was the only cross-sectional one in which group differences in children less than 8 years old and children 8 years and older were compared (Horsch & McManus, 2014).

Social Networks May Be a Key Factor in Alleviating Stress in Mothers

A diagnosis of T1D in a child has been described as a profoundly isolating experience for mothers, eliciting constant emotional turmoil (Sullivan-Bolyai et al., 2003). Mothers reported an unrelenting fear of diabetes complications. Mothers feared whether other caregivers could manage complicated daily treatment activities, and they were less likely to leave their children in daycare centers or with relatives or friends. When their children were outside of their direct care, mothers worried constantly about whether their children were safe, whether they had eaten recently, whether their insulin dose was peaking, and whether they have had enough insulin to cover any additional snacks or treats.

This constant worry was reported to be all-encompassing, isolating, and unrelenting, leaving mothers in a never-ending cycle of guilt, fear, and responsibility. Social networks of trusted individuals who could assist with daily tasks were a key factor for mothers who struggled with constant emotional stress and distress. Reliable caregivers, helpful partners, and connection with understanding peers all assisted mothers in managing their own PTSS and PTSD (Sullivan-Bolyai et al., 2003). Perceived social support networks, as measured by the Social Provisions Scale, was significantly associated with reduced PTSD and reduced emotional distress in mothers of children with T1D (Horsch, McManus, & Kennedy, 2012; Horton & Wallander, 2001). Mothers who adapted most successfully to their child's diagnosis reported that receiving support from trusted individuals was a primary reason for their successful coping (Koizumi, 1992). Mothers who struggled to cope with diabetes-related stressors also experienced significantly more symptoms of anxiety and depression (Jaser, Whittemore, Ambrosino, Lindemann, & Grey, 2009).

Higher feelings of isolation with regard to a child's T1D diagnosis worsened the trauma mothers' experienced associated with the diagnosis (Koizumi 1992). Many mothers reported lacking the social network of trusted helpers that they needed to meet their day-to-day tasks and 94% reported that they did not have a sufficient network of support to enable them to meet their own needs (Stewart, Ritchie, McGrath, Thompson, & Bruce, 1993). Mothers of very young children with T1D reported having limited access to the childcare support that they needed to alleviate some of their own caregiver burden, such as childcare providers who could reliably carry out daily T1D tasks (Sullivan-Bolyai et al., 2003). Maternal perception of paternal helpfulness and support was associated with fewer depressive symptoms and improved adherence to the treatment regimen irrespective of actual paternal involvement (Hansen, Weissbrod, Schwartz, & Taylor, 2012).

Management of PTSS and PTSD Symptoms May Improve T1D Outcomes

In a small experimental study, cognitive behavioral therapy was shown to assist mothers in self-management of their stress symptoms and improved maternal self-reported distress and perceptions of child's behavior (Hoff et al., 2005). These results suggested that alleviating maternal PTSS and PTSD improved not only perceived stress symptoms in mothers, but also improved mothers' attitudes toward their children's behaviors. Importantly, there is a significant gap in the literature regarding identification and management of PTSS and PTSD in mothers of children with T1D.

Limitations of the Available Evidence

There were relatively few studies in which researchers addressed directly the issue of stress and PTSS in mothers. Several studies were limited by small sample sizes. Design was also an important concern. Most of the studies were cross-sectional, which precludes drawing conclusions about time order or causality. In only two studies was long-term prevalence of maternal PTSS and PTSD explored, so it is not yet possible to ascertain how long lasting these symptoms are with this group of mothers. Maternal PTSS and PTSD differences based on child age were studied in only one paper. This is an important consideration as maternal responsibility for diabetes management largely depends on the age of the child at diagnosis, and caring for a preverbal infant or child was seen to be especially stressful for mothers.

Discussion

The aim of this literature review was to synthesize the empirical research on stress and PTSS, including a diagnosis of PTSD, in mothers of children with T1D. The prevalence of PTSS and PTSD in mothers of children with T1D is high, especially within the first 6 weeks after diagnosis. Mothers not only experienced PTSS and PTSD at diagnosis, but also continued to experience symptoms up to 5 years after diagnosis. Importantly, this pattern is also seen in mothers of children with other serious illnesses, including cancers, and severe injuries (Balluffi et al., 2004; Barakat, Alderfer, & Kazak, 2006; Hall et al., 2006; Kazak et al., 2004).

PTSS and PTSD in mothers of children with T1D were negatively associated with quality of life and adjustment in both mothers and their children. Mothers often take responsibility for the majority of disease management in their children, especially at the time of diagnosis (Koizumi, 1992). Mothers who were unable to manage their own emotional distress were less capable of performing the daily treatment tasks that their children required, leading to poorer metabolic outcomes.

Mental health in mothers was associated with their children's mental health. PTSS and PTSD in mothers were associated with stress symptoms in children. Children of mothers with PTSS and PTSD were more likely to have PTSS and PTSD themselves (Landolt et al., 2012). PTSS in mothers can lead to depressive symptoms in mothers and their children, as well as overall poorer maternal coping (Streisand et al., 2010). Maternal coping styles were closely correlated with the coping styles that their children eventually adopted (Pisula & Czaplinska 2010). Positive maternal coping, such as exercise, listening to music, reading, or

socializing, had many benefits in children, including more positive peer relations and improved self-management behaviors (Horsch & McManus, 2014; Kager & Holden 1992). Similarly, negative coping styles in mothers, such as anger, overeating, aggression, or substance abuse, negatively impacted the quality of life, self-worth, and metabolic outcomes of their children (Kager & Holden 1992; Streisand et al., 2010).

Social networks of trusted individuals who could help mothers with daily tasks and T1D care was a key factor in alleviating stress symptoms in mothers and promoting successful coping and adjustment. Mothers reported that their degree of isolation with regard to their child's diagnosis was part of the trauma that they experienced (Koizumi, 1992). Most mothers often did not have the network of trusted supporters that they needed to adequately perform their own self-care tasks and those of their children (Stewart et al., 1993). Maternal perception of paternal helpfulness was a critical element of adequate social support for mothers, irrespective of actual level of involvement (Hansen et al., 2012). When mothers felt supported by a partner, children demonstrated better adherence and therefore improved metabolic outcomes (Hansen et al., 2012). Increasing the social networks of trusted helpers available to mothers has been shown to have an ameliorating effect on PTSS and PTSD in mothers. Only one study included in this review was a treatment intervention trial, utilizing cognitive behavioral therapy (CBT), for addressing stress and trauma in mothers. Thus, this is an area that requires further investigation.

Implications for Practice With Families

There are multiple ramifications of maternal PTSS and PTSD in these families. It is important for health care providers to conduct regular mental health screening in mothers of children with T1D. The prevalence estimates indicate that screening for PTSS and PTSD in mothers is most needed shortly after diagnosis, and then again 1 year after diagnosis. Regular assessment may help to ensure that mothers struggling with emotional distress are not missed. Such screening should become a part of regular T1D clinic visits, especially for mothers of very young children. Currently, the PDS is a reliable assessment available for use as a brief screening measure.

As alleviating PTSS and PTSD symptoms in mothers will likely improve both diabetes-related outcomes and mental health outcomes in their children, future interventions should be aimed at exploring way to alleviate symptoms of emotional stress and trauma in mothers. Addressing the need for social support networks and systems may assist mothers in improving their ability to cope. Mothers who feel that they are solely responsible for their child's treatment regimen are often less able to take care of their own needs and are therefore unable to adequately manage their own emotional distress. Future interventions might include an in-person or online social support groups specific to mothers with T1D, developing a regular social activity for both children and their mothers such as a "camp day," weekly phone calls from a social worker offering support and feedback, or development of a cognitive behavioral intervention specifically for mothers of children recently diagnosed with T1D.

Recommendations for Future Research

Key areas that require further research include (a) larger scale studies that address the long-term prevalence of PTSS and PTSD in mothers; (b) determining the appropriate screening measures and the most effective time-points for screening for PTSS and PTSD in mothers; and (c) designing and testing interventions, such as CBT or tailoring social support networks or systems, that may improve emotional stress in mothers, therefore reducing PTSS and PTSD. Researchers should especially consider exploring interventions that improve social support networks or systems, such as therapist-guided or online support groups; regular contact with trained counselors or other mothers of children with T1D through texting, weekly phone calls, or regular follow-up visits at the diabetes clinic; or daycare centers that train care providers to adequately manage T1D in young children.

Limitations

This review has several limitations. Included articles were published between 1990 and 2015. As this is a large time span, the associations established in the earlier studies may not still be relevant, as treatment modalities have changed and diabetes management has changed enormously in the last 25 years. For example, within the last two decades, the Diabetes Control and Complications Trial (DCCT) demonstrated that intensive therapy of T1D reduces the risk of long-term microvascular complications (White et al., 2001). Thus, management of T1D has become even more complicated during this time period. In addition, prognosis of diabetes in children has improved and many measures of stress and posttraumatic stress have evolved in the last 25 years. We elected to search this broad time span to capture as much empirical evidence as possible, as there has been limited research in this area to date. As such, this review included only 19 studies, so findings must be interpreted with caution. Last, articles published in a language other than English were excluded.

Conclusion

PTSS and PTSD play important roles in the lives of many mothers of children with T1D, and have a significant impact on both mothers and their children. Maternal PTSS and PTSD lead not only to poorer maternal mental health, but also to poorer physiological and psychological outcomes in their children. Key gaps in the available research were identified. These gaps include the need for reliable long-term prevalence estimates, especially for mothers of children who have been diagnosed for 1 year or longer; more interventional research; and the development of additional interventions. Interventions that aim to improve coping skills and social support networks may help to alleviate PTSS and PTSD in mothers, and therefore may benefit two generations of family members and improve the daily management of T1D.

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Figure 1.
Data collection.

Table 1

Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies—NIH and National Heart, Lung, and Blood Institute (2014).

	Berg et al. (2007)	Chaney et al. (1997)	Hannonen et al. (2015)	Hansen, Weissbrod, Schwartz, and Taylor, (2012)	Horsch, McNamur, Kennedy, and Edge (2007)	Horsch, McNamur, Kennedy (2012)	Horsch and McNamur (2014)	Horton and Wallander (2001)	Jaser, Whittemore, Ambrosino, Lindemann, and Grey (2009)	Kager and Holden (1992)	Kokkonen, Taanla, and Kokkonen (1997)	Landolt, Vollrath, Laimbacher, Gnehm, and Sennhauser (2005)	Landolt, Ystrom, Sennhauser, and Vollrath (2012)	Pisula and Czaplinska (2010)	Streisand, Mackey, & Herge, 2010
Q1	F	F	G	G	G	G	G	G	G	F	F	G	G	G	F
Q2	G	G	G	F	G	G	G	G	G	F	F	G	G	P	P
Q3	U	G	G	P	P	P	P	G	P	G	G	G	G	U	F
Q4	G	P	G	P	G	G	G	G	G	F	G	G	G	U	U
Q5	P	P	G	G	P	P	P	F	G	P	P	G	G	P	P
Q6	NA	NA	NA	NA	G	NA	NA	NA	NA	NA	NA	NA	G	NA	NA
Q7	NA	F	NA	NA	F	NA	NA	NA	NA	NA	NA	NA	G	NA	NA
Q8	G	F	F	G	NA	G	G	F	G	G	F	G	G	G	F
Q9	F	G	F	G	G	G	G	F	G	F	P	F	G	F	P
Q10	NA	G	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	G	NA	NA
Q11	F	G	F	F	G	G	G	F	G	G	G	G	G	F	P
Q12	NA	G	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	U	U	NA
Q13	G	G	G	G	G	G	G	G	G	G	G	G	G	U	NA
Q14	G	G	G	G	P	G	P	F	G	G	P	G	G	NA	F

Note. F = fair; G = good; P = poor; U = unknown; NA = not applicable.

Table 2

Cochrane Collaboration's Tool for Assessing Risk of Bias.

	Hoff et al. (2005)
Random sequence generation (selection bias)	U
Allocation concealment (selection bias)	F
Blinding of participants and personnel (performance bias)	F
Blinding of outcome assessment (detection bias) (patient-reported outcomes)	G
Incomplete outcome data (attrition bias) (short term)	U
Incomplete outcome data (attrition bias) (long term)	NA
Selective reporting (reporting bias)	G

Note. U = unknown; F = fair; G = good; NA = not applicable.

Table 3

The U.K. Centre for Evidence Based Medicine's "Critical Appraisal Skills Program" Qualitative Checklist.

	Athasari et al., (2010)	Koizumi (1992)	Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, and Grey (2003)
Was there a clear statement of the aims of the research?	Yes	Yes	Yes
Is a qualitative methodology appropriate?	Yes	Cannot tell	Yes
Was the research design appropriate to address the aims of the research?	No	Cannot tell	Yes
Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes
Was the data collected in a way that addressed the research issue?	Cannot tell	Cannot tell	Yes
Has the relationship between researcher and participants been adequately considered?	Cannot tell	No	Cannot tell
Have ethical issues been taken into consideration?	Yes	Cannot tell	Yes
Was the data analysis sufficiently rigorous?	Yes	Cannot tell	Yes
Is there a clear statement of findings?	Yes	No	Yes
How valuable is the research?	Useful	Limited	Useful

Table 4

Data Abstraction Summary.

Author (Date)	Design	Sample	Age of children (M)	Measure of stress	Key findings
Athaseri et al. (2010)	Descriptive inquiry (qualitative)	22 mothers	6 to 12 years (9.95 years)	30-to 180-min interviews	The way that mothers interpreted the illness largely directed how well the disease was managed and how the family as a whole coped with the disease
Berg et al. (2007)	Cross-sectional	127 mothers	10 to 15 (12.85)	Structured Stress and Coping Interview	When children and mothers foster a positive and collaborative environment, coping and adjustment are improved
Chaney et al. (1997)	Longitudinal	50 mothers, 49 fathers	7 to 16(11.4)	Symptom Checklist 90-Revised	Increases in paternal distress over time are associated with poorer children's adjustment. A decline in paternal adjustment predicted a subsequent improvement in maternal adjustment
Hammonen et al. (2015)	Cross-sectional	63 mothers	9 to 10 (not reported)	Life-stress checklist	Mothers reported greater child-related stress than controls (mothers of children with dyslexia). Mothers also reported poorer well-being related to child's behavior
Hansen, Weissbrod, Schwartz, and Taylor (2012)	Cross-sectional	82 mothers; 43 fathers	7 to 14 (not reported)	Pediatric Inventory for Parents	Maternal perceptions of paternal helpfulness, regardless of paternal involvement in care, led to improved depressive symptoms in mothers and better child adherence
Hoff et al. (2005)	Experimental	34 parent couples (17 intervention/17 typical care)	<18(M intervention group 9.29; M typical care group 9.44)	Symptom Checklist 90-Revised	The intervention group reported significant reductions in maternal and paternal distress, and maternal reporting of child's behavior problems
Horsch, McManus, Kennedy, and Edge (2007)	Cross-sectional	60 mothers	< 16 (not reported)	Structured Clinical Interview: <i>DSM-IV</i> /PTSD; Posttraumatic Stress Diagnostic Scale	15% of these mothers met criteria for partial PTSD and 10% met criteria for full PTSD. 55% of these indicated the child's diagnosis as the stressor
Horsch, McManus, and Kennedy (2012)	Cross-sectional	60 mothers	< 16 (not reported)	Posttraumatic Stress Diagnostic Scale; Posttraumatic Cognitions Inventory	Cognitive variables were positive associated with PTSD; social support was the only noncognitive variable associated with PTSD
Horsch and McManus (2014)	Cross-sectional	60 mothers	< 16 (not reported)	Structured Clinical Interview: <i>DSM-IV</i> /PTSD; Posttraumatic Stress Diagnostic Scale	Identification and intervention in maternal PTSD improves adherence to disease regimen in children
Horton and Wallander (2001)	Cross-sectional	111 mothers of children with T1D, spina bifida, or cerebral palsy	5 to 18 (not reported)	Parents of Children With Disabilities Inventory	Hope was a moderator of the relationship between disability-related stress and maladjustment. Fostering a sense of hope may enhance coping skills in distressed mothers
Jaser, Whittemore, Ambrosino, Lindemann, and Grey (2009)	Cross-sectional	67 mothers	<8 (4.77)	Issues in Coping With Insulin-Dependent Diabetes Mellitus-Parent Scale	Lower threshold for coping with diabetes-related stress was associated with increased symptoms of anxiety and depression in mothers

Author (Date)	Design	Sample	Age of children (M)	Measure of stress	Key findings
Kager and Holden (1992)	Cross-sectional	64 mothers	7 to 15 (11.8)	Life Events Checklist	Maternal coping was associated with the child's general sense of self-worth
Koizumi (1992)	Qualitative (specific methodology not reported)	28 mothers	< 15 (not reported)	Interviews	All mothers expressed emotional trauma as a result of their child's diagnosis. Mothers' coping over time with various levels of success, the highest level being adaptation. Mothers reported that their degree of isolation while dealing with the diagnosis was traumatic
Kokkonen, Taanila, and Kokkonen (1997)	Cross-sectional	31 parent dyads	13 to 16 (14.3)	Semistructured interviews with a social worker	Two thirds of parents reported trauma at the time of diagnosis, while 40% of mothers reported continuous concern
Landolt, Vollrath, Laimbacher, Gnehm, and Sennhauser (2005)	Longitudinal	49 mothers, 48 fathers	6.5 to 15 (M not reported)	Posttraumatic Diagnostic Scale	PTSD rates in mothers were 22.6% at 6 weeks after diagnosis, 16.5% at 6 months after diagnosis, and 20.4% at 12 months after diagnosis. In fathers, PTSD rates were 14.6% at 6 weeks, 10.4% at 6 months, and 8.3% at 12 months
Landolt, Ystrom, Sennhauser, Gnehm, and Vollrath (2012)	Longitudinal	239 mothers, 221 fathers	6.5 to 16 (not reported)	Posttraumatic Diagnostic Scale	PTSD rates in mothers were 29.3% at 6 weeks after diagnosis and 14.6% at 12 months after diagnosis. In fathers, PTSD rates were 18.6% at 6 weeks and 7.9% at 12 months. Parents who reported initially high PTSS were more likely to have children who recovered more poorly from PTSS
Pisula and Czaplinska (2010)	Cross-sectional	107 mothers	12 to 17 (14)	Coping Inventory for Stressful Situations	Mothers' coping style predicts coping style in children
Streisand et al. (2008)	Cross-sectional	278 mothers	>17(12.1)	Assessed with four items	Mothers of non-White children or mothers from single-parent households seem to experience poorer physical and psychological well-being. In addition, poorer maternal coping was associated with poor physiological and psychological well-being
Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, and Grey (2003)	Naturalistic inquiry (qualitative)	28 mothers	>4 (2.9)	Interviews	Mothers reported "constant vigilance" in their daily lives. They reported frequent concerns about hypoglycemia and hyperglycemia. Mothers expressed stress learning to manage daily treatment regimens. They also reported limited access to supportive services

Note. *DSM-IV* = *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; American Psychiatric Association, 1994); PTSD = posttraumatic stress disorder; T1D = type 1 diabetes; PTSS = posttraumatic stress symptoms.