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Psychological Experience of Parents of Children With Type 1 Diabetes:

A Systematic Mixed-Studies Review

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Abstract

Purpose—The purpose of this review is to describe the prevalence of psychological distress in parents of children with type 1 diabetes (T1DM), the relationship between parental psychological distress and health outcomes, and parents' psychological experience of having a child with T1DM. Clinical and research implications are presented.

Method—A systematic mixed-studies review was undertaken to review the quantitative and qualitative research on the parental experience of having a child with T1DM. A total of 34 articles met the inclusion criteria and were included in the review.

Results—The prevalence of parental psychological distress across all studies ranged from 10% to 74%, with an average of 33.5% of parents reporting distress at diagnosis and 19% of parents reporting distress 1 to 4 years after diagnosis. Parental psychological distress in parents of children with T1DM, regardless of how it was defined, was associated with higher child self-report of stress and depressive symptoms, more problematic child behavior, and lower child self-report of quality of life. Parental psychological distress also had negative effects on diabetes management. Themes of the qualitative synthesis indicated that parents perceived T1DM as a difficult diagnosis that contributed to significant family disruption. Adjustment occurred over time; however, ongoing stress was experienced.

Conclusions—Screening for psychological distress in parents of children with T1DM is indicated, and preventive interventions are needed.

In children with type 1 diabetes (T1DM), parents are ultimately responsible for daily management of T1DM, which has a significant impact on family life. Daily management of T1DM is time-consuming and requires a change to many well-established family routines. Although technological advances have greatly enhanced the ability of parents to monitor and manage T1DM in youth,¹ the responsibility of T1DM management can contribute to parental stress, distress, and diminished quality of life. Understanding the experience of parenting a child with T1DM can provide insight into the challenges and needs of parents, thus informing the development of parental and/or family interventions. Considerable research has been undertaken to examine aspects of the parenting experience; however, there is a need to synthesize this literature to inform future research and clinical work.

Caring for a child with T1DM has been described as an overwhelming experience, requiring constant vigilance.² Parents must come to terms with having a child with a life-threatening

illness and carrying out a labor-intensive and complicated daily regimen.³ Parents live with constant worry about hypoglycemia or hyperglycemia, heightened feelings of responsibility for their child's health, and the desire to promote optimal growth and development.⁴ At different developmental phases, new issues arise that require a complete reevaluation of previously established and effective management strategies.⁵ The ongoing stress and worry manifest in elevated rates of parents' perception of stress and increased risk for depression and anxiety.

There is considerable research on the prevalence of parental psychological distress and the impact of such distress on child and family outcomes. Although the majority of parents of children with T1DM adjust well, approximately 20% to 30% of parents report clinically significant distress, which has been defined as stress (life stress or parenting stress) and symptoms of anxiety, depression, and/or posttraumatic stress.⁶⁻⁸ Parental psychological distress at the time of diagnosis has been found to predict later parental distress.⁹ In addition, parental psychological distress has health implications for the parent, the child with T1DM, and the overall functioning of the family.¹⁰ In parents of children with T1DM, psychological distress has been shown to affect family communication,¹¹ increase family conflict,¹² decrease the ability to parent effectively,¹³ negatively affect child psychological adjustment,⁹ and contribute to poor parental mental and physical health.¹⁴

Greater understanding of the relationship of parental psychological responses to having a child with T1DM is needed to guide clinical practice and future research. Thus, the purpose of this systematic mixed-studies review is to synthesize the research on the parental experience of having a child with T1DM, focusing on parental psychological adjustment. The aims are to describe the prevalence of psychological distress in parents of children with T1DM, the relationship between parental psychological distress and health outcomes, and the parental experience of having a child with T1DM. Clinical and research implications will also be presented.

Methods

Design

This systematic mixed-studies review was designed to identify and synthesize research pertaining to the parental psychological adjustment of having a child with T1DM. Although family conflict and communication around diabetes self-management may influence parental adjustment, the focus of this review was specifically on research examining parents' psychological adjustment. Given the complexities of psychological adjustment and the broad array of data sources that inform this body of research, a systematic mixed-studies review was considered most appropriate to synthesize this literature and adheres to the reporting guidelines for systematic mixed-studies reviews.¹⁵

Search Methods

A systematic search was conducted using the search terms *parent, children, adolescents, type 1 diabetes, and adjustment, stress, anxiety, depressive symptoms, and depression*. Databases included Pubmed, Scopus, CINAHL, and PsychInfo from 1994 to May, 2011, examining the literature post-Diabetes Control and Complications Trial until the present. Reference lists of publications were also reviewed. Inclusion criteria were (a) quantitative or qualitative research on parents of children with T1DM and (b) studies published in an English-language journal. Studies were excluded if the focus was on the child or family adjustment and did not include parental psychological outcomes or the parental perspective. Data were extracted from articles by category (qualitative and quantitative). Data display matrices were developed to compare and contrast research results by category. Content analysis was used

to synthesize the qualitative research by coding significant statements, grouping codes into categories, and collapsing categories into final themes.¹⁶

Quality Assessment

A reviewer assessed each article for quality using a scoring system appropriate for mixed-studies reviews.^{15,17} Two reviewers are doctoral students and 1 reviewer is a nurse-scientist. The challenges of evaluating and comparing disparate methods based on distinct ontological, epistemological, and methodological traditions precluded use of a single quality appraisal instrument. Therefore, 2 different quality instruments were used, 1 for quantitative studies and 1 for qualitative studies (available upon request). The methodological quality of each study was calculated by totaling all items on the instrument whereby a score of 0 indicated a study with low quality and a score of 100 indicated a study with high quality. The means of the quantitative and qualitative quality assessment scores were then calculated. Each article was then compared with the mean of the respective type of article. Quality assessment scores were used to analyze results; however, no articles were excluded based on quality, as results of low-quality studies were consistent with results of high-quality studies. A dialectical and complimentary stance was used to synthesize results from quantitative and qualitative studies: quantitative studies were used to describe the prevalence and relationships between parental psychological distress and health outcomes, whereas qualitative studies were used to describe the parental experience of having a child with T1DM.

Results

The initial search yielded 168 articles. All abstracts were reviewed for eligibility. A total of 34 articles met the inclusion criteria and were included in this review (14 qualitative and 20 quantitative). Reasons for elimination included focus on children, family functioning (without parental psychological assessment), and intervention evaluation. The overall quality of articles was moderate to high. The mean quality score of quantitative studies was 77.8 and ranged from 55 to 95. The mean quality score of qualitative studies was 77.5 and ranged from 45 to 90. Results of studies were consistent regardless of quality score.

Psychological Distress in Parents of Children With T1DM

The description of quantitative studies is summarized in Table 1. Of the 20 quantitative studies, the prevalence of psychological distress in parents of children with T1DM was reported in 9 studies (Table 1). There were 4 studies that evaluated mothers and fathers separately, 3 studies that evaluated parents and did not distinguish between mothers and fathers, and 2 that evaluated mothers only. The mean age of children in these studies ranged from 4.4 to 14.4 years, and duration of diabetes ranged from a new diagnosis to a mean of 4.4 years. The authors used various definitions of parental psychological distress including measures of stress (life and parenting stress), distress (problems in diabetes), and symptoms of anxiety, depression, or posttraumatic stress disorder (PTSD). The prevalence of parental psychological distress across all studies ranged from 10% to 74%, with an average of 33.5% of parents reporting distress at diagnosis and 19% of parents reporting distress 1 to 4 years after diagnosis. Longitudinal studies demonstrated a slight decrease in distress over time.^{18–20} The prevalence of anxiety symptoms ranged from 21% to 59%, depressive symptoms from 10% to 74%, psychological distress from 29% to 33%, and symptoms of PTSD from 19% to 24% in parents of children with T1DM. In the majority of studies, the prevalence of parental psychological distress ranged from 20% to 30%; there was 1 study of parents of children with newly diagnosed T1DM (mean age, 9.7 years) with much higher rates of anxiety and depressive symptoms than the other studies (59%–74%).²¹ Where assessed, mothers had higher rates of psychological distress compared with fathers.^{8,19,20}

Parents of children with T1DM were compared with matched controls in 3 studies.^{22,23} Higher parenting stress and lower parenting competence, self-efficacy, and parenting satisfaction were demonstrated in parents of children with T1DM in 2 of the 3 studies. Another comparative study indicated that parents of young children reported significantly more distress than parents of older children.²⁴ Thus, in the majority of studies, parents of children with T1DM experienced greater distress and problems with parenting than other parents, which may negatively affect their children.

Parental psychological distress in parents of children with T1DM, regardless of how it was defined, was associated with higher child self-report of stress and depressive symptoms,^{3,18} more problematic child behavior,^{10,22,25} and lower child self-report of quality of life.¹² The effects of parental distress on parenting and family life differed depending on whether the parent had increased depressive or anxiety symptoms. Parental depressive symptoms were associated with inconsistent discipline, lower parental involvement and warmth, lower family adaptability and cohesion, and higher family conflict.^{11–13} In contrast, higher parental anxiety was associated with higher maternal control and overprotectiveness.²⁶ Thus, parental psychological distress appears to have a consistent, negative impact on parenting and family life.

Parental psychological distress also had negative effects on diabetes management. Higher reports of parental depressive symptoms were associated with lower parental monitoring of diabetes management,¹³ which plays an important role in guiding the daily decision making of T1DM management. However, higher parental anxiety was associated with greater parental involvement in diabetes management and less shared management, suggesting that anxious parents desired more control over daily T1DM tasks. Higher parental anxiety was also associated with decreased ability of parents to learn diabetes management and lower parental self-efficacy for diabetes management,^{14,26} both of which could contribute to suboptimal T1DM management.

The relationship of parental psychological distress and metabolic control is still unclear and may be influenced by child age and how distress is defined. In 2 studies—both of which had samples of children younger than 5 years of age^{6,25}—no association between parental anxiety or parenting stress and metabolic control was found. In studies of parents with older children (mean age, 10.6 years), significant associations between increased life stress and poorer metabolic control were reported.^{27,28} In contrast, 1 study with parents of children younger than 9 years of age found that increased parenting stress was associated with better metabolic control.²⁴ Taken together, these findings suggest that life stress is associated with poorer metabolic control but the relationship between parental stress or anxiety and metabolic control may be influenced by other factors.

Factors associated with parental psychological distress were also explored in several studies. Younger child age and longer diabetes duration were associated with higher parental distress and parenting stress.^{24,29} Nighttime blood glucose monitoring and meal times have also been associated with higher parental stress and anxiety, particularly in parents of young children.^{22,30} Parents report considerable concern over hypoglycemia occurring during the night when children are sleeping and during meals if a child does not eat an adequate amount of carbohydrates. Across multiple studies, high levels of parental stress were consistently predictive of symptoms of anxiety and depression in parents regardless of child age and duration of T1DM.^{6,10,14,21}

Parental Experience

Synthesis of the qualitative research on the parental experience of caring for a child with T1DM provides additional insight into factors contributing to parental stress and distress.

Fifteen qualitative studies on the topic were identified (Table 2). Various qualitative methods were used, including qualitative description (n = 10), phenomenology (n = 3), and case study method (n = 1). The majority of studies were conducted in the United States (53%). Two longitudinal studies involved interviewing parents over 1 year.^{31,32} Both mothers and fathers were included in the majority of studies (n = 12), whereas 2 studies included primarily mothers, 1 study included only mothers,² 1 study included only fathers,³³ and 1 study did not specify parental gender.³⁴ Only 3 studies included single parents.^{4,31,34} The age of children with T1DM ranged from 1.5 to 17.3 years, age of parents ranged from 36 to 43 years, and duration of T1DM ranged from newly diagnosed to 8 years.

Parents of children with T1DM described the experience of caring for a child with T1DM as life-altering and all-consuming. Themes from the qualitative studies are summarized in Table 3. Parents experienced profound emotional distress at diagnosis that persisted as they learned to implement a complex and demanding daily treatment regimen. Family life was completely disrupted as life initially needed to revolve around caring for the child with T1DM. New routines had to be established and social isolation occurred due to the perceived need for structured and highly monitored care. Parents needed to devote considerable time and effort to develop a routine, grow personally and as a family, and feel confident in meeting their child's health needs. Personal and professional support was critical to the overall adjustment and experience of parents. Yet persistent stress and sadness were described, despite positive adjustment over time.

Difficult diagnosis—The experience of having a child diagnosed with T1DM was described as traumatic and devastating to parents. Parents described feelings of fear, anger, guilt, frustration, helplessness, hopelessness, sorrow, despair, and profound grief. As one parent stated, she felt “emotionally drained, exhausted, and wrapped up in grief” after learning about the diagnosis and treatment for her child with T1DM.³² Parents felt ill-prepared to deal with the situation and were overwhelmed with the responsibility of caring for a child with T1DM. Although they described feeling motivated to learn diabetes management, the amount and complexity of information provided was difficult to grasp. One parent stated, “It was like being handed a big city phone book and you have to learn all the names before you go home.”³³

Family disruption—The initial management of T1DM contributed to a dramatic disruption in family patterns and routines. Family life revolved around diabetes, with a constant focus on meals, blood glucose levels, and insulin administration. Parents expressed the need for “constant vigilance” to determine the meaning of child behavior that could be indicative of hypoglycemia or hyperglycemia.² They worried constantly about their capabilities in implementing the daily diabetes tasks and the effect on their child. Parents also expressed feelings of loss of spontaneity and freedom. They were initially reluctant to leave the house and expressed feelings of social isolation. They reported that alternate caregivers for their child were difficult to find due to the responsibility required for diabetes oversight. One parent stated that she felt “riveted to an inflexible regimen that left her drained and exhausted.”³²

Mothers were the primary caregivers in most families, and many had to rearrange work schedules or leave work in order to care for their child full-time. Parenting roles also changed dramatically. Parents noted that they experienced a disruption in the established parent-child relationship due to the need for them to control and supervise the child in new ways. One parent stated that he felt like the “food and time police.”³³ Parents reported challenges to regaining their sense of competence as parents and allowing their child developmentally appropriate levels of autonomy. They also reported that they needed to make a concerted effort to spend time with other children and as a family.

Adjustment: Over time, parents began to adjust to daily diabetes management tasks, developed a routine, and became more confident in their ability to care for their child. They worked hard to establish diabetes tasks as part of their everyday life and to ensure that their child had “as normal a life as possible.”⁴ Some parents felt that their family had grown more cohesive as a result of going through such a challenging experience together.

Parents identified both professional (health care professionals) and personal (spouse, friends, family, other parents with children with T1DM) sources of support. Easy and constant accessibility to health professionals was reported to be critical to parents’ ability to learn and carry out the daily diabetes care required for the health of their child.

Parents reported that shared responsibility with their spouse was also a significant source of support, particularly for the daily problem solving and decision making required to optimally manage diabetes. Single parents who had sole responsibility for their child reported more difficulties with T1DM management.³⁴ Although many parents reported that friends and family did not provide support initially due to their own fears and emotional responses, over time, friends and family often became sources of support for parents. Support groups were reported to be helpful to some parents. However, some low-income African American and Hispanic parents were unable to identify any form of support, personal or professional,³⁴ and several studies indicated that health professionals did not provide adequate emotional support to parents.^{35,36}

Parents identified effective coping strategies in some studies. These included the importance of developing a routine and making a conscious effort to “not let diabetes consume your life.”³⁷ Normalization, open communication, patience, persistence, flexibility, and creativity were reported as helpful for parents. Maintaining a positive attitude, being hopeful, and using humor were also expressed as effective coping strategies for some parents.

Ongoing Stress—Stress was reported to be an ongoing and pervasive aspect of caring for these children. Parents experienced stress due to the complex and time-consuming nature of the diabetes management tasks. Parents reported “a narrow road between high and low blood glucose” that was difficult to maintain.³⁸ Children’s blood glucose levels could be inexplicably high or low, and parents felt like a failure if their child’s blood glucose was not in the target range. Regularly inflicting pain on their child for blood glucose monitoring or insulin administration was a constant source of stress. Parents reported that their child would plead with them, “Mommy, please don’t hurt me anymore,”^{32,39} leaving parents feeling conflicted about their parental role to prevent harm and distress to their child.

The magnitude of responsibility for their child’s life was another source of stress for parents. Parents experienced feelings of stress as a result of the need to constantly monitor their child day and night, often to reassure themselves about their child’s safety. Furthermore, parents expressed daily worry about the child’s current health, concern whether they were adequately providing diabetes care, and concerns about long-term complications and the future health of their child. One parent reported that she “never stopped worrying.”³⁵

Episodic stress occurred with developmental or lifestyle transitions that altered effective diabetes management routines. Transitions to childcare, school, and adolescence were identified as being particularly stressful. The tension between encouraging experiences for their children to promote normal development and safety was always present. In addition, enduring sadness or “chronic sorrow” was expressed.³⁵ Feelings of loss—of a healthy child, control, freedom, and their ability to protect their child from harm—were still present for many parents 1 year after diagnosis.³⁵ For some families, the financial burden of caring for a child with T1DM was identified as a significant source of stress.³⁴

Discussion and Implications for Diabetes Educators

Our review suggests that a significant number of parents experience profound psychological consequences including increased stress and symptoms of anxiety, depression, and PTSD that have implications for parents, children, and families. This review provides insight into the range of psychological distress and the factors identified by parents of children with T1DM as stressful. Therefore, it is important for providers to consider assessing parents for sources of stress, symptoms of depression, and anxiety, all of which have implications for diabetes management, children's and parents' adjustment, and family functioning. Cameron and colleagues⁴⁰ have advocated for screening parents of children with T1DM for psychological distress.

Assessment and Screening

Addressing parental stress appears to be particularly important, as higher parental stress was consistently associated with greater symptoms of anxiety and depression in parents. Assessment of parental stress is complicated in that stress can be defined as life stress (eg, financial), parenting stress, or stress unique to parenting a child with T1DM. In addition, a certain amount of stress may be beneficial to motivate for diabetes management,²⁴ but too much stress may be overwhelming, resulting in a lack of motivation and feelings of helplessness.⁴⁰ A brief and private (without child present) assessment of parental perceived stress during clinic appointments is warranted. See Table 4 for recommended screening tools.

Parents—and particularly mothers—of children with T1DM are at increased risk for depression, which was associated with negative effects on parenting, the child's quality of life, and the child's psychosocial adjustment.^{6,9} Results of this review also indicated that depression in parents of children with T1DM contributes to inconsistent discipline, lower parental involvement in diabetes tasks, less adaptability, higher family conflict, and lower monitoring of diabetes management. Research in the general population has established that maternal depression is a risk factor for child psychopathological abnormalities, especially depression.⁴¹ Previous research supports the feasibility of having pediatricians screen mothers for symptoms of depression and stress at well-child visits to identify mothers with high levels and providing referrals to parents' primary care providers, mental health providers, or community resources.⁴² In this study, it took providers less than 5 minutes to screen and provide appropriate recommendations for 95% of mothers (3% took 5–10 minutes and 2% took >10 minutes) using a 2-item screening tool.⁴² Other commonly used depression questionnaires are identified in Table 4. The American Diabetes Association recommends screening of children with diabetes age 8 or older for depressive symptoms. Perhaps parental screening could be incorporated at the same time.

Assessing for anxiety in addition to depression in parents may also be indicated. Parental anxiety and depression have differential effects on family communication, conflict, adaptability, and parental involvement, all of which are critical to optimal management of diabetes and family functioning. Results of this review indicated that anxiety in parents contributed to increased maternal control, overprotectiveness, greater parental involvement in diabetes tasks, and lower self-efficacy. A review of observational studies with anxious parents and their children indicated that anxious mothers are more likely to be controlling or intrusive and less warm during interactions with their children.⁴³ It is possible that maternal anxiety leads mothers to take on responsibility for the majority of their children's treatment management, which conflicts with developing needs for autonomy and independence in youth, resulting in either withdrawn or defiant behavior.^{26,44} The State Trait Anxiety Inventory could be used as a brief screening tool for parental anxiety⁴⁵ (Table 4).

Screening and Intervening in Practice

It is well-recognized that there are numerous barriers to providing psychosocial care for parents in primary and specialty care, particularly with respect to the care of children with T1DM. Constraints on clinical time lead to shorter appointments in the clinic, with the primary focus on practical aspects of diabetes management and improvement of metabolic control. Since parents are not seen separately from children, parents may be reticent to discuss their emotional concerns in front of their child. If a child's blood glucose is in target range, underlying emotional problems may be missed.³⁵

This review indicates that it would be ideal to screen parents for psychological distress at the time of the child's diagnosis, during the first year of diagnosis, annually, and/or during child developmental transitions. High-risk parents, such as single parents or those from minority groups, should be assessed more frequently. Once sources of parental stress and symptoms of depression or anxiety have been determined, a protocol could be developed to delineate appropriate treatment options (see Table 4 for clinical recommendations). In several studies, parents indicated that they did not receive adequate psychosocial support from diabetes providers^{34,35}; therefore, providers may want to consider efficient mechanisms to address this. At minimum, providers should tell parents that stress and distress are common and should discuss the potential negative impact on the child and the possible benefits of supportive services. Parents may also need encouragement to seek support from partners, family, peers, and professionals.

Parental Interventions

Research has been conducted on family-centered interventions for parents of children with T1DM. Family-centered interventions have focused on teamwork and communication,^{46,47} behavioral family systems therapy,^{48,49} and coping skills training.⁵⁰ Reviews of family-centered interventions have indicated the potential of these interventions to improve metabolic control, family communication, and relationships while decreasing family conflict.^{51,52} Although parents were included in these interventions, most interventions were aimed at improving diabetes management, youth adjustment, and family functioning. Fewer interventions have focused on reducing parental psychosocial distress.

Interventions focused on parental psychological distress have been provided to parents either at the time their children are diagnosed with diabetes^{30,53} or several years after diagnosis.^{50,54} These interventions have demonstrated significant improvements in parent stress and distress,^{30,54} child behavior,⁵⁴ and family outcomes.^{50,53,55,56} Despite relatively small samples in intervention studies, psychosocial support for diagnosis.^{50,54} These interventions have demonstrated significant improvements in parental stress parents of children with T1DM appears to be beneficial. Future research could target parents who are identified as higher risk (ie, those above the clinical cutoff on symptom measures of anxiety and depression), similar to the work of Wysocki and colleagues⁴⁸ in which families with high conflict were targeted for intensive psychosocial interventions. Increasing the intensity or length of the interventions may be warranted. Successful interventions for parents may build on the strategies parents identified as being most helpful, including developing routines, finding and activating sources of support, and identifying effective coping strategies. The outcomes of screening and referral of parents to mental health services should be evaluated. Preventive interventions may be beneficial and may have greatest effects with young children and/or early in diagnosis.⁴⁰

Limitations

There are several limitations of this review. We included only included published reports and did not attempt to find dissertations or unpublished research. Given the heterogeneity of

the samples (eg, child age range, time since diagnosis), measures of parental distress, and overall diversity of studies included, it was challenging to make comparisons across studies. Finally, many of the studies had limited diversity in race, ethnicity, or family composition (ie, single parents) and included small samples.

Conclusion

Parents of children with T1DM experience considerable stress related to the trauma of diagnosis and the demands of treatment management. Although many parents find ways to effectively manage this stress, such as developing routines and finding sources of support, others experience clinically significant levels of psychological distress, including symptoms of depression, anxiety, and posttraumatic stress. These symptoms have been shown to have negative effects on parenting, child quality of life, and child's metabolic control. A better understanding of the experience of parenting a child with T1DM may help providers to identify parents at highest risk. Screening and preventive interventions are needed.

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Table 1

Description of Quantitative Research

Author	Sample Characteristics	Prevalence of Distress	How Distress Was Measured	Findings
Auslander et al 1993 ²⁷	N = 53, 89% white Age: 11.1 y (4.3)		<i>Stress</i> : Family Inventory of Life Events and Changes	Family stress was a significant predictor of metabolic control after controlling for family resources and C peptide level.
Cameron et al 2007 ²⁶	N = 59 Age: 15.9 y (1.1) Duration: 7.3 y (4.1)		<i>Anxiety</i> : STAI	Maternal anxiety associated with maternal reports of higher diabetes involvement and lower adolescent management skills and with adolescent reports of higher maternal control and parental overprotectiveness.
Chaney et al 1997 ¹⁸	N = 48 Age: 11.4 y (2.4) Duration: 2.94 y (3.2)	27% mothers at time 1, 21% at time 2; 31% fathers at time 1, 32% at time 2	<i>Distress</i> : Symptom Checklist 90–Revised	Increased mother and father distress associated with increased child distress.
Eckstein et al 2010 ¹³	N = 61 Age: 14.4 y (2.2) Duration: 4.4 y (2.8)	10% parents depressive symptoms (92% mothers)	<i>Depression</i> : Brief Symptom Inventory	Higher level of parental depression associated with lower parental monitoring, ^a inconsistent discipline, ^a and lower parental involvement/warmth. ^b Parental depression had indirect effect on youth depression through involvement/warmth. Parenting had direct effect on metabolic control and indirect effect through youth depression.
Hilliard et al 2010 ⁵⁷	N = 73, 69% white Age: 4.4 y (1.1) Duration: 1.5 y (1.1)	21% parents anxiety (97% mothers)	<i>Anxiety</i> : STAI; <i>Stress</i> : Pediatric Stress Inventory	Parental stress/anxiety associated with problematic child behavior. ^b Blood glucose level or variability not associated with stress/anxiety or child behavior.
Jaser et al 2008 ¹²	N = 108 81.7% white Age: 9.1 y (1.46) Duration: 3.6 y (2.8)	22.2% mothers depression	<i>Depression</i> : CES-D	Maternal depressive symptoms were associated with greater negative impact of diabetes on child's quality of life, higher levels of family conflict, and lower levels of family adaptability, cohesion, and child's perception of family warmth/caring.
Jaser et al 2009 ⁶	N = 67, 86% white Age: 4.8 y (1.5) Duration: 1.4 y (1.3)	21% mothers anxiety, 24% mothers depressive symptoms	<i>Depression</i> : CES-D; <i>Anxiety</i> : STAI	How upsetting it was for mothers to cope with T1DM was greatest predictor of anxiety and depressive symptoms. Anxiety and depressive symptoms not related to A1C.
Landolt et al 2002 ⁸	N = 38 Age: 10.5 y (2.5) Newly diagnosed	24% mothers PTSD, 51% mothers partial PTSD, 22% fathers PTSD, 41% fathers partial PTSD	<i>Stress</i> : Post Traumatic Diagnostic Scale	
Landolt et al 2005 ¹⁹	N = 49 Age: 10.5 y (2.7) Newly diagnosed	22.4% mothers PTSD at 6 wk, 16.3% at 6 mo, 20.4% at 12 mo; 14.6% fathers PTSD at 6 wk, 10.4% at 6 mo, 8.3% at 12 mo	<i>Stress</i> : Post Traumatic Diagnostic Scale	The number of preceding life events, ^b PTSD symptoms at 6 wk, ^a and PTSD symptoms at 6 mo ^c predicted PTSD symptoms at 12 mo in mothers.
Mitchell et al 2009 ¹⁰	N = 43, 77% white Age: 4.5 y (1.1) Duration: 1.3 y (1.0)		<i>Stress</i> : Pediatric Parenting Stress <i>Anxiety</i> : STAI	Parenting stress predicted greater state anxiety ^a and maternal rating of child behavior problems. ^a Fathers completed <20% of daily diabetes care.
Monaghan et al 2009 ³⁰	N = 71, 66% white Age: 4.5 y (1.2) Duration 1.5 y (1.1)		<i>Stress</i> : Pediatric Inventory for Parents;	Parents who performed nighttime blood glucose monitoring had higher anxiety ^b and parenting stress ^a than

Author	Sample Characteristics	Prevalence of Distress	How Distress Was Measured	Findings
Mullins et al 2004 ³	N = 43, 93% white Age: 10.1 y (1.4) Duration: 3 y (2.6)		<i>Anxiety</i> : STAI <i>Stress</i> : PSI	parents who performed nighttime blood glucose monitoring rarely or never. Parenting stress and child vulnerability associated with higher levels of depressive symptoms in child. Parental stress mediated relationships between child vulnerability and depression in that stress magnifies relationship.
Northam et al 1996 ²⁰	N = 124 Age: 7.6 y (3.6) Newly diagnosed	38% mothers at diagnosis, 24% at 12 mo, 27% fathers at diagnosis, 22% fathers at 12 mo	<i>Distress</i> : General Health Questionnaire	Psychological distress decreases but does not disappear at 12 mo.
Powers et al 2002 ²²	N = 40, 85% white Age: 4.6 y (1.2) Duration: 1.94 y (1.1)		<i>Stress</i> : PSI	Parents of child with T1DM had higher stress compared with controls. ^a Children with T1DM had more feeding behavior problems compared with controls. ^b Feeding behaviors associated with parental stress. ^b
Rodrigue et al 1994 ²³	N = 53 Age: 8.7 y (1.6) Duration: 3.4 y (1.4)		Parenting Sense of Competence	Parents of child with T1DM had lower parenting competence, ^a lower self-efficacy, ^b and lower parenting satisfaction ($P = .06$) compared with controls. Parenting competence associated with child behavior problems. ^b
Stallwood 2005 ²⁴	N = 73 (parents) Age (parents): 35.1 y (8.6) Duration: 2.5 y (1.9)		<i>Distress</i> : Problem Areas in Diabetes	Families of younger children have higher levels of distress. ^a Higher levels of perceived distress were associated with lower levels of A1C. ^b
Streisand et al 2005 ¹⁴	N = 134, 79% white Age: 12.9 y (2.0) Duration: 4.9 y		<i>Stress</i> : PSI	Increase parental stress associated with greater parental worry of hypoglycemia, ^a decreased ability to learn illness management, ^a increased child stress, ^a and decreased child self-management. ^a
Streisand et al 2008 ²¹	N = 102, 78% white Age: 9.7 y (4.0) Newly diagnosed	74% parents mild and 61% clinical depression, 59% clinical anxiety, 61% mothers	<i>Depression</i> : CES-D; <i>Anxiety</i> : STAI; <i>Stress</i> : Pediatric Parenting Inventory	Anxiety associated with parental diabetes self-efficacy ^a and parenting stress. ^a Depression associated with parental stress. ^a
Sullivan-Bolyai et al 2002 ²⁹	N = 28, "majority white" Duration: 0.3–2.8 y		<i>Stress</i> : PSI	No difference in parental stress compared with matched controls. Stress associated with increased diabetes duration. ^b
Viner et al 1996 ²⁸	N = 43 Age: 10.2 y (3.16)		<i>Stress</i> : Family Inventory of Life Events	High family stress associated with metabolic control.

Abbreviations: CES-D, Center for Epidemiologic Studies–Depression; PSI, Parenting Stress Index; TSD, posttraumatic stress disorder; STAI, State–Trait Anxiety Inventory; T1DM, type 1 diabetes mellitus.

^a $P < .05$.

^b $P < .0$.

Table 2

Description of Qualitative Research

Author	Method	Purpose	Sample Characteristics	Findings
Bowes et al 2009 ³⁵	Qualitative study with in-depth interviews	To explore parents' longer term experience of having a child with type 1 diabetes	N = 17 (10 mothers, 7 fathers) Child age: range 9–23 y T1DM duration: 7–10 y Wales, UK	Diagnosis: Grief, some blamed themselves. Experience over time: Became accustomed to daily tasks and accepted routine as part of life. Never really accepted diagnosis. Recurring feelings of sadness. Felt "alone." Stress: Practical management of diabetes was difficult. Knowledge of consequences. Constant worry. Transition to adolescence. Sources of support: Taking it in blocks of time. Support groups for some.
Buckloh et al 2008 ³⁶	Qualitative description with focus groups	To explore parents' experience of learning about diabetes complications	N = 47 (30 mothers, 14 fathers, 3 other) Child age :13.2 y (2.5) T1DM duration: 4.5 y Diversity = 15% US	Diagnosis: Emotional time with depression, sadness, anxiety. Overwhelmed. Focused on diabetes management. Experience over time: Adolescence difficulty and frustrating. Stress: Anxiety over long-term complications. Concerns over insurance, life span of child. Sources of support: Having optimism.
Edmonds- Myles et al 2010 ³⁴	Qualitative description	To explore psychosocial impact of T1DM in low-income families	N = 21 Child age: 10–18 y T1DM duration: 4.0–6.3 y Diversity: 66% US	Experience over time: Began to adjust to diagnosis and T1DM care. Some felt that nothing was easier over time. Stress: Constant worry. Time-consuming regimen. Responsibility and hypervigilance. Financial pressures. Single parenthood. Sources of support: Professionals for white families. Friends and family for some. Faith. Humor.
Faulkner 1996 ³⁷	Descriptive with interviews	To explore how parents respond to school-age child with T1DM	N = 27 (from 7 families) Child age: 10.7 y T1DM duration: 4.6 y Diversity not reported US	Diagnosis: Shock, anger, denial, fear of child death. Experience over time: Learning. T1DM care difficult

Author	Method	Purpose	Sample Characteristics	Findings
Hatton et al 1995 ³²	Qualitative interpretive (phenomenology)	To generate understanding of parents' experience of infant or toddler with T1DM	N = 8 (2-parent families) Child age: 1.5 y T1DM: New to 2.5 y Canada	at times. Began to share T1DM with child. Mothers mostly provided care. Stress: Insulin reactions. Worry about complications. Giving injections. Causing pain to child. Sources of support: Faith. Not allowing T1DM to consume life. Diagnosis: Horrifying experience. Fear of child death. Overwhelmed. Very emotional (shock, grief, sadness). Exhausted. Social isolation. Experience over time: Struggles with growing child and child need for independence. Challenge with school. Stress: Taking child home. Immense responsibility. Complex and all-pervading regimen. Inflicting pain on child. Unpredictable blood sugar. Sources of support: Professionals. Sharing responsibility with spouse.
Lowes et al 2004 ⁵⁸	Qualitative approach with in-depth interviews	To explore parents' experience of having child with T1DM >1 y	N = 38 Child age: not reported New diagnosis Wales, UK	Diagnosis: Shocked, distressed, overwhelmed. Experience over time: Routines established. Becoming more flexible. Promoting "normal life." Continued sense of loss. Loss of spontaneity. Maintaining vigilance. Stress: Hypoglycemia. Inexplicable highs and lows. Constant worry. Sources of support: Professionals. Take it 1 day at a time. Other people with knowledge of T1DM. Optimism.
Lowes et al 2005 ³¹	Qualitative longitudinal (Hermeneutics)	To explore parents' experiences of child with T1DM >1 y	N = 38 Child age: not reported New diagnosis Wales, UK	Diagnosis: Shocked, distressed, grief, fear, ill-prepared for situation.

Author	Method	Purpose	Sample Characteristics	Findings
Marshall et al 2009 ³⁹	Phenomenology	To explore parental experience of child with T1DM from diagnosis onward	N = 11 (10 mothers, 1 father) T1DM duration: 10 m to 8 y Some diversity, but statistics not reported UK	Experience over time: Still aware of losses (control, healthy child, etc). Feelings of sadness and guilt. More confident about T1DM care. Developing a routine. Stress: Constant worry. Constant planning around T1DM care. Sources of support: Optimism Diagnosis: Grief, loss of healthy child, confidence Experience over time: Disruption in family patterns and parent-child relationship. Stress: Inflicting pain on child. Transition of T1DM care to child.
Mellin et al 2004 ⁵⁹	Content analysis	To explore parents' perceptions of impact of T1DM on family	N = 30 (24 mothers, 6 fathers) Child age: 17.7 y (4.1) T1DM duration: 7.7 y (4.1) Diversity = 16% US	Diagnosis: Huge emotional impact. Guilt. Experience over time: Organized home life around T1DM care Stress: Long-term complications. Constant burden and responsibility for diabetes care. Keeping blood sugar regulated. Change of own lifestyle. Sources of support: Maintaining positive attitude.
Seppanen et al 1999 ⁶⁰	Case study	To explore process of parental coping and experiences of social support	N = 2 (2-parent families) Child age: 3 and 4 y Newly diagnosed Finland	Diagnosis: Guilt and lack of information. Disbelief. Highly motivated to learn care. Experience over time: Reorganized life. Felt alone in responsibility for child's care. Stress: Injections. Very demanding regimen. Nighttime blood glucose. Focus on meals and eating. Child rebellion. Sources of support: Professionals. Relatives and friends. Emotional support from spouse and shared responsibility. Positive attitude.
Smaldone et al 2011 ⁵	Content analysis	To explore perceptions of psychosocial	N = 14 Child age: 11.1 y (3.5)	Diagnosis: Fear and doubt. Feeling totally overwhelmed.

Author	Method	Purpose	Sample Characteristics	Findings
		adaptation in parenting young children with T1DM from diagnosis through childhood	T1DM duration: 8.0 y (3.7) Diversity US	Experience over time: No parents felt they had achieved mastery (ongoing challenges, always changing). Tension between promoting normal development of child and keeping child safe. Stress: Complicated regimen. School experience. Child's future. Sources of support: Availability of diabetes team. Sharing responsibility with spouse. Support groups for some.
Sullivan- Bolyai 2003 ²	Qualitative description	To describe the day-to-day experiences of mothers of young children with T1DM	N = 28 Child age: 2.9 y (0.6) T1DM duration: 1.3 y (0.7) Diversity: 11% US	Diagnosis: Hard to learn T1DM care. Experience over time: Rigid rules at first. More relaxed and confident over time. Modified T1DM care with change in developmental needs. Stress: Constant vigilance. Daily tasks. Fear of hypoglycemia. Nighttime and nap time. Day care issues. Concern about complications. Sources of support: Professional. Spouse. Family, friends. Support group for some. Patience. Inner strength.
Sullivan- Bolyai 2006 ³³	Qualitative description	To describe fathers' experience of young child with T1DM	N = 14 Child age: 5.0 y (2.0) T1DM duration: 1.4 y (0.8) Diversity = 0% US	Diagnosis: Shock. Traumatic experience. Quick move to action. Overwhelmed with care and what was needed to learn. Experience over time: Gaining confidence. Providing respite for spouse. Treating child "normally." Enduring sadness. Stress: Injections and causing pain. Fear of giving too much insulin. Nighttime. Worry about complications and child in school. Sources of support: Professionals. Sharing responsibility with spouse.

Author	Method	Purpose	Sample Characteristics	Findings
Wennick et al 2006 ³⁸	Qualitative longitudinal (hermeneutics)	To understand family lived experience when child diagnosed with T1DM	N = 12 (2-parent families) Child age: 9.5 y Newly diagnosed Sweden	Diagnosis: Sorrow and despair. Tearful. Powerlessness. Trying to make sense of diagnosis, reviewing symptoms. Experience over time: Reconstructing everyday life. Family life had to be carefully planned. Focus on blood sugar. Stress: Worry about complications and death. Complex T1DM care. Maintaining blood glucose. Nighttime. Child going to school or friends.

Abbreviation: T1DM, type 1 diabetes mellitus.

Table 3

Summary of Themes in Qualitative Research on Parents of Children With Type 1 Diabetes Mellitus

Theme	Experience of Parent
Difficult diagnosis	Traumatic and devastating Profound emotional distress Ill-prepared to deal with the responsibility Information to learn was complex and difficult.
Family disruption	Disruption of family routines Constant worry Social isolation Rearrangement of parenting roles
Adjustment	Increased ability to manage over time Incorporated diabetes tasks into family routines Tried to make child's life normal Sought personal and professional support
Ongoing stress	Maintaining metabolic control Complex and time-consuming regimen Inflicting pain on child Magnitude of responsibility Changing life transitions

Table 4**Clinical Recommendations for Parents of Children With Type 1 Diabetes Mellitus**

<p>Assess parental stress, anxiety, and depression with a brief assessment form or in private consultation.</p> <p>Stress—Pediatric Inventory for Parents⁶¹</p> <p>Anxiety—State–Trait Anxiety Inventory (STAI)⁴⁵</p> <p>Depression</p> <p>Center for Epidemiologic Studies–Depression (CES-D)⁶²</p> <p>Beck Depression Inventory (BDI)⁶³</p> <p>Brief Depression Screening Tool⁴²</p> <p>Anxiety and Depression</p> <p>General Health Questionnaire (GHQ)⁶⁴</p> <p>Psychosocial Adjustment</p> <p>Psychosocial Assessment Tool (PAT2)⁶⁵</p> <p>Identify high-risk parents such as single parents, those from minority groups, or those without social support.</p> <p>Inform parents that stress and distress are common in parents of children with T1DM.</p> <p>Encourage parents to actively seek support from family, friends, peers, and professionals.</p> <p>Provide parents with Internet sources of peer support.</p> <p>Refer parents with elevated symptoms of stress, anxiety, or depression to their primary care provider or a mental health professional.</p> <p>Educate parents with elevated symptoms of stress, anxiety, or depression that their emotional status not only affects them negatively but also affects their child and family, thus reinforcing the importance of effective management.</p>
