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## A concept analysis of psychological distress in parents related to diabetes management in children and adolescents

Diana Arabiat  
*Edith Cowan University*

Mohammad AL Jabery

Lisa Whitehead  
*Edith Cowan University*

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## **A concept analysis of psychological distress in parents related to diabetes management in children and adolescents**

### **Abstract**

**Purpose:** To report a concept analysis of parents' psychological distress in the context of diabetes management among children and adolescents. A clear understanding of the possible impact of diabetes management on parents will help to inform how nurses can work with parents to support glycaemic control in children and adolescents.

**Design and Method:** Concept analysis using Walker and Avant's eight-stage approach was used as a guiding framework. PubMed, OVID (CINAHL, Medline, PsychInfo), the Cochrane library and the Joanna Briggs library were searched for the past 50 years.

**Results:** Thirty-three studies provided data for the concept analysis. Attributes included difficulty coping; changes in emotional status; and manifestations of mental health problems.

**Practice Implication:** Based on the literature synthesis, we suggest all facets of distress related to diabetes can in principle be inferred through the proposed relationship between distress and other interactions of individual coping, caring burden and family relational functioning. The proposed conceptual model linking antecedents' factors and individual characteristics of parents to the concepts of psychological distress may assist researchers to design interventions for supporting diabetes management in children and adolescents.

**Keywords:** Diabetes; psychological distress; concept analysis; children; adolescents.

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### **What is currently known?**

- Families caring for a child diagnosed with diabetes experience ongoing stress and chronic sorrow.
- Psychological distress in parents may negatively influence the management of a child's illness.
- The concept of psychological distress is an area that is yet to be fully clarified and integrated by researchers and healthcare professionals.

### **What does this article add?**

- Psychological distress can be viewed on a continuum of behaviour ranging from achieving personal growth and resilience to clinical manifestation of mental illness. Child outcomes as treatment adherence and glycaemic control were found to be affected by levels of psychological distress in their parent.
- Further research is needed to consensually confirm the interrelated set of factors contribute to coping with psychological distress relevant to supporting diabetes management in children, and to test and advance current conceptual model of distress in parents.

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## 1. INTRODUCTION

Supporting diabetes management in children and adolescents has been described as a time filled with a range of emotional work, technical tasks, and new responsibilities (Pinquart, 2018). Adding to the emotional toll of having a child diagnosed with diabetes; families most often are required to assume a set of new responsibilities and role expectations that influences every dimension of daily life (Pierce et al., 2017a).

Daily management of type 1 diabetes includes frequent insulin injections, blood glucose monitoring, and attention to dietary intake and physical activities. Caregivers of children with diabetes indicated that parents experienced ongoing stress (Whittemore et al., 2012), and chronic sorrow that did not resolve (Lowes & Lyne, 2000). Whittemore et al., (2012) reported that 19% of parents reported clinically significant level of distress regardless of time since diabetes diagnosis. Psychological distress in parents supporting chronic condition management in children may negatively influence the management of a child's illness (Pinquart, 2018). Stress related diabetes management can also impact diabetes outcomes, including quality of life, self-management, and glycaemic control (Hillirad et al., 2018; Pierce et al., 2017b).

Despite recognition of the impact of tasks related to parenting a child with diabetes on parent's distress it is difficult to draw conclusions from the literature when the notion of 'distress' itself is poorly operationalised in nursing studies. This often means that the notion of psychological distress is defined as a patient-reported symptom rather than a disease category (Carolan, Smith, & Forbat, 2015). Long-term emotional adaptation to diabetes in children has been constructed as chronic sorrow or episodic grief (Bowes et al., 2009; Lowes & Lyne, 2000). Parents who receive a diagnosis of diabetes for their child often experience

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intense feelings that reflects the grief of losing the hoped-for-typical healthy child (Pierce et al., 2017a; Whittemore et al., 2012). In the case of children diagnosed with diabetes, parent's psychological distress may result not only because of diabetes diagnosis, but also from an overwhelming belief among parents that ongoing emotional support for themselves should be available as and when needed (Bowes et al., 2009). When early symptoms of distress go unrecognised by health care professionals, there is an increased risk that parents may experience additional psychological distress and decreased functional status (Castensøe-Seidenfaden et al., 2017). Therefore, understanding how psychological distress is conceptualised in parents constitutes an important area of knowledge in relation to the potential for improved health outcomes and family functional status. It is important to understand how psychological distress is conceptualised in parents related to diabetes management because how parents experience distress will likely impact on both their child's and their own health outcomes (Hillirad et al., 2017). Understanding the variables that mediate the relationship between diabetes management in children and manifestation of psychological distress in parents, will further highlight support needs and inform the design of psychosocial interventions.

## **2. AIMS AND METHODS**

The purpose of this study was to clarify the concept of psychological distress in the context of type 1 diabetes management in children and adolescents using Walker and Avant's (1995, 2011) criteria to determine the attributes, antecedents, and consequences of the concept of psychological distress based upon the findings of the previous literature.

### **2.1. Design**

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The methodology includes an eight-stage process: (1) selecting a concept; (2) determine the aims or purposes of analysis; (3) identification of all uses of the concept, (4) determination of the defining attributes, (5) construction of a model case, (6) construction of borderline, related, and contrary cases, (7) identification of antecedents and consequences, and (8) defining empirical referents (Walker & Avant, 1995, p. 39). This methodology was chosen for its systematic and logical approach.

## **2.2. Data sources**

PubMed, Ovid databases (CINAHL, MEDLINE, PsycINFO), the Cochrane Library and the Joanna Brigg's Library were chosen to identify literature examining parents' psychological distress in the context of supporting diabetes management in children and adolescents. A systematic search of electronic databases was conducted using the followings keywords: 'psychological distress', 'anxiety', or 'depression', and 'parents', 'caregiver', 'mother', or 'father', and 'management, or 'diabetes control' (Table 1). Inclusion criteria were English language articles that included primary or secondary data on parent's experiences of psychological distress related to diabetes management in their child or adolescent.

[INSERT TABLE 1 ABOUT HERE]

## **2.3. Data selection and analysis**

Studies included peer-reviewed research studies using mixed methods, quantitative or qualitative methodologies together with discussion and review papers focusing on parents' experiences of psychological distress in relation to diabetes management in children and adolescents. The database search and selection process resulted in 33 papers for inclusion in the concept analysis (Figure 1).

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[ INSERT FIGURE 1 ABOUT HERE]

The abstracts and titles of all studies identified by the search strategy were reviewed. Each document was read at least twice to gain an overview of the concept, and to extract findings related to psychological distress in parents related to diabetes management in children or adolescents.

A range of methodologies were used in the 33 studies included in this review including critical appraisal, cross-sectional survey, longitudinal survey, and structured and unstructured in-depth interview design. Two papers were literature review or discussion articles (Table 2). Key themes and significant findings related to the parents' experiences of psychological distress in relation to diabetes management were identified and categorized, then subjected to a meta analysis and collapsed into three defining attributes.

[INSERT TABLE 2 ABOUT HERE]

### **3. RESULTS**

#### **3.1. Common definitions and uses**

One of the dictionary definitions of the noun 'psychological' is: related to the mental and emotional state of a person, while the word 'distress' is defined as: extreme anxiety, sorrow, or pain ( Lexico (2019). The term 'distressed' originated in the 13<sup>th</sup> century. Lexico (2019) indicates that the term originated from the Latin word 'distringere' which means to 'stretch apart'. The word was translated into Old French 'destresce' (noun), 'destrecier' (verb), and then into the Old English word 'distress'

In nursing literature, there are several definitions of psychological distress in use. The notion of psychological distress has been defined as a unique discomforting; emotional state

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that is experienced by an individual in response to a specific stressor or demand that may result in temporary or permanent harm to the person (Ridner, 2004). The National Comprehensive Cancer Network (NCCN) has defined distress as ‘a multi-factorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment’.

Review of the uses of the concept ‘psychological distress’ in our sample has identified three terms used to describe this concept. First, psychiatric symptoms (Canning et al., 1996; Hansen et al., 2012; Northam et al., 1995); second, depression and anxiety (Jaser et al., 2014; Moreira et al., 2014; Williams et al., 2009); and emotional stress (Haugstvedt et al., 2010; Mitchell et al., 2009; Rumburg et al., 2017). Across the qualitative studies, the use of the term psychological distress varies and included several descriptive themes (Table 3).

[INSERT TABLE 3 ABOUT HERE]

The most common definition characterizes psychological distress as constant feeling of worries (Lindstorm et al. 2017; Pierce et al. 2017,) and ‘chronic sorrow’ (Lowe et al. 2004). Presumably, distress was noted as an overall term encompassing feeling of emotional exhaustion, fear, sadness and social isolation (see table 3). The terms ‘anxiety and/ or depression’ and ‘mental symptoms’, however, tend to be used interchangeably in the literature. With this definition, the researchers operationally defined psychological distress as clinical manifestation of anxiety and depressive disorders.

### 3.2. Defining attributes

Defining attributes of a concept are the characteristics most frequently associated with the concept and that help differentiate it from other concepts (Walker & Avant, 1995). Three

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key attributes of psychological distress in parents emerged. These were: (1) difficulty coping, (2) changes to emotional status, and (3) manifestations of mental health problems. Each is discussed below.

### ***3.2.1. Difficulty coping***

The main characteristic of this attribute was difficulty coping with the stress related to treatment management. Coping strategies reflect a range of responses to psychological distress available and successfully used by the parent. Unresolved coping strategies may have a negative impact on parents, such as feeling emotionally overwhelmed (Buckloh et al., 2008; Castensøe-Seidenfaden et al., 2017;), emotionally exhausted (Pierce et al., 2017a; Seppanen et al., 1999) or burned out (Lindstrom et al., 2017). Never being able to achieve mastery of the diabetes were also reported as another characteristic of this attribute (Buckloh et al., 2008; Castensøe-Seidenfaden et al., 2017; Sullivan- Bolyai, 2006).

Distress may be prevented or decreased when parents believe coping with the stress of their child's diabetes is possible and employ problem solving strategies (Pierce et al., 2017a). Parents reported feeling "normal" and demonstrated flexibility in daily living (Lowes et al., 2004; Lowes et al., 2005; Marshall et al., 2009; Pierce et al., 2017a).

### ***3.2.2. Changes to emotional status***

Various emotions were reported among parents related to diabetes management. The most pronounced emotion was fear of hypoglycaemia (Bolyai, 2003; Edmonds- Myles et al., 2010; Seppanen et al., 1999; Sullivan-) and excessive worry about the need for constant vigilance (Jaser et al., 2009). Being preoccupied with how to handle issues related to the child's diabetes, such as meal plans or insulin injections, and how the stress of treatment management is perceived were characteristics of this attribute (Jaser et al., 2009; Lawton et

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al., 2014; Pierce et al., 2017a). The manifestation and uses of the term ‘psychological distress’ varied across studies and included a number of descriptive themes. As presented earlier in table 2, some of the emotional symptoms manifested by the parents included feelings of fear or constant worry, sadness or chronic sorrow, vulnerability, social isolation or loneliness, frustration, loss of control, constant vigilance, sleep deprivation, guilt, anger, and fatigue.

### ***3.2.3. Manifestations of mental health problems***

Depression or symptoms of anxiety are used throughout the literature to describe symptoms of mental health (psychiatric symptoms) that are associated with psychological distress. High levels of anxiety and/or depression were the most highly cited notions used in studies to define attributes of psychological distress in parents. Northam et al., (1995) reported psychological distress defined as meeting clinical levels in parents related to diabetes management and studies by Hungerbuehler et al., (2011) and Canning et al., (1996) reported significantly higher psychological distress compared to community norm ( $p < .001$ ). Similarly, the words clinical anxiety and depression were used in these studies to measure level of clinical psychological distress in parents or families. In a qualitative study by Pierce et al., (2017a), manifestation of mental health issues as depression, anxiety, and post-traumatic stress disorders (PTSD) were reported among parents, including hospitalisation due to distress.

### **3.3. Developing a model and additional cases**

In concept analysis, developing a model and additional cases are valuable in explaining the concept of interest. The selection of a model case aims to provide a clear and realistic example of the use of the concept (Walker & Avant, 1995, 2011). Model cases

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include all of the defining attributes associated with the concept. Another constructed example of the concept use is the borderline case. Borderline cases include some of the defining attributes, whereas contrary cases include none of the defining attributes of the concept (Walker & Avant, 1995, 2011). An example of a model case, a borderline case, and a contrary case are presented here.

### **3.3.1. Model case**

Mrs John is a 34-year-old mother of three children. Her youngest child, Rose, developed T1DM two years earlier. Whilst taking a blood glucose reading for Rose, she cried and kept saying ‘I don’t know how to cope with this’ She was forced to leave the workforce so she can visit her daughter’s school every couple of hours to support her diabetes management and administer insulin. The nursing staff noted that Mrs. John appears increasingly worried and withdrawn. She expressed to the nurse that ‘she is not sure if she has the energy to keep doing this’. Her family lives away and her husband is unable to assist with the daily diabetes management due to long working hours. She appears overwhelmed and has developed signs of clinical anxiety and depression.

The case illustrates that Mrs. John is feeling unable to cope with the demands associated with diabetes management and is experiencing emotional distress communicated to the nursing staff as symptoms of anxiety and depression. In this case, the defining attributes of psychological distress were present and evident.

### **3.3.2. Borderline case**

Mrs Smith was told by her son’s primary care physician that her son has poor glycaemic control and that he needs to pay more attention to prevention of, and intervention to address hyperglycaemia or hypoglycaemia. Mrs. Smith told her son’s physician that she

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worries that her son is missing his lunchtime dose of insulin because no one at the school is confident to give the injection. She stated that she worried about the potential consequences of not keeping his diabetes under control over the long term. Mrs. Smith was worried and sad, yet she had been positive that her son would work hard to keep his diabetes under control. Although she was overwhelmed and saddened by the things he needs to do, she was grateful that her son was an active boy that would not allow diabetes to get in his way.

This is a borderline case portraying some defining attributes of psychological distress as feelings of sadness, excessive fears and being overwhelmed by diabetes, but not the feeling of being unable to cope.

### **3.3.3. *Contrary case***

Miss Joy, a 45-year-old sales manager attended the diabetes clinic with her 6-year-old child. She had joined a carer support group three weeks earlier. She was encouraged to talk to a councillor regarding her caring role, or to organise respite care to give herself a break. Miss Joy told her child's physician not to worry and that she felt confident in her new role, would be just fine, and did not need further assistance with her child's diabetes care. She did not exhibit difficulty in coping, manifestation of emotional symptoms, or symptoms of mental health. In this case, none of the attributes of the concept are present.

## **3.4. Antecedents and consequences**

Antecedents are the events that must exist before occurrence of the concept, and consequences are the events that occur as a result of the concept having happened (Walker & Avant, 1995, 2011).

### **3.4.1. *Antecedents***

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Several antecedents' factors have been identified as impacting on the psychological distress of parents and related to diabetes management in children. Clinical and demographic factors of parents and children influence the parents' experiences of psychological distress. Specifically, mothers are more likely to express psychological distress than fathers (Hansen et al., 2012; Haugstvedt et al., 2010; Streisand et al. 2008). Levels of distress are also influenced by family income (Canning et al., 1996; Jaser et al., 2009) where lower family income was significant predictors of depression and anxiety level in parents. Likewise, parents experienced major emotional stress and anxiety over handling child's development (Buckloh et al. 2008), and over their child's growing up and becoming independent (Marshall et al. 2009). The psychological impact of diabetes in low-income families was higher among mothers of pre-school children (Edmonds-Myles et al. 2010), and in mothers of children under 4 years and adolescents (Northam et al. 1995). Parents of adolescents aged 13-18 years reported significantly higher psychological distress than parents of children aged 8-12 years in Moreira et al. (2014).

Family relational functioning and perceived family burden have also been reported to be an antecedent factor to psychological distress in parents (Canning et al., 1996). Low family cohesion (Hungerbuehler et al., 2011; Mellin et al., 2004; Moreira et al., 2014) and/or increased diabetes-specific family conflict (Williams et al., 2009) may be particular risks associated with severe psychological distress in parents. Shared responsibility with spouse (Seppanen et al., 1999; Smaldone et al., 2011; Sullivan- Bolyai, 2006), and the parent-child relationship or perceived behavioural problem in child (Marshall et al., 2009; Mitchell et al., 2009) also influenced the levels of psychological distress experienced by parents. For example, higher level of stress in fathers was associated with child's difficult behavior and father's sense of low self-efficacy about diabetes management (Mitchell et al. 2009). Sharing

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diabetes responsibility among parents was significant source of support that helped parents to adapt (Hatton et al. 1995; Seppanen et al. 1999; Sullivan-Bolyai, 2006; Smaldone et al. 2011).

### **3.4.2. Consequences**

Psychological distress in parents can be positioned anywhere along a continuum of behaviour ranging from mild distress, such as feeling sad to extreme distress that may take the form of clinical anxiety or depression. The experience of psychological distress among parents has been directly linked to clinically significant sleep problems in parents (Hansen, 2012; Wennick et al. 2006) and/or hospitalisation (Sullivan- Bolyai 2003; Pierce et al. 2017a). Hansen et al. (2012) reported chronic sleep deprivation among 66% of mothers and 44% of fathers of children and adolescents with diabetes.

Additionally, outcomes such as treatment adherence (Hansen et al., 2012) and glycaemic control (Rumburg et al., 2017) were found to be affected by levels of psychological distress among parents. The higher the mother's depression level (Rumburge et al. 2017), or diabetes-specific family conflicts and anxiety (Williams et al. 2009), the more likely is that the child will experience poor glycaemic control or HBA1c values.

On the other hand, when experiencing extreme distress, parents can still achieve personal growth and return to baseline functioning. More than half of parents (62.7%) showed at least a moderate degree of posttraumatic growth (PTG) at 3-year follow-up of 126 parents of children diagnosed with T1DM or cancer (Hungerbuehler et al., 2011). This growth is thought to evolve in the absence of posttraumatic stress, or they can coexist beside or in spite of it (Folkman, 2008). When experiencing extreme distress, parents can still

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identify new possibilities, more meaningful relationships with others, and achieve increased appreciation for life (Hungerbuehler et al., 2011).

### 3.5. Empirical referents

The identification of empirical referents to make the concept of interest measurable is the final stage in the concept analysis framework (Walker & Avant, 2011). It includes categories or classes of the actual phenomena that demonstrate the existence of the concept (Walker & Avant, 2011), and methods in which the concept can be measured or observed. Based on the synthesis, we suggest that all facets of psychological distress proposed in the operational definition of concept can, in principle, be inferred through the proposed relationship between distress and other interactions. The proposed definition of psychological distress experienced by parents related to diabetes management in their child or adolescent is a multidimensional, subjective, emotional response to the diagnosis, diabetes related demands, and the social context they are in. This negative impact was frequently measured by Paediatric Parenting Stress (PPS), a construct used to define stress associated with raising a child with a chronic illness (e.g., the Pediatric Inventory for parents; PIP and the Parenting Stress Index; PSI). In addition to a variety of measures related to manifestation of psychiatric symptoms in parents, including The General Health Questionnaire (GHQ-30), Brief Symptom Inventory (BSI), The Harvard Trauma Questionnaire – Part IV (HTQ), and Symptom Checklist 90 Revised (SCL-90-R).

Previous studies support the notion that parental distress related to diabetes management in children is not a linear analytic process, but instead involves a multi-dimensional concept that needs to be evaluated in terms of the relationship between distress itself and other interactions that impact on individual's coping strategies (Mitchell et al.,

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2009; Jaser et al. 2014; Jaser et al., 2009), perceived burden of care (Canning et al., 1996; Hansen et al., 2012; Haugstvedt et al., 2010), family relational functioning (Hungerbuehler et al., 2011; Jaser et al., 2014; Moreira et al., 2014;) and the child's adjustment or behavioural problems (Mitchell et al., 2009; Marshall et al., 2009). The concept of psychological distress proposed in the literature suggests a multidimensional approach to the phenomenon, therefore a multidimensional assessment of distress can, to some extent be used to demonstrate the actual existence of the concept. With no multidimensional measure of psychological stress in existence, researchers need to use multiple measures to assess the multidimensional nature of psychological distress or to develop and test a multidimensional parental psychological distress measure.

#### 4. DISCUSSION

The purpose of this paper was to clarify the concept of psychological distress in the context of diabetes management among children and adolescents. Our findings are consistent with, and build on, previous studies to identify key components in a conceptualisation of distress relevant to chronic disease management in children and adolescents. An earlier conceptualisation of psychological distress demonstrated that psychological distress is a complex multidimensional concept that is presented as a continuum of emotions ranging from feeling vulnerable to the manifestation of clinical depression and/or anxiety (Carolan et al., 2015). Attributes of psychological distress identified in this analysis are consistent with those identified among adult cancer patients (Albrecht & Rosenzweig, 2014; Gundelach & Henry, 2016). However, we have expanded the concept of psychological distress beyond adult and cancer patients to include an interrelated set of factors which contribute to coping with

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psychological distress relevant to supporting diabetes management in children and adolescents.

In this analysis, we identify three major attributes of psychological distress that prevail in the context of diabetes management: (1) difficulty coping, (2) changes in emotional status, and (3) the manifestation of mental health problems. What is clear from this analysis is that several factors combine to affect intensity, duration and manifestation of psychological distress experienced by parents related to diabetes management. The antecedents, defining attributes and consequences identified in this analysis offer a foundation on how to conceptualize and operationalize psychological distress among parents involved in diabetes management.

[INSERT FIGURE 2 ABOUT HERE]

Through a synthesis of previous studies, we propose a model of psychological distress in parents that includes both antecedents and consequences, which have been reported to influence the level of psychological distress in parents and related to diabetes management in children and adolescents (Figure 2). This conceptual model links antecedent factors and individual characteristics of parents to the concepts of psychological distress related to diabetes management in children and adolescents with type 1 diabetes.

The proposed definition of psychological distress can be conceptualised as an ongoing process of facing adversity and enormous family burden relating to the medical treatment of type 1 diabetes in children. Parents' presentations of psychological distress may be influenced by the individual characteristics of parents including demographics (e.g. age and development of the child, family income), personality (e.g. coping style or use of hope),

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perceived social support (e.g. family cohesion, shared responsibilities) as well as adjustment or behavioural problems of the child.

As shown in figure 2, we propose a conceptual framework in which supporting diabetes management in children and adolescents influences psychological distress in parents through interrelated constructs. Overall, the relationship between supporting diabetes management and manifestation of psychological distress may depend upon the social environment and/or socio and clinical demographics. For example, distress in parents is strongly related to family relational functioning, individual coping styles and caregiver burden. Low family cohesion (Hungerbuehler et al., 2011; Moreira et al., 2014), lack of professional or social support (Seppanen et al., 1999; Smaldone et al., 2011; Sullivan- Bolyai, 2006), and behavioural problems (Mitchell et al., 2009) may be particular risks for severe psychological distress among parents. Furthermore, the impact of demographic and clinical characteristics on distress have reported that mothers showed a higher risk of anxiety-depression than fathers (Hansen et al., 2012; Haugstvedt et al., 2010).

While the conceptualization of psychological distress as an interrelated construct is evident through the analysis, the proposed relationships between quality of family relations/cohesion and caregiving burden are tentative, as these have not been studied extensively. To understand psychological distress in the context of diabetes management not only means the context of diabetes management demands, but also the everyday demands including family, financial and social burdens related with the phenomenon.

## 5. LIMITATIONS

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There are several limitations of the current study. The studies included in this analysis referred to parents of a general pediatric population at different developmental stages (e.g., young children and adolescents); therefore, diabetes management was presented in a broad context in studies that included heterogeneous groups of children at different developmental stages. Restricting the search to empirical literature of homogenous diabetes populations (e.g. parents of young children or parents of adolescents) may have provided more focused outcomes.

Another limitation is the assumption that daily management of diabetes includes frequent insulin injections. As insulin administration was not assessed in the selected studies, we were not able to measure the differences in parental psychological distress among children and adolescents using continuous subcutaneous insulin infusion vs. multiple daily injections. Additionally, there was no intra- or inter-reliability assessment of included studies, so there is the potential for subjectivity in the analysis. Reporting bias can affect the reporting of themes and categories related to psychological distress. The majority of documents included in this analysis were limited to Western countries, therefore; the findings may not be applicable to the global context. In an already long article, we were not able to include more detailed information or discussions of the quantitative findings related to parent's lower self-efficacy, or loss of hope in the analysis, but we believe the studies in this analysis are a good representation of distress research that will enable researchers, teachers, nurses and other health care professionals to better understand how psychological distress is conceptualised in parents of children diagnosed with type 1 diabetes.

## 6. IMPLICATIONS

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There is evidence to suggest that nurses have a lack of knowledge, interest, and experience of the impact of diabetes management in children and adolescents on their parents' mental health (Nikitara, Constantinou, Andreou, & Diomidous 2019). To maintain an effective diabetes management in children and adolescents, a clear understanding of how parents conceptualise psychological distress is imperative. Psychological distress is an important concept for nurses working with families to support chronic disease management in children and adolescents. It is important that health care professionals, nurses, teachers, and policy makers recognize the need to offer support for parents in their challenging role, as well as to maintain effective diabetes management in children and adolescents.

The implications of the conceptual model linking antecedents' factors and individual characteristics of parents to their psychological distress are various. The greatest implication is the conceptualisation of distress as a process involving the interplay of several variables none of which can be assumed constant in the parent's life. The implications for nursing practice and education will be leaning away from the traditional support practice based on providing psychological care to leading and designing interventions and focusing upon a multidisciplinary services approach designed to describe and influence the antecedents' factors. To integrate and maintain diabetes management practices, health care professionals, teachers, and policy makers should have an understanding of the interrelated set factors which contribute to cope with increased psychological distress in parents of children living with diabetes. Nurses may find this analysis useful to implement comprehensive yet individualised care for children and their families.

With the current focus on Family Centered Care for children and their families (Authors, 2018), conceptualising psychological distress in parents related to diabetes management can be considered as a preliminary step in theory development with the goal of

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refining and testing the conceptualized model. This finding has significant implications for research. Researchers are encouraged to (a) operationalize this multidimensional concept, select a design, and choose and/or develop appropriate measures to test the model; (b) explore differences in psychological distress among single versus married parents; and among children using insulin pumps versus injections. If the future studies explore those differences, then the impact of supporting diabetes management upon parents may be studied with greater reliability.

Supporting diabetes management in children can evoke an intense emotional distress, including a high risk of anxiety and/or depression (Whittemore et al., 2012). Recognition of the complex nature of daily management of diabetes and the possibility of clinical anxiety and depression indicates a need for early intervention to protect parent's wellbeing. Policy makers need to consider routine assessment of parental distress levels in clinical and school settings. Respite care is important, including provision of education and training resources and fostering diabetes management practices within the school setting (Authors, 2019). Meeting parents' needs, acknowledging the increased emotional, financial, and care giving burden are also key elements in fostering positive coping among parents.

## 7. CONCLUSION

The concept of psychological distress in the context of diabetes management is best conceptualised by the relationship between the antecedents, consequences, and parents' ability to adapt or to cope with the daily management of diabetes. Parents' psychological distress can be positioned anywhere along a continuum of behaviour ranging from mild distress to extreme distress. Psychological distress in parents may be influenced by other factors, including demographics, coping style, family relationships, care demands and financial burden. Based on this definition, the presentation of attributes, antecedents and

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consequences of psychological distress proposed in figure 2 should enable nurses to identify early signs or risk for psychological distress when present in parents and to plan for early intervention.

## CONFLICT OF INTEREST STATEMENT

No conflict of interest has been declared by the authors.

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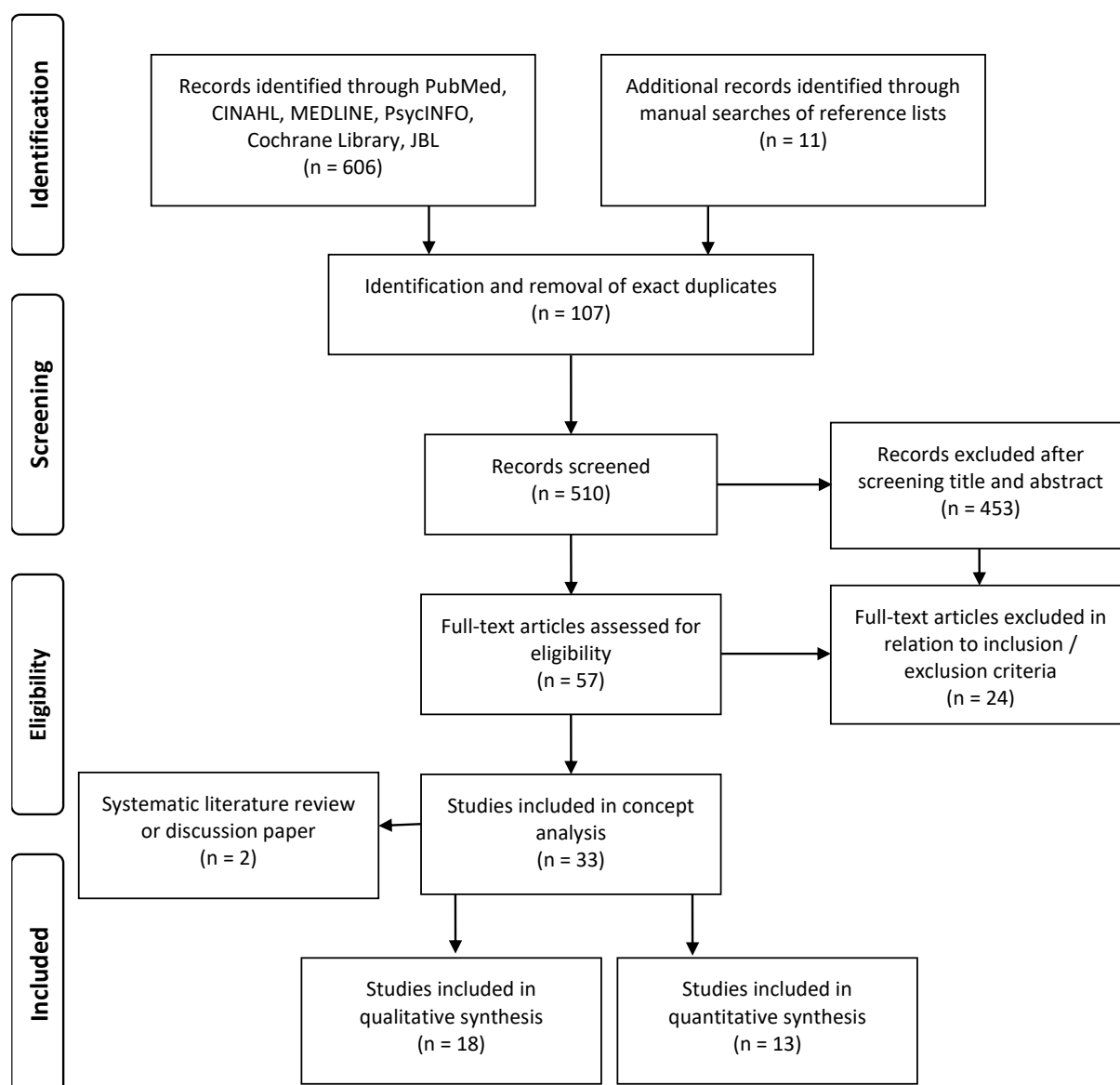
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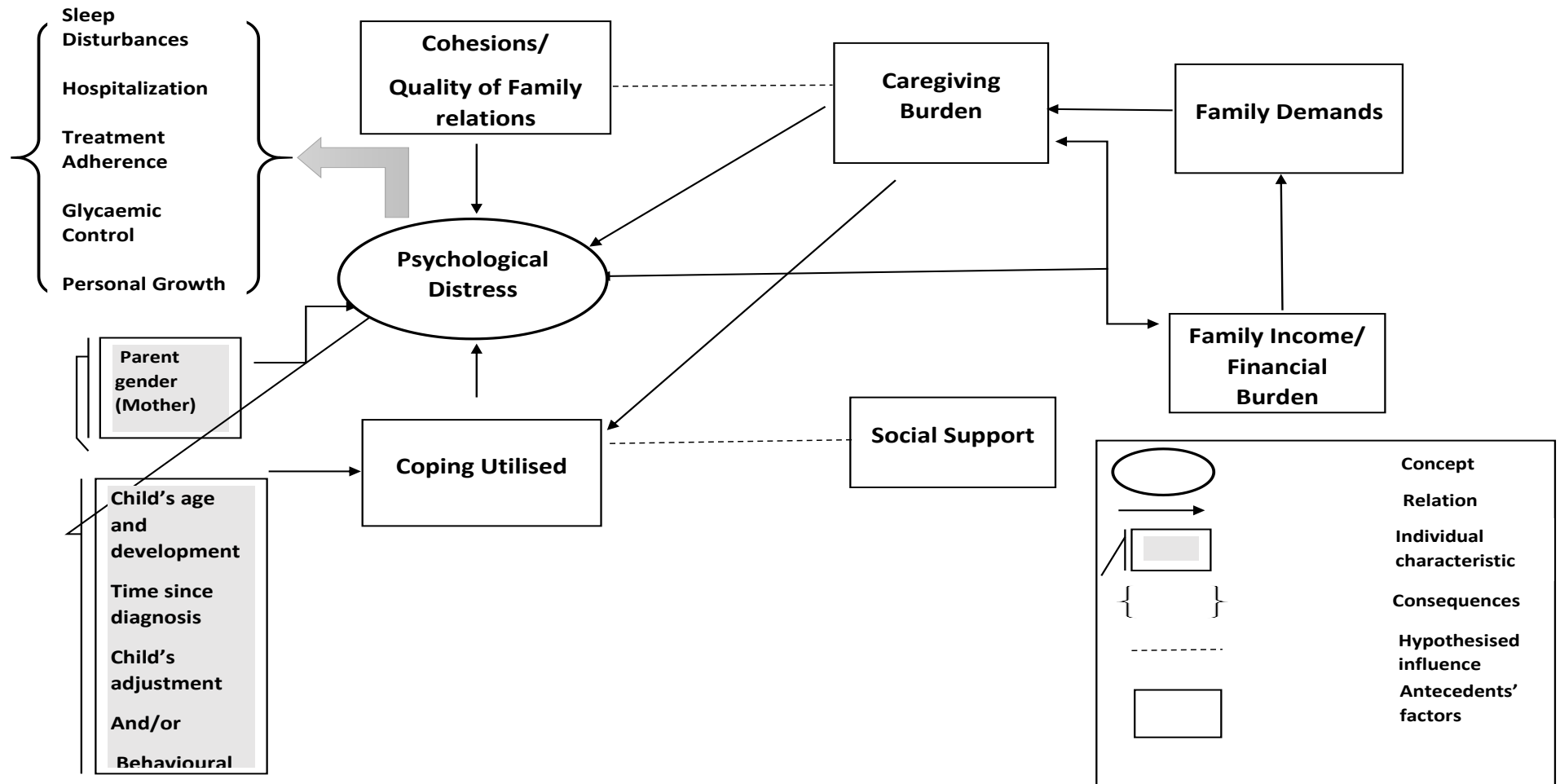
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**Figure 1. PRISMA flow diagram of literature search**

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**Figure 2** A conceptual model linking antecedents' factors and individual characteristics of parents to the concepts of psychological distress related to diabetes management in children and adolescents with type 1 diabetes.



**Table 1.** Search results.

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- 
- # 1 'Psychological distress' OR 'depression' OR 'anxiety'
- # 2 'Parents' OR 'caregivers' OR 'mother' OR 'father' OR 'parent'
- # 3 # 1 AND #2
- # 4 'Diabetes management' OR 'diabetes control'
- # 5 # 3 AND #4
- 

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**Table 2.** Study characteristics and psychological distress-related outcomes of studies included in the concept analysis

Citation	Study type	Sample (Country)	Measure of distress	Aim	Key findings related to distress
Pierce et al., 2017a (USA)	A qualitative descriptive study	N = 218 parents of children with T1DM	Open-ended question using Parent Crowd and Diversity Focus Group.	To explore the pervasive challenges and coping among parents having a child diagnosed with T1DM.	<ul style="list-style-type: none"> <li>• Parents adapted to diabetes and achieved normalcy and flexibility.</li> <li>• Distress was reported as feeling fatigue, sleep deprivation, socially isolated, being constant vigilance and worried about child's eating and competency of staff at school.</li> <li>• Physical and emotional intimacy was challenged, in addition to feeling vulnerable and socially isolated from friends.</li> <li>• Parents reported grief as they mourned the loss of a more spontaneous lifestyle, felt isolated and expressed guilt, anger, and worry about the child's future. Mental health problems, such as depression, anxiety, and posttraumatic stress were also reported among some parent.</li> <li>• Positive emotions included feeling resilient, deeper faith and spirituality, enhanced attentiveness, assertiveness, and Empathy.</li> <li>• Sharing responsibility and the use of Internet coping resources helped some parents to cope.</li> </ul>

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Castensøe-Seidenfaden et al., 2017 (Denmark)	A qualitative explorative study	N = 13 parents of adolescents with T1DM	visual storytelling as part of individual interviews.	To explore the experiences of adolescents and their parents living with T1DM.	<ul style="list-style-type: none"> <li>Parents described feeling worried, guilty, frustrated incompetent in managing diabetes, as well as feeling a lone with their worries and fears, and in loss of control.</li> <li>Parents 'whom thoughts and feelings were isolated from other family members felt more alone, worried and frustrated, so their concerns and challenges remain unsolved.</li> </ul>
Lawton et al., 2015 (UK)	A qualitative study	N = 54 parents of children with T1DM	In-depth interviews	This paper reports on a study exploring the difficulties parents encounter in trying to achieve clinically recommended blood glucose levels in children diagnosed with T1DM.	<ul style="list-style-type: none"> <li>Parents supporting glycaemic control in their children experience constant worry, anxiety and little control.</li> <li>Many parents described feeling anxious, upset and frustrated related to the lack of insight into their realities while caring for a child with type 1 diabetes.</li> </ul>
Whittemore et al., 2012	A systematic mixed-studies review	N = 34 studies		To describe the prevalence of psychological distress in parents of children with T1DM and parents' psychological experience of having a child with T1DM.	<ul style="list-style-type: none"> <li>The prevalence of psychological distress in parents 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.</li> <li>T1DM as a difficult diagnosis that contributed to significant family disruption.</li> <li>Adjustment occurred over time; however, ongoing stress was experienced.</li> <li>View of diabetes impact on family included anxiety, fear, and distress, including increased responsibility, hypervigilance and financial pressure related to T1DM care.</li> <li>Feeling 'preoccupied with diabetes most or all of their time' was reported among mothers of</li> </ul>
Edmonds- Myles et al., 2010 (USA)	A qualitative study	N = 21 parents of children with T1DM.	Semi-structured interviews	To explore the psychosocial impact of T1DM among low-income families	<ul style="list-style-type: none"> <li></li> </ul>

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					<p>preschool children.</p> <ul style="list-style-type: none"> <li>• Support systems, including family and friends helped parents coping with diabetes.</li> </ul>
Lowes & Lyne, 2000	A review of literature (Critical appraisal)		Critical appraisal	To provides a critical appraisal of the evidence concerning grief reactions in parents of children with diabetes.	<ul style="list-style-type: none"> <li>• On the long-term, most parents were able to adapt to the management of their child's diabetes.</li> <li>• Emotional responses to T1DM continued for several years post child's diagnosis.</li> <li>• Despite successful coping with child's diagnosis and related diabetes demands, parents may still experience chronic sorrow and recurring sadness.</li> </ul>
Bowes et al., 2009 (UK)	A qualitative study	N = 17 parents of children with T1DM.	In-depth interviews	This paper reports on a study exploring parents' longer-term experiences of having a child with T1DM.	<ul style="list-style-type: none"> <li>• Parents adapted to the needs of diabetes management, but they never accepted diagnosis.</li> <li>• Parents experience chronic sense of grief, sorrow, and constant worry.</li> <li>• Feeling alone, upset, anger and guilt were also common feelings among parents.</li> </ul>
Lowes et al., 2004 (UK)	A qualitative longitudinal study	N = 38 parents of children with T1DM.	In-depth interviews	To explore parents' experience of having a child with T1DM managed at home.	<ul style="list-style-type: none"> <li>• Parent felt shocked, distressed, and overwhelmed at the time of their child's diagnosis.</li> <li>• Over time, routines were established and parents started to be more Flexible, yet they continued to experience sense of loss, constant worry and loss of spontaneity.</li> </ul>
Streisand et al., 2008 (USA)	Observation al; cross-sectional	N = 102 parents of children with T1DM.	The State-Trait Anxiety Inventory (STAI); The Center for	To examine demographic and clinical characteristics, of parents of children	<ul style="list-style-type: none"> <li>• Prevalence of distress among parents; 74% mild depression, 61% clinical depression, and 59% clinical anxiety.</li> <li>• Mothers reported more anxiety and depression</li> </ul>

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	survey.		Epidemiologic Studies Depression (CESD) scale; The Pediatric Inventory for Parents (PIP).	newly diagnosed with T1DM that are associated with parental anxiety and depression.	<ul style="list-style-type: none"> <li>than fathers (<math>p &lt; 0.003</math>, <math>p &lt; 0.01</math> respectively)</li> <li>Anxiety level in parents associated with parental diabetes self-efficacy.</li> </ul>
Buckloh et al., 2008 (USA)	A qualitative study	N = 47 parents of children with T1DM.	Focus groups	To explore parents' experiences with learning about T1DM complications.	<ul style="list-style-type: none"> <li>Parents experiences depression, sadness, anxiety, guilt and being overwhelmed early at diagnosis.</li> <li>Over time, parents started to experience anxiety and concern over handling daily management tasks, long-term complications, child's development, life span, and insurance.</li> <li>Parents of adolescents reported being angry, frustrated and feeling helplessness (burnout).</li> </ul>
Marshall et al., 2009 (UK)	A qualitative phenomenological study	N = 11 parents of children with T1DM	Conversational interview	To explore parental experiences of living with diabetes from diagnosis onward	<ul style="list-style-type: none"> <li>Parents experienced a sense of loss (loss of their healthy child, loss of freedom, and loss of confident).</li> <li>Grieving in parents evoked radical disruption in family patterns and parent-child relationship.</li> <li>Parents' reported major emotional stress related inflicting pain on their child, and being anxious about their child growing up and becoming independent.</li> <li>Parents thrived toward 'being normal' so it became normal to live with diabetes.</li> </ul>
Faulkner, 1996 (USA)	A qualitative study	N = 7 families of children with T1DM	Semi-structured interviews	To investigate family responses to school-age children living with T1DM and related impact on self-care.	<ul style="list-style-type: none"> <li>Parents reported feeling shock, anger, denial, and fear of child death at diagnosis, yet this stress was not overwhelming.</li> <li>Parents experienced uncertainty, worry about complications, and vigilance about possible</li> </ul>

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Hatton et al., 1995 (Canada)	A qualitative Interpretive phenomenological study	N = 8 families of children with T1DM	In-depth interviews	To investigate the day-to-day experience of parents caring for infant or toddler with T1DM.	<ul style="list-style-type: none"> <li>insulin reactions.</li> <li>Mothers assumed major responsibility for management of the child's diabetes at home and school.</li> <li>Parents reported significant stress at the time of child's diagnosis, including sense of shock, grief, and sadness.</li> <li>Parents felt overwhelmed, exhausted, socially isolated, and immense responsibility.</li> <li>Parents reported concerns over child's growth and development, achieving glycemic control, inflicting pain, and struggles with school.</li> <li>Sharing diabetes responsibility among parents is significant source of support.</li> </ul>
Lowes et al., 2005 (UK)	A qualitative, longitudinal hermeneutic design	N = 38 parents of children with T1DM	In-depth interviews	To explore parental grief responses and adaptation to childhood diabetes.	<ul style="list-style-type: none"> <li>Parent's experienced constant worry, sadness, and sense of guilt and losses.</li> <li>Parents developed a routine and adjusted their life around accommodating T1DM care, yet parents never fully accept the diagnosis.</li> </ul>
Mellin et al., 2004 (USA)	A qualitative study	N = 30 parents of adolescent girls with T1DM.	Semi-structured interviews.	To explore the impact of T1DM on the family.	<ul style="list-style-type: none"> <li>Parents reported constant worries and concerns about diabetes long-term complications and poor glycaemic control in their child.</li> <li>Parents reported feeling guilty with constant burden and responsibility for glycaemic control.</li> <li>Family cohesion associated with better parenting experience</li> </ul>
Seppanen et al., 1999 (Finland)	Case study	N = 2 families of a child with T1DM	Interviewing and observation	To explore coping process and experiences of social support among parents of children with diabetes	<ul style="list-style-type: none"> <li>Parent described feeling exhausted, distressed, and alone in their responsibility for diabetes care.</li> <li>Other feelings included sense of loss of control, stress related to the insulin injection, and</li> </ul>

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					<ul style="list-style-type: none"> <li>nighttime blood glucose.</li> <li>Shared responsibility with spouse, professional and social support from relatives and friends helped parents to adapt.</li> </ul>
Smaldone et al., 2011 (USA)	A qualitative descriptive study	N = 14 parents of children with T1DM	Semi-structured Interviews	To explore parents perceptions of psychosocial adaptations to T1DM in children from diagnosis through childhood	<ul style="list-style-type: none"> <li>Parents' experience of psychological distress was described as feeling frustrations, fears and doubt at the time of diagnosis. Feelings were overwhelming.</li> <li>Parents described isolation in caring for their child's diabetes, never mastering diabetes management, and never adopted to the diabetes care.</li> <li>Major concerns over promoting child's development, feeling afraid/ anxiety about child's safety at school.</li> <li>Sharing responsibilities with spouse and availability of diabetes team promoted a better experience.</li> </ul>
Sullivan- Bolyai, 2003 (USA)	A qualitative descriptive study	N = 28 mothers of young children with T1DM	In-depth interviews	To explore the day-to-day experience of mothers of young children living with T1DM.	<ul style="list-style-type: none"> <li>Mothers reported feeling constant vigilance, concerned about hypoglycaemia, and diabetes complications, in addition to being vigilant and worried about the abilities of staff at the day-care.</li> <li>Other feelings described included feeling angry, bitter, frustrated, isolated, incompetent and experiencing chronic sleep deprivation, and overwhelmed with the daily care.</li> <li>Other emotional outcomes included depression, weight gain or loss, and migraines, and being hospitalised.</li> <li>Most mothers identified their spouse or significant others as sources of support.</li> </ul>

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Sullivan- Bolyai, 2006 (USA)	A qualitative descriptive study	N = 14 fathers of children with T1DM	In-depth Interviews	To explore fathers' experiences in supporting T1DM management in their children	<ul style="list-style-type: none"> <li>Fathers reported feeling shock and awe at diagnosis, then quickly adapted to diabetes management. They reported feeling overwhelmed with care and what was needed to learn.</li> <li>Fathers described enduring sadness, anxiety and fears about causing pain or hypoglycaemia to their child. Other worries included night-time, child's growth and development and child's safety at school.</li> <li>Co-parenting (Sharing responsibility with spouse) helped fathers adapt.</li> </ul>
Wennick et al., 2006 (Sweden)	A hermeneutic phenomenology study (longitudinal)	N = 12 families of children with T1DM	Open-ended questions	To explore family lived experience when a child is diagnosed with diabetes	<ul style="list-style-type: none"> <li>Initial feelings included feeling powerlessness, tearful, sorrow, and despair.</li> <li>Family adapted to the diagnoses, yet felt insecure and unprepared. Feeling uncertainty, anxious and worried about glucose level.</li> <li>Parents experiences feeling of being a total failure, sleep deprivation, high anxiety at night, and lack of confidence in transferring responsibilities to staff at school.</li> </ul>
Mitchell et al., 2009 (USA)	Observational; cross-sectional survey.	N = 43 fathers of young children with T1DM	The Pediatric Inventory for Parents (PIP); The State-Trait Anxiety Inventory – State scale (STAI); The Hope Scale	To explore the experiences of fathers of children recently diagnosed with T1DM.	<ul style="list-style-type: none"> <li>Fathers experience relatively mild stress.</li> <li>Fathers who experience more state anxiety and whose children display more behaviour problems report higher levels of paediatric parenting stress than those with lower anxiety and fewer child behaviour problems.</li> <li>Stress level in fathers associated with their concurrent state anxiety and their child's difficult behaviour.</li> <li>State anxiety in fathers and children's difficult</li> </ul>

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Moreira et al., 2014 (Portugal)	Observational; cross-sectional survey design.	N = 88 parents of children/adolescents with T1DM.  N= 121 parents of healthy children/adolescents	The Hospital Anxiety and Depression Scale (HADS);  The Parenting Stress Index (PSI)	To explore parenting stress, depressive symptoms, and anxiety symptoms in parents of children with T1DM and whether its related to family cohesion and children's quality of life.	behaviour independently predicted greater paediatric parenting stress. <ul style="list-style-type: none"> <li>• Greater paternal paediatric parenting stress was correlated with fathers' psychological resources, including lower self-efficacy about diabetes management, more fear of child experiencing hypoglycaemia, more state anxiety, and less hope.</li> <li>• Higher levels of anxiety and parenting stress were found among parents of children with T1DM (<math>p &lt; .01</math>)</li> <li>• No group differences were found for depressive symptoms.</li> <li>• Parents of adolescents (13–18 years) reported significantly more parenting stress than parents of children (8–12 years).</li> <li>• Parents of children with T1DM perceived less cohesion in their family environment and felt more anxious and stressed about parenting tasks than parents of healthy children.</li> <li>• Parents who perceive their family relationships as supportive, positive, and caring are likely to feel less distressed by caregiving tasks,</li> </ul>
Hansen et al., 2012 (USA)	Observational; cross-sectional survey design	N= 82 mothers and 43 fathers of children with T1DM	The Hospital Anxiety and Depression Scale (HADS);  Pediatric Inventory for Parents (PIP);  Dads Active Disease Support Scale,	To examine the relationship between fathers' diabetes care and paternal psychological functioning	<ul style="list-style-type: none"> <li>• 26% of mothers and 19% of fathers meeting cut-offs for a possible depressive disorder.</li> <li>• 55% of mothers versus 23% of fathers meeting cut-offs for a possible anxiety disorder.</li> <li>• Fathers may be more prone to depression while mothers are more prone to anxiety in response to a child's diabetes.</li> <li>• Parents reported high levels of psychological distress.</li> <li>• 66% of mothers versus 44% of fathers reporting</li> </ul>

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			(DADS); Pittsburgh Sleep Quality Index (PSQI); Dyadic Adjustment Scale (DAS).		<ul style="list-style-type: none"> <li>clinically significant sleep problems.</li> <li>41% of mothers and 38% of fathers obtaining scores suggestive of possible marital distress.</li> <li>Greater father involvement in diabetes care was associated with better maternal psychological and marital functioning, and child adherence.</li> </ul>
Lindstrom et al., 2017 (Sweden)	Qualitative, descriptive design	N = 21 mothers of children with T1DM	semi-structured interviews	To describe the experiences of burnout among mothers of children living with T1DM.	<ul style="list-style-type: none"> <li>Mothers reported feeling constant worry and stress due to the treatment of diabetes.</li> <li>Overwhelmed and feeling never being able to achieve mastery of the disease.</li> <li>Feeling of frustration in the daily achievements of mothering their child</li> </ul>
Rumburg et al., 2017 (USA)	Observation al; cross- sectional survey design	N =81 mothers of children with T1DM	The Parent Diabetes Distress Scale (P-DDS); Patient Health Questionnaire (PHQ)	To explore diabetes distress in relation to maternal depressive symptoms and adolescents' glycaemic control.	<ul style="list-style-type: none"> <li>26% of mothers were above the clinical cutoff for diabetes distress.</li> <li>49% were above the clinical cutoff for mild depressive symptoms and 25% were above the cutoff for moderate depressive symptoms.</li> <li>37% of the mothers reported a psychological disorder (most common diagnosis was depression.</li> <li>Maternal depressive symptoms is a significant predictor of adolescents' glycemic control (P=0.025).</li> </ul>
Williams et al., 2009 (USA)	Observation al; cross- sectional survey design.	N=187 primary caregivers of 187 children and adolescents with T1DM.	The Centre for Epidemiologic Studies-Depression Scale (CES-D); The State-Trait Anxiety Inventory (STAI)	To examine whether background factors, diabetes variables, and psychological distress in parents and their children were associated with diabetes-specific family conflict.	<ul style="list-style-type: none"> <li>23% of parents reported clinically meaningful symptoms of depression (score cut-off <math>\geq 16</math>).</li> <li>15% and 18% of parents reported clinically meaningful symptoms of state anxiety (score cut-off <math>\geq 46</math>) and trait anxiety (score cut-off <math>\geq 44</math>) respectively.</li> <li>Parents reported a significant positive association between diabetes-specific family conflict and overall anxiety, and between HbA1c</li> </ul>

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Jaser et al., 2009 (USA)	A randomized clinical trial.	N = 67 mothers of children with T1DM	The Center for Epidemiologic Studies–Depression (CES–D) scale; The State-Trait Anxiety Inventory (STAI); The Issues in Coping with IDDM–Parent scale.	To explore symptoms of anxiety and depression in mothers of young children with T1DM in relation to mothers' fears of hypoglycemia, perceptions of coping, and children's metabolic control.	<p>levels and trait anxiety.</p> <ul style="list-style-type: none"> <li>• 21% of mothers reported clinically significant levels of symptoms of anxiety.</li> <li>• 24% of mothers reported clinically significant levels of depression.</li> <li>• Lower family income and higher levels of upset in coping with diabetes were significant predictors of higher maternal symptoms of depression and anxiety.</li> </ul>
Jaser et al., 2014 (USA)	Observational; cross-sectional survey design	N=118 mothers of 118 children with T1DM	Responses to Stress Questionnaire (RSQ);  Centre for Epidemiologic Studies Depression Scale (CES); State-Trait Anxiety Inventory (STAI)	To describe coping in mothers of adolescents with T1DM and how coping is related to maternal and child adjustment.	<ul style="list-style-type: none"> <li>• All mothers reported some diabetes-related stress: mean total stress score 12.4 (range 5-22) out of a possible 30.</li> <li>• Primary and secondary control coping strategies (e.g. problem solving, acceptance) were associated with fewer symptoms of anxiety and depression and less family conflict (all <math>p &lt; .05</math>).</li> <li>• Secondary control coping was found to partially mediate the relationship between diabetes-related stress and symptoms of anxiety (<math>p = .005</math>), depression (<math>p = .004</math>) and family conflict (<math>p = .017</math>).</li> <li>• Disengagement coping strategies (e.g. avoidance) were associated with greater symptoms of depression and anxiety (both <math>p &lt; .01</math>).</li> <li>• 18% of mothers reported clinically meaningful symptoms of depression (score cut-off <math>\geq 16</math>).</li> <li>• 13% of mothers reported clinically meaningful symptoms of anxiety (cut-off not specified).</li> <li>• Caregivers reported significantly higher psychological distress compared to community norm (<math>p &lt; .001</math>).</li> </ul>
Canning et al., 1996 (USA)	Observational; cross-sectional	N=116 mothers and fathers of 116 children with cancer,	Brief Symptom Inventory (BSI); Global Severity	To evaluate factors influencing distress in caregivers of chronically	

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survey design.	cystic fibrosis, inflammatory bowel disease, or T1DM	Index (GSI);	ill children.	<ul style="list-style-type: none"> <li>• 19% caregivers had psychological distress levels above clinically meaningful cut-offs.</li> <li>• No significant differences found in psychological distress between four chronic condition groups.</li> <li>• Lower family income and female children were significant independent predictors of greater psychological distress (<math>p&lt;.001</math> and <math>p&lt;.05</math>).</li> <li>• Child impairment was a significant predictor of greater caregiver distress (<math>p&lt;.01</math>).</li> <li>• Caregivers perceived family burden was a significant predictor of greater psychological distress (<math>p&lt;.01</math>).</li> </ul>
Haugstvedt et al., 2010 (Norway)	Observational; cross-sectional survey design	N=200 parents of children with T1DM	Hopkins Symptom Checklist-25 (HSCL); Family Burden Scale (FBS)	To explore the association between parental fear of hypoglycaemia and (i) the prevalence of hypoglycaemia and diabetes treatment factors in children with T1DM and (ii) emotional distress in mothers and fathers <ul style="list-style-type: none"> <li>• Significantly greater emotional distress experienced by mothers compared to fathers (<math>p&lt;.001</math>). Scores indicated considerable symptomatic emotional distress in 11% mothers vs. 5% fathers (cut-off <math>\geq 1.75</math>).</li> <li>• Nocturnal hypoglycaemic episodes associated with increased emotional distress (<math>p&lt;.05</math>).</li> <li>• Percentages of parents reporting caring aspects to be major burdens were 54% (long-term health concerns), 29% (medical treatment), 14% (physical/psychological problems), 11% (family disruption) and 9% (restrictions in social/school activities).</li> <li>• Mothers reported significantly greater family burden relating to medical treatment compared to fathers (<math>p&lt;.048</math>).</li> <li>• All 5 subscales of perceived burden significantly positively correlated with emotional distress in mothers (<math>p&lt;.001</math> to <math>p&lt;.014</math>) but none significantly correlated in fathers.</li> <li>• More frequent blood glucose monitoring at night</li> </ul>

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Hungerbuehler et al., 2011 (Switzerland)	Observational; longitudinal survey design	N=126 parents of 67 children with T1DM or cancer	Brief Symptom Inventory (BSI); Global Severity Index (GSI); Adaptation of Posttraumatic Growth Inventory (PTGI); Family Relationship Index (FRI)	To examine medical, individual and family-related long-term predictors of parental Posttraumatic growth (PTG)	associated with increased burden ( $p<.05$ ).  <ul style="list-style-type: none"> <li>• Mothers and fathers showed significantly higher levels of psychological distress 1 month post child's diagnosis compared to community norm (<math>p&lt;.001</math>).</li> <li>• Mothers showed significantly higher psychological distress than fathers (<math>p=.01</math>).</li> <li>• 62.7% parents showed at least a moderate degree of posttraumatic growth.</li> <li>• Greater psychological distress at 1 month post diagnosis was a significant positive predictor of posttraumatic growth at 3 year follow-up (<math>p&lt;.01</math>).</li> <li>• Quality of family relations at 1 month post diagnosis was a significant positive predictor of posttraumatic growth at 3 year follow-up (<math>p&lt;.05</math>).</li> </ul>
Northam et al., 1995 (Australia)	Observational; longitudinal survey design	Study Group (SG): N=188 parents of children with T1DM. Comparison Group (CG): N=289 parents of healthy children	The General Health Questionnaire (GHQ-28)	To explore the initial impact and subsequent adjustment to the diagnosis of insulin-dependent diabetes mellitus (IDDM).	<ul style="list-style-type: none"> <li>• Parents scored within clinical range for psychological distress at diagnosis compared to women and men in general population (<math>p&lt;.01</math> and <math>p&lt;.05</math> respectively).</li> <li>• Prevalence of clinical psychological distress was among mothers 38% at diagnosis and 24% at 12 months.</li> <li>• Prevalence of clinical psychological distress among fathers was 27% at diagnosis, and 22% at 12 months</li> <li>• Mean scores for anxiety subscale at diagnosis significantly higher in SG parents of children &lt;4 years and 4-11 years compared to CG (all effect size <math>&gt;.05</math>). Differences not significant at 1 year.</li> <li>• Mean scores for social dysfunction subscale at diagnosis higher for mothers of children under 4 years and adolescents, and for fathers of children</li> </ul>

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- under 4 years compared to CG.
  - Psychological distress decreases but does not disappear at 12 mo.
-

**Table 3.** Themes generated from included qualitative studies.

Citation	Main Findings												
	Major themes to describe psychological distress												
	Emotional exhaustion	Fear/ constant worries	Sadness/ chronic sorrow	Vulnerability	Social isolation/ lonely	Frustration	Loss of control	Constant vigilance	Sleep deprivation	Guilt	Anger	Fatigue	Mental symptoms
Pierce et al., 2017a	*	*			*				*	*	*	*	*
Castensøe-Seidenfaden et al., 2017		*			*	*	*			*			
Lowes & Lyne, 2000			*										
Lawton et al., 2014	*	*	*										*
Lowes et al., 2004		*	*										
Bowes et al., 2009		*	*		*					*	*		
Buckloh et al., 2008		*	*			*				*	*		*
Edmonds- Myles et al., 2010		*						*					*
Faulkner, 1996	*			*	*						*		
Hatton et al., 1995		*	*							*			
Lowes et al., 2005		*	*				*			*			
Marshall et al., 2009		*	*				*						
Mellin et al., 2004		*								*			
Seppanen et al., 1999	*	*					*	*		*			
Smaldone et al., 2011	*	*			*		*						
Sullivan- Bolyai, 2003		*			*			*					*
Sullivan- Bolyai, 2006	*	*	*										
Wennick et al., 2006		*	*	*			*		*				
Lindstrom et al., 2017	*	*					*						

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