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The impact of Covid-19 pandemic on mental health, well-being, and lifestyle of primary-age children with Type 1 diabetes and their parents in Kuwait

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The impact of Covid-19 pandemic on mental health, well-being, and lifestyle of primary-age children with Type 1 diabetes and their parents in Kuwait

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Declarations

‘I hereby declare that this thesis is the results of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references. This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.

I confirm that I am submitting this work with the agreement of my Supervisor(s).’

‘Yr wyf drwy hyn yn datgan mai canlyniad fy ymchwil fy hun yw’r thesis hwn, ac eithrio lle nodir yn wahanol. Caiff ffynonellau eraill eu cydnabod gan droednodiadau yn rhoi cyfeiriadau eglur. Nid yw sylwedd y gwaith hwn wedi cael ei dderbyn o’r blaen ar gyfer unrhyw radd, ac nid yw’n cael ei gyflwyno ar yr un pryd mewn ymgeisiaeth am unrhyw radd oni bai ei fod, fel y cytunwyd gan y Brifysgol, am gymwysterau deuol cymeradwy.
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Summary

Diabetes is a long-term health condition. All individuals with diabetes should have access to psychological care and support to alleviate psychological suffering and promote self-management (Diabetes UK, 2022). Type 1 diabetes is usually diagnosed in childhood and affects both children and their families. However, to date, there had been very little research into psychological effects on primary-age children (8-11 years) and their carers. This thesis explored the relationship between mental health, well-being, and lifestyle of children with Type 1 diabetes and their healthy counterparts in Kuwait. It also investigated the effects that COVID-19 restrictions had on psychological functioning and lifestyle variables in child-parent dyads. The thesis consists of three main sections.

- Systematic reviews of the literature: These present what is known about psychological and lifestyle characteristics in children with Type 1 diabetes and their parents. It was concluded that most studies examined wide age ranges, and few were adequately powered with appropriate control groups. There was a gap in the literature for using developmentally appropriate, narrower age range and appropriate methodology to elucidate the psychological variables associated with Type 1 diabetes in children and the effects on parents, particularly when primary-age children are increasingly reported to have poor mental health.
- A comparison study was conducted to investigate the link between the mental health, well-being, and lifestyle of 8-11-year-old children with Type 1 diabetes and their parents, as well as a healthy comparison group (*N*=200 dyads). It was concluded that children with Type 1 diabetes may experience more mental health and well-being concerns than their peers. Moreover, a relationship between higher BMI and poorer mental health was found in the diabetes group. It was concluded that concerns can be identified at a young age, which would be helpful in designing preventative interventions. However, no differences in mental health

and well-being were detected between parents of children with Type 1 diabetes and parents of the control group.

- COVID-19 study: The purpose of this study was to determine the effect of Kuwait's first lockdown on the mental health, well-being, and lifestyle of children with Type 1 diabetes and their parents (*N*=70 dyads). Baseline measures came from the diabetes cohort in the comparison study, and follow-up measures were administered a year later. The findings suggest that the COVID-19 lockdown had a significant psychological and possibly physiological effect on children and parents with Type 1 diabetes. As a result, there is a need for mental health support services tailored to these populations.

Overall, the findings reported in this thesis add to the literature investigating psychological functioning of primary-age children with Type 1 diabetes and their parents, and call attention to the importance of healthy lifestyle, well-being, and mental health in this, previously under-researched, population.

Contents

Chapter 1: An Overview of Childhood Diabetes

Diabetes Background

Diabetes is a serious chronic disease. It occurs either due to a lack of the pancreas-produced hormone insulin, or because the body cannot effectively use the insulin that is produced (Egan & Dinneen, 2014). The effect of inadequate insulin is an excess in blood glucose concentration (hyperglycaemia; Watkins, 1982). Diabetes also places a considerable burden on the individual patient because it requires constant monitoring of blood glucose, daily treatment, lifestyle changes, and numerous visits to hospital (Egan & Dinneen, 2014).

The first physician to mention Type1 diabetes was Aretaeus of Cappadocia during the Hellenistic period (323–31 B.C.). Aretaeus coined the term diabetes and described it in the following manner: “life is disgusting and painful; thirst, unquenchable…and one cannot stop them either from drinking or making water” (Gale, 2014, para. 8).

Diabetes is now referred to as an autoimmune disease that leads to a series of metabolic conditions linked with hyperglycaemia caused by defects in insulin action. It occurs when white blood cells destroy the insulin-producing beta cells in the pancreas. There are two types of diabetes. Type 1, which is caused by a severe shortage of insulin production in the pancreas, it can occur at any age but usually begins at an early age or adolescence. Type 2 is the most common form and is mostly associated with obesity; it usually occurs in adults and causes the body to react differently to insulin, either by resisting and/or not responding appropriately to it, in a condition termed insulin resistance (Egan & Dinneen, 2014).

The symptoms associated with hyperglycaemia are extreme thirst (polydipsia), frequent urination (polyuria), weight loss and fatigue (American Diabetes Association, 2014), while symptoms associated with hypoglycaemia (also referred to as low blood sugar) are problems focusing, shaking, loss of consciousness and irritability (American Diabetes

Association, 2015). The long-term symptoms of diabetes Type 1 include microvascular complications (e.g., diabetic nephropathy or kidney failure) and vascular diseases such as damage to blood vessels of the heart, brain and limbs. Finally, peripheral nerve damage, eye diseases such as retinopathy, glaucoma and cataracts, stroke, and infections are often observed (Daneman, 2006).

There are only two common treatments for diabetes available today. Insulin Daily Injection (also called Multiple Daily Injections or MDI) and Continuous Subcutaneous Insulin Infusion (CSII, also known as insulin pumps) (Woerner, 2014).

Diabetes worldwide

Over the past few decades, diabetes has become a worldwide epidemic. It is a disease that has touched millions, both in terms of the people who have it and the people concerned about them, such as parents and caregivers. It is estimated that diabetes affects the United States of America more than any other nation. This issue is attributed to poor diet, lack of physical activity and several other factors that can facilitate the development of diabetes (Szabo, 2014). American children are among the most obese in the world and are therefore at a much higher risk of developing diabetes at an early age (Children and Diabetes - Diabetes in Childhood, 2017). Asian countries follow the United States of America in the prevalence of diabetes in children. In fact, children in Asian countries tend to develop diabetes at a younger age than children in other countries do (Hu, 2011). While diabetes among American children is thought to be a result of poor diet and lack of exercise, a common factor in many Asian countries is poor nutrition while still in the womb, followed by nutritional overcompensation after birth. Diets rich in refined carbohydrates also contribute to this disease because it is harder for the body to produce the necessary chemicals to break down such foods.

Kuwait is one of the most prominent nations that has diabetes as a serious health concern, with the number of patients with diabetes more than doubling in the past decade and standing at almost 15% of the population (3 million) as of 2010 (Al-Fuzai, 2015). These numbers, which would be troubling in any country, are of serious concern in a nation the size of Kuwait.

The United Kingdom has the world's fifth highest rate of diabetes, with the peak age for diagnosis in children being 9–14 years. It is estimated that approximately 1% of children under 15 years old in England and Wales have diabetes (Diabetes UK, 2013).

Chronic disease and diabetes

According to ICD-10 classification of the World Health Organisation (1992), a disease is considered chronic if its cure is rarely achieved, it has occurred more than three times in the last year and will probably last longer, and (for mental health conditions) it is resistant to treatment. Chronic disease can be divided into the following groups: mental illness, lung diseases, neurological disorders, diabetes, cardiovascular disease, chronic pain, cancer, muscles, and joint disorders (Martin, 2007). Asthma, diabetes, and cancer are the most common type of chronic disease for children (Gale, 2002)

Children of primary-school age are too young to maintain their own disease management and are not yet able to self-care and manage their disease (Beacham & Deatrick, 2013; Zysberg & Lang, 2015). It can take years for them to develop the ability to care for themselves. Therefore, they depend on their parents to take the main responsibilities related to disease management (American Diabetes Association, 2013; Sullivan-Bolyai et al., 2002). For parents living with a child with a chronic health condition, the responsibilities and challenges are beyond their usual duties (e.g., more attention, more comfort, and specific diet). These duties involve co-ordination with teachers and childcare staff (Barton et al., 2005; Lee et al., 2006; Morawska et al., 2008), as well as seeking consultations with health professionals and observing and making judgments about health care (e.g., when to seek professional help and changes in medication) (Lee et al., 2006; Morawska et al., 2008; Sullivan, 2008). Parents of children with chronic disease report more emotional, financial, and social stress (Dodgson et al., 2000) and poorer well-being (Faulkner & Clark, 1998; Poston et al., 2003). Weitzenkamp et al. (1997) reported that parents with children with chronic disease are more emotionally affected by illness than the children themselves.

Hysing et al. (2007) reported that children with chronic disease are at increased risk of emotional problems and behavioural and psychiatric disorders. For example, the diagnosis of diabetes leads to a lifetime of blood glucose monitoring, exercise, diet restrictions, and insulin administration (Compas et al., 2012). Disease management can interfere with many aspects of daily life not only for children with chronic disease, but also for their parents and siblings (Barlow & Ellard, 2006).

The experiences of parents of children with diabetes

Diabetes disease management is essential, yet it is time-consuming and can never be suspended even for a single day, especially for parents of young children. Parents can spend at least 11 hours per week coordinating plans and providing care, such as by monitoring diet, exercise, and blood glucose levels and administering insulin (Siminerio et al., 2014). In contrast, poor management can lead to physical complications such as poor glycaemic control, diabetic ketoacidosis, and hypoglycaemia (American Diabetes Association, 2009). Furthermore, family conflict, including stress, predicts poor diabetes outcomes, while positive family environments can promote better outcomes in diabetes care (Williams et al., 2009). The Quality of Life (QoL) of parents of children with a chronic illness such as diabetes is greatly reduced (Ferrell, 1995), and such parents report greater emotional, social, and financial strain (Dodgson et al., 2000). Incorporating disease management into daily life is necessary but challenging (Barton et al., 2005; McQuaid et al., 2007; Sullivan, 2008). Parenting stress is associated with a higher level of parental responsibility for treatment management (Nieuwesteeg et al., 2016), higher levels of depressive symptoms, hopelessness, and poorer life satisfaction (Helgeson et al., 2012), anxiety, poorer marital satisfaction, and greater sleep disturbances (Hansen et al., 2012). Complex childcare arrangements can risk repeat hospitalisations and poor diabetes control (Anderson et al., 1997; Grey & Tamborlane, 2003).

Childhood diabetes

Diabetes in children can cause intense psychological trauma, leading to severe behavioural problems. The psychological and emotional impacts on a child can create confusion and interrupt their regular development, leading to a wide variety of problems. Anxiety, anger, and depression are common emotions experienced by children and their families upon receiving a diagnosis (Diabetes and Emotions - Coping with Diabetes, 2017).

Silverstein et al. (2005) stated that primary school-age children with diabetes reported anxiety and mild depression, which resolved six months after diagnosis; however, anxiety decreased only for boys, while it increased for girls over the first six years, and depression symptoms increased after 1–2 years. Children in this scenario may feel different from their peers as a result of their illness, which might cause difficulties in their life and with their social capacity (Silverstein et al., 2005).

Frank (2005) suggested that parents, particularly mothers, reported feelings of anxiety and depression during the first year of diagnosis, which may be associated with concerns or guilt about their child's future. However, metabolic control and psychosocial adjustment has yet to increase the risk of later problems.

Primary school-age children with diabetes face challenges with the management of their illness because many of them require insulin administration away from home, particularly at lunchtime, when most of them are at school. This issue requires that parents, school personnel, and healthcare teams work closely together to facilitate communication and flexibility. However, children at this age lack the ability to think abstractedly, which limits their management choices and requires their parents or healthcare team to make the most of the treatment decisions. Close adult supervision is required in most cases even if the children are able to self-treat their hypoglycaemia. Even if such children can report, recognise, and seek treatment, when it is combined with diabetes and the psychological issues linked with puberty, it is likely that this age group are the most sensitive to issues related to intensive glucose control (Silverstein et al., 2005).

Psychological interventions for children with chronic illnesses and their parents

Cognitive Behavioural Therapy (CBT). CBT is a method for addressing behavioural issues that utilises several approaches, including methodological, technological, philosophical, assessment-oriented, and theoretical techniques (O'Donohue & Fisher, 2008). Numerous studies have reported that CBT significantly enhances patient functioning and quality of life (QoL; Society of Clinical Psychology, 2017). CBT is founded on the principles of learning and behaviour psychology (Skinner, 1953), social psychology (Bandura, 1989), and cognitive psychology (Beck, 1970). CBT is an empirically validated form of psychotherapy, and its efficacy has been demonstrated in over 350 outcome studies analysing various mental disorders, such as depression, eating disorders, and anxiety, as well as in the treatment of both stress coping and relationship problems at an individual and group level (Butler et al., 2006; Öst, 2008; Roth & Fonagy, 2005). During CBT, the therapist guides the client toward new insights, enabling them to relearn and correct emotional experiences in a setting devoid of judgment, condemnation, or preconceived notions. Common CBT techniques include cognitive restructuring, exposure therapy, discriminative learning, trigger identification/consequence analysis, problem-solving, validation, emotion regulation, behaviour experiments, and behaviour activation (O'Donohue & Fisher, 2008). Stress Inoculation Training (SIT) is a type of cognitive behavioural intervention (CBI) created in the 1980s by Meichenbaum (Meichenbaum & Novaco, 1985). SIT is a broad-based CBI that provides a set of procedural guidelines individually tailored to a client's needs, characteristics, and the specific type of stress being experienced. SIT is divided into three stages: conceptual education; skill acquisition, consolidation, and rehearsal; and application and follow-through (Meichenbaum et al., 1985). CBI has led to the development of other stress management techniques, which, in conjunction with SIT, teach new skills to improve stress coping, whereby clients learn to cope with stressful situations by using behaviours and thoughts. Most CBI-based stress management techniques include psychoeducation regarding the biopsychosocial model of stress, coping skills (e.g., relaxation and coping thoughts), and lifestyle changes designed to reduce stress and improve QoL (Meichenbaum et al., 1985).

Mindfulness therapy. Mindfulness is defined as awareness of thoughts, feelings, body sensations, and the surrounding world in each moment (Vinney, 2020). Acceptance is part of mindfulness and is defined as individuals paying attention to their thoughts and feelings without judging them or thinking there is a positive or negative way they should think or feel (Vinney, 2020). Both mindfulness-based stress reduction (MBSR) and mindfulness-based cognitive therapy (MBCT) have demonstrated efficacy in reducing distress, anxiety, depression, and other mental conditions (Benn et al., 2012; Marchand, 2012; Martin-Asuero & Garcia-Banda, 2010; Segal et al., 2013; Teasdale et al., 2000). Mindfulness training aims to teach participants how to pay closer attention to a wider range of experiences and sensations, to describe their thoughts and feelings without passing judgment or wishing they were otherwise, to learn to let negative and stressful thoughts pass, and to act consciously and effectively while maintaining self-compassion, resulting in positive psychological outcomes (Kabat-Zinn, 1982; Segal et al., 2013). Several meta-analyses have found that mindfulness-based interventions (MBIs) reduce stress-related mental illness and improve QoL (Khoury et al., 2015). A systematic review of 209 studies by Khoury et al. (2013) concluded that MBI is a moderately effective treatment for a variety of psychological problems, being particularly effective at reducing anxiety and depression. In pre-post comparisons, MBI's efficacy did not significantly differ from CBT or other behavioural therapies.

Acceptance and commitment therapy (ACT). ACT was created in the 1980s by Hayes, a University of Nevada psychology professor. Hayes' own experience, particularly his history of panic attacks, inspired ACT. Hayes vowed that he would stop running from himself and instead accept himself and his experiences (Hayes, 2008). Relational frame theory (RFT) serves as the theoretical foundation for ACT (Hayes et al., 2006). According to RFT, language and cognition enable the comparison of various concepts (Hayes, 2004; Hayes et al., 2004; Vilardaga et al., 2007). ACT focuses on accepting life experiences as they come rather than evaluating or attempting to change them. It is a skill acquired through mindfulness exercises that encourage individuals to develop a compassionate relationship with difficult experiences, which can help reduce obsessive negative thinking (Hayes, 2008). The ACT framework defines psychological inflexibility as the inability to engage in behaviours that are consistent with one's values, resulting from cognitive fusion and experiential avoidance (Fletcher & Hayes, 2005). ACT aims to increase psychological flexibility, enabling individuals to engage with what is occurring in the present moment and make values-aligned decisions even when they experience psychological difficulties (Hayes et al., 2004; Wilson & Murrell, 2004). Psychological flexibility can be increased by developing six processes:

acceptance (not trying to control thoughts and feelings), defusion (realising that thoughts are not facts), self-as-context (realising that the self is an observer and is separate from self-evaluation), present moment (using mindfulness to be aware of the present), values (identifying personal values that can guide behaviours), and committed action (engaging in behaviours based on values; Ciarrochi et al., 2010). Several studies have demonstrated the efficacy of ACT in treating a variety of psychological problems in adults (A-Tjak et al., 2015; Hacker et al., 2016; Powers et al., 2009; Ruiz, 2012)

A-Tjak et al. (2015) reviewed the clinical efficacy of ACT, focusing on randomised controlled trials (RCTs) involving adults with depression/anxiety, addiction, other mental health problems, and somatic health problems. A meta-analysis found that ACT outperformed control conditions (including treatment as usual and placebo conditions) and was as effective as cognitive therapy, CBT, and habituation therapy. Powers et al. (2009) conducted a review of 18 RCTs that investigated the efficacy of ACT as an intervention for a variety of mental and physical health issues, including depression, distress problems, and physical health difficulties. ACT was found to be significantly more effective than control conditions but not more effective than other active intervention controls. Murrell and Scherbarth (2006) conducted a review summarising the available ACT research involving children and young individuals. The review uncovered 15 articles investigating the efficacy of ACT in treating young individuals dealing with a variety of issues, such as persistent pain, anxiety, physical health issues, anorexia, and risky behaviour. ACT interventions were linked to a decrease in risk-taking behaviours, improved school attendance, and improved functioning of individuals with chronic pain. Furthermore, in a theoretical overview of ACT for young individuals, Coyne et al. (2011) identified 12 studies that investigated anorexia nervosa, chronic pain, psychosis, parenting interventions, the prevention of risky sexual behaviours, anxiety, and depression. ACT was associated with improved symptoms, QoL, and psychological flexibility, and it was concluded that ACT processes were the same for adults and children.

Psychological interventions are defined as psychotherapeutic treatment that aims to modify parent behaviour or cognition, or both, to improve child outcomes s (Eccleston, Fisher, Law, Bartlett, & Palermo, 2015). These interventions, each with a different focus, have evolved over time for parents of children with chronic illnesses. Some are aimed solely at parents, while others are aimed at both parents and children. These interventions aim to improve parent, child, and family health s (Eccleston et al., 2015; Eccleston, Palermo, Fisher, & Law, 2012). The Cochrane review (Eccleston et al., 2015; Eccleston et al., 2012) is based on 35 randomized controlled trials (RCTs) that involved a total of 2,723 primary participants, which were parents of children and adolescents (under the age of 19) with a chronic illness. These participants were compared to an active control group. The children had painful chronic illnesses like traumatic brain injury T1D, asthma, cancer, inflammatory bowel diseases, gynaecological disorders, or skin conditions. The treatment duration in the studies examined ranged from three to sixteen hours. Data for each medical condition across all treatment classes were analysed at two time points (immediately post-treatment and the first available follow-up) and by treatment class - CBT, Family Therapy (FT), Problem Solving Therapy (PST), and Multisystemic Therapy (MST). The main findings of this review demonstrate that, across all treatment modalities, psychological therapies involving parents significantly reduced the immediate post-treatment symptoms of painful conditions in children (Eccleston et al., 2012). CBT significantly reduced child symptoms across all medical conditions, and PST (which employs cognitive behavioural strategies) significantly reduced parent behaviour and parent mental health after treatment. All effects were immediately post-treatment. However, there were no significant findings for any treatment effects for any condition at follow-up.

More long-term benefits have been shown in a Swedish study that measured changes in self-rated clinical burnout and performance-based self-esteem to assess the effect of a group intervention (PBSE). Using the Shirom-Melamed Burnout Questionnaire (SMBQ), all parents who showed signs of clinical burnout were then asked to join a group intervention. The group intervention consisted of eight sessions over a period of twelve weeks and included education about burnout-related behavior, cognition, and symptoms. The objective of the intervention was to help parents develop effective coping and stress-reduction strategies. The SMBQ and PBSE scale measurements both showed a significant decrease, and these improvements persisted six months after the intervention (Lindström, Åman, Anderzen-Carlsson, & Lindahl Norberg, 2016). A group MBSR study included 44 parents, mostly mothers of children with chronic illness. Caregivers reported high levels of stress and mood disturbance prior to the intervention. Symptoms decreased significantly over the 8-week program, with a 32% reduction in stress symptoms and a 56% reduction in total mood disturbance (Minor, Carlson, Mackenzie, Zernicke, & Jones, 2006).

It has been proposed that ACT-based interventions are effective in improving long-term conditions and chronic diseases (Graham et al., 2016). In long-term conditions, promising results have been observed in terms of effectiveness in psychological flexibility, parenting of children with long-term conditions, seizure control in epilepsy, and disease management (Graham et al., 2016; Lundgren, Dahl, Melin, & Kies, 2006). According to Hoseini et al. (2014) and Kaboudi et al. (2017), an ACT intervention had a significant impact on participants' mental health and promoted self-management behaviors. A group intervention using ACT was found to be effective in reducing feelings of guilt and depression in diabetic children and adolescents between the ages of 12 and 15, as well as in boosting their psychological well-being (Moghanloo, Moghanloo, & Moazezi, 2015). However, although diabetes types 1 and 2 have somewhat different treatment regimens, the study failed to take these differences into account by combining them in one study setting.

Overall, the literature shows that CBT and Mindfulness are effective methods for reducing stress-related mental illness in general (Hofmann et al., 2012). According to the Cochrane review (2012), CBT significantly improved child symptoms across all medical conditions, and PST significantly improved parent mental health and behaviour immediately after treatment. Furthermore, the Cochrane review suggests that interventions that target specific strategies aimed at improving parents' mental health and problem-solving skills are more likely to achieve those effects than interventions that include parents but do not specifically target strategies. Moreover, according to a meta-analysis and review summarizing the effectiveness of ACT, these interventions are probably effective for treating chronic pain and tinnitus and may also be effective for drug abuse, depression, mixed anxiety, psychotic symptoms, work-related stress, and obsessive-compulsive disorder (Öst, 2014). Although some encouraging results have been attained, ACT interventions are not yet confirmed to be an evidence-based treatment for any disorder, according to both Öst (2014) and Hayes et al. (2006).

Chapter 2

Theoretical Approaches to Study of Chronic Illness in Children

To study a child's mental health development and lifestyle, we must consider not only the child's immediate environment but also the interaction with the larger environment. It is imprudent to consider chronic-disease research or interventions without fully accounting for and comprehending the layers of impact and influence that surround them. Moreover, healthy behaviours are maximised when social environments and influences are considered (Glanz et al., 2008; WHO, 1986).

The following section outlines the major theoretical models that had been applied to chronic illness in children to identify which are salient to the proposed research and which are not. Of course, the present review of theories is not meant to be comprehensive. For example, a prominent model used in health psychology is Ajzen's theory of planned behaviour. The theory of planned behaviour (TPB; Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975) is a development of the theory of reasoned action (Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975) that was necessitated by the limitations of the original model in addressing behaviours over which people have incomplete volitional control. It divides beliefs into three categories: behavioural, normative, and control. The intention to perform a given behaviour is a crucial component of the theory of planned behaviour. It is assumed that intentions capture the motivational factors that influence behaviour; they indicate how hard people are willing to try and how much effort they intend to exert in order to perform the behaviour (Ajzen,1991). However, this model has not been applied to young children with chronic disease because it does not take into account the factors that influence behavioural intention and motivation, such as past experience, threat, mood, or fear. Moreover, it continues to disregard factors such as the environment or the economy that could affect a person's intention to engage in a behaviour (Wayne, 2019). The research in the present thesis is not meant to test these theories, but it is necessary to consider how they may fit into the existing theoretical frameworks.

The health belief model

Health Belief Model (HBM) was developed in the early 1950s by social scientists at the United States Public Health Service to help explain why people do not engage in disease prevention strategies or screening tests for early disease detection (Hochbaum, 1958; Rosenstock, 1960). Additionally, the HBM was used to assess patients' responses to symptoms and adherence to medical treatments. The model predicts a person's likelihood to adopt a recommended health behaviour or action based on their belief in a personal threat of illness or disease and their belief in the effectiveness of the recommended health behaviour or action (Wayne, 2019).

The HBM is based on psychological and behavioural theories, and it is based on the premise that the two components of health-related behaviour are: 1) the desire to avoid illness and to be healthy, and 2) the belief that a specific health measure will prevent or treat disease. Finally, an individual's behaviour is frequently influenced by their perceptions of the benefits and drawbacks of health-related behaviour (Janz & Beker, 1984; Rosenstock & Strecher, 1988).

The HBM is made up of six constructs, as demonstrated in Figure 2.1. The first four were created as the HBM’s founding principles. After further research into the model, the final two features were added by Rosenstock and Strecher (1988). The six constructs according to Wayne (2019) are as follows: 1) Perceived Susceptibility – the subjective assessment of the risk of contracting an illness or disease, which involves the person’s perceptions of their personal vulnerability to illness or disease. 2) Perceived Severity - a person’s reaction to the seriousness of contracting a disease or illness. When evaluating severity, a person often considers the medical consequences (e.g., death or disability) as well as the social consequences (e.g., family life and social relationships). 3) Perceived Benefits - a person's judgement of the efficacy of various interventions aimed at minimising the risk of illness or disease. It may also involve a course of action in preventing or curing illness or disease, which is determined and evaluated based on their perceived vulnerability and perceived benefit, with the person taking the recommended health action if it is thought to be beneficial. 4) Perceived Barriers - a person's feelings about the barriers to carrying out a recommended health action. Perceptions of barriers, or impediments, vary widely and prompt the individual to employ a cost-benefit analysis. They assess the acts' effectiveness against their perceived cost or hazard. The latter could include side effects, the unpleasantness (physical pain), and time commitment or inconvenience. 5) Cue to Action – the stimulus required to activate the decision-making process for a recommended health action to be accepted. These cues can be internal (e.g., wheezing or chest pains) or external (e.g., newspaper article, family member's illness, or advice from others). Finally, 6) Self-Efficacy - a person's level of confidence in their ability to do a task successfully (Wayne, 2019).

Bandura (1997) distinguished self-efficacy expectations from outcome expectations, which are a person's predictions that a particular behaviour will result in specific outcomes. The HBM concept of perceived benefits is similar to outcome expectations, but they are not the same. Numerous behavioural theories, such as Social Cognitive Theory (SCT), incorporate self-efficacy as a construct since it is directly related to whether or not an individual eventually executes the intended behaviour (Wayne, 2019). The HBM original model was developed in the context of relatively straightforward preventive health actions (immunisation or accepting a screening test) that were not perceived to require complex behaviours. Additionally, for behaviour change to succeed, individuals must feel threatened by their current behavioural patterns (perceived susceptibility and severity) and believe that a particular type of change will result in the desired outcome at an acceptable cost (perceived benefit). Correspondingly, they must believe in their own competence (self-efficacy) to overcome perceived barriers to action (Bandura,1997). One of the most appealing aspects of self-efficacy in health behaviour is that it is a modifiable factor that can be influenced; sources of self-efficacy include persuasion, personal experiences, and vicarious experiences learned from observing others or from modelling (Glanz et al., 2008). However, although learning through media has a powerful influence on knowledge, behaviours, and beliefs, especially in the context of edutainment (education through entertainment), it is difficult to empirically test this assumption without isolating other factors that influence social change (see Glanz et al., 2008).

In a study conducted by Bond, Aiken, and Somerville (1992) to predict adherence to a complex, ongoing medical regimen in a chronically ill young person, aged from 10 to 19 years old, using the Child Self-Administered Questionnaire (CSAQ), three Child Compliance Telephone Interviews (CCTls) with the adolescent on three randomly chosen days over a three-week period, and three Parent Compliance Telephone Interviews (PCTIs) with the parents, the authors discovered that as adolescents aged, their adherence to the regimen's exercise, injection, and frequency components decreased, as predicted by the HBM. Another study conducted by Wdowik et al. (2001) examined the relationships between the Expanded Health Belief Model constructs and the characteristics of college students who successfully managed their Type 1 diabetes. The Diabetes College Scale was created and used to assess diabetes-related attitudes and behaviours in college students. Moreover, the instruments used were a questionnaire and telephone interviews. Self-care practices such as diet, exercise, blood glucose self-monitoring, insulin administration, and hypoglycaemic reactions were discussed, as well as college life issues such as stress and alcohol. The results suggested that some attitudes appear to have had a significant impact on the process of engaging in recommended diabetes self-care behaviours. However, the researcher also suggested that if significant barriers or negative emotions exist, even students with positive attitudes and good intentions may be unable to engage in desired self-care behaviours.

The HBM has certain limitations, including its failure to take into account an individual's attitudes, beliefs, and other personal characteristics. Moreover, it does not address the economic and environmental factors that influence a person's health choices (Wayne, 2019). For example, a lack of financial resources to afford fresh fruits and vegetables can be a significant impediment to making healthy food choices (Boskey, 2022). Furthermore, the model focuses on health-related reasons for behaviours but ignores the fact that people often act for other reasons, such as in pursuit of social acceptance (Boskey, 2022). Additionally, the HBM is descriptive rather than explanatory in nature and makes no recommendations for changing health-related behaviours through the development of treatments or interventions (Wayne, 2019). Finally, according to Glanz (2008), only a few studies that have developed or modified instruments to measure HBM constructs conducted adequate pre-research reliability and validity testing. Moreover, in terms of effectiveness in predicting and influencing behavioural change, Harrison et al. (1992) performed a meta-analysis of studies in adult populations that used the HBM, with the goal of quantifying the independent relationships between each of the four main components and reported health behaviours. They discovered that effect sizes were small, accounting for between 0.1 and 9% of the variance. While the HBM has been used to forecast the behaviour of individuals suffering from acute and chronic illnesses (Becker, 1974; Becker & Maiman, 1975), it is only relevant to behaviours that are under an individual's control (Hochbaum, 1958; Rosenstock, 1966). Therefore, the likelihood of someone taking a health action is thought to be influenced by the individual's perceptions of his or her susceptibility to illness and the severity of the illness's consequences. Furthermore, Klepac (1996) asserts that individuals will not engage in health-related behaviour unless they possess a minimum level of health motivation and knowledge, perceive themselves as vulnerable and the condition as threatening, and are convinced of the efficacy of the health behaviour.

Overall, in the case of young children, it is the parents that make the health-related decision (BMA guidance, 2020). While the HBM requires an individual, who has a good understanding of his/her actions, it could be in principle applied to older adolescent or parents rather than young children. This is probably why, to this date, there are no studies published investigating the mental health, well-being, and lifestyle of children with Type1 diabetes and their parents using the HBM.

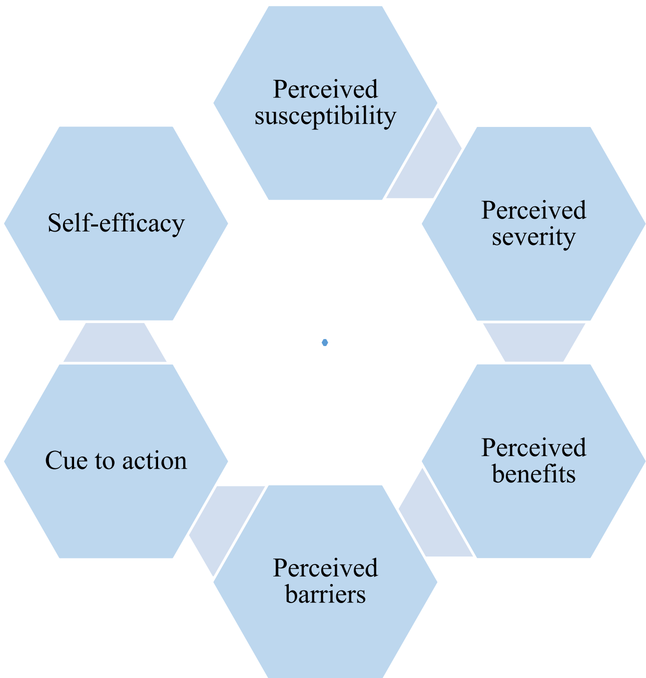

Figure 2.1. Structure of the Health Belief Model

Social cognitive theory

Social Cognitive Theory (SCT) resolves a long-standing conflict between human agency and social structure by introducing the concept of reciprocal determinism, which asserts that human agency and the environment interact and influence one another, resulting in individual and social change (Bandura, 1989). The SCT perspective contains five constructs: Psychological determinants of behaviour; observational learning, environmental determinants of behaviour, self-regulation, and moral disengagement (see Figure 2.2; Glanz et al., 2008).

The main determinant of SCT is outcome expectations, which are defined as “beliefs about the likelihood of various outcomes that might result from the behaviours that a person might choose to perform, and the perceived value of those outcomes.” (Glanz, 2008, p.172). SCT extends this concept by demonstrating that human values and expectations are subjective, and that people's actions are not solely determined by objective reality but also by their perceptions of it.

According to Bandura (1986), observational learning is central to SCT, especially via mass communications. Observational learning is governed by four processes (Bandura, 1986, 2002): (1) attention, (2) retention, (3) production, and (4) motivation. Different factors contribute to distinct processes. For instance, a person's ability to observe certain behaviours is determined by his or her access to family, peers, and media models. Cognitive retention of observed behaviour is influenced by intellectual abilities such as reading ability. Performance of the modelled behaviour is dependent on physical and communication skills, as well as self-efficacy for performing, or learning to perform, the observed behaviour. Outcome expectations about the costs and benefits of observed behaviour determine motivation. Peer modelling is a well-known method for influencing behaviour because many studies have shown that models are most frequently imitated when observers perceive the models to be similar to themselves (Schunk, 1987). For instance, children are more likely to imitate peers their age or older (Brody, & Stoneman, 1981).

SCT provides a thorough and well-supported conceptual framework for comprehending the factors that influence human behaviour and the learning processes. The application of SCT to the design of interventions to meet important practical challenges in medicine and public health has given it greater significance (see Clark, & Zimmerman, 1990; Kok et al., 1996; Elder, Ayala, & Harris, 1999). Knol et al. (2016) conducted research to develop and test the feasibility of a home-based obesity prevention programme using mindful eating strategies and SCT constructs. The participant were families comprised of a parent, a grandparent, and one child aged three to five years old. After a three-week period, the results showed significant improvements in mindful eating and several key behaviours were observed using SCT. In a study aimed at improving diabetes patients' adherence to physical activity, Qiu et al. (2012) reported that self-efficacy, as well as social support from family, friends, and healthcare professionals, were found to be important factors in the beginning and for maintaining regular physical activity. Furthermore, Bai et al. (2009) reported social support and self-care behaviours are positively correlated, implying that social support influences self-care behaviour. Similarly, in a two-year study, Barrera and colleagues demonstrated that people's social support networks, such as their friends, family, and neighbours can aid in behaviour changes like increasing physical activity and reducing fat intake (Barrera et al., 2008).

SCT is extremely broad, and ambitious in scope, as it seeks to account for virtually all human phenomena (Bandura, 1986). However, due to its broad scope, it has not been thoroughly tested in the same way that other health behaviour theories have been. Self-efficacy is found to be linked to many different types of behaviour so often that assessments of the factors that influence behaviour may be incomplete if self-efficacy is not taken into account (Moritz, Feltz, Fahrbach, & Mack, 2000). However, this does not imply that the theory is correct in its entirety (Wayne, 2019). Due to the fact that self-efficacy is a dynamic psychological state, special attention should be paid to the time interval, which should be as brief as possible (less than two weeks), Moreover, one must consider the implications of Bandura's theoretical concept, which states that self-efficacy instruments should assess perceived capability ("I can do") for performing specific tasks (Frei et al., 2009). Other than through references to previous experience, the theory does not focus on emotion or motivation. These aspects receive very little attention. Moreover, the theory places a strong emphasis on learning processes while ignoring hormonal and biological factors that may influence behaviour, regardless of prior experience or expectations (Thojampa, 2019; Wayne, 2019). However, as with any other theory, applying all SCT's constructs to a single public health problem can be challenging, particularly when developing focused public health programmes (Bandura, 2004).

Overview, according to SCT, an individual's behaviour is shaped by his or her ability to regulate his or her behaviour, as well as the ability to shape his or her environment. It is impossible for individuals with Type1 diabetes to change their behaviour (lifestyle) without considering their surroundings, including social support, and health beliefs. Individuals with diabetes can improve their metabolic control and achieve their self-management goals with increased social support in diabetes self-management (Thojampa, 2019). In terms of HbA1c (glycated haemoglobin), social support accounted for a large portion of the variance (Thojampa & Mawn, 2017).

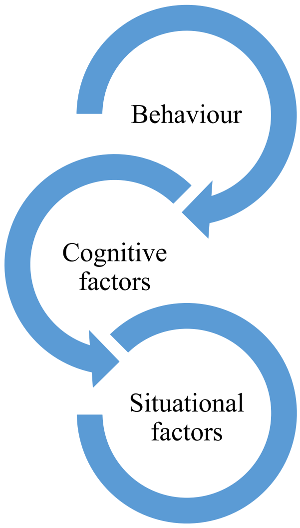

Figure 2.2. Structure of Social Cognitive Theory

The social ecological model

Environmental influences on a child's development are seen as a multi-level system in Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1977b, 1979). These influences range from the immediate settings of home and school to broader cultural values, legislation, and customs. Several authors have argued that parents and children managing diabetes can benefit from clinical practice recommendations based on the social ecological framework (see Naar-King, Podolski, Ellis, Templin, & Frey, 2006). Ecological models provide comprehensive frameworks for understanding the numerous and interconnected determinants of health behaviours, and illness management in multiple systems, such as child, family, peer, and medical treatment teams. More importantly, ecological models can be used to create comprehensive intervention strategies that target change mechanisms at every level of influence (Sallie et al., 2008).

The social ecological model, proposed by American psychologist Urie Bronfenbrenner in the 1970s, is based on the ecological theory. Human development happens largely throughout childhood, but also throughout life, through more intricate reciprocal interactions between an evolving, active biopsychological human being and the people, things, and symbols in its immediate environment (Bronfenbrenner, 2008). According to Bronfenbrenner, these proximal interactions must occur consistently over a long period of time in order to effectively shape the individual. Interactions between a parent and a child, or between a youngster and their peers, are examples of these processes.

Beginning with the individual, *microsystems* refer to the smallest environmental structures that comprise the environment in which an individual lives. These microsystems are comprised of an individual's most recent transactional interactions with family, friends, teachers, and others with whom they have regular, ongoing interaction (Bronfenbrenner, 2008). They include the patterns of activities, social roles, and interpersonal relationships through which an individual personally functions daily. As a child matures, their microsystem expands, incorporating an increasing number of people. When two or more microsystems connect or interact, this is referred to as a mesosystem. A mesosystem connection is a connection between an adolescent's parents and teachers, or between an adolescent's peers and a religious organisation. Adolescents' mesosystem connections expand as they progress through adolescence and their social worlds expand. When two or more settings are connected but at least one of the settings does not include the individual, an exosystem is created. As a result, the exosystem has an indirect impact on the individual (Bronfenbrenner, 2008). For example, we can consider the microsystem of parental work. While an adolescent usually does not have any direct contact with their parent's workplace, they are still affected by their parent's work hours, income, and stress. Moving beyond the microsystems of individuals, the *macrosystem* encompasses the larger cultural context (Bronfenbrenner, 2008). Macrosystems are defined by the cultural practices that are most common in the typical exosystem and mesosystem. These practices include beliefs, customs, and lifestyles. The ecological model also takes into account the *chronosystem*, which is a reference to the passage of time. According to Bronfenbrenner, microsystems, mesosystems, exosystems, and macrosystems are not static. As a result, the development of an individual is influenced by the degree of change or consistency that occurs over time and across systems.

The widespread acceptance of ecological models as applied to health behaviour is reflected in authoritative documents that guide national and international public health programmes. These documents include Healthy People 2010 (United States Department of Health and Human Services, 2000a); the World Health Organization's (WHO) strategy for diet, physical activity, and obesity (World Health Organization, 2004); childhood obesity prevention (Koplan et al., 2005); Institute of Medicine reports on health behaviours (Institute of Medicine, 2001); and the WHO Framework Convention on Tobacco Control (World Health Organization, 2003). The adaptability and robustness of ecological models are demonstrated by this diversity (Sallie et al., 2008). Additionally, the social ecological model has been used to assess chronic conditions like Type 1 diabetes. For instance, Naar-King et al. (2006) evaluated diabetes management among high-risk adolescents (aged 10-16) using the social ecological model. Similarly, Armstrong et al. (2011) used the social ecological model to investigate the impact of a critical parenting style (an interpersonal factor) on the self-efficacy (an intrapersonal factor) of pre-adolescents aged 9-11 and discovered that critical parenting behaviours appear to be associated with adolescents' self-efficacy in managing diabetes.

The Ecological Model Applied to Chronic Diseases

Bronfenbrenner's ecological model has been used to evaluate the impact of a child's chronic illness on the family, as seen in Figure 2.3. A family that cares for a child with a long-term illness is shaped by that illness. According to Brown (2002), examples of illness-specific microsystemic influences include the nature of the child's chronic illness and its effects on the child and other family members, such as parents and siblings. The family's daily routine may have to change to fit the behaviours needed to properly care for the child's diabetes. Such accommodations affect both parents' and siblings' routines. For instance, the parents of a child with diabetes may anticipate that the sibling will become involved in the child's daily care, or the sibling may believe that chronic illness affords the child with diabetes special privileges, such as staying up later or receiving special treats (Loos, & Kelly, 2006). As a result, it is not surprising that siblings of children with chronic illnesses are more likely to experience adjustment difficulties (Bellin, & Kovacs, 2006).

Diabetes may also impact a child's relationship with their peers. Fearing stigma, a child with diabetes may be hesitant to reveal their diagnosis to peers or to include friends in illness-management tasks (Buchbinder et al., 2005). Similarly, when children with diabetes are with their peers, they may be disinclined to complete their diabetes care to conform to social norms, especially if the child perceives those peers as unsupportive of the illness or the illness-management tasks (Wysocki & Greco, 2006). However, for a child with a chronic illness such as diabetes, peers are an important source of social support (Brown, 2002). Possessing a group identity that promotes health and well-being, such as being an athlete, and having supportive friends, both aid in illness adaptation and improve illness-management behaviours (La Greca et al., 2002).

Chronic illness affects the family's social ecology mesosystems (Brown, 2002). A family's relationship with the child's medical care providers is crucial because a child's illness and treatment options are influenced by that relationship (Brown, 2002). The amount of information that both parents and medical care providers have when making decisions about a child's illness and treatment options is influenced by the relationship between the family and the care providers. For instance, if a pattern of open communication is lacking between parents and medical care providers, those providers may overestimate or underestimate the degree to which parents are involved in the daily illness-management regimen (Buchbinder et al., 2005).

A family's connections with extended family and alternative caregivers are included in the mesosystem connections category. Extended family members are the most common source of illness-related behaviours, both supportive and non-supportive, in both children and adults (Patterson et al., 1997). The family's ability to support the demands of caring for a child with diabetes, which includes being informed and educated about the illness-management behaviours required to care for the illness, directly affects a child's and family's adjustment (Brown, 2002), Moreover, the degree to which teachers and school personnel are properly informed about the illness-management practices required during the school day also has a significant impact on the child.

As a child with diabetes matures, the family's culture and beliefs can have an impact on the child's life (Brown, 2002). For example, caregivers' attitudes toward parenting and behaviour-monitoring affect the child. The likelihood of children with diabetes completing their illness-management tasks can be increased or decreased by parental monitoring (Ellis et al., 2007). For example, children in low-monitoring families may avoid their self-care without being noticed, whereas children in high-monitoring families may complete illness care because caregivers are monitoring these tasks (Carcone, 2010).

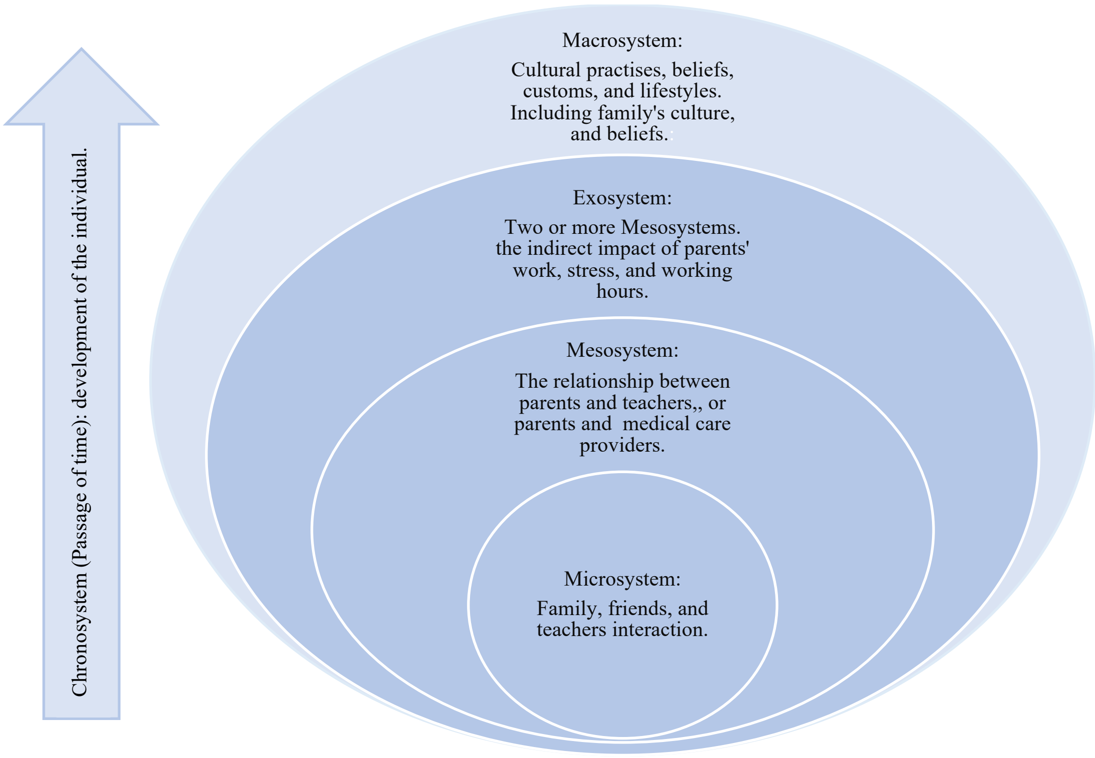

Figure 2.3. Ecological Model Applied to Chronic Disease

Focusing on multiple levels of influence to increase treatment and intervention options is a key strength of ecological models (Sallie et al., 2008). However, because these models specify multiple levels of influence and often have multiple variables at each level, determining which possible interactions are the most important may be difficult (Glanz, 2008). As a result, expanding the understanding of these interactions across levels is an empirical challenge. Moreover, ecological models are most effective when they are tailored to a specific behaviour, such as environmental and policy variables (Glanz, 2008); for example, the presence of bicycle trails in suburban neighbourhoods may encourage people to cycle or walk, but it is unlikely to make people drink less alcohol. The need to identify environmental and policy variables that are unique to each behaviour presents a challenge when using ecological models.

Self-management training appears to improve diabetes management (Norris et al., 2002). Self-management is frequently conceptualised as an individual responsibility in which "only the patient is accountable for his or her daily care throughout the duration of the illness" (Lorig, & Holman, 2003, p.1). However, research does not support the assertion that self-management interventions empower individuals to manage their disease on their own. Rather than that, a meta-analysis of diabetes self-management programmes discovered that benefits began to decline abruptly a few months after the interventions concluded (Norris et al., 2002). These findings are consistent with an ecological perspective in which the individual's long-term success in self-management is influenced by the contexts in which they live. From an ecological standpoint, people with diabetes require a variety of resources and self-management supports in order to manage the disease in their daily lives (Glanz, 2008). These include (1) opportunities to learn diabetes-specific skills (such as blood sugar measurement) and to address challenges, such as negative emotions, that may interfere with management; (2) collaborative goal setting, (3) individualised assessment, (4) follow-up and assistance on an ongoing basis, (5) resources in the community, such as those for regular physical activity and a healthy diet, and (6) continuity of quality clinical care. Individualised assessment and collaborative goal setting are frequently addressed at the individual level, whereas others, such as access to resources and the continuity of high-quality clinical care, require attention at the group, community, and policy levels of the health system. Individuals acquire skills to access resources as a result of policies, which is consistent with the ecological models' emphasis on interactions between levels (Geisz, 2010)

Overall, the theoretical framework of ecological models appears to be promising in terms of promoting understanding of Type 1 diabetes children and their parents' interactions with their environments. Moreover, the theory illuminates the idea of the surrounding environments as well as the interaction between those environments, for example: staying at home for a long period of time during the pandemic and it is impact on parents and children. Since this knowledge can be applied to the development of effective multi-level strategies for improving the health behaviours of affected children, we have considered this theory to be the closest to our research.

Chapter 3

Psychological Variables and Lifestyle in Children with Type 1 Diabetes and Their Parents: A Systematic Review of the Literature.

- This chapter presents a systematic review of papers reporting empirical research with children with Type 1 diabetes and their parents in order to understand the relation between their mental health, well-being, and lifestyle. The aim of this review is to find the relevant literature in order to identify studies that looked at behavioural problems in children with diabetes, and to seek the best measures that should be used to test the study hypotheses. Moreover, to identify and highlight areas where future study might expand on previous investigations. This paper was accepted for publication by The Clinical Child Psychology and Psychiatry Journal, a peer-reviewed open-access journal (IF=2.08).

Abstract

Diabetes may impact physical and psychosocial well-being; the diabetes incidence has seen a drastic increase globally. There is also a rise in poor mental health and well-being in children with and without chronic illness; problems are being seen at a younger age. The objective of this review was to understand the determinants of these problems in a family context. We conducted a systematic review to investigate what lifestyle and psychological factors influence children with Type 1 diabetes and their parents. A focused literature search was performed using a combination of keywords that covered the relevant terminology for diabetes, target population, and associated emotional distress, using electronic bibliographic databases containing publications until May 2022. Methodological quality was assessed using the Quality Assessment Tools for Quantitative Studies. Twenty articles met the inclusion criteria. Quality scores were weak because of a lack of comparison groups, information about the type of therapy, or adequate sample sizes. Many of the studies included a wide age range in their sample. The majority of the studies reported that parents and their children showed depression symptoms, fear of hypoglycaemia, and higher parenting stress. We conclude that sufficiently powered studies employing appropriate control groups and measures are needed to elucidate the psychological variables associated with Type1 diabetes in children and the effects on parents, especially considering primary-age children who are increasingly reported to suffer from poor mental health, and its implications. This should help to introduce better targeted interventions and improve behavioural outcomes.

Keywords: Type1 diabetes, systematic review, children and parents, anxiety, depression.

Introduction

Diabetes mellitus Type 1, commonly known as Type 1 diabetes, is caused by the destruction of islet ß cells in the pancreas, usually leading to absolute insulin deficiency (Donath et al., 2003). Over the years, diabetes has become a major public health concern globally, affecting not only people with diagnosis, but also their families and caregivers. According to the available literature, this disease is becoming more common in children and their parents (Saraswathi, Al-Khawaga, & Elkum, 2019). Anxiety, anger, and depression are common emotions experienced by children and their families upon receiving the diagnosis (Diabetes and Emotions, 2017). In one longitudinal study, primary school-age children with diabetes reported anxiety and mild depression, which resolved six months after diagnosis; while depression symptoms increased after one to two years, anxiety decreased only for boys, while it increased for girls over the first six years (Silverstein et al., 2005). In this situation, children with diabetes may perceive that they are different from their peers and may be at risk for difficulties in social competence. Type 1 diabetes in children can be intense and may lead to behaviour-related disease management problems such as anxiety, depression, social anxiety, and lower self-esteem. Diagnosis often leads to worry and stress-related responses regarding the complex care plan that needs to be adhered to by the patient and delivered by the caregivers (Silverstein et al., 2005). For example, a child with diabetes may potentially be anxious about how their condition will develop in the future, be fearful of leaving their house or communicating with others, and be prone to avoid social interactions with others (Diabetes and Anxiety, 2017). It may also affect the household in numerous ways; financially, socially, and emotionally (McCarthy, & Kushner, 2007). Therefore, it is imperative for families to learn management and coping with diabetes, and the effects that the disease might have on their children's life-span development (including normal peer relationships) as early as possible. Yet there are few published studies regarding this situation, especially among younger-aged children (e.g., 8-11 years), who are increasingly likely to report poor mental health, even in the absence of chronic illness (Silverstein et al., 2005).

Coping with behavioural changes as a result of the disease can be challenging for both children and families (Calentine, & Porter, 2012). Considering the effects of diabetes diagnosis and illness, it is expected that children's behaviour will have an effect on their diet, education, and lifestyle. If families are not aware of the risks, the situation may become more difficult to manage and control in the future for both parents and children.

The area of diabetes and depression in children and adolescents has not been researched extensively. Children with diabetes have a two-fold higher prevalence of depression, and adolescents have a three-fold higher prevalence than their non-diabetic peers (Grey, Whittemore, & Tamborlane, 2002). The combination of diabetes and depression is influenced by many variables, including gender, family behaviours, and poorer metabolic control. Diabetes and depression co-morbidity is a significant issue in children and adolescents, affecting an estimated 20% of diabetic individuals, compared to less than 7% of youth without diabetes (Grey, Whittemore, & Tamborlane, 2002). This presents the risk of disability, and negative long-term consequences. Therefore, health practitioners need to pay attention to the emotional functioning and family functioning of children with diabetes, as diabetes can cause a significant impact on families and caregivers in terms of providing support and promoting a healthy family environment (Hood, Huestis, Maher, Butler, Volkening, & Laffel, 2006).

Lowes et al. (2014) conducted a qualitative study aimed to explore the experience of attending paediatric diabetes services and living with and managing Type 1 diabetes. They recruited children aged 7 to 15 years old and their parents. Most parents reported that attending the clinic was a source of anxiety. For example, one carer said, "I often feel stressed up to about a week before I go to clinic. I worry about what my son's HbA1c results will be." Children also worried about attending the diabetes clinic and reported that their experience is often represented negatively. Some parents reported feeling exhausted as a result of the responsibility of caring for their child. Children expressed their feelings of fear, unhappiness, anger or distress about the presence of Type 1 diabetes in their lives. For example, one child told the researchers, "I don't like having diabetes. I don't like injections (insulin). I don't like going out with other people for the day cos they don't understand diabetes. My friends sometimes say they don't like me because I have diabetes so I feel sad." The findings of this study also showed that paediatric diabetes nurses interacted with patients and families in a more compassionate manner than medical professionals. A mother said, "Feeling confident when going to clinic and speaking to members of the team is crucial in the learning process and enables you to ask questions as often as you need to! Parents with diabetic children have lots of questions and fears!" Similarly, Hawthorne et al. (2011) found that children with Type 1 diabetes and their parents or careers believe that doctors struggle to link the demands of diabetes with daily life, such as school and social activities, in their consultations, and to consider the emotional impact of living with Type 1 diabetes. However, it is well documented that most parents are likely to experience significant distress (e.g., anxiety and depression symptoms) after their child is diagnosed with Type 1 diabetes (Kokkonen, Taanla, & Kokkonen, 1997). Kovacs et al. (1997) and Jaser et al. (2008) reported that increases in parental distress have been linked to higher levels of child distress; maternal depressive symptoms are one of the most powerful risk factors for depressive symptoms and a lower quality of life in children. Ongoing parental involvement in treatment management is linked to improved health and psychosocial outcomes in children with Type 1 diabetes (Anderson et al., 2002). Furthermore, observational research may shed light on specific aspects of parent-child interactions that influence diabetes adaptation. One study found that higher levels of observed emotional support, acceptance, and conflict resolution in children and their parents, as well as lower levels of observed parent anger and sadness, were related to better glycaemic control during a diabetes-related task (Martin et al., 1998). Another study discovered that higher levels of observed hostility by mothers, as well as lower levels of child-centered behaviour and positive reinforcement, were associated with poorer psychosocial adjustment and glycaemic control in adolescents (Jaser et al., 2010). A higher frequency of negative parent-child interactions has also been linked to a lower quality of life (Weissberg-Benchell et al., 2009). This intense level of responsibility is likely to increase family stress and conflict, especially as children reach adolescence, which is unique to Type 1 diabetes.

Overall, the relationship between psychological variables and lifestyle in children with Type 1 diabetes and their parents at primary age has not been reviewed in the existing literature. We conducted a systematic review of quantitative studies to investigate what lifestyle and psychological variables influence children with Type 1 diabetes at primary age and their parents.

Method

Search Process

A literature search was carried out in five databases using a web browser: ProQuest; Science Direct, Web of Science, Google Scholar, via Bangor University Library. This search reviewed scientific and electronic literature without employing a specific set of years, until May 2022. The report follows PRISMA guidelines for systematic review. The terms used in the search as keywords or phrases to describe the target population were in the English language: (childhood diabetes), (children with diabetes), (diabetes mellitus in children), (children with Type 1 diabetes), and (parenting and Type 1 diabetes in children). Psychological variables were also used in the search: (psychological status of children with

Type 1 diabetes), (psychological problems in children with diabetes), (depression in children with diabetes), and (psychological problems in parents of children with Type 1). Due to the number of different constructs investigated across the papers, a meta-analysis of studies was not conducted.

Literature Search Selection

Two reviewers independently screened titles, abstracts, and full texts to determine article eligibility. Any disagreements were settled through discussion. The titles and abstracts were read to choose studies to be included in the present review. We considered cohort studies, randomised and non-randomised controlled trials, cross-sectional studies, and case-control studies including the following criteria: (1) they reported on children with Type 1 diabetes and their parents; (2) included in the sample primary school age range; (3) included parents of children with diabetes; (4) included psychological variables, and /or (5) examined lifestyle and physical activity. Studies were eliminated if: (1) the sample were over 11 years of age; (2) results were neuropsychology based; (3) interventions were used without targeting both children and their parents; (4) results solely reported memory problems and cognitive behaviour; (5) sample did not include children with Type 1 diabetes and their parents. The papers published in the past two years on the effects of the COVID pandemic mostly fell in the last category; some relevant results have been reported for children, or for parents, but not for both.

Data Extraction and Quality Assessment Tool for Quantitative Studies (QATQS)

We extracted the following data; first author, year of publication, participants' characteristics, measurements used in the study, analysis, main finding, therapy type (pump or daily injection), and HbA1c.

The Effective Public Health Practice Project (EPHPP, 1998) generic tool was used to assess all selected studies in this review (Quality assessment tool for quantitative studies, 2020). The EPHPP tool was chosen for its inclusiveness of a variety of research study designs, not restricting to only Randomised Controlled Trials (RCTs), but also considering nonrandomised studies. This tool has been shown to have good content and construct validity (Quality assessment tool for quantitative studies, 2020). The components of the study methodology were assessed across six key domains: selection bias, study design, confounding variables, blinding, data collection methods, and withdrawals and dropouts. Following the guidelines for the quality assessment tool, each domain was rated as either strong, moderate, or weak, and scores were collated to provide the total score (Quality assessment tool for quantitative studies, 2020; Thomas, Ciliska, Dobbins, & Micucci, 2004). Based on the final scores, those with no weak ratings and at least four strong ratings were considered strong; less than four strong ratings and one weak rating were considered moderate, and those with two or more weak ratings are considered weak (Thomas, Ciliska, Dobbins, & Micucci, 2004).

Results

Out of the 815 studies gathered by the search, 300 were removed due to duplicate records, and 421 were excluded based on the title, abstract, and combination of Type 1 and Type 2 diabetes. Out of the remaining 94 studies, 36 were excluded because children were not in the primary age range; 38 studies out of 58 were excluded for not investigating both parents and children with Type 1 diabetes. Therefore, the total number of studies included in the final review was 20. Figure 1 summarises the selection procedure.

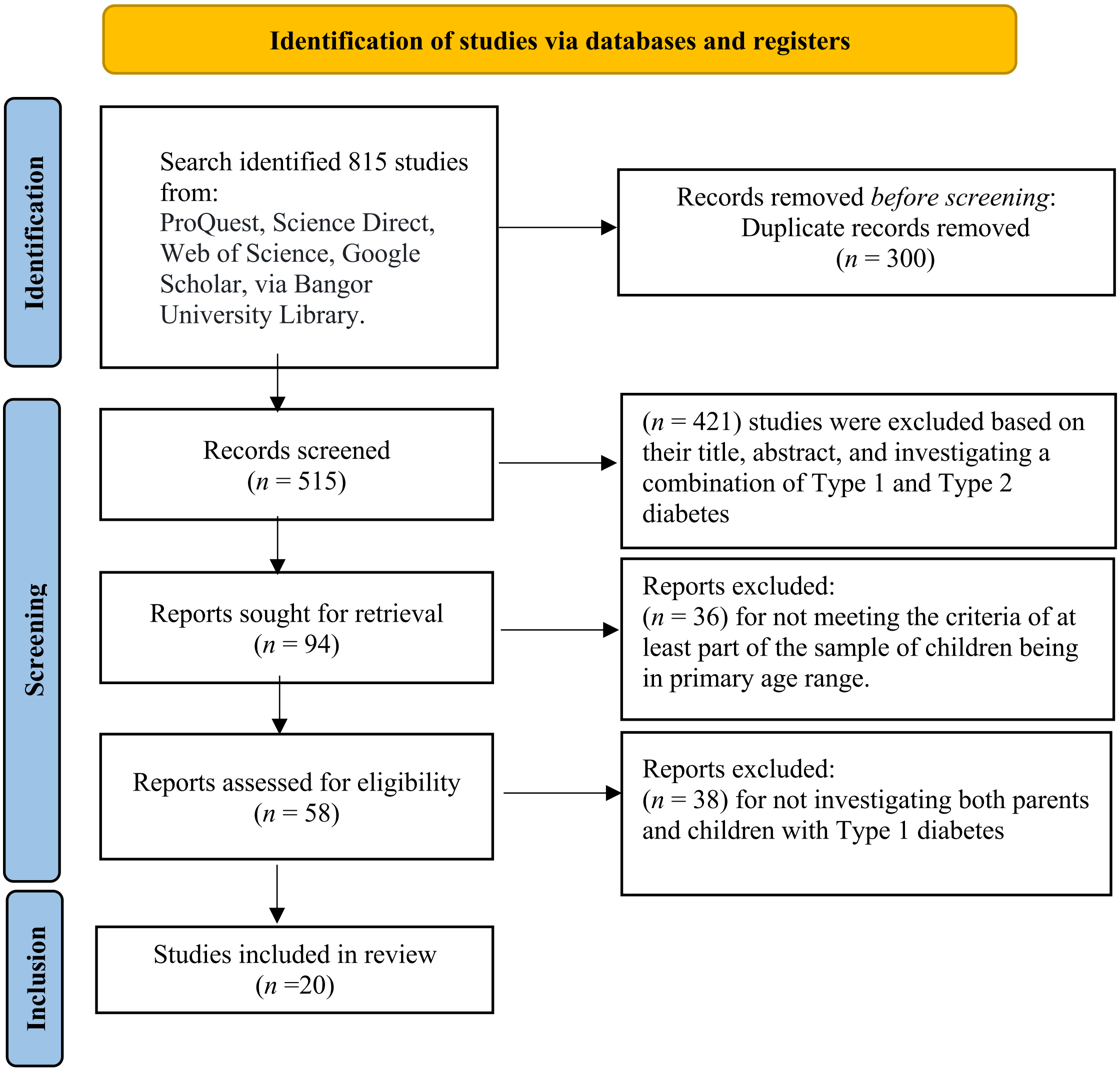

Figure 3.1. Flow diagram of literature search and study selection

Results of QATQS of Included Studies

The overall quality scores, shown in Table 1 indicated that 16 studies were rated as weak, 3 studies were rated as moderate, and 1 study was rated as strong. Regarding the selection bias, 12 studies were rated as moderate, because participants were referred from a clinic and the participating percentages were 60% to 79%. Only six studies were rated weak because the participation was less than 60% of the total number. In accordance with the QATQS criteria on study design, 18 studies were rated as weak because they used cross-sectional designs, and only the two randomised control trial studies were rated as strong

(Armstrong, Mackey, & Streisand, 2011, Sweenie, Mackey, & Streisand, 2014). Eighteen studies were rated as strong in the confounders domain because there was no difference between groups, whiles 2 studies were rated as weak. With respect to their data collection methods, 17 studies were rated as strong due to the clarity, validity, and reliability of their data collection tools, and the remaining 3 studies were rated as weak. Regarding blinding, 14 studies were rated as weak due to the participant's knowledge of the research question, while 6 studies were rated as strong. 15 studies were rated as weak in the withdraw and drop-out domain, while 3 studies were moderate and only 2 studies were rated as strong, due to retention greater than 80%.

Study Characteristics

Table 2 shows the summary of the finding and the characteristics of the studies included in the present review. These clinical trials were performed in several countries, including the United States of America (USA), Italy, Canada, Portugal, and Belgium. Most of the studies were conducted without a comparison group; only one study had a comparison group. Seven studies did not specify the therapy type of the participants. Regarding the haemoglobin (HbA1C) measurements, seven studies specified the mean of the HbA1C, nine studies reported the range of HbA1C, and four studies did not report this measure. All the studies included in this systematic review used self-report questionnaires for both children and their parents. Their data analysis was conducted using IBM SPSS Statistics, and most of the studies were correlational in design.

Table 3.2.
Quality assessment according to EPHPP assessment tool for quantitative studies.

Authors in alphabetical order	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawals and dropouts	Overall quality score
Armstrong et al. 2011	M	S	S	W	S	M	M
Barzel et al. 2011	W	W	S	W	S	W	W
Cohen et al. 2004	W	W	W	S	W	W	W
Feeley et al. 2019	M	W	S	S	S	S	M
Gruhn et al. 2016	M	W	S	W	S	W	W
Jaser et al. 2008	W	W	S	W	S	W	W
Jaser et al. 2010	M	W	S	W	S	W	W
Jaser et al. 2014	W	W	S	W	S	W	W
Jabbour et al. 2016	M	W	S	S	S	W	W
Jaser et al. 2017	M	W	S	W	S	W	W
Michaud et al. 2017	M	W	W	W	S	M	W
Moreira et al. 2014	M	W	S	S	S	S	M
Mullins et al. 2004	W	W	S	W	S	W	W
Patton et al. 2011	W	W	S	W	S	W	W
Sweenie et al. 2014	M	S	S	S	S	M	S
Troncone et al. 2017	W	W	S	W	W	W	W
Viaene et al. 2017	M	W	S	W	W	W	W
Van Gampelaere et al. 2020	M	W	S	W	S	W	W
Whittemore et al. 2003	W	W	S	W	S	W	W
Wilson et al. 2009	M	W	S	S	S	W	W

Note: Studies were rated as strong (S), moderate (M), or weak (W) on each specified dimension

Study Findings

The following summary of the studies' findings from the present review is divided into categories based on the target outcome behaviour.

Mental Health (Anxiety, Depression, and Stress) and Wellbeing

Eleven of the included studies focused on children's and parents' mental health as well as their wellbeing. Armstrong et al. (2011) aimed to examine the reported self-care behaviours, depressive symptoms, and self-efficacy in children with diabetes and the influence of critical parenting behaviours. The results, indicating that children who reported critical parenting behaviours tended to have lower self-efficacy and more depressive symptoms, suggested that these children are at greater risk than their healthy peers for psychiatric disorders. The relationship between self-efficacy and critical parenting was partially mediated by depressive symptoms. In the second model, the relationship between self-care and depressive symptoms was fully mediated by self-efficacy, which was linked with fewer self-care behaviours. Mediation analyses were carried out in accordance with Baron and Kenny's (1986) recommendations.

The collaborative, as well as intrusive, parenting effect upon glycaemic control and depression amongst children with diabetes was examined by Gruhn et al. (2016). The analyses of linear regression and bivariate correlation revealed that low HbA1c was related to higher levels of collaborative parenting; one can conclude that parental communication reinforces proper management behaviours in youth. Conversely, greater child depressive symptoms were linked to higher levels of observed overinvolved and non-collaborative parenting after one year; this study suggested that intrusive parenting in the form of behavioural control and lecturing may be aversive for children. This finding might be a result of parents becoming more overbearing and critical in response to their children's poor adherence. Notably, it has been discovered that there is a bidirectional relationship between parent and child behaviour (Kiff, Lengua, & Zalewski, 2011). Furthermore, this study found that overinvolved parenting is a strong predictor of depressive symptoms in children using insulin injections versus insulin pumps.

Jaser et al. (2008) sought to examine the existing relations between the mother's and the child's depressive symptoms, while also trying to determine family and child psychosocial factors. The results reported that there was significant association between the mother's and the child's depressive symptoms ($r= .44$, $p < .001$). Maternal depressive symptoms were negatively correlated to family functioning, perceptions of coping, and the child's quality of life; the relationship between the mother's and the child's depressive symptoms was mediated by family warmth. This is because mothers with high levels of depressive symptoms contribute to increased depressive symptoms in children with Type 1 diabetes due to difficulty in providing support for their children, suggesting inadequate coping and a lower quality of life.

Jaser et al. (2010) aimed to determine the relationship between the observed parenting behaviours and the adjustment amongst those children with diabetes together with their mothers. The results indicated that mothers' symptoms of depression and anxiety were linked to a low level of child-centered parenting; this aligns with a similar study which suggested that parents attempt to control the treatment of their child, which may results in the child becoming depressed and withdrawn (Berg et al., 2007; Cameron et al., 2008; Weinger et al., 2001). Lower levels of maternal hostility, parental influence, positive reinforcement, and higher levels of observed child-centered parenting were linked to improved psychosocial adjustment in adolescents. For example, they had better metabolic control, better quality of life, and fewer depressive symptoms.

The aim of the study by Jaser et al. (2014) was to characterise coping in mothers of children with diabetes and to examine the relationship between mothers' coping strategies, diabetes-related stress, and psychological distress, such as depression and symptoms of anxiety. The results indicated that secondary control coping (acceptance) was interposed within the relationship between depression, maternal symptoms of anxiety, and diabetes-related stress. The use of strategies, such as primary control coping (problem-solving) and secondary control coping (acceptance) was related to fewer symptoms of family conflict, depression, and anxiety. Race/ethnicity and marital status-related differences in the use of disengagement coping techniques were found to be significant. First, compared to White mothers, mothers of colour reported using more disengagement coping mechanisms. This racial/ethnic disparity may be a result of coping methods that vary across cultures. Evidence indicates that Black and Latina women are more likely to view health issues fatalistically (Shelton et al., 2011), which could lead to an increase in the use of disengagement coping mechanisms, like avoidance or wishful thinking (Roesch et al., 2001). However, the study did not examine the association between children with diabetes outcomes and maternal coping. Nevertheless, the way in which mothers of children with diabetes cope with diabetes-related stress was linked to family conflict and psychological distress. A limitation of this study is that the parents were of high income and socioeconomic status, which may affect generalisability.

Mullins et al. (2004) aimed to examine perceived child vulnerability and parental overprotection correlation with parents' self-reported depressive symptoms. The results showed that high levels of depressive symptoms were related to two factors: child vulnerability and parenting stress. A regression analysis indicated that parental stress moderated the relationship between depressive symptomatology and perceived child vulnerability. Therefore, children with diabetes Type 1, whose mothers experience significant parental stress and child vulnerability, are likely to experience depressive symptomatology. The author suggested that the nature of diabetes Type 1 and its life-threatening complications heightened the sense of vulnerability in parents since they must monitor insulin levels and exercise to prevent hypoglycaemia. In addition, no relationship between overprotection and child depressive symptoms was found.

Patton et al. (2011) aimed to test various psychological correlations of paediatric parenting stress in parents of children with diabetes. The results indicated that higher stress difficulties were linked to higher fear and parental depression symptoms; this relationship was also observed by Streisand et al. (2008) in parents of newly diagnosed children. 58% of the variance in stress frequency was linked with parental depressive symptoms and were identified by regression analyses. It is possible that parents who experience higher levels of paediatric parenting stress may have fewer coping mechanisms available to them, making them more susceptible to depressive symptoms and hypoglycaemia anxiety. It is also possible that depression symptoms and a fear of hypoglycaemia could make parents more sensitive to the stress that comes with raising a child with diabetes. Further, the study enrolled participants with a high rate of insulin pump use versus injection. It is known that pump therapy has more flexibility for the patients in terms of dosing and timing, which might help to ease some of the stress associated with diabetic management.

Sweenie et al. (2014) aimed to investigate the association among paediatric parenting stress, critical parenting behaviours, and child problem behaviours in children with diabetes. The results indicated that parents, who reported a child's psychological behaviour as more problematic, also stated more difficulty with paediatric parenting stress. While critical parenting behaviours and child problem behaviours were linked to each other, they were also connected to increased paediatric parenting stress. This showed the importance of the relationship between parents and child in diabetes management during childhood. This study provides significant evidence that problematic externalizing behaviours are associated with negative critical parenting behaviours in preadolescents with Type 1 diabetes, which may influence disease management. Moreover, it indicates that parental involvement and glycaemic control decrease in children as they grow up. (La Greca et al., 1990; Johnson et al., 1992). Furthermore, parents are often more involved in Type 1 diabetes care during preadolescence than later adolescence (Anderson et al., 1997), which may maintain good glycaemic control and explain the lack of association between medical outcomes and psychosocial variables despite worrisome behaviours and elevated stress. Thus, glycaemic control may not decrease until preadolescence.

Van Gampelaere et al. (2020) compared families with young children (aged 2 to 12) with Type 1 diabetes to families without any chronic diseases in terms of parenting behaviour, wellbeing, and parental distress. As reported by mothers, the results indicated that children with Type 1 diabetes had more adjustment difficulties; mothers perceived their child's behaviour as more problematic than fathers did. This difference in perception could be explained by the elevated levels of maternal stress found in the study sample. Stress can heighten parents' sensitivity to behavioural issues in children with Type 1 diabetes, even to inappropriate behaviours that are thought to be typical at a certain age (Cohen et al., 1988). Moreover, only mothers reported anxiety, stress, and depression symptoms. Rather than Type 1 diabetes itself, suboptimal child glycaemic control and its consequences may induce maternal stress and depressive symptoms. Alternately, maternal stress and depressive symptoms may predict (indirectly) child HbA1c. While lower quality of life was reported by both mothers and fathers, higher quality of life was reported by the children themselves, as compared to control. This is a surprising finding that have not been replicated in other research.

Viaene et al. (2017) aimed to extend the existing knowledge regarding parenting stress and Fear of Hypoglycaemia (FoH) amongst parents whose children have diabetes. The study also investigated the relationship between metabolic control and children's FoH, as reflected by HbA1c. The researchers discovered an indirect association between HbA1c values and parental FoH through parenting stress. While there was no indirect association between HbA1c and parental FoH, the author suggested that FoH may adaptive as it encourages frequent monitoring (Irvine, Cox, & Gonder-Frederick, 1994). They concluded that FoH predicts parental stress, and this in turn predicts metabolic control. Moreover, other studies suggested that social anxiety may have an impact on the adherence of adolescent patients with Type 1 diabetes (Di Battistaet al., 2009). However, the sample size was relatively small, with limited demographic information.

Whittemore et al. (2013) examined the child–parents and family factors associated with metabolic control and quality of life in primary school-aged children with Type 1 diabetes undergoing intensive treatment. The results reported that families who have children with diabetes Type 1 are often able to achieve metabolic control, experience good quality of life, manage their diabetes, and cope with treatment and its demand. However, they reported an increase of depressive symptoms in both parents (29%) and children (8%). In addition to the illness itself, it is not surprising that children who are exposed to maternal depression symptoms exhibit an increased risk for psychosocial problems and behaviour problems. Primary school-aged children, living with parents with increased depressive symptoms, may develop psychopathology during childhood.

Lifestyle (physical activity and sleep)

Two studies focused on physical activity. Jabbour et al. (2016) aimed to identify the barriers to the lifestyle of children with diabetes based on recognised barriers in adults with diabetes. The barriers found by the study included the threat of hypoglycaemia, work schedule, fear of losing control of diabetes, and external temperature, i.e. high heat that leads to dehydration. The study used a sample which was divided into two groups: younger than 12 years of age and 12 years of age or older. The results indicated that external temperature, fear of hypoglycaemia, work schedule, and loss of control of diabetes had the highest barrier scores among children younger than 12 years of age, while the lower overall barrier scores were associated with a greater parental support for both older and younger children. Furthermore, parental support was highlighted as an important factor to enhance an active lifestyle for children. More generally, it has been suggested that those with Type 1 diabetes who exercise in hot weather dehydrate more quickly than their non-diabetic friends, which leads to decreased performance and cramping that restricts their physical activity (Riddell & Perkins, 2006).

Michaud et al. (2017) aimed to compare the activity profile of children with diabetes under insulin injections to those under insulin pumps to see if they were a barrier to exercise, and to investigate whether the lifestyles of their parents had an influence. The relationship between the components (exercise barriers, Physical Activity (PA) profile, and sedentary habits) of those who used a pump and those who injected insulin was similar. The only barrier in both groups was mainly the fear of hypoglycaemia. The study showed the absence of a relationship between the treatment type (injection vs. pump) and activity level of a paediatric patient with diabetes, whereas numerous PA practices by parents were linked to less screen time in children with diabetes and more moderate to vigorous PA. Moreover, a wider range of parental PAs also seemed to be more significant than parents engaging in PAs with their children and the level of parental PA itself. Unfortunately, the questionnaire used made it impossible to determine the actual length of the parents' activities. Investigating subgroups whose sample sizes are inevitably smaller could have led to statistical differences being absent regardless of the large clinical differences found.

Two studies focused on sleep-related problems. Feeley et al. (2019) examined the correlations in sleep between young children (aged 6 to 12) with diabetes Type 1 and their caregivers. The study found strong to moderate correlation for several measures: sleep measure based on actigraphy; mean sleep duration, mean daily wake after sleep onset, and mean sleep efficiency. In this study, caregivers might have experienced a negative influence on sleep quality due to fear of overnight blood checks and overnight hypoglycaemia, which could have interfered with their ability to get adequate sleep quality. In this population, elevated Wake After Sleep Onset (WASO) may be caused by a variety of factors, including nightly glucose checks or difficulty falling asleep after nightly glucose checks. Co-sleeping or undiagnosed sleep disordered breathing are additional possibilities (such as obstructive sleep apnea). It is possible that some children had undiagnosed sleep disorders even though those who had diagnosed sleep disorders were not allowed to participate.

Jaser et al. (2017) aimed to determine whether there is a characteristic sleep disturbance in children with diabetes and their parents. They also investigated whether there was a relationship between adherence, glycaemic control, child sleep, nocturnal caregiving behaviour, parental sleep, wellbeing, and parental fear of hypoglycaemia. In this study, only 67% of the children met the criteria for poor sleep quality, and the results showed that poor glycaemic control was related to child sleep quality. Children with low sleep quality were more likely to suffer from severe hypoglycaemia; this was the source of stress for parents. Moreover, parents' poor sleep quality had a negative impact on their emotional wellbeing. Additionally, poorer sleep quality in children was associated with poor parental wellbeing, sleep quality, and fear of hypoglycaemia. The study also found that child sleep was not linked to the use of diabetes-related technology (i.e. insulin pump vs. injection) and concluded that sleep is a modifiable factor to reduce parental stress and enhance glycaemic control. Furthermore, considering that many parents show interest in adopting Continuous Glucose Monitoring (CGM) as a strategy to lessen concern surrounding nocturnal hypoglycaemia and reduce the need for night-time caregiving, the lack of a link between

CGM use and parental or child sleep quality was also unexpected. It is possible that objective sleep measurements rather than self-reports are required to show how CGM affects sleep.

Quality of Life

Two studies focused on quality of life. Barzel et al. (2011) aimed to explore the general, as well as the specific, issues involving co-parenting and children with diabetes and to additionally evaluate the psychosocial and medical adjustments for both parents and children. The results showed that co-parenting conflicts occurred whenever children internalised or externalised their problems, mostly because of poor diabetes management behaviours and poor quality of life, but not their levels of HbA1c. Moreover, the relationship between children's psychosocial adjustment and co-parenting were different for fathers and mothers. Children with fewer internalizing problems were specifically associated with mothers' coparenting cooperation around general childrearing tasks, whereas this significant finding did not emerge for fathers' coparenting cooperation. The coparenting cooperation of mothers, which promotes a sense of emotional security and stability in the family, may then help children better regulate their emotions by showing their support and respect for fathers. The findings also indicated that children were more likely to experience both internalising and externalising issues when mothers unnecessarily drew the child into parental conflict (i.e., triangulation). On the contrary hand, there was a significant correlation between fathers' triangulation behaviours regarding general childrearing issues and children's externalising but not internalising problems. This study highlighted the important role of fathers and mothers in influencing child adjustment, as well as the independent contribution of both parents in influencing child outcomes.

Moreira et al. (2014) sought to determine if family cohesion and children's HRQOL were linked via three indicators of parental psychological adjustment (parenting stress, depressive symptoms, and anxious symptoms) and if these links varied with the child's age.

Regardless of the age of the child, the results indicated that higher HRQOL ratings were associated with higher levels of cohesion via lower levels of parental stress. Compared to parents of healthy children, parents of children with Type 1 diabetes perceived less cohesion and experienced greater anxiety and stress regarding parenting duties, implying that the intensive treatment regimen and responsibility for Type 1 diabetes management may be overwhelming for parents; disrupt family functioning and relationships within family systems; and reduce perceptions of proximity, connectedness, and support within the family. This indicated that parents of children with Type 1 diabetes have a higher risk of psychological maladjustment.

Troncone et al. (2017) aimed to recognise the psychological impact of implantable devices on children with diabetes. The researchers evaluated the effects of an injection port used by patients on their quality of life. The study assessed the caregivers' burden and the treatment satisfaction. The results showed that no significant differences were found in z-BMI values and HbA1C. However, after three months of treatment, the results showed an increasement in WE-CARE subscale (acceptance of insulin administration and treatment satisfaction). After 6 months, the results showed significant improvement in diabetes symptoms subscales, paediatric quality of life total (PedsQL), and WE-CARE subscale (psychological wellbeing, acceptance of insulin administration, and treatment satisfaction). The parents described the therapy as associated with an improvement in psychosocial, wellbeing, and treatment satisfaction with a reduction in perceived burden. Additionally, there was no significant PedsQL finding regarding the parents. However, the study did not have a control group. These results are likely related to the reduction of some issues frequently associated with diabetes treatment that typically affect patient, caregiver, and their well-being, which may be related to the convenience of this alternative method of insulin administration—reducing the number of daily injections.

Diabetes Management

Two studies focused on diabetes management. Cohen et al. (2004) examined how problems related to the behaviour of a child and the functioning of a family predicted good treatment adherence habits as well as regulation of glucose amongst children from economically disadvantaged families. The results from the multivariate analysis showed that high levels of family cohesion predicted good adherence and better control of glycaemia, which suggested that children without internalising behaviour had better adherence and experienced less difficulty adhering to their medical regimen. In contrast, a child may feel less concerned, receive less monitoring, and receive fewer reminders to engage in healthy behaviours when there is a lack of family cohesion. Other predictors of enhanced glycaemic control were the absence or presence of externalising and internalising behaviour problems, respectively. Moreover, adherence did not serve as a mediator between glycaemic control and family functioning or behavioural problems.[1]

Wilson et al. (2009) aimed to investigate the association between parental discipline strategies and the behaviour problems of children with diabetes. Results indicated that over-reactive parental discipline was associated with common child mealtime misbehaviour, the author suggested that parents tend to provide more prompts for their child as the meal progresses, and children tend to eat less as the meal progresses. They also found that over-reactive discipline was linked to reports of less time spent managing the child's illness, which suggested that parents who report less involvement with illness management were less acclimated to diabetes-related issues and more reactive when disciplining medical situations.

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[1] According to Holmbeck (1997) and Baron et al. (1986), mediation takes place when three criteria have been met. First, there must be a strong correlation between the predictor (such as behaviour issues or family functioning) and the outcome (HbA1c), as well as between the predictor and the potential mediator (adherence) and the outcome itself. Second, while accounting for the predictor, the potential mediator must continue to be relevant to the result. Finally, once the mediator is incorporated into the complete model, the predictor's effect must be significantly reduced.

Moreover, parental discipline strategies play an important role when working with children with diabetes and their misbehaviour. The study had a relatively small and homogeneous sample, instead of a large and more diverse sample.

Table 3.3.
Characteristics of the 20 studies included in the present review and their main results.

Author	Country	Sample	Measurement	Analysis	Main results	Therapy type	HbA1c
Armstrong et al. 2011	USA	Children with diabetes (*N* = 84) and their parents. Age 9-11 years.	- Diabetes Family Behaviour Checklist. - Self-Efficacy for Diabetes Questionnaire. - Child Depression Inventory. - Child Version of the Self-care Inventory.	Correlation.	Children who reported critical parenting behaviours tended to have lower self-efficacy and more depressive symptoms.	Pump-daily injection	8.1%
Barzel et al. 2011	Canada	Children with diabetes (*N* = 61) and their parents. Age 8-12 years.	- 14 item Co-parenting Questionnaire. - 14 items on the Diabetes-Specific Co-parenting Questionnaire. - Child Behaviour Checklist. - Self-Care Inventory. - Pediatric Quality of Life Inventory Diabetes Module. - Glycaemia and blood measurement HbA1c.	Correlation.	Co-parenting conflicts were observed whenever children internalised or externalised their problems.	-	8.1%
Cohen et al. 2004	USA	Children with diabetes (*N* = 116) and their parents. Age 6-17 years.	- Child Behaviour Checklist. - Family Adaptability and Cohesion Evaluation Scales. - Adherence Measures from Medical Chart. - Glycaemia and blood measurement HbA1c.	Correlations, Ancova and Multivariate Analysis.	High levels of family cohesion predicted good adherence and better control of glycaemia.	-	4.8-17.9%
Feeley et al. 2019	USA	Children with diabetes (*N* = 18) and their parents. Age 6-12 years.	- Pediatric Fatigue Short form. - PROMIS Pediatric Anxiety Short form. - Pittsburgh Sleep Quality Index. - PROMIS Sleep Disturbance Short form. - Perceived Stress Scale. - Center for Epidemiological Studies Depression Scale. - Sleep Diary. - Actigraph Sleep Measure.	Correlations.	Parents showed poor sleep quality in Pittsburgh Sleep Quality. There was a significant correlation between children sleep and parent as measured by actigraphy.	-	7.52 ± 0.75

Author	Country	Sample	Measurement	Analysis	Main results	Therapy type	HbA1c
Gruhn et al. 2016	USA	Children with diabetes (N = 93) and their mothers. Age 10-16 years.	- Iowa Family Interaction Rating Scales. - Child Depression Inventory. - Centre for Epidemiologic Studies of Depression Scale. - Responses to Stress Questionnaire. - State Trait Anxiety Inventory. - Glycaemia and blood measurement HbA1c.	*t*-test, Correlations, and Regression Analyses.	Lower HbA1c counts were related to higher levels of collaborative parenting. Significantly greater child depressive symptoms after one year were linked to higher levels of observed overinvolved parenting.	Pump-daily injection	5.4-12.9%
Jabbour et al. 2016	Canada	Children with diabetes (N = 201) and their parents. Age two groups; younger than 12 years, 12 years of age or older.	- Barriers to Physical Activity in Type 1 Diabetes scale.	Correlations and 2-way Analysis of Variance.	Fear of hypoglycaemia, external temperature, work schedule, and loss of control of diabetes had the highest barrier scores among children younger than 12 years. The lower barrier scores were associated with greater parental support for both younger and older children.	-	-
Jaser et al. 2008	USA	Children with diabetes (N = 108) and their mother. Age 8-12 years.	- Children's Depression Inventory. - Issues in Coping with IDDM—Child scale. - Diabetes Quality of Life Scale for Youth. - Diabetes Family Behaviour Scale. - Center for Epidemiologic Depression Scale. - Diabetes. - Responsibility and Conflict Scale. - Family Adaptability and Cohesion Scale. - Glycaemia and blood measurement HbA1c.	Linear Regression Analyses and Correlations.	There was a correlation between the maternal and the depressive symptoms of the children.	Pump-daily injection	7.0%

Author	Country	Sample	Measurement	Analysis	Main results	Therapy type	HbA1c
Jaser et al. 2010	USA	Children with diabetes (*N* = 30) and their mother. Age 10-16 years.	- Responsibility and Conflict Scale. - Iowa Family Interaction Rating Scales. - Center for Epidemiologic Studies of Depression Scale. - State Trait Anxiety Inventory. - Child Depression Inventory. - Paediatric Quality of Life Inventory. - Glycaemia and blood measurement HbA1c.	Correlation.	Mothers' symptoms of depression and anxiety were linked to a low level of child-centered parenting.	Pump-daily injection	5.5-13.4%
Jaser et al. 2014	USA	Children with diabetes (*N* = 118) and their parents. Age 10-16 years.	- Responsibility and Conflict Scale. - Centre for Epidemiologic Studies Depression Scale. - State Trait Anxiety Inventory. - Paediatric Quality of Life Inventory. - Child Depression Inventory. - Haemoglobin HbA1c.	Anova and Linear Regression Analyses.	Secondary control coping interposed in the relationship between depression, maternal symptoms of anxiety, and diabetes related stress. There was no significant association between children's outcomes and maternal coping.	Pump-daily injection	5.4-12.9%
Jaser et al. 2017	USA	Children with diabetes (*N* = 515) and their parents. Age 2–12 years.	- Child Sleep Habits Questionnaire. - Pittsburgh Sleep Quality Index. - Self-reported HbA1c values.	Separate Multivariable Linear Regression and Separate Multivariable Logistic Regression.	Poor glycaemic control was related to the child sleep quality. Poorer sleep quality in children were associated with parental well-being; fear of hypoglycaemia; and poorer parental sleep quality.	Pump-daily injection	7.8 ± 0.9%

Author	Country	Sample	Measurement	Analysis	Main results	Therapy type	HbA1c
Michaud et al. 2017	Canada	Children with diabetes (*N* = 188) and their parents. Age 6-17 years.	- Barriers to Physical Activity in Type 1 Diabetes scale. - Health Measures Survey. - World Health Organization norms on metabolic equivalent Task. - Parents own PA habits. - Glycaemia and blood measurement HbA1c.	Chi-square, Mann–Whitney-Wilcoxon tests, and Linear Regression.	The relations between the components were not significant. The hypoglycaemia phobia was the only barrier to physical activity.	Pump-daily injection	-
Moreira et al. 2014	Portugal	Children with diabetes (*N* = 88) and their parents. Children without diabetes (*N*= 121) and their parents. Age 8-18 years.	- Paediatric Health-Related. Quality of Life Measurement. - Self-Report Version of the DISABKIDS Chronic. Generic Module. - Family Environment Scale. - Hospital Anxiety and. Depression Scale. - Portuguese version of the Parenting Stress Index—Short Form. - Glycaemia and blood measurement HbA1c.	Anova and Two-Way Manova.	Higher levels of cohesion were linked to higher HRQOL ratings in children with diabetes and lower scores for parental stress. Parents of children with diabetes felt more stress, anxiety, and perceived less cohesion compared to parents of healthy children.	-	7.9%
Mullins et al. 2004	USA	Children with diabetes (*N* = 43) and their parents. Age 8-12 years.	- Single 7- Point Likert Scale. - Parent Protection Scale. - Child Vulnerability Scale. - Parenting Stress Scale. - Child Depression Inventory.	Correlations and Multiple Regression.	High levels of depressive symptoms were related to the two factors, child vulnerability and parenting stress.	-	5-14%
Patton et al. 2011	USA	Children with diabetes (*N* = 39) and their parents. Age 0-7 years.	- Behavioural Paediatric Feeding Assessment Scale. - Paediatric Inventory for Parents. - Hypoglycaemia Fear Survey-Parents of Young Children. - Beck Depression Inventory-Second Edition.	Correlations, and linear Regression Analyses.	Higher parenting stress was associated with a higher stress frequency, higher depressive symptoms, fear of hypoglycaemia, and greater mealtime issues.	Pump-daily injection	8.6 ± 1.3%

Author	Country	Sample	Measurement	Analysis	Main results	Therapy type	HbA1c
Sweenie et al. 2014	USA	Children with diabetes (*N* = 86) and their parents. Age 9-11 years.	- The Eyberg Child Behaviour Inventory. - Diabetes Family Behaviour Checklist. - Paediatric Inventory for Parents. - Glycaemia and blood measurement HbA1c	Hierarchical Linear Regressions.	Parents, who reported their child's psychological behaviour as more problematic, also stated more difficulty with paediatric parenting stress.	Pump-daily injection	8.1%
Troncone et al. 2017	Italy	Children with diabetes (*N* = 25) and their parents. Age 1-18 years.	- Patient's Health-related Quality of Life 3.0 DM. - Parent's Perceived Burden.	Anova.	- The patients were found to have lower global diabetes-specific problems and better experience. - Parents described the treatment to be linked to treatment satisfaction.	Daily injection	5.7-9.7%
Viaene et al. 2017	Belgium	Children with diabetes (*N* = 63) and their parents. Age 2-18 years.	- The Nijmegen Parenting Stress Index-Short form. - Parent's Fear of Hypoglycaemia Scale. - Children's Fear of Hypoglycaemia Scale. - Glycaemia and blood measurement HbA1c.	Correlation, and Mancova.	Results showed an indirect association between HbA1c values and parental FoH through parenting stress.	Pump-daily injection	8.2%
Van Gampelaer et al. 2020	Belgium	Children with diabetes (*N* = 105) and their parents. Age 2-12years Children without diabetes (*N* = 414) and their parents.	- Child Quality of Life Quality of Life Inventory-4.0. - Strengths and Difficulties Questionnaire. - Perceived Stress scale. - The Patient-Reported Outcomes Measurement Information System (PROMIS) for anxiety and depression. - Parental Overprotection Measure. - The Autonomy Support Scale.	Ancova.	Children with Type 1 diabetes (8-12 years) had higher quality of life compared with children without diabetes. Mothers of children with Type 1 diabetes showed more anxiety and depressive stress than their counterparts with children without diabetes.	Pump-daily injection	<7.5% (78) >7.5% (27)

Author	Country	Sample	Measurement	Analysis	Main results	Therapy type	HbA1c
Whittemore et al. 2003	USA	Children with diabetes (*N* = 56) and their parents. Age 8-12 years.	- Diabetes Quality of Life Youth. - Child Depression Inventory. - Issue in Coping with IDDM- Child Version Scale. - The Diabetes Family Behaviour Scale. - Centre for Epidemiologic Studies of Depression Scale. - Haemoglobin A1c.	Correlations, and Regression Analyses.	Families who found coping with diabetes less upsetting had children who reported a better quality of life. Children with diabetes Type 1 who experienced a better quality of life reported a fewer depression symptom.	Pump-daily injection	7.4%
Wilson et al. 2009	USA	Children with diabetes (*N* = 46) and their parents. Age 5-12 years.	- The Eyberg Child Behaviour Inventory. - Parenting Scale.	Correlations and Multiple Regression.	Over-reactive parental discipline was associated with common child mealtime misbehaviour, and it was also linked to reports of less time spent managing child's illness.	-	-

Discussion

In this systematic review, 20 research studies reported that children living with Type 1 diabetes suffered from psychological issues such as anxiety, depression, sleep disturbance, and lifestyle adjustment. At present, there is not much empirical evidence to draw inferences on the cause of these psychological issues. However, several studies pointed to the interactions and associations between child and parental variables. This would be expected because childhood chronic illness affects parents' mental health and life quality, while familial variables have been shown to affect child outcomes (Vonneilich, Lüdecke, & Kofahl. 2016).

With regards to the methodology, the authors of these 20 studies typically did not choose an adequate sample size prior to the examination, thus resulting in low statistical power. Further, 11 studies did not specify the age range of the target population. The examiners combined young children with older youth that can be considered adults in one category (e.g., 6–18 years old). These choices, probably driven by pragmatic concerns, cannot be justified in terms of child development: while older children may have developed their coping skills with the illness, the younger children were possibly at the beginning of developing their coping skills with the diagnosis and illness (Compas, Jaser, Dunn, & Rodriguez, 2012). The opposite could also be true, as older children may show a greater appreciation of the long-term problems likely to be caused by their illness, and show an increase in anxiety and depression symptoms. In addition, 18 studies did not have a comparison group, which is an important factor when focusing on the change variable necessary for making meaningful comparisons between the target cohort and the general population. In four studies, the authors did not provide sufficient medical data regarding the type of therapy used by the patients; whether the children used the pump or daily injection, which plays a significant role in understanding their quality of life (Birkebaek, Kristensen, Mose, & Thastum, 2012).

The weakness and limitations identified in the present review should be considered in future research. More detailed medical and technical data are required when investigating the children’s and their parents' behavioural problems. Getting a better understanding of the correlates of different behavioural outcomes for children diagnosed with Type 1 diabetes is crucial in helping them and their parents minimise the behavioural impacts of the illness. Future research should incorporate lifestyle variables with mental health outcomes because we know that having a healthy lifestyle in early age can reduce the burden of mental health in the future (Loewen et al., 2019). The researchers should consider that young children respond to traumatic events in ways that are different from older children and adults, especially in primary school age (Early Childhood Mental Health, n.d.). Establishing determinants of poor outcomes in younger, primary-aged children is essential for our understanding of the aetiology of psychological issues, and for introducing timely and targeted intervention to address the areas of need (e.g., parenting programmes, healthy lifestyle interventions).

Finally, we consider that stressors brought about by the enforced proximity, social isolation, medical care restrictions, and anxiety of the COVID pandemic, may have heightened or altered some of the relationships identified in pre-pandemic research. Familial studies in this age group will be needed to update our understanding.

Conclusion

The present review has investigated the psychological and lifestyle variables that may impact the health and well-being of primary-age children and their families. Despite the procedural limitations such as the lack of control groups for most of the studies, combining young children with older youth that can be considered adults in one category, and insufficient medical data, we can conclude that children with Type 1 diabetes and their parents are at risk of experiencing a multitude of psychological problems. Lifestyle changes contributing to this may include poorer sleep quality and reduced physical activity.

Chapter 4

Psychological Variables and Lifestyle Correlates in Children with Diabetes and Their Families: Systematic Review(s) of the Other Relevant Literature

The systematic review described in Chapter 3 identified 20 out of 58 studies, which met the criteria through looking at both parents of children with Type 1 diabetes and children with Type 1 diabetes between the ages of 8-11 years. This chapter presents the second part of the systematic review which used the same methods and procedures described in Chapter 3; however, because of the large number and diverse nature of the papers, the remaining 38 studies were categorised into four sections.

1. Investigating Psychological and Behavioural Variables in Children with Diabetes.
2. Comparing Children with Diabetes to Control Group.
3. Comparing Children with Diabetes to Children Diagnosed with Other Chronic Illnesses.
4. Investigating the Experience of Parents of Children with Diabetes.

The findings of the literature review have been presented at an international conference: Poster presented at the 14th International Conference on Child and Adolescent Psychopathology, UK, University of Roehampton London (see Appendix 10).

Section 1: A Review of Findings from Studies Investigating Psychological and Behavioural Variables in Children with Diabetes

In many cases, the investigators collected data on the psychological functioning of children with diabetes without comparing against a control group. If their parents were included, it was only to report on the target children's behaviour and not on their own. The present literature review identified nine such papers. In most cases, participants' age ranges were broad, and most of the children tested were adolescents; therefore, these findings should be interpreted with caution, as some of the results may not be applicable to younger, primary school aged children. A review of the QATQS results is presented next. Key attributes of each paper are summarised in Table 4.2.

Results of QATQS of Included Studies

The overall quality scores for nine studies shown in Table 4.1. indicate that five studies were rated as weak, three studies were rated as moderate, and one study was rated as strong. In regards to selection bias, four studies were rated as the percentage of people who completed the study was from 80%-100%, four studies were rated moderate, and one study were rated as weak. According to QASQT criteria on study design, seven studies were rated as weak because they used a cross-sectional design. Moreover, two studies were rated as moderate because they used a cohort design. Three studies were rated as weak in the confounders, three studies were rated as moderate, and three studies were rated as strong. Regarding to blinding, six studies were rated as weak, three studies were rated as strong because the participants did not know the research question. Eight studies were rated as strong due to clarity, validity, and reliability of their data collection tools, and one study rated as weak. Three studies were rated as weak in the withdrawals and drop-out domain, four studies were rated as moderate, and two studies were rated as strong.

Table 4.1.
Quality assessment according to EPHPP assessment tool for quantitative studies.

Authors in alphabetical order	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawals and dropouts	Overall quality score
Al-Khurinej, 2007	S	W	W	W	S	W	W
Cherubini et al. 2014	M	W	W	W	S	W	W
de Wit, & Snoek, 2011.	S	W	S	S	S	M	M
McCarthy et al. 2003	M	W	S	W	S	M	M
McDonnell et al. 2007	S	M	W	W	W	M	W
McGill et al. 2017	M	M	M	S	S	S	S
Reid et al. 1995	W	W	M	W	S	W	W
Storch et al. 2006	S	W	S	W	S	M	W
Şişmanlar et al. 2012	M	W	M	S	S	S	M

Note: Studies were rated as strong (S), moderate (M), or weak (W) on each specified dimension.

Study Characteristics

Tablet 4.2., is a summary of the characteristics and findings of the studies included in this review. These studies were performed in several countries, including the United States of America (USA), Italy, Turkey, Australia, Kuwait, and Netherlands. Six studies reported the range of haemoglobin measurements (HbA1C) and two studies did not report it. Three studies specified the therapy type of the participants. All the studies used self-report questionnaires for children.

Study Findings

Al-Khurinej. (2007) defined the prevalence of emotional and behavioural problems among children with diabetes to shed light on the relationship between emotional behavioural problems and demographic variables, as well as to establish the best predictors of problems in children grappling with the disease. The participants were 302 diabetic children who were aged 7 to 10 years and who came from Kuwait. The author found the following results: The children were more likely to have a higher independent risk factor for hyperactivity problems. The trauma of admission to hospital was a significant independent factor for emotional hyperactivity and overall difficulties. The only significant independent risk factor for emotional problems was haemoglobin levels. The study further showed that the children experienced emotional problems, such as nervousness, anxiety and fear, and that they engaged in problematic behaviours, including cheating, lying and a bad temper. Nevertheless, without a control group, it is not possible to say how prevalence differed in comparison to other children. The study had a good sample with narrow age boundaries, but the majority of the subjects were Kuwaitis; children from other cultures may not show the same results. Another limitation is the reliance on data obtained from parents, which could have affected the reliability of the findings.

Cherubini et al. (2014) study centered on whether Health-Related Quality of Life (HRQOL) in children with diabetes is affected by the nature of insulin treatments (Multiple Daily Injection [MDI] versus CSII). The participants, aged 10 to 17 years, were divided into insulin infusion (CSII, n = 306) and MDI (n = 271) groups. No significant differences between the groups were found with respect to variables such as social burden, psychological well-being, and diabetes concerns. However, multiple quantile regression analyses suggested that the individuals treated via CSII showed significant benefits in terms of HRQOL, with these subjects exhibiting higher improvements in treatment satisfaction, greater flexibility and better diabetes management compared with the individuals on MDI treatment. These findings indicate that providing enhanced healthcare that involves CSII treatment helps children with diabetes manage and control their illness.

De Wit and Snoek. (2011) examined the rates at which unmet psychological needs are unmet and depression in children with diabetes is unaddressed. The study recruited 233 children with diabetes (aged 9–19 years) from the Netherlands. An open-access web survey was used to collect data on self-reported HbA1c reading and demographics, and the Child Depression Inventory (CDI) was administered to the participants (Kovacs, 1985). A high prevalence of elevated depressive symptoms was found in the sample, indicating that the early treatment of depression is important, and that the early detection of emotional problems should be a priority in periodic outpatient consultations. According to the author, 25% of the depressed youth expressed a desire to consult a psychologist or psychiatrist but apparently were not provided with a referral. Additionally, half of the young individuals avoided discussing their emotions with their paediatricians or nurses. This finding suggests that many teenagers with diabetes are reluctant to speak about emotional issues during consultations, which renders the appropriate identification and management of psychological issues more difficult. However, the answers provided by the children in the web survey could not be verified because the data were collected remotely, and internet availability issues may have limited participation for some families.

McDonnell et al. (2007) enquired into the associations between intercurrent glycaemia and child behaviour. The researchers recruited 42 children with diabetes aged 5 to 10 years (15 boys and 27 girls). Each participant was asked to wear a glucose monitor for 72 hours in two study intervals; the first test was conducted to determine baseline levels, and the second was carried out six months later. Externalising behaviours were highly linked to intercurrent glycaemic status. For example, aggression, overactivity and conduct problems were related to poor blood sugar maintenance, showing the importance of this relationship and suggesting that externalising behavioural problems foster conditions that are conducive to hyperglycaemia occurrence. This study was limited in terms of the relatively small sample size and the ratio of girls to boys in the sample.

McGill et al. (2017) delved into depressive symptoms prospectively in diabetic children from the United States. They recruited 96 children with diabetes aged 10 to 17 years and divided them into a new onset group ($n = 54$) and a pump therapy group ($n = 42$). They measured the children's HbA1c levels via a blood test at the baseline and one month, six months, and 12 months after pumping initiation or diabetes onset. After one year, the groups derived similar Children's Depression Inventory (CDI) scores, but the children with higher CDI scores in the first 30 days after pumping initiation or diagnosis were more likely to have a CDI score of 13 or higher (the clinical range for depression) at six months or one year. These findings may be related to the effect of and potential overlap with adjustment reactions among individuals with newly emerging diabetes and disease-related distress in youth with the established form of the disease. These rates, however, are higher than the rates of elevated depressive symptoms in the general population, which may reflect greater depressive symptoms in young people with Type 1 diabetes or a different construct, such as diabetes distress. Youth with Type 1 diabetes frequently experience diabetes distress, which can be linked to emotions related to managing the condition, as well as to emotions such as helplessness and negative social perceptions (Fisher et al., 2015; Hagger, 2016). The results indicated that the children with depressive symptoms and new-onset diabetes in the first 30 days had higher levels of HbA1c after six months. However, the sample size was relatively small, which could have led to spurious findings and prevented the statistical identification of differences. Moreover, the participants were drawn from several ethnic groups, and the potential influence of cultural differences on the scores could have introduced 'noise' to the data.

McCarthy et al. (2003) probed academic achievement in children with diabetes, enrolling 244 children with diabetes (aged 8–18 years). The participants were divided into the early onset (contracted diabetes before the age of 5) and late onset (developed diabetes after the age of 5) groups. The parents of the children were directed to complete the Paediatric Behaviour Scale (PBS) (Lindgren & Koeppl, 1987) and school-administered achievement tests (Iowa Test of Basic Skills and Iowa Tests of Educational Development (ITBS and ITED). They were also asked to report their children's grade point averages (GPAs). Behavioural factors, poor metabolic control, serious hypoglycaemia, and socioeconomic status were more strongly linked to academic achievement than medical variables, indicating that higher academic achievement is generally associated with good diabetes control. However, the age range included older teenagers who could be considered adults (18 years); thus, whether the same conclusion applies to younger children is unclear.

Reid et al. (1995) analysed the need to consider the development of coping strategies for different situations among children with diabetes (56 children aged 8–18 years) in Ohio. The three diabetes-related situations used as coping strategies by the participants were interaction with peers on diabetes-related matters, diet, and finger pricking; the nonmedical situation covered general peer arguments. The participants were divided into the 8- to 12-year-old and 13- to 18-year-old groups. They were asked to complete the Self-Report Coping (Causey & Dubow, 1992), CDI (Kovacs, 1992) and the Self-Rated Coping Effectiveness designed by Aldwin and Revenson (1987) and Pargament et al. (1990). In addition, their teachers were given the Social Skills Rating System (SSRS) (Gresham & Elliot, 1990). The parents were administered a demographic questionnaire and presented the GPAs of their children. Older children with diabetes had significantly lower GPAs than youngsters. High levels of avoidance coping were related to increased levels of depression and lower GPAs in both groups. Avoidance coping may be detrimental to children's adjustment when used frequently, and avoidance-coping techniques may be adaptive in the early stages of a stressful episode or for short-term stressors (Suls & Fletcher, 1985). The frequent use of avoidance strategies would be ineffective in dealing with longer-lasting issues, such as the daily demands of diabetes-related tasks. This would compromise long-term adjustment, as measured by depression and GPA. The findings demonstrated that the relationship between age and coping styles affects children's well-being and academic success. An issue for consideration, however, is that the sample size may have been insufficient for division into two groups, resulting in small subgroups. This means that the connection between adjustment and coping should be interpreted with caution in terms of developmental differences. Replication with a larger sample is needed.

Storch et al. (2006) examined the association between diabetes-related bullying, depression, metabolic control, and self-management in children with diabetes. The participants were 167 diabetic children aged 8 to 17 years from Florida. A blood test for metabolic control (HbA1c) was taken over the previous two to three months. The results showed that diabetes-related bullying was negatively related to overall self-management and positively associated with HbA1c concentration. Depressive symptoms slightly mediated the link between self-management and diabetes-related bullying. An implication of the findings is that schools need to address the issue of illness-related bullying because it can diminish children's ability to cope with diabetes, especially if they show depressive symptoms. The results may have been affected by gender differences given that the study recruited more girls (107) than boys (60). For example, the incidence of depressive symptoms may be higher in girls, they may adopt different coping mechanisms, and they may react in varying ways to bullying.

Posttraumatic stress symptoms (PTSS) in children with diabetes in Turkey were analysed by Şişmanlar et al. (2012), who recruited a sample of 42 diabetic children aged 8 to 18 years for this purpose. The results showed that 18.5% of the diabetic individuals reported severe or very severe PTSS, whereas 51.9% identified their symptoms as being at a moderate level. The findings also reflected that PTSS is common in paediatric diabetes patients and that even in mild occurrences, a hypoglycaemic attack may be traumatic to a diabetic child. Caution in interpretation is advised, as the sample size used was small, and the results await replication in other cultures.

Conclusion

Overall, these studies suggest that not all children with diabetes experience the same behavioural or psychological challenges. In addition, the majority of studies used a small sample size and/or unequal group sizes, which may not lead to a clear conclusion and require future replication. However, age and glucose level have been shown to be two important factors when examining the behavioural and psychological status of children with diabetes. Other variables that were identified as significant included depression symptoms, coping styles, school performance, peer relationships, and bullying. Studies came from several countries, and different cultural influences which could affect the perception of health, beliefs about causes of disease, how pain and illness are expressed, and experienced.

Table 4.2.
Key information from nine reviewed studies that have explored psychological and behavioural correlates of diabetes in children.

Author	Country	Sample	Measurements	Analysis	Main result	Therapy type	HbA1C
Al-Khurinej, 2007	Kuwait	Children with diabetes (*N* = 302). Age 7-13. Mean age = 9.96.	- The Strengths and Difficulties Questionnaire. - Glucose Level (HbA1c).	Manova.	A significant independent risk factor for hyperactivity problems has been found. The child's admission to hospital was a significant independent factor, The final significant independent risk factor for emotional problems was haemoglobin.	-	-
Cherubini et al. 2014	Italy	Children with diabetes (*N* = 577). Age 10-17. Mean age =14.2.	- The Insulin Delivery System Rating Questionnaire. - Diabetes Quality of Life for Youth Questionnaire. - Glucose Level (HbA1c).	Chi-square test and Quantile Regression.	There were no significant differences between two diabetes groups including social burden, psychological well-being, and diabetes worries.	Daily injection - pump	8.1%

Author	Country	Sample	Measurements	Analysis	Main result	Therapy type	HbA1C
de Wit, & Snoek, 2011	Netherlands	Children with diabetes (*N* =333). Age 9-19. Mean age =15.5.	- Child Depression Inventory. - Self-Reported HbA1c.	*t*-tests, Spearman Correlations, and Kruskall–Wallis tests.	The results suggested high prevalence of elevated depression symptoms in children with diabetes.	-	8.1%
McCarthy et al. 2003	USA	Children with diabetes (*N* = 244). Age 8-18. Mean age = 15.3.	- The Paediatric Behaviour Scale. - School-Administered Achievement test (Iowa Test of Basic Skills and Iowa Tests of Educational Development. - Grade Points Averages. - Glucose Level (HbA1c).	Preliminary Analyses and Separate Analyses.	Poor metabolic control, serious hypoglycaemia, and socioeconomic status are strongly associated with academic achievement. These factors were more significant than medical variables for children with diabetes.	-	8.0%
McDonnell et al. 2007	Australia	Children with diabetes (*N* = 42). Age 5-10. Mean age = 8.3.	- The Behaviour Assessment System for Children. - Glucose Level (HbA1c).	Correlation Coefficient (*r*) and Linear Regression.	Externalising behaviours were significantly associated with intercurrent glycaemic status.	Daily injection	8.6%

Author	Country	Sample	Measurements	Analysis	Main results	Therapy type	HbA1C
McGill et al. 2017	USA	Children with diabetes (*N* = 96). Age 10-17. Mean age =13.1.	- The Children's Depression Inventory.	The Kruskal–Wallis test, Fisher exact test, Chi-square test, Spearman Correlation, and Analysis of Variance.	CDI scores were similar in the two groups after one year. Children with higher CDI scores in the first month were more likely to have a CDI score of 13 or higher at 6 or 12 months.	Daily insulin - pump	8.3%
Şişmanlar et al. 2012	Turkey	Children with diabetes (*N* = 42). Age 8-18. Mean age =13.67.	- Child Posttraumatic Stress Reaction Index. - Glucose Level (HbA1c).	Chi-square tests. Mann–Whitney U tests- Pearson Correlation Analyses- Multiple Regression Analysis.	18.5% of children with diabetes reported PTSS at a severe or very severe level; 51.9% reported a moderate level.	-	8.9%
Storch et al. 2006	USA	Children with diabetes (*N*= 167). Age 8-17. Mean age =12.8.	- Diabetes Related Bullying Scale. - The Diabetes Self-Management Profile used to diabetes self-manage. - The Children's Depression Inventory short form. - Metabolic control over the previous 2 to 3 months.	Cronbach's Alpha and *t*-test.	Diabetes related bullying was negatively related to overall self-management and positively related to HbA1c concentration.	-	-

Author	Country	Sample	Measurements	Analysis	Main results	Therapy type	Hb1AC
Reid et al. 1995	Canada	Children with diabetes (*N* = 56). Age 8-18. Mean age =13.0.	- Self-Report Coping. - Child Depression Inventory. - Social Skills Rating System. - Self-Rated Coping Effectiveness. - Grade Point Average (GPA). - Glucose Level (HbA1c).	*T*-scores, Manova and Anova.	Older children's age was significantly related to lower GPA. Higher levels of avoidance coping were related to higher levels of depression and lower GPAs.	-	-

Section 2: A Review of Findings Comparing Children with Diabetes and Control Group

The systematic review identified six studies in which the behaviour of children with Type 1 diabetes was directly compared to control group. Once again, there was a broad range of ages: Data was gathered from a diverse range of settings, and control groups were chosen according to a specified criterion. A review of the QATQS results is presented next, and a summary of their key characteristics is presented in Table 4.4.

Results of QATQS of Included Studies

The results of overall quality scores were presented in Table 4.3., indicate that all six studies were rated as weak. In regards to selection bias, four studies were rated strong, and two studies were rated moderate. Regarding the study design, six studies were rated weak, because they have used cross-sectional design. Six studies were rated strong in confounders. Moreover, six studies were rated weak in blinding due to the participants knowledge to the research question. Three studies were rated strong related to data collection methods, and three were rated weak. Furthermore, related to withdrawals and drop-outs, four studies were rated strong, while two studies were rated as moderate.

Table 4.3.
Quality assessment according to EPHPP assessment tool for quantitative studies.

Authors in alphabetical order	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawals and dropouts	Overall quality score
Nascimento et al. 2017	M	W	S	W	W	S	W
Pek et al. 2002	S	W	S	W	S	M	W
Ryan & Morrow, 1986.	S	W	S	W	S	M	W
Storch et al. 2004	S	W	S	W	W	S	W
Troncone et al. 2016	M	W	S	W	S	S	W
Zheng & Chen, 2013	S	W	S	W	W	S	W

Note: Studies were rated as strong (S), moderate (M), or weak (W) on each specified dimension.

Study Characteristics

Table 4.4. presents the summery of the finding and the characteristics of the studies included in the present review. These studies were completed in several countries, including Brazil, The United States of America (USA), Portugal, Italy, and China. All the studies included a control group. Most of the studies did not report a therapy type, only one study reported the therapy type used.

Study Findings

Nascimento et al. (2017), who were the first to use blood lactate dosage to evaluate the anaerobic threshold of children with diabetes, explored whether the disease affects the capacity of 10- to 14-year-olds to exercise. The authors enrolled 21 children with diabetes and 16 healthy children. No significant differences in anthropometric variables were found between the two groups, nor were there significant correlations between the subjects' maximum oxygen (VO_2 max) and HbA1c levels. The children with diabetes exhibited the same capacity for aerobic exercise as the healthy subjects. The results suggest that no hypoglycaemia should happen during exercise if the correct amount of insulin is administered, leading to normal physical fitness (Adolfsson et al., 2012). However, the findings should not be generalised to all children with diabetes because the subjects in this work were considered physically active or very active.

Pek et al. (2002) measured self-esteem in a Turkish sample of 44 children with diabetes and 44 healthy children aged between 10 and 14 years. The authors reported higher self-esteem scores among the children with diabetes than among the controls. The high scores appeared to be associated with a relatively long period of disease awareness after diagnosis (more than 2 years), compliance with follow-up visits, appropriate support from family and friends, awareness of disease course, education provided, and participation in social programmes. However, this finding should be viewed with caution because of the small sample size and the high lie scale scores in the study. That is, denial or social desirability may have influenced the performance of the respondents.

Ryan and Morrow (1986) examined the relationship between the age of onset of diabetes, gender and self-esteem in children afflicted with the disease. The authors recruited 125 children with diabetes aged between 10 to 19 years, among whom 46 had early-onset diabetes (diagnosed before 5 years of age). They reported that girls exhibited lower levels of self-concept than boys in the early onset group, but no sex-related differences were found in the late onset group or healthy controls. The authors speculated about possible reasons for the pattern of results, which suggest that boys and girls adopt very different coping mechanisms to deal with the physical and psychological issues brought on by their condition. Another explanation is that adolescent girls with chronic illnesses are more strongly affected by changes in physical appearance than boys (Kellerman et al., 1980). This difference possibly stems from the greater likelihood that the former regard their popularity as determined primarily by how they look, whereas the latter tend to view such popularity as driven principally by what they do.

Storch et al. (2004) examined the psychosocial and frequency correlates of peer victimisation in children with diabetes in a sample comprising 32 diabetic children and 32 healthy counterparts. The children were aged between 8 and 18 years. Compared with the healthy children, those with diabetes exhibited high rates of relational victimisation (threatening, insulting, hitting, pushing) along with low levels of prosocial peer support. This finding may be attributed to differences in the way children with diabetes are perceived by their peers. Given the fear of negative peer interactions, children may miss out on age-appropriate social and academic opportunities. Relational victimisation was also positively linked to loneliness, depression, and social anxiety in the diabetic sample, suggesting that unfavourable peer experiences are internalised and accordingly increase depression and rumination about the opinions of others. For instance, children who experience repeated bullying and insults from their peers may believe that they are unlikeable and that the accusations against them are true. Note, however, that this study had a relatively small sample size and that replication may be needed.

Troncone et al. (2016) evaluated body image perceptions in children with diabetes to identify symptoms of early eating disorders. The researchers used a projective technique as a clinical screening tool, and they recruited 81 children with diabetes and 219 healthy children. The children were between 5 and 10 years of age. Both the controls and their diabetic counterparts showed dissatisfaction with and an underestimation of their body sizes. In both groups, those with a high BMI more frequently underestimated and were more dissatisfied with their body sizes than those with a BMI lower than the group median. This finding implies that weight (BMI) plays a significant role. The greater discrepancies in the high-BMI subgroup can also be seen as a manifestation of difficulty in perceiving body size, which is frequently reported in overweight subjects, both adults and children (Duncan et al., 2011). Moreover, the results indicated that the girls in the diabetes group more accurately perceived their body sizes compared with those in the control group. However, the healthy sample had three times the number of children than the diabetes group, which may have affected the findings.

Zheng and Chen. (2013) investigated psychological behavioural changes in Chinese children with diabetes to provide advice to parents and nurses. The sample comprised 45 children with diabetes and 53 healthy children from China. The children were aged between 6 and 15 years. A blood test was conducted, after which the diabetic group was divided into two subgroups on the basis of their HbA1c levels: a well-controlled subgroup, which had stable HbA1c, and a poorly controlled subgroup, which did not maintain appropriate HbA1c.

Compared with the healthy group, the diabetic children derived significantly higher scores on withdrawal, anxiety, depression, internalising and externalising problems, delinquent and aggressive behaviours, and attention problems. The poorly controlled subgroup obtained significantly higher scores on somatic complaints than the well-controlled subgroup. The patients' intense frustration with these issues may have been driven by the following factors: their differences from other children, such as having to take insulin injections every day; changes in way of life due to long-term diet and insulin injection control; and parents' lack of understanding of diabetes. Despite the insights offered by this study, however, it provided insufficient information about the control group (healthy sample) and where they came from relative to the diabetic sample. The sample size was also excessively small, particularly when the children with diabetes were further broken down into subgroups.

Conclusion

In summary, these studies found that children with diabetes have more behavioural and mental health difficulties, such as depression and eating disorders, than control children; thus, children with diabetes require different approaches. Future studies may be required to replicate the results as some of these studies had a small sample size or unmatched control group, so their findings should be reviewed with caution.

Table 4.4.
Key information from six reviewed studies that have compared behaviour of children with diabetes to that of healthy children.

Author	Country	Sample	Control group	Measurements	Analysis	Main results	Therapy type	Hb1AC
Nascimento et al. 2017	Brazil	Children with diabetes (*n* = 21). Age 10-14. Mean age = 12.6.	Healthy children (*n* = 16). Age 10-14. Mean age = 13.1.	- International Physical Activity Questionnaire. - Glycaemia and blood lactate measurement - Incremental submaximal exercise test.	The Kruskal–Wallis test, Shapiro–Wilk Normality test, Medians and Quartiles Fisher's test.	There are no significant differences in anthropometric variables between the two groups. There were no significant correlations between VO2max and HbA1c levels in either groups.	-	6.9% - 8.1%
Pek et al. 2002	USA	Children with diabetes (*n* = 44). Age 10-14. Mean age =12.7.	Healthy children (*n* = 44). Age 10-14. Mean age = 12.7.	- Cooper smith Self-Esteem Inventory.	Chi Square, *t*-tests, and Cronbach's Alpha coefficient.	Children with diabetes had a higher self-esteem score than the control group.	-	-

Author	Country	Sample	Control group	Measurements	Analysis	Main results	Therapy type	Hb1AC
Ryan & Morrow, 1986	Portugal	Children with diabetes (*n* =125). Age 10-19. Mean age =14.	Healthy children (*n* = 82). Age 10-19. Mean age = 14.	- The Piers-Harris Self-Concept Scale.	Two Way Anova.	Girls reported lower levels of self-concept compared to boys in the early onset group, but no sex differences were found in the late onset group or in the healthy controls.	-	7.5%
Storch et al. 2004	USA	Children with diabetes (*n* = 32). Age 8-18. Mean age = 12.9.	Healthy children (*n* =32). Age 8-18. Mean age = 12.9.	- The Social Experience Questionnaire. - Children's Depression Inventory. - Social Anxiety Scale for Children. - Asher Loneliness Scale.	*t*-test.	Higher rates for relational victimization for children with diabetes. Children with diabetes showed lower levels of prosocial peer support compared to healthy children.	-	-
Troncone et al. 2016	Italy	Children with diabetes (*n* = 81). Age 5-10. Mean age = 8.11.	Healthy children (*n* =219). Age 5-10. Mean age = 8.11.	- Children's Body Image Scale. - Draw a Person: Screening Procedure for Emotional Disturbances.	*t*-test, Anova, and Cronbach's alpha.	Both Controls, and children with diabetes showed dissatisfaction with and underestimation of body size. Girls with diabetes group were more accurate in their perception of body size compared to the control group.	-	8.2%

Author	Country	Sample	Control group	Measurements	Analysis	Main results	Therapy type	Hb1AC
Zheng & Chen, 2013	China	Children with diabetes (*n* = 45). Age 6-15. Mean age =10.40	Healthy children (*n* =53). Age 6-15. Mean age = 11.11.	- Achenbach's Child Behaviour Check List.	Chi-square Bonferonni Correction, multiple *t* tests and Cronbach's alpha.	Children with diabetes had significantly higher scores for withdrawal, anxiety, depression, internalizing problems delinquent behaviour, externalizing problems, aggressive behaviour, and attention problems than healthy group. The poorly controlled subgroup had significantly higher scores in somatic complaints than well-controlled subgroup.	Daily insulin	7.5% - 8%

Section 3: Findings from Studies Comparing Children with Diabetes to Children Diagnosed with Other Chronic Illnesses.

This part of literature review focuses on the psychological effect of chronic illness and its implications for children with diabetes, cancer, and other chronic illness, and their parents. Eight studies included in this section compare behaviours of children with diabetes to a control group of children without diabetes. The sample selection specification, such as control groups, age, and other information, were selected according to a different criterion in each study. A review of the QATQS results is presented next and a summary of their key characteristics is presented in Table 4.6.

Results of QATQS of Included Studies

The overall quality scores, shown in Table 4.5., highlight that three studies were rated as moderate, and five studies were rated as weak. Regarding selection bias, seven studies were rated as strong, and one was rated as weak. Eight studies were rated as weak in study design because they used a cross-sectional design. One study rated strong for Blinding Domain, one study as moderate, and six studies were rated as weak. With respect to their data collection methods, seven studies were rated as strong, and one study was rated as weak. Moreover, three studies were rated as strong in withdrawal and drop-outs domain, four studies were rated as moderate, and one study were rated as weak.

Table 4.5.
Quality assessment according to EPHPP assessment tool for quantitative studies.

Authors in alphabetical order	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawals and dropouts	Overall quality score
Bawden et al. 1998	S	W	S	W	S	M	M
Bourdeau et al. 2007	W	W	S	W	S	W	W
Hullmann et al. 2010	S	W	S	S	S	S	M
Greening et al. 2017	S	W	S	M	S	S	M
Krik et al. 2011	S	W	S	W	S	S	W
Moreira et al. 2013	S	W	S	W	S	M	W
Mullins et al. 2010	S	W	S	W	S	M	W
Varni et al. 2012	S	W	S	W	W	M	W

Note: Studies were rated as strong (S), moderate (M), or weak (W) on each specified dimension.

Study Characteristics

Table 4.6. summarises the characteristics and findings of the studies included in the present review. These studies were conducted in several countries, including, The United States of America (USA), Canada, and Portugal. None of these studies reported the therapy type, and the HbA1C measurements. All the studies included in this systematic review reported a comparison between diabetes group and other chronic illness groups.

Study Findings

Bourdeau et al. (2007) examined three variables and their relationship to parents, as follows: Excessive parental protection, paternity stress for children, and perceived child vulnerability. They recruited 92 boys, 108 girls and their parents. The children were grouped into those with diabetes (n = 124), asthma (n = 48), and Cystic Fibrosis (CF) (n = 28); they were aged between 8 and 18 years. The results showed high levels of parenting stress associated with the lower ranking of their child's self-care behaviours; age was significantly associated with the diabetes group, and older children scored on lower levels of self-care. The findings suggest that when parents are stressed, their children engage in fewer self-care behaviours. Children of parents who report increased parenting stress perceive themselves as less engaged in self-care behaviours, though to a lesser extent. Children who engage in less self-care may create more day-to-day task demands for their parents, resulting in higher levels of parenting stress. It is also possible that stressed parents perceive their children to be less engaged in self-care behaviours.

Bawden et al. (1998) compared parental psychopathology, self-esteem, social skills and family functioning of children with Tourette's disorder and a chronic disease control group of children with diabetes. The participants were 26 children with Tourette's disorder and 26 children with diabetes. The children were aged between 7 and 15 years. The results showed that children with Tourette's disorder had a higher risk of peer relationship problems when compared to children with diabetes and had lower peer relationships than other participants. The focus of the medical management of children with Tourette's disorder is often on the control of their tic symptomatology (Leckman et al., 1989). This suggests that the presence of chronic disease does not appear to explain the peer relationship issues experienced by children with Tourette's disorder. In addition, mothers of children with diabetes had lower-level scores on depression, psych asthenia, hysteria, and hypochondriasis than mothers of children with Tourette's.

Hullmann et al. (2010) investigated variations in parenting capacity variables across chronic illness groups. The study enrolled 425 parents (14 custodial grandparents, 50 fathers, and 361 mothers) of children with cystic fibrosis (CF) (n = 61), asthma (n = 100), cancer (n = 115), and children with diabetes (n = 149). The children were between 7 and 18 years of age. Hullmann et al. used the Parent Protection Scale (PPS) (Thomasgard et al., 1995). Parents of children with CF and asthma had significantly higher perceived child vulnerability than parents of children with either diabetes or cancer. They observed that parents of children with asthma and diabetes expressed higher parenting stress than parents of children with cancer or CF. parenting stress than parents of children with cancer or CF. Such outcomes may be because children with asthma and CF are in fact more likely to experience acute respiratory infections, allergic reactions, and shortness of breath, which may necessitate ER visits or hospitalization. Additionally, CF is frequently linked to a poor long-term prognosis, which includes a higher risk of illness and the possibility of passing away by the time the child reaches adulthood (Rolland, 1987). However, the study used two recruitment methods for the participants: one was while attending a clinic appointment, and the other participants were sent postcards inviting them to participate. The difference between these two methods might require the participants to be ready to answer questions and come earlier, if necessary.

Greening et al. (2017) aimed to predict PTSD in mothers of children with cancer (n = 56) compared with mothers of children with diabetes (n = 35), while controlling for socioeconomic status (SES). Participants were asked to provide a salivary cortisol sample. The results indicated that mothers of children with diabetes had higher cortisol levels than those with cancer. Moreover, the results suggest that mothers of children with diabetes might be vulnerable to stress reactions, as cortisol levels indicate. This suggests that some paediatric diseases, such as Type 1 diabetes, may be more physiologically stressful than others. Type 1 diabetes is a life-threatening chronic illness that necessitates close monitoring of several daily treatment tasks (Silverstein et al., 2005). Failure to complete these tasks results in poor glycaemic control, which increases the risk of diabetic ketoacidosis and hypoglycaemia, which can result in death if left untreated (Silverstein et al., 2005). By contrast, patients with cancer do not always face lethal medical risks due to neglecting daily treatment tasks. Although there is a lethal threat during diagnosis and treatment, there is an end to the active treatment phase, with high remission rates for children with certain cancers. These distinctions between the two disease groups may explain why mothers of children with Type 1 diabetes are more stressed, measured by cortisol levels, than mothers of children with cancer. These results should be treated with caution because this study did not disclose the age of the children, and the mothers of the two samples were not matched.

Kirk et al. (2011) compared parenting characteristics between mothers of children with a Disorder of Sex Development (DSD) and mothers of children with diabetes. The study enrolled mothers of children with DSD (n = 49) and mothers of children with diabetes (n = 49), with a mean age of 10 years and a mean age of 5 years. The caregivers were divided into two groups: caregivers of girls and caregivers of boys. The results showed negative parenting practices and significantly high levels of stress with mothers of children with diabetes and mothers of children with DSD. This suggests that increased perceived child vulnerability is associated with higher levels of child internalising problems. In contrast, increased parenting stress is associated with higher illness uncertainty and lower parental self-care behaviours (Bourdeau et al., 2007; Mullins et al., 2004). Although DSD requires medication management, the daily regimen is less complicated than Type 1 diabetes. Inadequate treatment of life-threatening DSD poses additional health risks for affected children, including compromised final height, pseudo precocious puberty and unwanted virilisation for girls (Nebesio & Eugster, 2010). However, suboptimal treatment is less likely to result in immediate life-threatening sequelae. In addition, male children with non–life-threatening DSD and children with diabetes were observed to be more vulnerable by their caregivers. However, compared to children with Type 1 diabetes, children with DSD had a significantly longer illness duration and were significantly younger.

Moreira et al. (2013) examined and compared the psychological adjustment and levels of Quality of Life (QoL) of children with chronic illness conditions with healthy children and their parents. Participants were children with diabetes (n = 85), asthma (n = 308), epilepsy (n

= 68), cerebral palsy (*n* = 94), obesity (*n* = 110), and healthy controls (*n* = 299) and their parents. Children with obesity and epilepsy were at high risk of maladjustment and reported the lowest levels of QoL. Indeed, children with epilepsy face a variety of distressing issues that are common to chronic conditions in general (e.g., restrictions on pleasurable activities, frightening symptoms, and social stigma), as well as some that are unique to epilepsy (e.g., seizure unpredictability), all of which can harm their QoL and psychological adjustment. Furthermore, it has been suggested that children with neurologic disorders are more likely to develop psychopathology than children with non-brain dysfunctional conditions (Austin & Caplan, 2007; Pinquart & Shen, 2011). Parents of children with obesity indicated the lowest levels of QoL. One possible explanation for this finding is that most of these parents were overweight (38%) or obese (42.4%) and may struggle with self-esteem and stigmatisation issues, which are likely to have an impact on QoL. A so-called "obesogenic" family environment may contribute to the difficulties of parents and children and their obesity. This finding indicates that children with diabetes have a higher level of QoL than children with obesity and epilepsy. However, each group's sample size differed, which may have produced inconclusive results.

Mullins et al. (2010) explored the relationship between single-parent status and parenting capacity variables in mothers of children with chronic illnesses. They recruited 383 participants: mothers of children with sickle cell disease (*n* = 10), cancer (*n* = 94), asthma (*n* = 90), CF (*n* = 49), haemophilia (*n* = 17), and children with diabetes (*n* = 123). The children were between 1 and 18 years old. Participants were divided into two groups: married parents (*n* = 308) and single parents (*n* = 75). The results showed that single mothers had high levels of parenting stress and perceived vulnerability; however, the differences disappeared when there was a comparable income. In addition, low income was linked to higher levels of risk associated with single-parent status. These findings suggest that single parents with lower incomes may be more likely than single parents with higher incomes to experience parenting stress and perceived vulnerability.

Varni et al. (2012) aimed to evaluate self-reported generic health-related quality of life (HRQOL) among paediatric patients with moderate-to-severe plaque psoriasis (systemic inflammatory disease appears as red patches). The authors compared them to a healthy sample and participants with four common chronic diseases. The groups included the healthy sample (*n* = 5,079), arthritis sample (*n* = 62), asthma sample (*n* = 403), diabetes sample (*n* =191), and psychiatric disorders sample (*n* = 296). Participants were aged between 4-17 years; they were divided into two groups, 4 to 7 years old, and 8 to 17 years old. The results showed that participants with plaque psoriasis were significantly more impaired in the generic HRQOL than children with diabetes. However, the HRQOL was comparable with the arthritis and asthma groups. In addition, children with diabetes showed better physical, social and school functioning compared to participants with plaque psoriasis. Finally, these findings showed that moderate-to-severe plaque psoriasis has a significant negative multidimensional impact on the daily lives of these children and adolescents compared to healthy children and paediatric patients with other serious paediatric chronic diseases.

Conclusion

In summary, these studies suggest that children with diabetes and other chronic illness suffer from psychological problems, such as quality of life, parenting stress and post-traumatic stress disorder (PTSD). In addition, parents are vulnerable to considerable levels of stress and depression, which could affect the quality of life of the children and their families. These studies indicate that children with diabetes have different psychological challenges compared to other children with chronic illness. However, most studies used a small sample size, and the samples in the studies were not of comparable size (i.e., healthy controls and chronically ill) which may affect the results or call for replication.

Table 4.6.
Key information from eight reviewed studies that have explored differences between children diagnosed with diabetes vs another chronic illness.

Author	Country	Sample	Measurement	Analysis	Main results	Therapy type	HbA1C
Bourdeau et al. 2007	USA	Participant 92 boys and 108 girls. Children with diabetes (*n* = 124). Asthma (*n* = 48), Cystic fibrosis (*n* = 28), and their parents. Age 8-18. Mean age = 12.3.	- The Child Vulnerability Scale. - The Parent Protection Scale. - The Parenting Stress Index/Short Form.	Manova.	Results showed high levels of parenting stress were linked with less child self-care behaviours: Age was significantly positively related to diabetes group, especially for child and parent ranking of self-care.	-	-
Greening et al. 2017	USA	Mothers of children with diabetes (*n* = 35), and mother of children with Cancer (*n* =56). Parents mean age = 36.48.	- Posttraumatic Stress Disorder Checklist–Civilian Version. - State–Trait Anxiety Inventory. - Beck Depression Inventory–II. Life Events Checklist.	Mancova.	Mothers of children with diabetes had higher cortisol levels than mothers of children with cancer. Mothers of children with diabetes may be vulnerable to stress reactions.	-	-
Hullmann et al. 2010	USA	Participant (*N* = 425) parents 361, mothers 50, fathers, 14 custodial grandparents, children with diabetes (*n* = 149), cancer (*n* = 115), asthma (*n* = 100), and cystic fibrosis (*n* = 61). Children aged 7-18 years. Mean age = 9.7.	- Parent Protection Scale. - The Child Vulnerability Scale. - The Parenting Stress Index/Short Form.	Ancova.	Children with diabetes and asthma lead to higher scores of parenting stress compared to parents of children with cystic fibrosis or cancer.	-	-

Author	Country	Sample	Measurement	Analysis	Main results	Therapy type	HbA1C
Krik et al. 2011	USA	The sample comprised caregivers of children with diabetes (*n* = 49). Mean age = 10 years. caregivers of children with Disorders of Sex Development (DSD) (*n* = 49). Mean age = 4 years.	- The Parent Protection Scale. - The Child Vulnerability Scale. - The Parenting Stress Index/Short Form.	Chi-square Analyses.	The results showed Significant negative parenting practices and levels of stress in both groups-	-	-
Moreira et al. 2013	Portugal	The total sample comprised *N* = 964. Participant were children with diabetes (*n* = 85), asthma (*n* = 308), epilepsy (*n* = 68), cerebral palsy (*n* = 94), obesity (*n* = 110), and heathy (*n* = 299). Age 8-18 years.	- Children's Quality of Life. - Children's Psychological Adjustment of the Strengths and Difficulties Questionnaire. For parents: - Parents' Perceptions of Their Quality of Life.	Anova, and Two-way Mancova.	Children with diabetes had higher level of QoL than children with obesity and epilepsy.	-	-

Author	Country	Sample	Measurement	Analysis	Main results	Therapy type	HbA1C
Mullins et al. 2010	USA	Participant *N* = 383 mothers of children with diabetes (*n* = 123), cancer (*n* = 94), asthma (*n* = 90), cystic fibrosis (*n* = 49), haemophilia (*n* = 17), and sickle cell disease (*n* = 10). Age 1-18. Mean age = 9.7	- The Parent Protection Scale. - Child Vulnerability Scale. - Parenting Stress Index/Short Form.	Regression Analyses, and Post-Hoc.	The results showed that single mothers had high levels of parenting stress and perceived vulnerability, regardless of chronic illness.	-	-
Varni et al. 2012	USA and Canada	The psychiatric disorders (*n* = 296), healthy children (*n* = 5,079), arthritis (*n* = 62), asthma (*n* = 403), diabetes (*n* =191), psychiatric disorders; attention-deficit and disrup-tive behavior disorders, mood disorders, pervasive developmental disorders, and anxiety disorder (n = 296). Age 4-17 years. Mean age = 12.6	- The Paediatric Quality of Life Inventory Version 4.0.	*t*-tests.	Children with diabetes showed better physical, social, and school functioning when compared to participants with plaque psoriasis.	-	-

Section 4: A review of findings from studies investigating the experiences of parents and caregivers of children with diabetes.

This literature review identified 15 studies discussing the experiences of parents and caregivers of children with diabetes. These studies focus on the psychological effects on the parents, such as burden, well-being, anxiety, stress, sleep quality, and other factors. A review of the QATQS results is presented next, and a summary of their key characteristics is presented in Table 4.8.

Results of QATQS of Included Studies

The results of the quality scores, shown in Table 4.7. suggests that nine studies were rated as weak, and six studies were rated as moderate. Seven studies were rated as strong in selection bias; six studies were rated as moderate, and two studies were rated as weak. Regarding to study design, 14 studies were rated as weak, and one study were rated as moderate because it was a randomised control trial study. All of the 15 studies in the confounder domain were rated as strong. Blinding reported five strong studies, seven studies were rated moderate, and three were rated as weak. In reference to data collection methods, 13 studies were rated as strong, while two studies were rated as weak. Moreover, eight studies were rated as moderate in withdrawals and drop-out, and seven studies were rated as weak.

Table 4.7.
Quality assessment according to EPHPP assessment tool for quantitative studies.

Authors in alphabetical order	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawals and dropouts	Overall quality score
Blankfeld et al. 1996	S	W	S	S	S	M	M
Capistrant et al. 2017	M	W	S	S	W	M	W
Hansen et al. 2012	S	W	S	S	S	M	M
Haugstvedt et al. 2011	S	W	S	S	S	M	M
Horsch et al. 2012	S	W	S	S	S	W	W
Kobos, & Imiela, 2015	S	M	S	W	S	M	M
Landolt et al. 2002	S	W	S	W	S	W	W
Landau et al. 2014	W	W	S	W	S	W	W
Monaghan et al. 2012	S	W	S	M	S	W	W
Moreira, & Canavarro, 2016	W	W	S	M	S	W	W
Patton et al. 2011	M	W	S	M	W	M	W
Streisand et al. 2005	M	W	S	M	S	M	M
Streisand et al. 2008	M	W	S	M	S	W	W
Thorsteinsson et al. 2017	M	W	S	M	S	W	W
Zysberg et al. 2012	M	W	S	M	S	M	M

Note: Studies were rated as strong (S), moderate (M), or weak (W) on each specified dimension.

Study Characteristics

Table 4.8. shows the summery of the finding and the characteristics of the studies included in the present review. These studies were performed in several countries including; Poland, The United States of America (USA), Israel, Switzerland, Portugal, The United Kingdom (U.K), Norway, and Australia. Eight studies out of 15 reported HbA1C measurements and eight studies reported a specific therapy type. All the studies used self-report questionnaires.

Study Findings

Blankfeld and Holahan. (1996) used an integrative cross-sectional model to test the roles of maternal and family support coping approaches in predicting reduced depressive symptoms among mothers whose children had diabetes. Family support was significantly and positively linked to the proportion of mothers who had a positive attitude towards coping, which in turn was linked to fewer symptoms of depression. Hence, as foreseen, family support presented an indirect link to lessening depression symptoms in mothers facilitated by positive coping methods. This suggests that several mechanisms may link family support to adaptive coping. Emotional aspects of support, for example, may boost self-esteem and a sense of coping efficacy (Cutrona & Troutman, 1986). Moreover, informational aspects of support may help with coping option exploration and getting helpful feedback on how effective coping is (Sargent, 1985). However, a limitation of this study is that the sample size was too small to confirm that mothers usually have depression after their children have been diagnosed with diabetes.

Capistrant et al. (2017) assessed mental health and overall well-being among caregivers of children with diabetes. The findings suggested that caregivers or parents with a high subjective caregiving burden had worse depression when compared to parents with a low subjective burden. Given the gendered nature of caregiving in India, mothers may provide more direct care at home (such as monitoring insulin dosage and administration). In comparison, fathers may provide more indirect care (such as taking a child to the doctor). A caregiver's subjective assessment of the emotional challenges of providing care may be significantly influenced by their gender.

Hansen et al. (2012) assessed the perceived participation of fathers in caring for their children with diabetes, and its connection to the fathers' and mothers' paediatric childcare, depression, stress, anxiety, sleep, marital contentment, and to the diabetes schedule devotion and glycaemic regulation of their children. The results showed that the perceived involvement and helpfulness of fathers in disease care were linked to enhanced satisfaction and fewer depression signs in mothers. However, most participants had a high level of educational achievement and an above-average income. Mothers may only feel less psychological distress when they have faith in their fathers' ability to effectively care for their children's illnesses (Gavin & Wysocki, 2006; Wysocki & Gavin, 2006). Alternatively, psychological distress may adversely impact mothers' perceptions of their fathers' helpfulness. In contrast, the level and helpfulness of fathers' involvement were related to mothers' marital satisfaction. However, the direction of this relationship cannot be determined due to the cross-sectional nature of the data.

Haugstvedt et al. (2012) explored perceived family burdens and emotional distress in the mothers and fathers of children with diabetes. They also explored the association between distress, parental burden and factors related to the child. They found that emotional distress was significantly correlated with mothers' perceived burden. The most significant burden was related to long-term health concerns, as reported by both mothers and fathers, which were associated with their emotional distress. This indicates the need for a forum where mothers can express their concerns about their children's future health to prevent emotional distress. Perceived parental burden was significantly associated with night-time blood glucose measurements. However, the sample size prevented the researchers from conducting a separate regression analysis for the fathers to compare with the mothers to demonstrate gender variations.

Horsch et al. (2012) evaluated the relationship between non-cognitive and cognitive variables in PTSD. This illness happened after a severe and frightening experience in the mothers of children recently diagnosed with diabetes. The non-cognitive variables included psychiatric history, trauma severity, and social support. On the other hand, the cognitive variables included dysfunctional cognitive appraisals and negative cognitive appraisals. The results showed that negative and dysfunctional cognitive appraisals were positively linked to PTSD. On the other hand, the non-cognitive variables were considerably (negatively) linked to PTSD symptoms. The results supported the significance of negative appraisals and dysfunctional coping behaviours in maintaining PTSD. However, the authors did not assess the fathers of children with diabetes. Such a test is essential to assess whether a child's illness has a comparable impact on both parents. Moreover, the finding that social support was negatively associated with PTSD symptoms is consistent with previous studies that have identified social support as a protective factor against the onset of PTSD (Brewin et al., 2000).

Kobos and Imiela. (2015) investigated the various factors that affect the burden of parents of children diagnosed with diabetes. A burden is defined as a negative influence on everyday tasks related to caregiving. The results showed that general strain and disappointment were associated with a high burden. The findings also revealed that the level of burden was directly linked to the parent's education level, financial status, and the children's ages. However, these are only some of the factors that influence the level of burden. Measuring the impacts of these three factors enabled the development of effective support programmes for parents and children. According to studies conducted by other authors, the role of fathers is often marginal in solving practical problems arising from the everyday treatment of children (Dashiff et al., 2008; Dashiff et al., 2011). However, the research emphasises the importance of fathers' involvement in caregiving to improve family functioning and provide a buffer for the perception of burden (Gavin & Wysocki, 2006; Swallow et al., 2011). Caregivers for young children fear that others will be unable to provide adequate care, making it challenging to divide responsibilities, and may result in greater levels of burden.

Landolt et al. (2002) aimed to define the rates of posttraumatic stress disorder (PTSD) and its symptoms in parents with children diagnosed with diabetes for the first time. The results showed that 22% of the fathers and 24% of mothers met the diagnosis criteria for PTSD. Additionally, about 41% of fathers and 51% of mothers met the criteria for subclinical or partial PTSD. The authors found that there was a low co-occurrence of PTSD in couples. The gender and age of the child did not correlate with posttraumatic stress symptomatology, family structure, length of hospital stay or socioeconomic status. Regarding the aetiology of PTSD, this research does not provide a definitive conclusion. Two potential etiologic factors must be considered: the traumatic aspects of medical treatment (chronic stressors) and the diagnosis of shock (acute stressors). This is the first study to examine PTSD symptoms in the parents of children with diabetes, and according to the authors, it must be replicated to confirm the results.

Landau et al. (2014) examined the sleep quality of parents of children diagnosed with diabetes before and during a glucose monitoring system. Parents were asked to wear an actigraph (a wristwatch-size motion detector) for at least one week before using the continuous glucose monitoring system (CGMS) and again 4-8 weeks after using CGMS. The results indicated that six participants had extreme sleep problems when using and not using the CGMS. The study also found that awakening episodes were more frequent when using CGMS than when not using CGMS. The actigraph results showed that participants experienced more wakening bouts when using CGMS than before. The introduction of CGMS alone may make parents more anxious, causing them to get out of bed more frequently to check the device's accuracy. Additionally, parents may take more time than the recommended 4–8 weeks to get used to the new device.

Monaghan et al. (2012) investigated the parenting stress and the parenting style of parents with children with diabetes and how the involvement of parents in diabetes care can improve adherence to treatment. The findings revealed no differences in metabolic control, but more authoritative parenting was linked to greater behavioural adherence and less difficulty in managing paediatric parenting stress. Increased age-appropriate child behaviour adherence and decreased paediatric parenting stress may result from more authoritative parenting practices, highlighting the significance of parental involvement in the developmentally appropriate management of chronic illness. However, metabolic control was associated with demographic factors, such that the parents of non-Caucasian and lower-income children had children with relatively poorer metabolic control.

Moreira and Canavarro. (2016) investigated whether anxiety and avoidance related to attachment are connected to childcare stress in caregivers of adolescents and children with diabetes. They also studied whether this connection was facilitated by parents' insight into the effects of diabetes on the family or weakened by the age of the children with diabetes. High levels of attachment avoidance (a degree to which a person tries to maintain independence and emotional distance from others) related to similarly high levels of parenting stress were found and related to an increasingly negative perception of the effect of diabetes. This suggests that parents with higher levels of avoidance may find raising a child with diabetes extremely stressful due to their greater difficulty managing stressful situations (Mikulincer & Florian, 2001). Parents with a child who needs ongoing care and observation due to a chronic condition may typically believe that they are less qualified to care for others effectively and that others are less deserving of their assistance (Moreira & Canavarro, 2015; Reizer & Mikulincer, 2007). Moreover, the stress parents experience is explained not only by their avoidance levels but also by their negative assessments of the effects of diabetes on their lives.

Patton et al. (2011) studied the connection between paediatric parenting stress and depressive symptoms among parents of children with diabetes. The results indicated that higher parenting stress was associated with a higher stress frequency, higher depressive symptoms, fear of hypoglycaemia and more mealtime issues. Factors other than mealtime behaviour may have a greater impact on parents' paediatric parenting stress frequency levels in a sample of young children mainly receiving pump therapy. Moreover, no correlation was found between mealtime problems and parental stress levels in children. The existing literature suggests that many parents of young children with T1DM may view mealtimes as problematic. Furthermore, the study enrolled a small and relatively homogenous sample of parents of young children with diabetes; the majority were white, married and from the middle to upper-middle socioeconomic class. These demographic variables could have affected the parents' understanding of depressive symptoms or their stress reporting. The results may not be generalisable to all parents, particularly single parents or parents from a lower socioeconomic class.

Streisand et al. (2005) conducted a study on paediatric parenting stress in parents of children newly diagnosed with type 1 diabetes, which is linked to parental anxiety and depression. They sought to examine the behavioural and psychological correlates of their stress. The results indicated that paediatric parenting stress was multifaceted. In this case, the frequency of parenting stress was negatively linked to the age of the child as well as the socioeconomic status of the family. Also, the frequency of increased parenting stress was positively linked to single-parent status and the complexity of the regimen status (injections vs insulin pump). Regarding multivariate analyses, the authors established that a significant part of the differences related to stress frequency and difficulties were linked to parental behavioural and psychological functioning. This included aspects such as the fear of hypoglycaemia and the responsibility involved in diabetes management, suggesting that some anxious parents may become more involved in their child's diabetes management to control their feelings about diabetes (problem-focused coping). In contrast, others may feel overburdened by the work required to manage their child's diabetes daily.

Streisand et al. (2008) investigated the anxiety and stress associated with caring for children with diabetes. They also examined the clinical and demographic characteristics associated with parental stress and self-efficacy caused by caregiving to children recently diagnosed with diabetes. The study's results revealed that parents experienced signs of depression and anxiety upon their children's diagnosis, and depression seemed to be related to lower self-efficacy. When comparing mothers and fathers, the study revealed that mothers experienced more anxiety, depression and parenting stress. Moreover, in the days and weeks following their child's diagnosis, parents were likely to report that worrying about the effects of their child's illness and feeling helpless were particularly difficult for them. Parents in the newly diagnosed phase appear to suffer from depression, anxiety and acute worry about their ability to help their children. Their communication abilities, emotional functioning, the responsibility for carrying out the child's medical care regimen, and their shifting role function within the family, at least in part, appear to be the driving forces behind these experiences.

Thorsteinsson et al. (2017) examined maternal functioning and well-being among mothers of children with diabetes. The results indicated that the mothers of the children who had diabetes possessed moderately lower mean quality of life scores compared to the mothers of children who did not have diabetes. The current findings suggest that mothers of diabetic children are more likely to perceive their health as poor and believe it is likely to get worse, to experience fatigue more frequently, to have fewer opportunities for social interaction, to experience problems with daily activities because of emotional health and to feel more anxious and depressed than mothers without a diabetic child. Moreover, mothers report better functioning when they have a more optimistic view of their self-efficacy, consistent with other research that has consistently shown a link between self-efficacy and better physical and mental health. Furthermore, and according to the findings of this study, mothers who do not feel sufficiently equipped to manage their child's diabetes may let this feeling of inadequacy affect other aspects of their lives. Low self-efficacy may also make it less likely that appropriate cognitive coping mechanisms will be used to lessen adverse effects successfully. To boost their confidence and increase self-efficacy, mothers of children with diabetes who report a poor quality of life may benefit from additional diabetes education, counselling or problem-solving training.

Zysberg et al. (2012) examined the possible role of a comparatively new perception in accounting for family factors connected with the outcome of children's health in diabetes. The caregivers filled out two measures of emotional intelligence (EI) and a demographic questionnaire. When contextual variables, such as gender, ethnicity, and education, were considered, there was no connection in the pattern of results. However, the authors found that income level was connected to mean glucose values. Moreover, the differences in results between the two different EI measures could be attributed to methodological rather than conceptual factors. Given that both measures followed the ability EI approach, it is logical that self-reporting would be a less reliable indicator than a performance-based test. Nevertheless, about 40 parents were excluded from the study, as most did not understand the questionnaire questions.

Conclusion

Overall, these studies were credible and reliable as they had sufficient sample sizes, appropriate assessment, and data analyses tools. The findings of the studies reviewed reveal that taking care of children with diabetes is often stressful and poses a heavy burden for parents and caregivers. Significant variables that were considered when measuring the experience of parents of children diagnosed with Type 1 diabetes included age, financial status and its effect on the parents, depressive symptoms, post-traumatic stress disorder, and the role of parenting style. The studies reviewed were conducted in different geographical locations, meaning that these findings can be applied globally.

Table 4.8.
Key information from fifteen reviewed studies investigating the experiences of parents and caregivers of children with diabetes.

Author	Country	Sample	Measurements	Analysis	Main results	Therapy type	HbA1C
Blankfeld et al. 1996	USA	Participant (N = 52) caregivers of children with diabetes.	- Family Environment Scale. - Coping Responses Inventory. - Health and Daily Living Form.	Lisrel Analyses, and Correlations	Family support was substantially linked to a positive attitude to coping which was substantially inversely connected to symptoms of depression.	-	-
Capistrant et al. 2017	USA	Participant (N= 178) caregivers of children with diabetes. Mother's mean age = 40.66.	- The 12-item Zarit Caregiving Burden scale. - The PHQ-9 scale, a 9 item scale of depression and anxiety. - The Centers for Disease Control ''Healthy Days" measure.	Chi-square tests, One-way Analyses of variance, and Two different types of Regression models.	Caregivers with subjective caregiving burden had worse depression compared to parents with low subjective burden.	-	-

Author	Country	Sample	Measurements	Analysis	Main results	Therapy type	HbA1C
Hansen et al. 2012	USA	Participant (*N* = 125) caregivers of children with diabetes. Mother's mean age 41. Father's mean age = 44.	- Dads Active Disease Support Scale. - Paediatric Inventory for Parents. - Pittsburgh Sleep Quality Index. - Hospital Anxiety and Depression Scale. - Dyadic Adjustment Scale. - Self Care Inventory.	A Post Hoc Power Analyses, Multivariate Regression, and *t*-tests,	Perceived involvement and helpfulness of fathers in disease care were linked to enhanced satisfaction and fewer depression signs in mothers.	Daily injecting - Pump	7.5%
Haugstvedt et al. 2011	Norway	Participant (*N* = 200) caregivers of children with diabetes. Mother's mean age = 39.00 Father's mean age = 42.	- Family Burden Scale. - Hopkins Symptom Checklist-25 Items. - Blood Glucose Measurement.	Wilcoxon Matched-Pairs, and Regression Analyses.	- The biggest burden was related to long-term health concern. - Nighttime blood glucose measurements were considerably linked to perceived parental burden.	Daily injecting - Pump	8.1%

Author	Country	Sample	Measurements	Analysis	Main results	Therapy type	HbA1C
Horsch et al. 2012	U.K	Participant (*N* = 150) caregivers of children with diabetes. Parent's mean age = 40.	- Posttraumatic Stress Diagnostic Scale. - Posttraumatic Cognitions Inventory. - Responses to Intrusions Questionnaire. - Social Provisions Scale.	Non-Parametric multiple linear Regression Analyses, and Kolmogorov-Smirnov test.	- Cognitive variables were linked to PTSD symptoms. - Non cognitive variables were linked to PTSD symptoms	-	-
Kobos, & Imiela, 2015	Poland	Participant (*N* =112) caregivers of children with diabetes. Mother's mean age = 39.6.	- Burden Scale. - Interview.	Shapiro-Wilk test, Spearman's Correlation, and Mann–Whitney U test.	- High Level of burden was associated with disappointment. - Level of burden was directly linked to the parents' education level and financial status and child's age.	Daily injecting - Pump	7.5%
Landolt et al. 2002	Switzerland	Participant (*N* = 73) caregivers of children with diabetes.	- Posttraumatic Diagnostic Scale.	*t*-test and Chi-square tests.	22% of the fathers and 24% of mothers met the criterial of diagnosis for present PTSD.	-	-

Author	Country	Sample	Measurements	Analysis	Main results	Therapy type	HbA1C
Landau et al. 2014	Israel	Participant (*N* = 13) caregivers of children with diabetes. Parent's mean age = 39.	- Pittsburgh Sleep Quality Index. - The sleep diary.	Kolmogorov–Smirnov test, *t*- test, and McNemar test.	- Extreme sleep problems when using CGMS. - Awakening episodes were more when using CGMS than when not using it. - Participants experienced more wakening bouts when using CGMS than before using it.	Daily injecting - Pump	-
Monaghan et al. 2012	USA	Participant (*N* = 95) caregivers of children with diabetes. Parent's mean age = 40.	- Parenting Styles and Dimensions Questionnaire. - Paediatric Inventory for Parents. - Self-Care Inventory. - General and Medical Information Questionnaire.	Pearson Correlations, and Ancovas.	The findings revealed that authoritative parenting style enhances behavioural adherence, improves metabolic control among the children, and reduces parenting stress.	Daily injecting	7.9%

Author	Country	Sample	Measurements	Analysis	Main results	Therapy type	HbA1C
Moreira, & Canavarro, 2016	Portugal	Participant (*N* = 105) caregivers of children with diabetes. Parent's mean age = 41.	- Experiences in Close Relationships – Relationship Structures Questionnaire. - Impact on Family Scale Revised. - Parental Distress subscale of the Parenting Stress Index–Short Form.	Multivariate Analyses, Regression, and Correlations	High levels of attachment evasion that were related to high levels of parenting stress through an increased adverse thought about the effect of diabetes.	Daily injecting - Pump	7.6%
Patton et al. 2011	USA	Participant (*N* = 39) caregivers of children with diabetes. Parent's mean age = 35.	- Behavioural Paediatric Feeding Assessment Scale. - Paediatric Inventory for Parents. -Hypoglycaemia Fear Survey-Parents of Young Children. - Beck Depression Inventory-Second Edition.	Correlations, and linear Regression Analyses.	Higher parenting stress was associated with a higher stress frequency, higher depressive symptoms, fear of hypoglycaemia and greater mealtime issues.	Daily injecting - Pump	8.6%

Author	Country	Sample	Measurements	Analysis	Main results	Therapy type	HbA1C
Streisand et al. 2005	USA	Participant (*N* = 134) caregivers of children with diabetes. Parent's mean age = 42.	- Self-Efficacy for Diabetes Scale. - Diabetes Family Responsibility Questionnaire. Hypoglycemia Fear Survey.	Point-Biserial Correlation, and Hierarchical Regression Analyses.	Difficulty of parenting stress is negatively related to the child age.	-	-
Streisand et al. 2008	USA	Participant (*N* = 102) caregivers of children with diabetes. Parent's mean age = 40.	- The State-Trait Anxiety Inventory. - The Center for Epidemiologic Studies. Depression. - The Self-Efficacy for Diabetes Scale. - The Paediatric Inventory for Parents.	Multiple Regression and Correlations.	Parents experienced signs of depression and anxiety upon the diagnosis of their children. Mothers experienced more anxiety, depression, and parenting stress.	Daily injecting - Pump	8.4%
Thorsteinsson et al. 2017	Australia	Participant (*n* = 63) caregivers of children with diabetes, and (*n* =114) caregivers of children Without diabetes. Parent's mean age = 39.	- Mother's Quality of Life. - General Self-Efficacy Scale. - Dyadic Adjustment Scale. - Short Form Social Support Questionnaire.	*t*-test*s*, Standard test, Multiple Regression Analyses, and Meta-Analysis.	Mothers who had children with diabetes had a lower quality of life.	-	-

Author	Country	Sample	Measurements	Analysis	Main results	Therapy type	HbA1C
Zysberg et al. 2012	Israel	Participant (*N* = 81) caregivers of children with diabetes. Parent's mean age = 41.	- Audiovisual Test of Emotional Intelligence. - Schutte Self Report Emotional Intelligence Test. - Haemoglobin A1C (HbA1C). Daily Blood Sugar Tests.	Pearson Correlations, Regression Models, Chi-square tests, and Root mean square.	Most contextual variables such as gender, ethnicity, and education were not connected with the result variables.	-	7.5%

Chapter 5

This chapter presents two sections. The first section describes aims of the present research, and our hypotheses, which were derived from consideration of the studies reviewed in the previous chapters, and other relevant literature. The second section describes the setting in which our research took place; all data were collected in Kuwait. It is important to acknowledge that contextual differences between Global West countries, where most of the existing research took place, and Kuwait, could impact on the results and the applicability of findings to other settings.

Section 1: Thesis Aims and Hypotheses

The original aim of the present research was to explore why some children with Type 1 diabetes show a higher incidence of poor mental health and behavioural problems such as depression, anxiety, and disordered eating patterns, whilst others do not. Moreover, we planned to examine how variables identified in the existing research interact to produce these outcomes in primary school age children, who were previously underrepresented in the sampling. The present thesis is the first, to our knowledge, to explore the influence of parenting, family, lifestyle factors, and self-esteem on behavioural outcomes (mental health indices) such as disordered eating, depression, and anxiety in 8 to 11 years old children diagnosed with Type 1 diabetes.

In the previously published research that was considered in the systematic review of the literature, children with diabetes had been found to have poorer health and well-being than their healthy counterparts. However, these studies had typically looked at teenagers and adolescents. The present research was set up to explore whether children aged 8 to 11 years old have comparable problems, using age-appropriate indices of well-being. This would fill a gap in the literature and provide new information about the onset of these issues in childhood.

We also planned to examine the influence of lifestyle factors such as habitual eating behaviour and physical activity, which have been shown to be important for physical and mental health, development of eating disorders, and well-being across ages, in children with and without chronic illness. We expected that poor dietary patterns and lower levels of physical activity would be associated with poorer physical and mental health, and lower well-being in our samples (Type 1 diabetes and healthy matched controls).

We examined the psychological factors such as self-esteem; coping skills, sleep habits, parental coping skills, fear, shame, mental health, and parenting skills and their relation with the children's well-being. Parental variables have been shown to be relevant in older children, and we considered that may be of considerable importance for our younger, primary school age sample. We expected that children with diabetes (and their parents) may have higher levels of stress, anxiety, and depression than healthy children. This is why we planned to collect comparable data from a matched sample of children with no history of chronic illness and their careers. Sample control data also enabled us to establish whether any patterns observed in children with diabetes are universal, or specific to that population.

Initially, we have planned to use the findings to identify any areas of concern, and drawing upon behavioural change literature, to develop an appropriate intervention to address the problems. However, after data collection was completed for Study 1, the global pandemic changed the health landscape and our research agenda. We decided to examine the impact of the COVID-19 pandemic on the mental health, well-being, and lifestyle of children with Type 1 diabetes, and their parents.

Study 2 was conducted in Kuwait during the lockdown. Since we already had the baseline data collected previously in 2019, we decided to use the same measures on the same participants (children with Type 1 diabetes and their parents) in 2020. Unfortunately, we could not follow up the matched control group because their contact numbers were not available, due to the original sampling methods (through schools rather than clinics).

Because of profound changes that affected most families during the pandemic restrictions, we expected that children with Type 1 diabetes may have a higher level of stress, anxiety, and depression at this point, compared to pre-pandemic baseline. We also expected to see less healthy lifestyles, with an increase in sedentary behaviour and decrease in physical activity, and unhealthy dietary changes. Regarding the parents, we expected that they would show a higher level of depression, anxiety, fear, and shame due to the lockdown challenges, poorer health care provision, and isolation from the outside world.

Section 2: Kuwait Overview

This section focuses on the state of Kuwait and presents an overview of the context in which the research took place.

Kuwait is an Arab country situated in the Arabian Peninsula between Iraq in the north, Saudi Arabia in the south, and the Arabian Gulf on the east. The name Kuwait is derived from Kut, which means "fort." It was established in 1756 by the Sheikhdom ruling family of Al Sabah (Anthony et al., 2021). Kuwait is a constitutional monarchy, although the legislative power remains in the National Assembly (Majlis Alummah), which is comprised of 50 members elected to four-year terms by the Kuwaiti citizens. The country is in the desert and its total area is 17.818 km^2. The 2021 population is 4,321,373, and Kuwaiti citizens represent 37% of the total population (Kuwait population, 2022).

Climate

The desert climate turns green from March to April, but the summer heat is severe, reaching around 44 °C during the day and occasionally approaching 50 °C. Winter rainfall averages from 1 to 7 inches between October and April. Kuwait's vegetation consists of low bushes, scrubs, grass in the spring, and salt-loving plants along the coast. Although the climate is harsh, there are a few types of wild mammals, such as civets, foxes, lizards, and rare venomous sand snakes (Kuwait, 2022). Most outdoor activities are practised during autumn, winter, and spring due to the hot weather in Kuwait. That includes swimming, walking, cycling, open parks, camping, and boat trips (Kuwait, 2022).

People, language, and religion

Kuwaitis are a minority in their own country despite government policies to reduce foreign workers. Others who reside in Kuwait include expatriates from other Arab states or from Southeast and South Asia. These residents do not enjoy political or economic citizenship rights, which are reserved for Kuwaitis, defined as those who can prove their ancestry before 1920. The official language spoken in Kuwait is Arabic, followed by English, and both are taught in public schools. Kuwaitis are usually Muslims; however, foreigners have many different religions depending on their background or where they come from. The average 2020 household size in Kuwait was 5.7 members, and families are close-knit. It is common for young Kuwaitis to live with their parents until marriage, and even after marriage. Grandparents are usually taken care of by their children, and contribute significantly to child rearing; for example, responding to any concerns from school, and taking care of children in case parents are absent (Kuwait, 2022).

Economy

All of Kuwait's wealth is derived from overseas investments such as petrol processing and extraction. The oil industry has significantly helped the development of the economy since 1970. Kuwait refines its oil domestically and sells 250,000 barrels a day in its European retail markets under the name Q8, giving Kuwait one of the highest per capita incomes in the world. Other income comes from manufacturing and agriculture (Kuwait, 2022).

Social welfare and education

Social welfare has a comprehensive scheme in Kuwait. The poor and needy can obtain financial support from the government, and the Ministry of Social Affairs and Labour has programmes that provide affordable housing with modern facilities for Kuwaitis with limited income. The government has a highly developed national healthcare system represented by the Ministry of Health. The ministry has built 17 hospitals divided into six regions, and 70 general practice branches since its establishment (Kuna, 1999; Kuwait, 2022). To reduce the waiting time for patients and provide better services in the face of high patient loads, each region has established branches to accommodate services near the clinics with its own outpatient pharmacy and emergency pharmacy to serve inpatients (World Health Organization, 2014). Some hospitals also have an internal pharmacy and paediatrics pharmacy.

The Kuwaiti constitution states that any Kuwaiti citizen and foreigner living in Kuwait has the right to free health care, and patients will be sent overseas if necessary. According to the World Health Organization, in 2014, there were 59 midwives and nurses and 26 physicians per 10,000 population, which is high, it is worth noting that in the United States of America there are 26 physicians per 10,000, while in the Kingdom of Bahrain, which is in the same region, there are 19 physicians per 10,000. In general, patients that are diagnosed in the general practice are referred to specialised outpatient clinics for follow-up.

Children with diabetes are diagnosed in a paediatric diabetic clinic, and they are given appointments and blood tests every two months. During each visit to a clinic, height and weight are recorded by the nurse, followed by a meeting with a nutrition specialist and a psychologist. However, this medical attention is only available in the government regional hospitals, not in private clinics. Many Kuwait residents choose private clinics because of convenience. Kuwait's mental health system is organised around a single psychiatric hospital with psychiatrists, psychologists, social workers, and psychiatric nurses on staff. Psychiatric outpatient clinics are also located in prisons and special schools in addition to the five regional hospitals (14 clinics; WHO, 2001). Kuwait’s healthcare system includes trained mental health professionals and primary care clinics that are readily frequented by people who suffer from mental illnesses, according to some reports (Almazeedi, & Alsuwaidan, 2014). However, it is possible that poor mental health is still stigmatised in a small country with a traditional culture (Almazeedi, & Alsuwaidan, 2014).

In Kuwait, education is compulsory and entirely free, and includes books, transportation, and medical attention in schools. Nearly all the population is literate. Kuwait University was founded in 1964 and about 60% of the students are women. Moreover, many students attend universities and colleges overseas on a state scholarship (Kuwait, 2022). Furthermore, each government school has its own well-trained school nurse, who records the weight, height, and eye test results for each student every year and gives medical attention to all students, including children with diabetes and other chronic diseases.

In Kuwait, rapid economic growth and urbanisation have been accompanied by significant lifestyle changes, including the replacement of traditional diets of vegetables, fruits, and wholegrain products with fast foods and sugar-sweetened beverages, as well as lower levels of physical activity in all population groups (Al-Isa, 1997; El-Bayoumy, Shady, & Lotfy, 2009). Excessive consumption of energy, soft drinks, and fast foods, frequent snacking, and a lack of physical activity are all major risk factors for overweight and obesity among Kuwaiti children, according to the National Nutrition Surveillance System's most recent report (Allafi et al., 2014). Furthermore, adolescent gender differences in physical activity and food intake are common (Sallis et al., 1996).

Healthcare and education during the COVID-19 pandemic

The coronavirus disease was discovered in Wuhan, China, in 2019, and spread rapidly worldwide. It caused a wide range of symptoms, such as respiratory failure, multiple organ failure, mild infection of the upper respiratory tract, and death. Therefore, it was declared a pandemic by the World Health Organisation in 2019. Governments have taken strict measures due to Covid-19's highly contagious nature, including cancelling public transportation to reduce infection, isolating infected people and their families, establishing curfews, and implementing social distancing (Alsairaf et al., 2021). In Kuwait, schools and universities closed until summer 2021, and studies were shifted onto online teaching systems. Hospitals began to only accept emergency cases, all outpatient clinics were closed, and medical specialists arranged follow-ups by phone with their patients. Prescriptions were sent to patients' homes by Ministry of Health employees to encourage people to stay at home (Kuwait Ministry of Health, 2020). This affected regular appointments at the childhood diabetes clinics and measurements that would normally have been performed with the children.

Family life was affected because many parents had to stay away from their families for long periods of time, if designated as key workers, and others worked from home. Restrictions on movement and gatherings meant that many leisure opportunities were not available to the families, and regular childcare was unavailable to some parents. Social isolation also meant that family gatherings were no longer possible. Parents and carers of children were faced with uncertainty and worries about illness and future (Lebow, 2020).

Chapter 6

Methodology Used in Research Reported in This Thesis

Ethical Considerations

The research reported in this Thesis was approved by the School of Psychology Research Ethics and Governance Committee (Ethics reference number: 2019-16571A14583). Ethical approval was also granted, and research conducted on behalf of the Kuwaiti Ministry of Health (reference number: 3161). The questionnaires were given approval by the ministries of health and education and were officially stamped for data collection to proceed.

Study Design

Initially, this research was meant to use a cross-sectional correlation design. In Study 1, participants (children and their parents) were asked to contribute their data once. Each dyad completed several questionnaires measuring health, well-being, and lifestyle factors. Cross-sectional study designs involve the collection of relevant information (data), often in the form of a questionnaire at a single point in time. This means that all information (data) collected is only necessarily accurate at or around the time of its collection (Kesmodel, 2018). However, a cross-sectional study has many advantages, such as understanding disease aetiology in public health planning and generating hypotheses (Levin, 2006).

We also intended to use an independent groups design, with the first factor being presence or absence of diabetes (children with diagnosis vs matched controls) and the second being countries (UK and Kuwait). However, as a result of COVID-19 pandemic lockdown restrictions, data collection in the UK was terminated. Accordingly, the design was altered, and we collected data for children with diabetes and their parents before and during lockdown in Kuwait, with follow-up data collected for diabetes dyads in Study 2. Therefore, this study employed a repeated-measures design, which has the advantage of making the research more efficient and helps to keep variability low. This increases the validity of the results while allowing for smaller participant groups (Minke, 1997).

Analysis Plan

Figure 6.1. represents the study variables. We have initially designated child mental health and wellbeing as putative outcome variables; they were assessed with a variety of tools previously validated for use with primary age children. The study aimed to examine the relations between the outcome variables alongside a set of multiple predictor variables (child and parent measures). The focus was to analyse the effect of the predictor variables on mental health and then draw a comparison between children with Type 1 diabetes and their counterparts (see Chapter 5). Given the exploratory nature of the research – no studies have been identified in the literature review that looked at health, wellbeing and lifestyle of primary-age children and their parents – associative relationships have also been investigated in both empirical studies reported in this thesis.

Initially, we envisaged using the findings to elucidate areas where support may be needed for children and their parents, using comparative data from Kuwait and UK to investigate cultural differences, then designing and piloting an intervention that would be helpful to this group of dyads. However, due to the nature of the Covid 19, we had to modify our study design, change our data analysis, and shift to more exploratory analysis rather than predicting outcomes (using a data-driven rather than theoretically driven approach).

The new plan of analysis for the first study allowed for the structural relations between the main variables of interest to be identified (e.g., with correlation) and then the patterns of correlates for the children with diabetes and matched control were used to formulate pathways to predicted children's mental health outcomes with hierarchical and linear regression (see Figure 6.1). In addition to identifying the structural relations between variables and predictive pathways within the two groups, differences on the scores for the main variables of interest within (diabetes treatment type, managed vs unmanaged diabetes, BMI classification, and control group) and between the groups were also identified. The full analysis alongside the decision rules applied during the inferential analysis process is reported in Chapter 7.

The second study provided us with the opportunity to investigate the unique impact of COVID-19 on the mental health and wellbeing of both children and parents in Kuwait. We followed up 70 of the original dyads and this allowed us to identify any changes in parent and child status. The changes in mental health and wellbeing were identified through employing repeated measures parametric and non-parametric tests with effect size calculations (e.g., *t*-tests and Cohen's *d*). The employment of correlational analysis in this study also allowed for the calculation of reliable change indices (RCIs) of the magnitude of change in child and parental mental health and wellbeing scores. These RCIs were then used to build hierarchical regression models of child wellbeing, parental outcomes, and parental mental health after inspecting the patterns of correlates for the RCIs. The full analysis is reported in Chapter 8 and is in keeping with the path model shown in Figure 6.1 and the inferential analysis techniques utilised in Chapter 7.

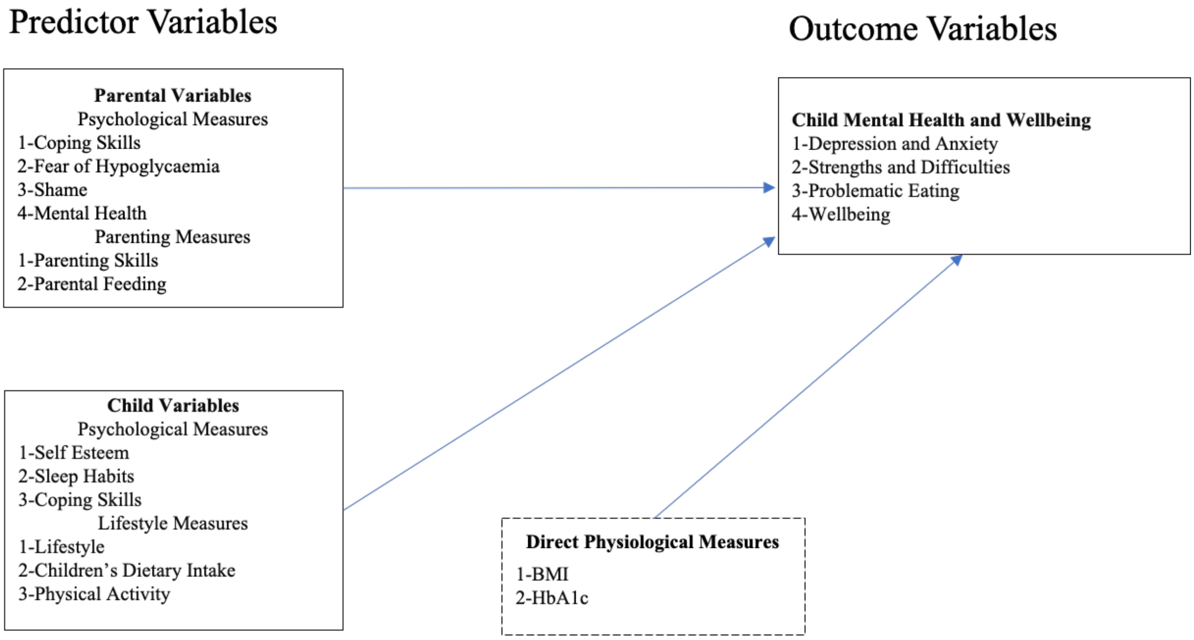


Fig 6.1. Diagram presenting outcome and predictor variables.

Measures

Data collection in Study 1 was administered in person (see Chapter 7 for description of the procedure); follow-up data collection in Study 2 took place online (see Chapter 8). The same measures were administered in both studies.

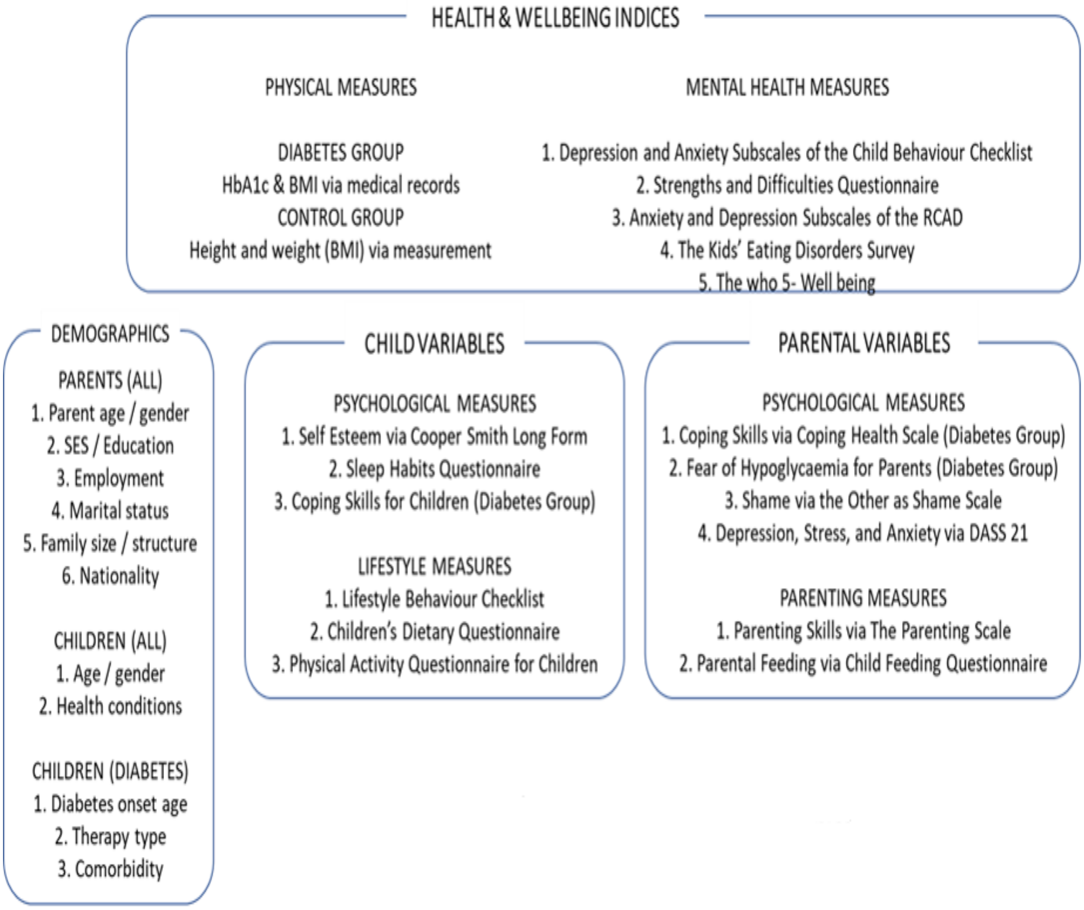


Fig 6.2. An overview of the variables and measures used in Study 1 and Study 2.

Most of the measures shown in Figure 6.2. were translated from English to Arabic except for the Coppersmith Self-Esteem Inventory-School Form, The World Health Organization-five Well-being Index (WHO-5), the Child Behavior Checklist, and the Strengths and Difficulties Questionnaire, which had already been translated to Arabic at their source. The measures were translated by a professional translator from English to Arabic and back to English again; this forward- and back-translation procedure was used to provide accurate versions of the measures (WHO, 2021). All the Arabic scripts were also checked by the researcher. Parents answered demographic questions about their age; gender, qualifications, household members, employment status, nationality and any history of mental health problems or illness. Measures were divided in to four sections: Measures Completed by Children (see Appendix 3), Measures Completed by Parents Regarding Children (see Appendix 4), Parental Self-Report Measures (see Appendix 5) and COVID Measures (see Appendix 6). All the measures have a good internal consistency, alpha >.70 (Kline, 2013).

Direct measures

HbA1c is the standard medical measure of average blood sugar concentration over a period of 8–12 weeks (Little & Sacks, 2009). For children with Type 1 diabetes, a healthy range is considered to be HbA1c scores of <7.5% (<58 mmol/mol) according to the guidelines of the International Society of Pediatrics and Adolescents (Rewers et al., 2009). Height (in centimeters) and weight (in kilograms) were taken from children's hospital medical files for calculating body mass index (BMI). For control children in schools, height and weight measurements were recorded by school nurses as part of their regular duties.

Measures completed by children

Self-esteem.

The Coopersmith Self-Esteem Inventory-School Form (CSEI; Lane, White & Henson, 2002) is a 58 item questionnaire to gauge attitudes toward the self in four areas (general self, social self, school academic and home parent). It is a well-known tool extensively used in clinical research and practice (Potard, 2017), and it has been widely translated, including into Arabic. A two-point Likert scale is used, where children from 8 to 15 years are required to decide whether the statement is "like me" or "unlike me", and the measure has a good internal consistency (α = .78; Lane et al., 2002). For example, children are asked whether they agree with statements such as "Things usually don't bother me" or "I give in very easily". To calculate the final score, the total of the four categories is calculated and multiplied by two.

Eating.

The Kids Eating Disorder Survey (KEDS, Childress et al., 1993) is a 12 item questionnaire for children aged 9 to 15, intended to discover eating disorders and attitudes such as body dissatisfaction and binge eating. Although this study made use of it, it did not employ items 8–10. The range of the scale is 0-2: A0 implies the absence of a behaviour, A1 means it is possibly present and A2 shows it is definitely present. KEDS has good internal consistency ($\alpha = .73$). The Likert scale was used, whose values "yes", "no" and "unsure" were used to answer questions in which children were asked what they thought of their physical appearance and what they desired to look like. For example, respondents were asked "are you planning to reduce weight?" and "do other people consider you a fat person?" Besides exhibiting good internal consistency in prepubescent children (Childress et al., 1993), KEDS results illustrate excellent test-retest validity and reliability. It is worth mentioning that the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) eating disorders in children are not diagnosed by KEDS (Childress et al., 1993), it can nevertheless act as a simple, quick, and reliable technique for screening.

Well-being.

The WHO-5 Well-Being Index (WHO-5, WHO, 1998) is a self-report measure that describes quality of life in the previous two weeks for parents and children. The index uses a six-point scale that ranges from 0 = "at no time", to 5 = "all the time", with good internal consistency ($\alpha = .89$). WHO-5 asks respondents to consider statements like "I am an ambitious and passionate individual". To calculate the questionnaire results, the figures for the five answers were summed up to obtain the raw score, which could be anywhere between 0 to 25, with 25 depicting the best possible and 0 the worst possible quality of life. The raw score is multiplied by 4 to get a percentage score. A percentage score of 100 indicates the best possible quality of life, whereas a score of 0 indicates the worst possible. Poor well-being is indicated when a score is below 13 (i.e., 52%). WHO-5 is a short questionnaire that has diverse applications. Besides determining outcomes in clinical trials, WHO-5 is a valid tool for screening for depression. In studies of elderly and younger people, item response theory points out that as a unidimensional scale, the measure has resulted in good construct validity through which population well-being is measured (Topp et al., 2015). WHO-5 has been translated into many languages, including Arabic.

Mental health.

The Revised Child Anxiety and Depression Scale (RCADS, Chorpitra et al., 2000) is used to examine aspects of depression and anxiety in children aged 8 to 18. RCADS addresses 47 items in six categories (panic disorder, social phobia, separation anxiety, major depression, obsessive compulsive behaviour and generalized anxiety). Answers are recorded using a four-point Likert scale ("never", "sometimes", "often" and "always"), where higher scores indicate higher levels of anxiety and depression. Respondents answer statements such as "I am tired a lot". RCADS has a good internal consistency rating (α = .76–.95; Kosters et al., 2015). To calculate the scale score, the sum of the completed items for each category is divided by the total number of items. RCADS, as referred to in DSM-IV, is user-friendly, freely available and translated into 16 languages other than English.

Coping behaviour (only for children with diabetes)

The Coping Questionnaire for Children and Adolescents is for individuals aged 8 to 18 with chronic health conditions (CODI, Petersen et al., 2004). The questionnaire contains 29 items in six categories (avoidance, acceptance, distance, cognitive palliative, wishful thinking and emotional reaction). A five-point Likert scale is employed by the questionnaire (from 1 = "never" to 5 = "always"), where problems are depicted by higher scores and responses are sought to statements such as "I know how to deal with my illness". This questionnaire presents a good internal consistency rating (α = .69–.83, when Avoidance α =

.72, Acceptance α = .83, Distance α = .70, Cognitive–Palliative α = .69, Wishful Thinking α = .81 and Emotional Reaction α = .82). To calculate the final score, each category is summed up. This questionnaire is designed to examine coping behaviour in children with chronic illness such as diabetes, asthma, or cystic fibrosis, and has been tested in six European countries.

Measures completed by parents regarding children.

Mental health.

The Child Behaviour Checklist (CBCL, Achenbach & Rescorla, 2001) is a questionnaire containing 29 items from four categories (depressive problems, anxious depressed, anxiety problems, and withdrawn depressed) for children aged 6 to 18. The CBCL is completed by parents to distinguish behavioural and emotional issues in their children and adolescents that might be linked with mental health. A three-point Likert scale is used for measurement that ranges from 0 = "not true" to 2 = "very true" and invites responses to statements such as "Does not eat well". The questionnaire has good internal consistency (α = .78–.84; Achenbach & Rescorla, 2004). The strength of the reliability and validity data across a number of cultures and languages can exhibit the high values. Scoring is done in an individual problem items using raw data.

Behavioural and emotional difficulties are measured through the Strengths and Difficulties Questionnaire (SDQ, Goodman, 1997) for children aged 2 to 17. The SDQ consisted of 25 items in six categories (conduct problem, emotion symptoms, peer problem, hyperactivity, difficulty global score, and pro-social). This questionnaire demonstrates good internal consistency (α = .70–.84; Goodman & Goodman, 2009). A three-point Likert scale, ranging from 0 = "not true" to 2 = "certainly true", was used to measure responses to statements such as "Has at least one good friend", with higher scores indicating clinical problems. The scores are computed using the following equation: Summary score = Number of items x items scores / completed items. The questionnaire has been translated into more than 80 languages. Researchers and clinicians with concerns regarding determinants of service and psychiatric events can make the significant use of the questionnaire (Goodman, 1999).

Sleep quality.

The Child's Sleep Habits Questionnaire examines sleep behaviour in children aged 4 to 10 (CSHQ-A, Owens et al., 2000). It contains 22 items in four categories (bedtime, waking during the night, sleep behaviour, and morning wake up), with high scores indicating sleep disturbance. The questionnaire displays internal consistency with α values ranging from .78 to .93. Responses in CSHQ-A are measured on a five-point Likert scale that ranges from "always" if a sleep behaviour occurs 7 times per week, though "usually" (if this behaviour occurs 5 or 6 times), "sometimes" (if it occurs 2 to 4 times) and "rarely" (for a single time) to "never" (for no occurrences in the course of the week). Questionnaire statements eliciting a response include such examples as "Child displays a similar pattern to go to bed". The final score is calculated by adding the scores for each category. The questionnaire has been translated into many languages across many countries.

Diet.

The Children's Dietary Questionnaire measures the food intake in children aged 4 to 16 over the previous 7 days or the previous 24 hours (CDQ, Magarey et al., 2009). It comprises 28 question statements in five categories (vegetables and fruit, sweetened beverages, fat from dairy, and non-core food, which denotes sugar or high-fat food); higher scores in all categories except vegetables and fruit suggest unhealthy dietary intake. Statements to which respondents provide answers include questions like "How many times in the past 7 days did you eat peanut butter or Nutella?" The questionnaire has shown an acceptable internal consistency (α = .51 to .90; Magarey et al., 2009). Scoring for fruits and vegetables is calculated by summing up the scores for statements measuring fruits per day or vegetables per day for one week, and then dividing by seven. This questionnaire was designed to be an easily administrated and easily scored tool to measure dietary intake and obesity (Magarey et al., 2009).

Lifestyle.

The Lifestyle Behaviour Checklist measures problems identified in the behaviour of overweight children aged 4 to 11, focusing on their weight, eating and activity (LBCL, West & Sanders, 2009). The questionnaire contains 26 items in two categories; the behaviour associated with food (whining, refusing food and arguing about food) is explored in questions 1-15, while questions 16-26 investigate social situations and physical activity. A seven-point Likert scale is employed that ranges from 1 = “not at all” to 7 = “very much”, and is applied to statements such as “Eats too quickly”. Higher scores in each category indicate specific problems. The questionnaire demonstrates good internal consistency (α = .90). Scoring is done by adding the total score for each category. The LBCL is useful for parents of obese children.

Activity.

The Physical Activity Questionnaire for Children aged 5 to 19 measures the frequency of certain activities during the week during school time, spare time and at the weekend (C-PAQ, Anderson et al., 2017). An extended checklist of 30 physical activities such as “Football” and “Dancing” was incorporated in the proxy-report version of the CLASS questionnaire. Higher scores denote higher levels of physical activity. Parents have to circle “yes” or “no” for each physical activity on the checklist to indicate whether that activity is performed by their child during a typical week (Monday to Friday) and during a typical weekend (Saturday and Sunday). The “Typical week” includes school time and is exclusive of school holidays. If ‘yes’ is circled, the parents then describe the frequency of that activity (between Monday to Friday and Saturday to Sunday) and the total time their child spends performing that activity during the week. The questionnaire had low values (α = .40) due to the proxy report nature of the questionnaire for young children (Anderson et al., 2017). Calculating the scores is done by adding the total for each item.

Hypoglycaemia fear (only for children with diabetes).

Parents’ fear of hypoglycaemia in their children is measured through the Hypoglycaemia Fear Survey (HFS-P, Cox et al., 1987). There are 27 items in HFS-P in two categories, “behaviour” and “worry”, which are assessed using a five-point Likert scale that ranges from 1 = “never” to 5 = “very often”. A higher score suggests greater fear of hypoglycaemia. The questionnaire demonstrates good internal consistency (α = .89). Both categories are used to determine parents’ behaviours for inhibiting hypoglycaemia and their concerns that their child may have a hypoglycaemic episode, asking respondents to address such statements as “Consume large snacks at sleep time”. To calculate the extent of parents’ fears, each score is divided by the total number of items in each category. HFS-P is designed to be specific to parents/caregivers of young children with Type 1 diabetes.

Parental Self-Report Measures

Parental shame.

External shame is measured by the ‘Other as a Shamer’ questionnaire (OaS; Allan et al., 1994). It contains 18 items and displays good internal consistency (α = .92). Higher scores depict greater shame. A five-point Likert scale ranging from 0 = “Never” to 4 = “Always” allows respondents to state the frequency of their experiences and feelings in response to statements such as “I feel other people might dislike me”. Scoring is done by adding up all items.

Coping behaviour (only for children with diabetes).

The objective of the Coping Health Inventory for Parents is to explore parents' assessment of behaviours. It is used to manage the scenarios in which parents have a child with a chronic illness. **(**CHIP; McCubbin et al., 1981). The inventory contains a 45 item self-report questionnaire divided into three categories. “Coping 1” references family integration and collaboration with an optimistic definition of the situation; “Coping 2” references social support as well as psychological stability and self-esteem; and “Coping 3” explores understandings of the health care situation through effective communication with other parents and health consultants. A three-point Likert scale is employed by CHIP and ranges from 0 = “not helpful” to 3 = “extremely helpful”. The questionnaire exhibits good internal consistency (α = .79) and it is well known. It invites parents to imagine their child and his / her well-being. To envisage how a family adjusts under a chronic stress situation, information about coping behaviours is required by the Resiliency Model of Family Stress, Adjustment and Adaptation. According to this model, coping is defined as a process incorporating both the development of new behaviours and resources as well as the utilization of existing family resources, through which the family unit will be supported, and the impact of stressor events will be mitigated. Coping will also enable the family unit’s recovery. If the parents have a seriously ill child, the Coping Health Inventory for Parents (CHIP) contributes significantly to the parents' appraisal of behaviours used to manage family life. CHIP contains a checklist of forty-five specific behaviours and is a self-report instrument. Parents have to mark how supportive (on a scale of 0 to 3) each behaviour is in their family situation. If they do not use a coping behaviour, the respondent records in this manner: “I do not cope like this, since I prefer not to use it”. CHIP is available in 2 languages. Scoring is performed by adding each circled number for each statement in the questionnaire.

Mental health.

The Depression Anxiety Stress Scale **(**DASS-21, Lovibond & Lovibond, 1995) is designed to measure stress, anxiety, and depression; it contains 21 items in three categories. DASS-21 uses a three-point Likert scale that ranges from 0 = "never" to 3 = "almost always" to respond to statements such as "I realized my mouth was dry". Higher levels of stress, anxiety and depression are indicated by values greater than 14. This questionnaire demonstrates good internal consistency regarding depression (α = .72), stress (α = .70) and anxiety (α = .77) (Tran et al., 2013). Adding the scores in each category calculates the final scores for depression, stress, and anxiety.

Parenting.

The Parenting Scale (Arnold et al., 1993) contains 30 items in three categories (Laxness, Verbosity and Over-reactivity) and demonstrates good internal consistency (α = .82). Responses are measured on a seven-point Likert scale on which low scores are indicative of good parenting and high scores suggest dysfunctional parenting. Each item is scored on a 1 to 7 scale, where 1 represents a high likelihood of employing an effective, alternative discipline strategy and 7 represents an ineffective method. The sum of all items divided by 30 results in the total score. It is also possible to add the item scores and divide by the number of items to obtain a factor score. In the revised Parenting Scale, the items have seven on the left side, while the right side have: 2, 3, 6, 9, 10, 13, 14, 17, 19, 20, 23, 26, 27, 30.

Parental child feeding behaviour.

The Child Feeding Questionnaire (CFQ, Birch et al., 2001) measures attitudes and practices linked to child feeding. This questionnaire contains 31 items in seven categories (parental weight, responsibility, child weight, concern about child weight, pressure to eat, monitoring and restriction). The parental beliefs associated with child obesity are measured on four of these categories, while the attitudes to child feeding and parental control practice are addressed in the remaining three. The questionnaire demonstrates good internal consistency ($\alpha > .70$), incorporating Parental Responsibility (3 items; $\alpha = .52$), Perceived Child Weight (4 items; $\alpha = .87$), Perceived Parent Weight (4 items; $\alpha = .73$), Parental Concern about Child Weight (3 items, $\alpha = .86$), Pressure to Eat (4 items; $\alpha = .64$), Use of Restriction (8 items; $\alpha = .77$) and Monitoring (3 items; $\alpha = .94$) (Vu et al., 2020). Statements addressed by respondents include such examples as "My child should always eat all the food on their plate". To calculate the score, the total number for each category is added up.

Covid-19 Measures

The parents' questionnaire about COVID-19's impact in 2020 is a 12 item questionnaire that was designed by the researchers especially for this study in order to assess the impact of the pandemic on both the parents' and their children's daily lives in lockdown. Answers were presented on a five-point Likert scale ("strongly agree", "agree", "neither agree nor disagree", "disagree" and "strongly disagree"). Each item response was followed up with a further question about how the pandemic lockdown had impacted the respondents in the relevant situations. The statements the respondents answered included such examples as "COVID-19 has had a negative impact on our family relationships". Participants were also invited to offer additional comments; these were noted by the researcher during the interviews, which were conducted online.

Chapter 7

Exploring the determinants of mental health, well-being and lifestyle in 8-11 year old children with Type 1 diabetes and their healthy counterparts in Kuwait

This chapter discuss diabetes group and their parents compared to control group and their parents. The aim is to explore whether children with Type 1 diabetes have comparable problems to the control group or not. Moreover, to examine and influence of lifestyle factors, such as habitual eating and physical activity, which are important for physical and mental health prevention of eating disorder and general well-being. This chapter contains an introduction, methodology, results, and conclusion. This paper had been published in December 2022 by *PLOS One Journal*, a peer-reviewed open-access journal (IF=3.24). The preliminary finding have been presented as a poster at the Bangor University Winter Conference (2019; see Appendix 11).

Abstract

Type 1 diabetes is a chronic disease with an early onset, but little is known about its psychological effects in middle childhood. The present study was the first to explore the relationship between mental health, well-being, and lifestyle of 8-11 years old children with Type 1 diabetes and their parents, and a healthy comparison group. A total of 200 parent-child dyads were recruited in diabetic clinics and from primary schools in Kuwait. Both groups completed a series of psychometric and physical assessments relating to health, well-being, and lifestyle. A significant relationship was found between higher Body Mass Index (BMI), and poorer mental health, including low academic self-esteem, depression, and anxiety in the young diabetes group. The diabetes group had significantly higher mean scores in mental health problems, and lower scores in well-being, compared with the control group. Both groups had poor dietary habits and low levels of physical activity. Unlike previous studies, no differences were found between parents' mental health for children with Type 1 diabetes and parents of the control group. Although elevated problem scores on a variety of indices remained within normal range, the pattern of results indicates that children with diabetes would profit from early screening and preventative intervention to reduce the likelihood of psychological and behavioural difficulties later on.

Keywords**:** type 1 diabetes, children, primary school age, parents, mental health, lifestyle.

Introduction

Type 1 diabetes is an immune-associated disease caused by the destruction of islet ß cells in the pancreas, usually leading to absolute insulin deficiency (Devendra, Liu & Eisenbarth, 2004; Egan & Dinneen, 2014). It is a life-changing condition that involves daily glucose monitoring, insulin therapy, and carbohydrate counting (Chiang, Kirkman, Laffel, & Peters, 2014). Poor disease management and inadequate glycaemic control can be serious, leading to short- and long-term complications that affect children's quality of life (Chiang, Kirkman, Laffel, & Peters, 2014). Even with good management, there is often an increase of body mass index (BMI) compared to children without Type 1 diabetes (Chiang, Kirkman, Laffel, & Peters, 2014), which is especially significant in the context of increasing rates of childhood overweight and obesity worldwide. Kuwait has the largest percentage of overweight children, regardless of diabetes, in the Middle East (Chiang et al., 2014; Elkum et al., 2016), and one of the largest incidence rates of Type 1 diabetes in the world (Elkum et al., 2016).

A relationship between a diagnosis of Type 1 diabetes, well-being, and child mental health, was often reported in the existing literature (de Wit et al., 2007, de Wit et al., 2011). It is likely that a diagnosis leads to additional mental health challenges. Compared to children without this diagnosis, those affected are more likely to experience depression, anxiety, behavioural problems, and attentional difficulties (Alkhurinej, 2007; Zheng et al., 2013). Children with Type 1 diabetes may also have more challenges with self-esteem compared to controls (Pek et al., 2002; Ryan & Morrow, 1986). A possible reason for this is that children with Type 1 diabetes are less likely to have prosocial peer support and experience more occurrences of bullying, especially those with unmanaged diabetes (Storch et al., 2004; Storch et al., 2006). It had also been reported that girls with Type 1 diabetes may develop a more accurate perception of their body compared to girls who do not have Type 1 diabetes (Troncone et al., 2016).

Having a child with Type 1 diabetes presents many challenges for parents. The possibility and severity of long-term complications, as well as the increased responsibility of having a child with this diagnosis, may become "all-consuming" for parents (Whittemore et al., 2012). These parents tend to experience significantly more parenting stress, depression, and anxiety, especially with newly diagnosed children; they also may report lower quality of life, compared to controls (Malerbi et al., 2012; Van Gampelaere et al., 2020; Thorsteinsson et al., 2017). Unsurprisingly, parents without adaptive coping strategies have been reported to be more likely to experience higher subjective caregiving burden, which leads to an increase in depression severity (Thorsteinsson et al., 2017). However, parents who use positive coping strategies, especially utilising familial support, may be less likely to experience depression, or may have a reduction in its severity (Blankfeld et al., 1996).

To this date, the majority of the studies focusing on Type 1 diabetes have been conducted in Western countries. Perhaps partly because of cultural stigma, there is limited research conducted in Middle Eastern countries (Mohammadzadeh et al., 2020). Overall, the existing literature focused more on adolescents, and children in primary age have been underrepresented, even though the incidence of mental health problems in this age group had been growing for some time (Alazmi et al., 2022). Most of the studies to date have looked at the relationships between the psychological variables, while lifestyle factors were seldom taken into account (Alazmi et al., 2022). This is an omission, because healthy lifestyle plays a significant role in improving mental health, psychiatric, and medical diseases (Zaman et al., 2019).

Our study had been designed to fill some of these gaps in the literature. Our overall aim was to explore whether primary-school aged children with Type 1 diabetes experience poorer mental health, have poorer lifestyle, and report more problems than their peers who do not have this diagnosis. To make these comparisons, we have administered the same measures to both cohorts in Kuwait. We investigated these children's mental health indices and also examined the influence of lifestyle factors such as habitual eating behaviour and physical activity, which are important for physical and mental health, prevention of eating disorders, and general well-being across ages (Paediatric Diabetes-Healthy Eating, 2019). We investigated psychological factors such as self-esteem; coping skills, and sleep habits, as well as parental coping skills, fear, shame, mental health, and parenting skills, and their relationship to child well-being. Parental variables have been shown to be relevant in older children, and we considered that they may be of considerable importance for our younger, primary school age sample.

Methods

Design and Sample

The study was performed in Kuwait between July and December of 2019, utilising a cross-sectional, self-report design. The study group included 100 children aged 8 to 11 years with Type 1 diabetes and their parents. The children were under follow-up care from three paediatric diabetes clinics. A matched control group included 100 children without diabetes and their parents from four schools; they were matched on gender and age. No significant differences in demographic variables were noted between the two groups (all $p>.05$). Demographic and clinical characteristics of children and their parents are shown in Table 7.1. and Table 7.2. respectively.

Table 7.1.
Demographic and Clinical Characteristics of Children

Characteristics	Diabetes cohort (*n*=100)	Control cohort (*n*=100)
HbA1c scores*	46 under 7.5 and 54 over 7.5	-
Therapy type	84 insulin injection and 16 pump	-
Children's gender	54 girls and 46 boys	50 girls and 50 boys
Median age	10 years (Range 8-11 years)	10 years (Range 8-11 years)
Median weight	39 kg (Range 20-106 kg)	34 kg (Range 20-55 kg)
Median height	139 cm (Range 125-164 cm)	133 cm (Range 122-150 cm)
Median BMI percentile	82 % (Range 1-99 %)	85 % (Range 1-98 %)
Nationality	84 Kuwaiti and 16 non-Kuwaiti	96 Kuwaiti and 4 non-Kuwaiti

**Note*: The International Society for Pediatric and Adolescent Diabetes (ISPAD, 2018) recommended the score of less than 7.5 for children with diabetes as healthy/desirable range. HbA1c is the standard medical measure of average blood sugar concentration over the period of 8–12 weeks (Little & Sacks, 2009)

Table 7.2.
Demographic and Clinical Characteristics of Parents

Characteristics	Parents of diabetes cohort (*n*=100)	Parents of control cohort (*n*=100)
Parent gender	88 mothers and 12 fathers	90 mothers and 10 fathers
Parent median age bracket	35–44 years	35–44 years
Median household size	6 Members (Range 3-8)	5 Members (Range 3-8)
Parental education	3 none, 12 secondary school, 32 college, 43 bachelor's degree, 1 master degree, 9 doctorate degree	3 secondary school, 19 college, 72 bachelor's degree, 3 master degree, 3 doctorate degree
Parental employment status	1 home carer, 21 unemployed, 1 self-employed, 1employed part-time, 76 employed full time	1 home carer, 6 unemployed, 3 self-employed, 1 working from home, 89 employed full time
Parental history of mental health problems	8 reported history of mental health problems	4 reported history of mental health problems

Procedure

All study procedures were granted ethical approval by Bangor University (UK), Kuwait Ministry of Health, and Kuwait Ministry of Education.

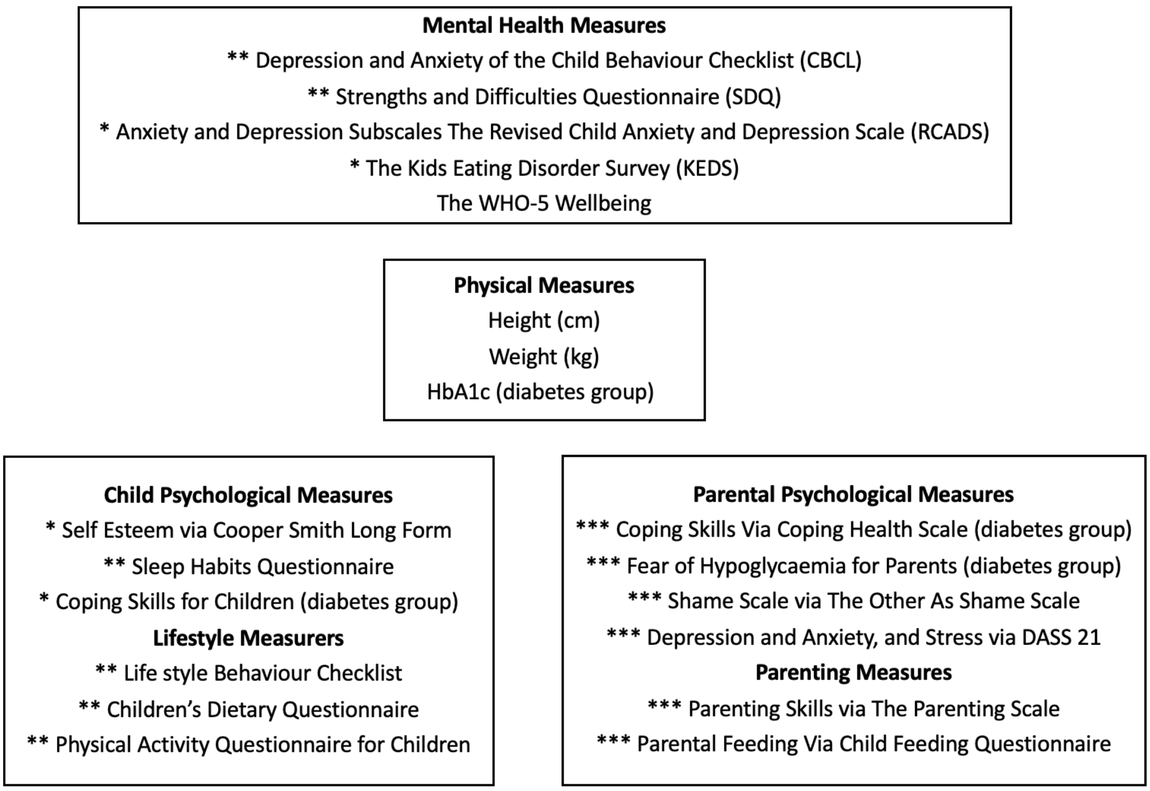
In the paediatric clinic, children and their parents were selected by a nurse and approached during their regular visits. The nurse asked the parents whether they would be interested in participating in a research study while in the waiting room prior to their consultation with the doctor. If they agreed to participate, the nurse took them to a meeting room provided by the hospital; this ensured anonymity and privacy. The researcher provided a written consent form and an information sheet for parents (See Appendix 1) to complete before participating. Parents and children were asked to complete measures related to mental health, well-being, and lifestyle. The researcher was available to assist if necessary, and to clarify or rephrase questions for the children. Height, weight, and blood glucose measurements were taken from children's pre-existing records, from the clinic. The questionnaires took less than an hour to complete in all cases. Parent and child dyads were thanked for their participation but no incentives or gifts were offered.

For the control group, we collected the data from four schools chosen by the Ministry of Education. The parental questionnaires were sent home with the child for parents to complete, along with an information sheet and consent form. The children completed their questionnaires at school in their class. The researcher was present, read the questions aloud, and assisted individual children if necessary. Children's weights and heights, recently measured by the school nurse, were taken from pre-existing records.

Measures

Measures were chosen for their suitability for primary school aged children, widespread use in previous research, and because they were validated and/or showed good internal consistency. They were translated from English to Arabic except for the Coppersmith Self-Esteem Inventory-School Form, The Child Behavior Checklist, The World Health Organization Five Well-being Index, and the Strengths and Difficulties Questionnaire, which were already available and validated in Arabic. The measures were translated by a professional from English to Arabic and back to English again; this forward- and back-translation procedure provided an accurate translation of the measures (WHO, 2021). All the Arabic scripts were also checked by the researcher who is a native Arabic speaker.

Figure7.3. shows the measures used in the present study. We have administered a battery of questionnaires to parents, asking about their own mental health and parenting, and also about their children's mental health, well-being, and lifestyle (including sleep quality, dietary habits, and physical activity). We have also asked children to provide answers about their own mental health (including anxiety, depression, and disordered eating), self-esteem, and coping skills. Cronbach Alpha were presented (See Appendix 7)



Note: * measures completed by children, ** child measures completed by parents, *** measures completed by parents. The WHO-5 Well-being measure was completed by both parents and children.

Fig.7.3. Measures used in the study.

Results

Preliminary Analysis and Decision Rules

Exploratory data analysis techniques were performed to identify the range, mean, and standard deviation of Child Self-Completed Measures, Parent-Completed Child Measures, and Parent-Completed Self-Report Measures (See Appendix 7 and 8). Variables that were found to score higher than ±2 for skew and kurtosis were investigated with non-parametric tests (Miles & Shevlin, 2001), because they did not meet the requirements of normality, linearity, or parametric assumptions. When parametric assumptions were met, one-way ANOVA, independent samples *t*-tests, Pearson's *r* product moment correlations, and hierarchical (or linear) regressions were employed. When parametric assumptions were violated, Mann-Whitney U and Spearman's Rho tests were used.

Chi-squares were performed with crosstabs to identify any differences in the parent and child demographic variables for the diabetes and control group. None were identified, meaning that the samples for each group were well matched. The additional findings related to diabetes management (insulin injection or insulin pump) and BMI classifications (e.g., overweight, and obese) are presented in the appropriate section.

Each set of inferential tests also included the corresponding effect size calculation when necessary (e.g., Cohen's *d,* Cohen's *f*-squared, eta-squared, and post-hoc power analysis). The raw scores for the Child Behavior Check List subscales were analysed instead of the *T*-scored data in accordance with Pandolfi, Magyar, and Dill, (2009) and Holmes et al. (2015), who established no differences in the findings reported from using the raw scores in the analysis as opposed to the *T*-scores. In addition, the *T*-scored data for the RCADS was also analysed in this study (Chorpitra et al., 2000).

The analyses were exploratory in nature but we have considered indices of mental health as outcome variables where appropriate. Cronbach alpha obtained for each measure in the present study and descriptive statistics for all measures are presented in Supplementary files (See Appendix 7 and 8). There were no missing data for any of the participants. The findings are presented in three sections for: (i) diabetes group; (ii) control group; and (iii) comparisons between the scores for the diabetes and control group. Only statistically significant results are listed in each section.

Section 1. Diabetes Group

Independent samples *t*-tests were carried out to identify differences between blood test scores (HbA1c) when comparing children with managed vs. unmanaged diabetes according to The International Society for Paediatric and Adolescent Diabetes (ISPAD, 2018) criteria. The managed group (n=46) had an HbA1c of less than 7.5%, and the unmanaged group (n=54) had an HbA1c of 7.5% or more. A significant difference was found between the groups when comparing their scores for parental shame; the parents in the unmanaged group (M=58.48, SD=8.84) reported being more manipulative than those in the managed group (M=54.52, SD=9.63), $t(98)=-2.14$, $p<.05$, $d=0.40$ (small-medium effect size).

A Mann-Whitney U test found that the managed group (Median=5.00) consumed more water than the unmanaged group (Median=4.00), U=910, z=-2.53, p=.01.

BMI Percentiles for Diabetes Group

A Pearson's *r* correlation was conducted to identify the relations between the children's Body Mass Index (BMI) percentiles and study measures. As shown in Table 7.4. a number of significant positive correlations were found to exist between the scores for BMI percentile; eating disorder survey body dissatisfaction, *T*-scored RCADS panic disorder, *T*-scored RCADS depression, and *T*-scored RCADS general anxiety scores. A negative correlation was also found to exist between BMI percentile and eating disorder scores items 1-7, parental DASS-21 stress scores, and children's self-esteem academic score.

Table 7.4.
Pearson's Correlations for Diabetes Group BMI Percentile with Other Study Variables

Measure	2	3	4	5	6	7	8
1. BMI Percentile	-.315**	.322**	.236*	.202*	.268*	-.226*	-.213*
2. Eating disorder survey items 1-7		-.128	-.171	-.001	-.074	.010	.091
3. Eating disorder survey body dissatisfaction			.267**	-.038	.310**	-.062	-.136
4. *T*-scored RCADS panic disorder				-.067	.478**	-.224*	-.272**
5. *T*-scored RCADS depression					-.040	-.165	-.204*
6. *T*-scored RCADS generalised anxiety						-.146	-.265**
7. DASS-21 stress							.224*
8. Self-esteem academic							

**Correlation is significant at the .001 level (two-tailed)
*Correlation is significant at the .05 level (two-tailed)

BMI Classifications for Diabetes Group

The BMI scores for the diabetes group were classified into four main categories: underweight; healthy weight, overweight, and obese. The underweight group was excluded from the analysis (*n*=1). Children whose BMI was classified as obese scored higher on eating disorders survey body dissatisfaction; and *T*-scored RCADS panic disorder, general anxiety, and sleep awake earlier. Overweight children scored higher on *T*-scored RCADS obsessive compulsive. Interestingly, children whose BMI was classified as healthy weight were found to be scoring higher on the eating disorder survey items 1-7 than those who were either overweight or obese (see Table 7.5.).

Table 7.5.
Diabetes Group One-Way ANOVA for BMI Classification

Key	Healthy weight (*n*=54) Mean (Sd)	Overweight (*n*=24) Mean (Sd)	Obese (*n*=21) Mean (Sd)	*F*	*p*	η^2
1	5.18 (2.53)	3.83 (2.66)	3.24 (2.07)	5.63	.005	0.10
2	0.98 (1.02)	1.42 (1.28)	2.43 (1.03)	11.18	<.001	0.19
3	54.37 (8.04)	56.38 (8.50)	61.38 (9.56)	5.16	.007	0.10
4	42.89 (6.33)	45.56 (9.33)	47.48 (6.83)	3.30	.041	0.06
5	45.93 (9.70)	51.83 (8.11)	51.81 (9.05)	5.03	.008	0.09
6	7.93 (2.60)	8.43 (2.99)	6.33 (3.23)	3.46	.036	0.07

Key: 1=Eating disorders survey items 1-7; 2=Eating disorders survey body dissatisfaction, 3=*T*-scored RCADS Panic disorder, 4=*T*-scored RCADS General anxiety, 5=*T*-scored RCADS Obsessive compulsive, and 6=Sleep: Morning wake-up. Eta-squared values: 0.01=small effect; 0.06=medium effect, and 0.14 or higher=large effect.

Mental Health and Well-being Variables for the Diabetes Group

A Pearson's *r* bivariate correlation was conducted to identify the relations between children's mental health and well-being scores (see Table 7.6.). A number of significant negative correlations were found to exist between the child's well-being and *T*-scored RCADS social phobia, *T*-scored RCADS depression, *T*-scored RCADS generalised anxiety, and eating disorder survey body dissatisfaction scores. This demonstrates that the elevated scores for (non-clinical) measures of social phobia, depression, generalised anxiety, and eating disorder survey body dissatisfaction may be associated with poorer well-being in children with diabetes. A positive correlation was also found to exist between the parents' well-being and children's self-esteem school academic scores.

Eating disorder survey binge eating scores were inversely correlated with coping avoidance, coping wishful thinking, and sleep morning wake up scores, indicating that children with poorer coping and sleep-related problems had elevated disordered eating behaviour.

Social phobia scores showed a significant negative correlation with coping avoidance, and academic self-esteem scores; children with an elevated social phobia appeared to engage in fewer avoidance techniques and had lower academic self-esteem. A significant inverse relation between separation anxiety and self-esteem total scores was also observed.

Higher scores for the raw CBCL withdrawn depressed subscale showed significant positive relation with parental shame, and with parents feeding perceived responsibility scores. There were also significant inverse relations between the raw CBCL anxiety/depressed and coping emotional reaction scores, and coping subscale 3 score.

Table 7.6.

Pearson's Correlations for Mental Health and Well-being Variables for Diabetes Group

Measure	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1. Child welling	-.215*	-.248*	-.217*	-.264*													
2. *T*-scored RCADS social phobia						-.216*				-.197*							
3. *T*-scored RCADS depression											-.247*						
4. *T*-scored RCADS generalized anxiety																	
5. Eating body dissatisfaction																	
6. Parental welling						.305*											
7. Self-esteem academic																	
8. Binge eating								-.222*	-.225*	.258*							
9. Coping wishful thinking																	
10. Sleep morning																	
11. Coping avoidance																	
12. Self-esteem total																	
13. Raw CBCL withdrawn depression													.231*	.217*			
14. Parental shame																	
15. Parental feeding responsibility																	
16. Raw CBCL anxiety/depressed																.231*	-.232*
17. Coping emotional reaction																	
18. Coping subscale 3																	

**Correlation is significant at the .001 level (two-tailed),

*Correlation is significant at the .05 level (two-tailed).

The scores for the main variables were inspected by diabetes management type to identify any differences on the main variables. Children whose diabetes was managed with an insulin pump scored higher on self-esteem general and social than those whose diabetes was managed by insulin injection. Children whose diabetes was managed by insulin injection scored higher on eating disorder survey binge eating and *T*-scored RCADS separation anxiety. The parents of the children who were managed by insulin pump registered more HFS behaviour scale related problems than those parents whose child was managed by insulin injection (see Table 7.7.). It is worth noting that the children with diabetes in this study were primarily managed by insulin injection.

Table 7.7.
Diabetes Management Differences on Main Variables

Variable	Injections (n=84) Mean (Sd)	Pump (n=16) Mean (Sd)	t	p	d
Self-esteem general	11.86 (3.28)	14.00 (2.56)	-2.47	.015	0.73
Self-esteem social	3.27 (1.70)	4.25 (1.65)	-2.11	.037	0.59
Binge eating score	0.53 (0.83)	0.06 (0.25)	*4.31	<.001	0.77
T-scored RCADS Separation anxiety	56.32 (8.20)	51.56 (7.81)	4.76	.035	0.59
HFS Behaviour scale	3.76 (0.81)	4.21 (0.52)	-2.15	.034	0.66

* Adjusted t- and p-value reported because Levene's homogeneity of variance test was violated. Cohen's d values: 0.20=small effect; 0.50=medium effect, and 0.80=large effect (Cohen, 1988).

Regression Analysis for Diabetes Group

Regression analysis were run to establish further the relations between the predictors and child mental health outcome variables after controlling for the effect of diabetes management type. Tolerance and Variance Inflation Factors (VIF) were examined to identify any collinearity issues in the models. This is important as it means the independent variables do not influence one another too much. Therefore, it can be identified to what extent each independent variable influences the dependent variables, separately. Tolerance varies between 0 and 1.00, for example, when the value is greater than 1.00 it means that the variable is completely uncorrelated with other independent variables. Moreover, the VIF value is supposed to be less than 2.00 (Miles & Shevlin, 2001).

The model for predicting children's eating disorder survey binge eating scores accounted for 18.9% of the unique variance $F(4,95)=5.54$, $p<.001$, $f^2=0.23$ (small effect size), power=.98. The model for predicting children's separation anxiety scores accounted for 17.5% of the unique variance $F(3, 96)=6.77$, $p<.001$, $f^2=0.21$ (small effect size), power=.98. The regression diagnostic tests applied to each model show that no multicollinearity issues occurred: model 1 VIF=1.01 to 1.09 and Tolerance .92 to .99 and for model 2: VIF=1.00 to 1.04 and Tolerance .96 to 1.00. For both models, β values and p values are shown in Table 7.8.

Table 7.8.
Regression Findings for Diabetes Group

Outcome Variables	Predictor Variables	β	*p value*
1. Eating disorder survey binge eating	Diabetes management type	-.222	.026
	Coping avoidance	-.284	.003
	Coping wishful thinking	-.211	.025
	Sleep morning wake up	-.124	.201
2. *T*-scored *RCADS* Separation Anxiety	Diabetes management type	-.212	.035
	Self-esteem total score	-.215	.032
	Sleep bedtime	.293	.002

Section 2. Control Group

BMI Percentile Control Group

A Pearson's *r* correlation was conducted to identify the relations between the BMI percentiles and the main study variables scores. As shown in Table 7.9. all eating disorder survey subscale scores were found to correlate with BMI percentile: items 1-7 score, binge eating score, and body dissatisfaction score. In other words, higher weight status was associated with higher disordered eating indices. However, a negative correlation was found between BMI percentile and peer problem scores from the strengths and difficulties questionnaire (SDQ).

Table 7.9.
Pearson's Correlations for Control Group BMI Percentile

Measure	2	3	4	5
1. BMI Percentile	.324**	.360**	.203*	-.204**
2. Eating disorder survey items 1-7		-.499**	-.664**	-.111
3. Eating disorder survey binge eating			.568**	-.094
4. Eating disorder survey body dissatisfaction				-.050
5. SDQ Peer Problem				-

**Correlation is significant at the .001 level (two-tailed)
*Correlation is significant at the .05 level (two-tailed)

A Spearman's Rho correlation was conducted on the scores for BMI percentiles and lifestyle variables scores. As shown in Table 7.10. a significant negative correlation was found between BMI percentiles and sleep waking during the night, and positive correlations with the amount and frequency of physical activity at the weekend. Surprisingly, higher weight status was associated with less interrupted sleep and more activity in the control group.

Table 7.10.
Spearman's Rho Correlations for Control Group BMI Percentile

Measure	2	3	4
1 BMI Percentile	-.284**	.296**	.291**
2 Waking during night		-.041	-.086
3 Physical activity weekend total			.088
4 Physical activity weekend frequency			-

**Correlation is significant at the .001 level (two-tailed),
*Correlation is significant at the .05 level (two-tailed).

BMI Classifications for Control Group

In a similar manner to the diabetes group, the BMI scores for the control group were reclassified into four categories; the underweight group was excluded from the analysis

(n=3). The healthy weight children scored higher on eating disorder survey items 1-7 than the other BMI classifications; obese children scored higher on eating disorder survey body dissatisfaction. Both these findings are in keeping with the diabetes group. A noticeable difference to the diabetes group is that the obese children in the control group were also scoring higher on eating disorder survey binge eating, *T*-scored RCADS major depression, and lower for raw CBCL anxiety problem. Surprisingly, the healthy weight children in the control group were found to be scoring the highest on CBCL anxiety problem and sleep: waking during the night (see Table 7.11.).

Table 7.11.
Control Group one-way ANOVA for BMI Classification on Main Variables

Key	Healthy weight (n=45) Mean (Sd)	Overweight (n=36) Mean (Sd)	Obese (n=16) Mean (Sd)	F	p	η^2
1	6.40 (1.42)	5.14 (2.17)	5.56 (1.97)	10.00	<.001	0.17
2	0.98 (1.16)	1.58 (1.40)	2.87 (1.67)	11.85	<.001	0.20
3	0.40 (0.72)	0.94 (1.16)	1.56 (1.21)	9.58	<.001	0.17
4	41.27 (5.95)	41.58 (7.54)	46.12 (5.78)	3.47	.035	0.07
5	3.24 (2.28)	2.36 (1.77)	1.44 (1.59)	5.28	.007	0.10
6	2.24 (1.48)	1.61 (1.20)	1.31 (1.30)	3.73	.028	0.07

Key: 1=Eating disorders survey items 1-7; 2=Eating disorders survey body dissatisfaction, 3=Eating disorders survey binge eating, 4= *T*-scored RCADS Major depression, 5= Raw CBCL Anxiety problem, and 6=Sleep: Waking during the night. Eta-squared values: 0.01=small effect; 0.06=medium effect, and 0.14 or higher=large effect.

Mental Health and Well-being Variables in the Control Group

A Pearson *r* bivariate correlation was conducted to investigate the relations between mental health and well-being scores (see Table 7.12.). A negative correlation was found to exist between well-being and *T*-scored RCADS depression scores. Children's higher *T*-scored RCADS obsessive-compulsive scores correlated with higher parental shame and parental child weight. However, raw CBCL anxious depressed subscale scores were found to share a significant negative correlation with shame and bedtime scores.

Unsurprisingly, children who reported higher scores for eating disorder survey binge eating also reported higher body dissatisfaction. However, eating disorder survey items 1-7 scores had a significant negative correlation with body dissatisfaction scores and binge eating scores. Unexpectedly, eating disorder survey items 1-7 scores were positively correlated with total self-esteem, academic self-esteem, and general self-esteem scores.

Table 11
Pearson's Correlations for Control Group Mental Health and Well-being Variables

Measure	2	3	4	5	6	7	8	9	10	11	12	13
1. Child welling	-.245*											
2. *T*-scored RCADS depression												
3. Eating survey binge eating			.568**									
4. Eating survey body dissatisfaction												
5. Eating survey items 1-7		-.499**	-.664**		.218*	.226*	.208*					
6. Self-esteem total												
7. Self-esteem academic												
8. Self-esteem general												
9. *T*-scored RCADS obsessive compulsive									.283*	.317**		
10. Parental shame												
11. Parental child weight												
12. Raw CBCL anxiety/depressed									-.197*			-.202*
13. Sleep bedtime												

**Correlation is significant at the .001 level (two-tailed),
*Correlation is significant at the .05 level (two-tailed).

Section 3. Comparisons Between the Diabetes and Control Group

Comparison data analyses were carried out with 100 children with Type 1 diabetes, 100 control children, and their parents. Table 12 shows the differences in the variable scores by group.

Differences for Diabetes and Control Group by BMI Classification

A one-way ANOVA with six groups was used to identify how children classified by their BMI as healthy weight, overweight, and obese in the diabetes and control group were scoring compared to each other. We examined the eating disorders survey items 1-7, binge eating, and body dissatisfaction, because both groups were found to be showing differences on these variables by BMI classification. ANOVA showed that children with a healthy weight classification in the control group scored the highest on the eating disorder survey items 1-7 compared to the other BMI classifications in either the diabetes or control group, $F(5,190)=8.37$, $p<.001$, $\eta^2=0.18$ (large effect).

For eating survey binge eating scores, those in the control group classified as obese scored higher than the other BMI classifications in either the diabetes or control group, $F(5,190)=6.69$, $p<.001$, $\eta^2=0.15$ (large effect). They also scored higher for body dissatisfaction, $F(5,190)= 9.35$, $p<.001$, $\eta^2=0.20$ (large effect). No other differences on main variables were identified ($p>.05$).

Parent Variables

Parents in the control group had significantly lower mean scores for feeding responsibility and had less monitoring over the feeding of their children. Parents of children with Type 1 diabetes had significantly lower mean scores on parenting sum, parenting laxness, and parenting verbosity than parents in the control group. However, there were no significant differences between the parents of each group on their reported levels of external shame, mental health, and well-being ($p>.05$).

Child Variables

Children with Type 1 diabetes had significantly lower mean scores for general self-esteem, social, home parents, school academic, and total self-esteem than the control group. There were no differences between the two groups on eating disorder survey body dissatisfaction. Children with Type 1 diabetes had significantly lower mean scores for the eating disorder survey items 1-7, while the control had significantly lower mean scores for eating disorder survey binge eating.

The state of well-being in the children with Type 1 diabetes was less positive than that of the control group. Compared with the control group, the children with Type 1 diabetes had significantly higher mean scores of *T*-scored RCADS subscales, raw CBCL subscales, and SDQ emotional symptoms subscale. Significantly lower mean scores in sleep habits were observed in children with Type 1 diabetes group, while the control group had significantly lower mean scores of sleep waking during night and sleep morning wake up.

Lifestyle Variables

The control group had significantly lower median scores for lifestyle food, fruits in the past 7 days, in the last week, and the average daily portions in their diet compared to children with Type 1 diabetes. However, children with Type 1 diabetes reported significantly lower median scores of vegetable meals in the last 24 hours, less non-core food for the past 7 days, less sweetened beverages in 24 hours, and a daily portion of non-core foods, compared to the control group. Children with Type 1 diabetes had significantly higher median scores than the control group when comparing the frequency of physical activities. However, it should be noted that, in both cohorts, diet was relatively poor and levels of activity low (see Table 7.13.).

Table 7.13.

Diabetes and Control Group Differences on Main Study Variables

Variables	Diabetes group *M (SD)*	Control group *M (SD)*	*U*	*t*-test	*p*	*d*
Child						
Self-esteem						
General self	12.20 (3.26)	13.55 (3.64)		2.76	.006	0.39
Social self	3.43 (1.72)	4.01 (1.47)		2.56**	.011	0.36
Home parents	3.08 (1.43)	3.91 (1.63)		3.81	<.001	0.54
School academic	3.21 (1.59)	4.16 (1.62)		4.17	<.001	0.59
Total score	10.96 (2.83)	12.81 (3.19)		4.38	<.001	0.61
Eating Disorder Survey						
Eating disorder items 1-7	4.47 (2.59)	5.58 (1.97)		3.41	.001	0.48
Binge eating	0.46 (0.78)	0.77 (1.02)		13.28	.001	1.88
Child well-being	17.59 (4.54)	21.15 (3.53)		6.18	<.001	0.87
RCADS						
T-scored Social phobia	42.30 (7.05)	35.61 (5.40)		7.53	<.001**	1.06
T-scored Panic disorder	56.25 (8.84) Median 56	45.56 (7.20) Median 45	46.12*		<.001*	1.32
T-scored Major depression	52.65 (9.34)	42.19 (6.66)		-9.11	<.001**	1.29
T-scored Separation anxiety	55.56 (8.28)	44.89 (6.09)		-10.37	<.001**	1.47
T-scored Generalised anxiety	44.38 (7.46)	36.71 (5.40)		-8.32	<.001**	1.18
T-scored Obsessive compulsive	48.72 (9.59) Median 49	38.07 (6.43) Median 37	78.2*		<.001*	1.30
Sleep Habits						
Bedtime	14.62 (4.16)	17.60 (6.90)		3.70	<.001**	0.52
Waking during night	3.77 (1.36) Median 4	1.88 (1.38) Median 2	61.71*		<.001*	1.37
Morning wake up	7.64 (2.99)	2.84 (2.78)		11.74	<.001**	1.66
CBCL						
Raw Depressive problems	5.15 (2.98) Median 5	3.02 (2.22) Median 3	25.24*		<.001*	0.80
Raw Anxiety problems	4.21 (1.96)	2.65 (2.08)		-5.44	<.001	0.77
Raw Anxious/depressed	5.88 (2.66)	3.78 (2.85)		5.37	<.001	0.76
Raw Withdrawn/depressed	3.41 (2.53)	1.61 (1.54)		-6.06	<.001	0.86
SDQ						
Emotional symptoms	2.73 (1.72)	1.77 (1.39)		-4.33	<.001**	0.61
Hyperactivity	2.11 (1.41)	5.28 (1.37)		16.1	<.001	2.28
Difficulties global score	11.14 (3.57)	13.48 (2.94)		5.06	<.001	0.72
Prosocial global score	3.68 (2.17) Median 3.5	2.79 (1.77) Median 2	9.27*		<.002*	0.44
Parents						
Parental feeding perceived responsibility	4.05 (0.86) Median 4	3.71 (0.83) Median 4	7.66*		.006	0.40
Parental feeding monitoring	3.71 (0.84)	3.46 (0.74)		-2.19	.029	0.31

Parental style sum	4.28 (0.67) Median 4	4.80 (1.12) Median 5	12.52*		<.001	0.56
Parental style laxness	4.34 (0.78)	4.60 (0.87)		2.17	.031	0.31
Lifestyle						
Lifestyle behaviour checklist						
Food	20.98 (8.26) Median 20	15.53 (8.21) Median 14	18.09*		<.001*	0.66
Children dietary questionnaire						
Fruits eaten in the last 7 days	6.59 (3.86) Median 6	4.83 (2.18) Median 5	19.00*		<.001*	0.56
Fruit last week	2.97 (1.41) Median 3	2.05 (1.29) Median 2	32.08*		<.001*	0.68
Vegetable in evening meal (24 hours)	1.00 (0.88) Median 1	1.21 (1.23) Median 1	4.92*		.026*	0.19
Vegetables last week	2.34 (1.43) Median 2	1.87 (1.25) Median 2	6.16*		.013*	0.34
Non-core foods past 7 days	22.43 (8.51) Median 21	27.46 (12.52) Median 25	4.50*		.034	0.46
Variables	Diabetes group *M (SD)*	Control group *M (SD)*	*U*	*t*-test	*p*	*d*
Sweetened beverage last 24 hours	1.07 (1.04) Median 1	1.99 (1.35) Median 2	15.07*		<.001*	0.57
Fruits eaten average daily portion	1.66 (0.72) Median 1.5	1.32 (0.56) Median 1.1	19.73*		<.001*	0.52
Non-core foods average daily portion	3.20 (1.21) Median 3	3.92 (1.78) Median 3.6	4.50*		.034*	0.47
C-PAQ						
Frequency on weekdays	36.71(35.08) Median .00	2.67 (2.26) Median .00	10.73*		.001*	0.28
Frequency on weekends	0.00 (.0.00) Median .00	0.23 (0.69) Median .00	10.73*		<.001**	0.00*

* Non-parametric analysis used due to the data not meeting the requirements of normality

** Adjusted *df* and *t*-value reported because Levene's homogeneity of variance test was violated.

Discussion

The present study was the first to investigate mental health, well-being, and lifestyle factors in young children with Type 1 diabetes and their healthy counterparts in Kuwait. The findings demonstrate the connections between a range of lifestyle and self-evaluative variables such as eating habits, self-esteem, shame, and peer interactions, with children's mental health and well-being. In most part, our results align with the findings reported in the existing literature from samples with broader age range, older children, and those from different cultures. However, some of the results were surprising.

Main Findings for the Diabetes Group

The main findings for the diabetes group analysis showed that some differences were due to HbA1c grouping (managed or unmanaged); BMI percentile and classification (e.g., obese, or overweight), and diabetes management type (insulin injection or pump). For HbA1c, the only notable findings were for the unmanaged group, where parents reported an increase in manipulativeness, and the children consumed less water than the managed group.

More findings were associated with BMI percentile and classification; three positive correlates were found to exist between *T*-scored RCADS mental health and BMI percentile scores. BMI percentile scores also shared one negative correlate (items 1-7) and one positive correlate (body dissatisfaction) with the eating disorder survey scores. These correlational findings are further supported by the one-way ANOVAs. Obese children were found to be scoring higher on body dissatisfaction and the panic and anxiety indices of the RCADS. Those who were overweight scored higher on the RCADS obsessive compulsive index. This pattern of correlates and ANOVA analyses clearly demonstrate the relations between BMI, mental health, and disordered eating patterns in the diabetes group. Other notable findings include inverse relations between BMI percentile and parental stress and children's self-esteem academic. We also found that healthy weight children scored higher on items 1-7 of the eating disorders survey and that obese children were waking earlier than the other BMI classifications.

Differences on self-esteem, mental health, and disordered eating indices were observed when investigating the role of diabetes management type. Children who were managed by insulin injection (n=84) were found to score lower on self-esteem general and social and higher on *T*-scored RCADS separation anxiety and eating disorder survey binge eating. Parents of children managed by insulin pump (n=16) recorded higher scores for the HFS behaviour scale than those managed by insulin injection, implying that they may be engaging in more avoidance behaviour to reduce their child's hypoglycaemic risk (Gonder-Frederick et al., 2013).

In summary, the elevated scores on the RCADS mental health and eating disorder survey items within the diabetes group were associated with differences in BMI percentile, BMI classification, diabetes management type, and with poorer self-esteem, coping behaviour, and sleep-related problems. This conclusion is supported by the regression analyses that show both binge eating and *T*-scored RCADS separation anxiety are predicted by a combination of being maintained by insulin pump injection, self-esteem, coping behaviour, and sleep-related problems. Broadly, our findings correspond to the existing literature: Melnyk et al. (2006) and Halfon et al. (2013) reported a correlation between scores for depression, low self-esteem, school problems, number of missed school days, and a high BMI. A negative relationship found to exist with binge eating, coping avoidance, and sleep habits in our study is consistent with the findings reported by Burt et al. (2014). Poor well-being in children with diabetes may be associated with depression, general anxiety, social phobia, and body dissatisfaction. A similar association was also reported by de Wit et al. (2007) who found that children with Type 1 diabetes reported higher social phobia scores and lower academic self-esteem and avoidance technique scores; whereas those with higher levels of anxiety reported low self-esteem. These finding are also in keeping with those reported by Ayla et al. (2014) and Yemane et al. (2016).

In our sample, the scores for mental health and disordered eating indices that were elevated within the diabetes group did not yet fall into a clinical range. Nevertheless, our findings imply that the screening and assessment of younger children with Type 1 diabetes may be needed to identify those who may profit from early (preventative) intervention.

Main Findings for the Control Group

Our study was the first to explore the relationship between lifestyle, well-being, and mental health indices of healthy primary-school age children from an Arab country.

The BMI percentiles for the healthy control group shared positive correlations with three disordered eating indices (eating disorder survey items 1-7; binge eating and body dissatisfaction), as previously reported in the literature by Munkholm et al. (2016). These findings differ to those for the diabetes group, which showed an inverse relation between BMI percentile and eating disorder survey items survey 1-7. An additional difference observed is the inverse relation between the strengths and difficulties questionnaire (SDQ) peer problems scores and BMI percentile for the control group, whereas no relations between SDQ subscale scores and BMI percentile were observed in the diabetes group.

An unexpected finding was the positive relations between BMI percentile and the amount and frequency of physical activity in the control group. This may be due to the number of overweight and obese children in each group (control *n*=52 and diabetes *n*=45), or because the scores for physical activity were lower than expected for this age-range in each group. This finding needs to be replicated in another study to further elucidate the relations between BMI and physical activity.

The main findings in relation to BMI classification for the control group are the higher scores for obese children on eating disorder survey binge eating and *T*-scored RCADS major depression. They may be at risk of engaging in emotional or loss of control eating to regulate depression related symptoms (Tanofsky- Kraff et al., 2007).

In general, the pattern of BMI classification for the controls is identical to that for the diabetes group when it comes to eating disorder survey items 1-7 and body dissatisfaction. An unexpected finding is the scores for healthy weight children on the raw CBCL anxiety problem scale and sleep waking during the night. This was contrary to the findings reported by Kanellopoulou et al. (2021) who found that poor sleep patterns and sleep duration are associated with higher weight status. Although these scores are elevated in our sample, they do not fall within a clinical range. The same also holds for the healthy weight children's positive pattern of correlates for disordered eating (items 1-7) and self-esteem indices (total, academic and general) and the negative relations between well-being and *T*-scored RCADS depression scale.

The present study also identified the links between child mental health and other variables such as parental shame, behavioural difficulties in children, their sleep habits, and self-esteem. As was expected, better well-being was found to be related to fewer behavioural and emotional problems, including depressive symptoms (see also England, 2021). By contrast, differences were observed between previous studies and the current study, as children with higher scores for disordered eating reported higher scores for self-esteem (Reilly et al., 2003).

Comparisons Between Diabetes and Control Group

We found that the control group scored higher on all the disordered eating variables (e.g., binge eating) than the diabetes group, Troncone et al. (2016) suggested that it is most likely the result of the increased attention that children with Type 1 diabetes are forced to pay to their bodies, both in terms of function and size (weight loss/gain), and the knowledge of the value of nutrition, exercise may exacerbate a person's self-consciousness, irrespective of BMI classification.

In our sample, diabetes group scored lower on measures of: self-esteem; eating disorder survey items 1-7, well-being, *T*-scored RCADS subscales (all), raw CBCL subscales (most), and sleep habits. Lower levels of self-esteem in the diabetes cohort could be linked to how a young person sees their own efficacy in the home, at school, and in other situations (Kanellopoulou et al., 2021; Yorukoglu et al., 1986). Their higher mental health problem scores may put them at greater risk of experiencing depression, anxiety, and social phobia related problems in the future. Our findings are in line with other published studies: they could be associated with patient frustration with the differences between themselves and other children, the need to take daily insulin shots, lifestyle changes as a result of long-term disease management, and poor understanding of their condition among parents (Dahlquist et al., 2007; Zheng et al., 2013). Increased family conflict and low self-esteem are also likely to be linked to poor well-being (de Wit et al., 2011). Children with Type 1 diabetes have been reported to have more sleep disturbances, such as night-time waking, compared to their healthy counterparts, due to hypoglycaemia or parents' night-time caregiving practices (Jaser et al., 2017).

Surprisingly, some indices showed that fruit and vegetable consumption was higher in the diabetes group and they consumed less non-core food (e.g., snacks), less sweetened beverages, and had higher physical activity levels than the control group. This would be good news, because healthy pattern makes blood sugar easier to control and could prevent obesity and any long-term related complications, such as cardiovascular disease and stroke. Excessive weight has been found to enhance the body's resistance to insulin, resulting in increased insulin needs and more weight gain (Patient information, 2019). Unfortunately, it needs to be noted that most children's consumption of healthful foods was extremely low in both groups, and their Median BMI was high. The same can be said about their levels of physical activity. There are probably cultural reasons for this pattern. With respect to the diabetes group, it had previously been reported that diabetic teenagers tend to avoid physical activity due to fear of hypoglycaemia (Yoynk et al., 2009), even though physical activity can lower HbA1C levels and improve quality of life (Bernardini et al., 2004; Fox, 1999). Overall, we consider that healthy lifestyle interventions promoting fruit and vegetable consumption and physical activity would benefit both cohorts.

Some variations in parental behaviours were also observed. Parents in the control group scored lower on the child feeding related variables (e.g., feeding responsibility) than the parents of children with Type 1 diabetes; this may be due to added responsibilities in the latter group related to diabetes management. The opposite trend was seen for parenting related problems (e.g., laxness), with parents of children with Type 1 diabetes scoring lower. Many previous studies have shown that parents of children with diabetes show symptoms of anxiety, depression, and stress compared to control groups (Malerbi et al., 2012; Van Gampelaere et al., 2020). However, our study did not find any differences in the mental health and well-being scores for parents of young children with Type 1 diabetes and the control group. This could be the result of the higher sensitivity to moral values, and the higher levels of prosocial behaviours exhibited among Kuwaiti parents, as Kuwait is considered a religious country (de Oliveria Maraldi, 2020). It may be that relative wealth and traditional extended family structure act as protective factors for these parents. However, there is also a possibility that parents did not want to disclose any mental health issues, as indicated by limited research regarding mental health in the Middle East, as well as the social and cultural stigma surrounding this topic (Mohammadzadeh et al., 2020). Almazeedi and Alsuwaidan,, (2014) claim that stigma makes people less likely to disclose negative behaviours related to poor mental health or well-being. Therefore, they are less likely to seek treatment or more information regarding these issues. In addition, religion, shame on the family, and a lack of community support can also act as barriers to mental health disclosure and support in countries such as Kuwait (Almazeedi et al., 2014).

Strengths, Limitations, and Recommendations

The strengths of our research include: examining the relations between mental health, well-being, and lifestyle factors (previously not used in a single sample) in diverse cohorts that reflect the population but were nevertheless well matched at the outset on a range of demographic variables; recruiting 8-11 year old primary-aged children (rather than older children or a very broad range of ages, as was typical in the existing literature); looking at parent-child dyads; and reporting the result from an under-researched population.

We also note some limitations to the conclusions that can be drawn from the study. This research relied mainly on self-report measures, which can be prone to biases in both children and adults (Burt et al., 2014); however, the alternatives would have been both impractical and, in some cases, arguably less reliable. We asked the children to complete some of the questionnaires; similar data collection methods to ours have often been used in the existing literature with this age group and measures (Adam et al., 1993; Allgaier et al., 2012; Koster et al., 2015). However, it is possible that some of our findings may have been different had the parents been asked to assist their children. Some of our measures were translated into Arabic for this study, and not previously validated in this sample; however, the Cronbach alpha scores indicated their suitability. Finally, we have not assessed pubertal status of the children although this variable may affect their psychological functioning and recommend that this should be done in follow-up research.

Overall, our findings indicate that children with Type 1 diabetes, and their parents, could benefit from targeted psychosocial support. Given that a range of potential issues have been identified in a primary age cohort, such support should be offered early to prevent development of more serious problems later on.

Chapter 8

Changes in mental health, well-being, and lifestyle of children with Type 1 diabetes and their parents during the quarantine due to the COVID-19 pandemic in Kuwait

This chapter focuses on the COVID-19 lockdown, and the study it reports investigated the impact on mental health, well-being, and lifestyle in children with Type 1 diabetes and their parents before and during the pandemic. This chapter had been written up as a paper and submitted to a peer-reviewed journal. The preliminary findings have been presented at “How to live with COVID-19?” conference Sponsored by Arab Open University in Kuwait in July 2021 (see Appendix 12).

Abstract

The COVID-19 lockdown has substantially affected people's health and rapidly changed daily routines globally. This study investigated the impact on mental health, well-being, and lifestyle in primary school children with Type 1 diabetes and their parents during the first lockdown in Kuwait. A questionnaire battery related to mental health, well-being, and lifestyle was administered at baseline in Summer 2019 (face-to-face, at a diabetes outpatient clinic) and at follow up during lockdown in Summer 2020 (via telephone, in adherence with COVID-19 restrictions). Data were collected for 70 dyads with children aged 9-12 years. Significant differences were found for children with Type 1 diabetes and their parents when comparing scores before and during the COVID-19 lockdown. Their mental health worsened to a higher level of depression, anxiety, stress, and a poor level of wellbeing. The average scores on the follow-up tests fell within a clinical range on these measures. Moreover, significant differences were found in their lifestyle compared to before the lockdown, such as decreases in physical activity and healthy core nutritional intake. Our findings indicate that the COVID-19 lockdown has had a significant psychological and possibly physiological impact on children with Type 1 diabetes and their parents. Hence, there is a need for mental health support services focusing on these groups.

Keywords: COVID-19, pandemic, lockdown, children with Type1 diabetes, mental health, parent well-being.

Introduction

Type 1 diabetes is a chronic disease that requires close medical attention and supervision of glucose monitoring (Hassan, 2006). Being diagnosed with Type 1 diabetes in childhood can lead to behavioural and mental health problems such as anxiety, depression, social anxiety, and lower self-esteem (Powers, 2017). A diagnosis often leads to worry and stress-related responses regarding the complex care plan that needs to be adhered to by the patient and delivered by the caregivers (Silverstein et al., 2005). A child with diabetes may potentially be anxious about how their condition will develop in the future, be fearful of leaving their house or communicating with others and be prone to avoid social interactions with others (Diabetes and Anxiety, 2017).

A diagnosis may also affect the entire household in numerous ways financially, socially, and/or emotionally (McCarthy & Kushner, 2007). Coping with the disease can be challenging especially for primary school aged children and their families (Calentine & Porter, 2012). Therefore, it is imperative that families learn to manage and cope with the effects that the disease might have on their children's life-span development, yet there are few published studies regarding this situation, especially among younger, primary school aged children (Alazmi, Bu Bashiru, Viktor, & Erjavec, 2022, in submission).

Such children may be more vulnerable to poorer mental health than their counterparts not diagnosed with a chronic illness (Wake, Hesketh, & Cameron, 2000). In the existing literature, older children with Type 1 diabetes have been found to have poorer mental health such as anxiety, depression, aggressive behaviour, and attention problems than healthy children (Zheng & Chen, 2013).

Regarding their lifestyle habits, children with Type 1 diabetes suffer from poor sleep quality, and less physical activity due to hypocalcaemia phobia (Jaser et al., 2017; Michaud et al., 2017). Parents of children with Type 1 diabetes also suffer from anxiety and parental stress compared to parents of healthy children (Moreira et al., 2014).

In March 2020, The World Health Organization (WHO) declared COVID-19 a pandemic. Also referred to as Coronavirus, it is a novel, highly contagious illness that has spread rapidly around the world (Russell et al., 2020). The so-called lockdowns quickly changed people's daily routines globally (Passanisi et al., 2020). In Kuwait, the first lockdown period was from May to August 2020. There was reduced access to hospitals and follow up visits to outpatient departments were limited to emergency cases to help reduce the spread of the virus (COVID 19 Update, 2021).

During the lockdown, measures were implemented that restricted individual freedoms, such as self-isolation and social distancing, and many people were forced to stay at home to reduce infection opportunities (Singh et al., 2020). This was likely to have been detrimental to people's well-being; for example, a Chinese study reported that the impact of the long period of separation from the world led to fear, guilt, and shame of being infected; these factors resulted in mental health issues, such as loneliness, panic, anxiety, depression, and sleep disorders (Duan et al., 2020).

Parents were burdened with additional caregiving roles during the pandemic; evidence suggests that parents respond negatively and more intensely to disasters compared to children, causing anxiety and posttraumatic stress (Russell et al., 2020). Furthermore, undefined periods of lockdown may lead to unprecedented impacts on parents' mental health and well-being, with unknown effects on parent–child relationships (Russell et al., 2020). It had been reported that patients with chronic illness had higher levels of depression, anxiety, and stress compared with healthy counterparts during the lockdown in Spain (Ozamiz-Etxebarria et al., 2020). To our knowledge, there are no published studies relevant to the impact of the pandemic on the mental health, well-being, and lifestyle of children with chronic diseases such as Type 1 diabetes.

The pandemic was rapid in onset and therefore, in most cases, the effects it may have had could only be estimated in retrospect. However, in Summer 2019, we collected data on mental health, well-being, and lifestyle with a large cohort of children with Type 1 diabetes and their healthy counterparts (Alazmi, Viktor, & Erjavec, in submission).

In Summer 2020, the first author was able to contact most of the parents in the diabetes group, all of whom consented to participating again. The aim of the present study was to identify the impact of the pandemic by re-examining the children's and caregivers' responses to a questionnaire battery and physiological measurements (e.g., Body Mass Index). The measurements taken in this study were administered before and during the COVID-19 lockdown. We predicted that children with Type 1 diabetes would have higher levels of stress, anxiety, and depression during the pandemic compared to pre-lockdown. Regarding the parents, we also predicted that they would have higher levels of depression, anxiety, stress, fear, and shame due to the lockdown and isolation from the outside world. In this chapter, the changes in mental health, well-being, and lifestyle indices (e.g., eating habits and physical activity) for 70 dyads are reported.

Methodology

Design and Sample

In July 2019, as part of a study looking at determinants of children's mental health and well-being, we recruited 100 children (and their parents) from three Paediatric Diabetes Centres in Kuwait. The children were aged between 8–11 years and diagnosed with Type 1 diabetes; they had been undergoing intensive insulin treatment for at least six months via an insulin pump or multiple daily injections and did not have any other chronic disease. Follow up measurement was conducted one year later, during the COVID-19 pandemic in July 2020, for 70 of the original dyads. We were unable to reach the remaining 30 dyads because their telephone numbers had changed, or they moved to another clinic. There were no systematic differences between this subgroup and the final sample of 70 participating dyads (all $p>.05$ on baseline measures).

Table 8.1. shows the demographic characteristics of the retested dyads

Table 8.1.

Demographic characteristics of children and their parents (N=70) at follow up.

Therapy Type	59 insulin needles and 11 pumps
Children's gender	35 girls and 35 boys
Median age	11 years (Range 9-12 years)
Median weight	35 kg (Range 27-82 kg)
Median height	139 cm (Range 125-163 cm)
Median BMI Percentile	76 % (Range 20-99%)
Nationality	58 Kuwaiti and 12 non-Kuwaiti
Parents' gender	64 mothers and 6 fathers
Parents' age range	35-44 years old
Median household size	6 members (Range 3-8 members)
Qualification	9 secondary school, 27 college, 24 bachelor's degree, 1 master's degree, 7 doctorate degree
Employment status	1 home carer, 15 unemployed, 1 self-employed, 1 employed part time, 52 employed full time

Procedure

All study procedures were granted ethics approval by Bangor University, school of psychology research and governance committee (UK) and the Kuwait Ministry of Health. At baseline, parents of children aged 8–11 years were approached by a nurse during their regular clinic visits; those interested in participating were taken to a meeting room provided by the hospital for confidentiality and privacy. The researcher provided written and verbal information and debrief (see Appendix 1) about the nature of the study and then parents signed the consent form (see Appendix 1). Parents and children were asked to complete a questionnaire battery containing measures related to their mental health, well-being, and lifestyle. The researcher assisted the children when needed.

A year later, in July 2020 during the COVID-19 lockdown, we obtained participants' contact phone numbers from hospital records and invited them to participate in a follow up. All parents who were contacted accepted this invitation. The researcher collected data via telephone calls with parents and children to avoid face-to-face contact and ensure compliance with lockdown restrictions and hospital regulations. The consent forms were sent via e-mail or smartphone application (WhatsApp, see Appendix 1). All participants completed the same questionnaire battery as in the baseline. An additional brief set of questions regarding their lockdown experience was also administered (see Appendix 6 and reported upon in the results section).

Measures

All measures were translated from English to Arabic either by their publishers, authors or by the research team, following the appropriate guidelines (WHO, 2021). They have been widely used in previous research and the Cronbach's alphas for all measures before and after COVID are reported (see Appendix 9). Parents also answered the same demographic questions at baseline and follow-up (see Table 8.1).

Physiological Measures

HbA1c is the standard medical measure of average blood sugar concentration over the period of 8–12 weeks (Little & Sacks, 2009). The International Society for Pediatric and Adolescent Diabetes (ISPAD, 2018) recommended values of less than 7.5 for children with diabetes. HbA1c scores, height (in centimetres), and weight (in kilogrammes) were taken from the children's hospital records at follow-up and compared to their baseline scores.

Child Self-Completed Measures

Self-Esteem

The Coopersmith Self-Esteem Inventory-School Form (CSEI; Lane, et al., 2002) is designed to measure attitudes toward the self on four subscales (general self, social self, home parent, and school academic).

Eating

The Kids Eating Disorder Survey (KEDS; Childress, Brewerton, Hodges & Jarrell, 1993) is a questionnaire that identifies eating disorders and attitudes through three subscales (body dissatisfaction, disordered eating, and binge eating).

Well-being

The WHO-5 Well-being Index (WHO-5; WHO, 1998) measures health related quality of life in the last two weeks, with a higher score indicating better well-being. Parents also self-completed this questionnaire.

Mental health

The Revised Child Anxiety and Depression Scale (RCADS; Chorpitra et al., 2000) is a questionnaire that examines aspects of depression and anxiety in youth (subscales: social phobia, panic disorder, major depression, separation anxiety, generalized anxiety, and obsessive compulsive). Higher *T*-scores indicate more mental health related problems.

Coping behaviour

The Coping Questionnaire for Children and Adolescents (CODI; Petersen et al., 2004) has six subscales (acceptance; avoidance, cognitive palliative, distance, emotional reaction, and wishful thinking) with higher scores indicating coping-related problems.

Parent-Completed Child Measures

Mental health

The Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001) consists of 29 items across four subscales (depressive problems; anxiety problems, anxious depressed, and withdrawn depressed) with higher raw scores indicating mental health problems.

Strengths and Difficulties Questionnaire measures emotional and behavioural difficulties (SDQ; Goodman, 1997). The SDQ contains 25 items across six subscales (emotion symptoms; conduct problem, hyperactivity, peer problem, difficulty global score, and prosocial), with higher scores indicating mental health problems.

Sleep quality

The Child's Sleep Habits Questionnaire examined sleep behaviour (CSHQ-A; Owens, Spiritio, & McGinn, 2000) and contains 22 items across four subscales (bedtime, sleep behaviour, waking during the night, and morning wake up); a higher score means more disturbed sleep.

Lifestyle

The Lifestyle Behaviour Checklist (LBCL; West & Sanders, 2009) uses 26 items that are focused on weight gain and eating activities. It consists of two subscales; behaviour associated with food (whining, arguing about, and refusing food), and physical activity and social situations, with higher scores on each subscale indicating a specific lifestyle-related problem.

Dietary behaviour

The Children's Dietary Questionnaire measures food over the past seven days or the past 24 hours (CDQ; Magarey, Golley, Spurrier, Goodwin, & Ong, 2009). It contains five subscales (fruit and vegetables, sweetened beverage, water, fat from dairy, and non-core food which means high fat, salt, or sugar food). Higher scores on all subscales, except fruit and vegetables, suggest an unhealthy dietary intake.

Physical activity

The Physical Activity Questionnaire for Children (C-PAQ, Anderson et al., 2017) estimates general levels of physical activity in children over a week (during free time, school time, and the weekend). Higher scores show higher levels of physical activity at each timepoint, and higher sedentary behaviour scores are indicative of lower levels of physical activity at each timepoint.

Parent-Completed Self-Report Measures

Parental shame

The Other as a Shamer scale aims to measure external shame (OaS; Allan, Gilbert & Goss, 1994); a higher score means that parents may be feeling or experiencing more externally related shame.

Parental coping behaviour

The Coping Health Inventory for Parents aims to appraise the behaviours that they are currently using to manage family life when they have a child with a chronic illness (CHIP; McCubbin et al., 1981). There are three subscales (Coping 1: cooperation and an optimistic definition of the situation, family integration; Coping 2: self-esteem and psychological stability, social support; and Coping 3: understanding the health care situation through communication with other parents and consultation with the health care-team). A higher score indicates more engagement with positive coping behaviours.

Parental fear of hypoglycaemia

Hypoglycaemia Fear Survey (HFS-P; Cox et al., 1987) contains 27 items across two subscales (behaviour and worry), with higher scores suggesting greater amounts of parental fear associated with managing their child's possible hypoglycaemia.

Parental mental health

Depression Anxiety Stress Scales (DASS-21; Lovibond & Lovibond, 1995) contains three subscales (depression; anxiety, and stress), with a total score over 14 suggesting a clinical condition may exist.

Parenting behaviour

The Parenting Scale (Arnold, O'Leary, Wolff, & Acker, 1993) contains three subscales (laxness; over reactivity, and verbosity) with higher scores indicating dysfunctional parenting, and low scores indicating good parenting.

Parental child feeding behaviour

The Child Feeding Questionnaire was used to assess parents feeding beliefs, practices, and attitudes related to child feeding (CFQ; Birch et al., 2001). It has seven subscales (responsibility; parental weight, child weight, concern about child weight, pressure to eat, monitoring, and restriction), with higher scores indicating less adjustment in their intake in response to differences in caloric density of food.

COVID-19 impact measure

The parents' questionnaire about COVID-19 impact in 2020 is a 12 item questionnaire that was designed specifically for this study by the researchers to assess the impact of the pandemic on both the parents and their children's daily life under lockdown. Answers were elicited on a five-point Likert scale (strongly agree; agree, neither agree nor disagree, disagree, and strongly disagree). Each item response was followed up with a further question about how COVID-19 had impacted the respondents in the relevant situations (individual items are listed in Table 8.4).

Data Analysis and Decision Rules

Statistical analyses were performed using Statistical Package for the Social Sciences (SPSS) version 25. The distribution of scores for all scales and subscales were checked for skewness and kurtosis prior to undertaking inferential analysis (see Appendix 9); those that scored higher than ± 2 were investigated with non-parametric tests (Miles & Shevlin, 2001).

Thus, baseline vs follow-up comparisons were performed by either repeated (paired or correlated) samples *t*-tests or Wilcoxon's signed-ranks tests alongside the appropriate repeated measures effect size and power calculations. The raw data scores for The Child Behavior Check List subscales were analysed instead of the *T*-scored data (Holmes et al., 2015; Pandolfi, Magyar & Dill, 2009). The *T*-scored data for the RCADS were used.

Changes in parent and child scores from baseline to follow up were represented by Reliable Change Indices (RCIs). According to Ferguson, Robinson, and Splaine (2002, p. 509), RCIs are a statistic that can be used to identify the magnitude of change score on a self-report measure for it to be considered reliable. Hence, RCIs were used to identify significant changes on mental health variables from baseline to follow up in this study. The RCIs for the variables included in the regression analysis were calculated with the Leeds Reliable Change Indicator (Morley & Dowzer, 2014). RCIs can be used in regression analysis to identity the strength and direction of the predictor variables (see Busch, Lineweaver, Ferguson & Haut, 2015).

All tests were two-tailed; even though we predicted that parent's and children's scores on mental health variables would increase during the pandemic, this is an unprecedented event and directional hypotheses could not be made based on the existing literature regarding specific measures. Cohen's *d* statistics for repeated measures were used as indices of effect size (Cohen, 1992).

Results

Across all measures, parent's and children's scores changed from the 2019 baseline to 2020 follow-up. Statistically significant changes are shown in the figures, and corresponding effect sizes are tabulated and shown in Table 8.2. and 8.3. A description of the clinical range for parents and children is tabulated in Appendix 9.

Figure 8.4. shows the mean scores for the child-completed self-report measures and parent-completed child measures at baseline and follow-up. Starting at the top left corner, it can be seen that children's self-esteem (total and general), measured by CSEI, decreased. The same was also seen for children's well-being scores, which shows that children had poorer self-esteem and well-being at follow-up compared to baseline. KEDS body dissatisfaction scores increased from baseline to follow up, although children's eating disorder scores (KEDS items 1 to 7) decreased. All child mental health scores (*T*-scored RCADS, raw CBCL, and SDQ subscales) showed increases with large effect sizes at follow up compared to baseline. These follow-up scores fell within a clinical range according to each measures' cut-off point (as seen in Table 8.2. below). Their CODI scores, pictured at the bottom left, indicate that children showed a decrease in acceptance, avoidance, and emotion reaction coping at follow-up; however, they also show an increase in wishful thinking coping scores.

The bottom middle figure shows the sleep habits subscales: there was an increase in sleep bedtime; sleep behaviour, waking during the night, and morning wake up scores, which all indicate that children experienced more sleep-related problems during the pandemic.

Figure 8.5. shows mean scores for the parent-completed self-report measures. The top left graph shows that shame total score decreased from baseline to follow up. In a similar manner, CHIP scores for subscales 1, 2, and 3 also show a decrease at follow up from baseline. The top middle figure shows a decrease in well-being scores from baseline to follow up, as evidenced by the large effect sizes reported in Table 8.2. below. The HSF-P scale

scores show a decrease, whilst the HFS-P worry scale scores show an increase from baseline to follow up. The top right figure shows the DASS-21 subscale scores for depression, anxiety, and stress. All three subscale scores show an increase from baseline to follow up with large effect sizes. These increases are also deemed problematic according to the cut-off scores provided by the scale's authors (Lovibond & Lovibond, 1995).

At the bottom left, the parenting subscale shows a decrease in score from baseline to follow up. The bottom right figure shows the six CFQ subscales; five out of six subscales show a decrease in score from baseline to follow-up, whilst the CFQ parental weight shows an increase from baseline to follow up.

Figure 8.6. shows mean scores for the lifestyle measures and HbA1c. The top left shows the children's physical activity subscale scores**.** First score is sedentary behaviours total time in minutes on weekday, and second score is sedentary behaviours total time in minutes weekend (video games) scores show an increase from baseline to follow up. It is noteworthy that parents did not report any physical activities during the lockdown. Non-parametric or distribution-free tests (Wilcoxon Signed Rank Test) were used because the data did not meet parametric assumptions. The top middle figure shows that HbA1c scores increased from baseline to follow up, with 33 out of 70 children scored below 7.5 HbA1c (managed group) and 37 children out of 70 above 7.5 HbA1c (unmanaged group) in baseline, while 12 children out of 70 scored below 7.5 HbA1c (managed group), and 58 children out of 70 above 7.5 HbA1c (unmanaged group) in the follow up. Hence, from baseline to follow-up the children's diabetes status went from being managed to unmanaged.

The top right figure shows the LBCL food score, and that physical activity and situation scores decreased from baseline to follow up. The bottom left and the middle figure show children's dietary behaviour from baseline to follow up to determine the intake of recommended foods and fluids (vegetables, fruit, and water etc.) or discouraged foods and fluids (foods high in salt, sugar, and fat, and carbonated sweet drinks). The figure shows a decrease in fruit and vegetable consumption from baseline to follow up in terms of daily and weekly basis, while the consumption of water did not change from baseline to follow up. However, discouraged food (non-core) consumption increased from baseline to follow up.

Table 8.2.
The Cohen's d for the Repeated Measures t-tests

	Effect Size (Cohen's *d*)
SE Total Score	0.3*
SE General Self	0.4*
ED Items 1-7	0.1*
ED Body Dissatisfaction	0.5**
Well-being	1.2***
RCADS Social Phobia	0.7**
RCADS Panic Disorder	1.7***
RCADS Separation Anxiety	1.6***
RCADS General Anxiety	1.4***
RCADS Major Depress	1.6***
CBCL Depress Problem	1.6***
CBCL Anxious Depress	1.9***
CBCL Withdraw Depress	2.1***
CBCL Anxiety problem	2.2***
COP Accept	0.2*
COP Avoid	0.1*
COP Emotional Reaction	0.1*
COP Wishful Thinking	0.7**
Sleep Bedtime	0.6**
Sleep Behaviour	1.5***
Waking During The Night	0.8***
Morning Wake Up	1.0***
SDQ Emotion Symptoms	0.8***
SDQ Conduct Problem	1.6***
SDQ Hyper Activity	1.2***
SDQ Peer Problem	0.9***
SDQ Global Score	1.7***
SDQ Pro Social	0.4*
Shame Total	0.7**
COP Subscale1	0.3*
COP Subscale2	0.8***
COP Subscale3	1.5***
Parent Well-being	1.0***
HFS Behaviour	0.4*
HFS Worry	0.5**
DASS-21 Depression	2.0***
DASS-21 Stress	1.5***
DASS-21 Anxiety	1.6***
Parenting Style Laxness	0.5**
Parenting Style Over Reactivity	0.5**
Parenting Style Verbosity	0.3**
Parenting Style Sum	0.8***
Parental Feeding Perceived Responsibility	1.2***
Parental Feeding Perceived Parental Weight	0.1***
Parental Feeding Perceived Child Weight	0.3*
Parental Feeding Concern About Child Weight	0.8***
Parental Feeding Restriction	0.1*
Parental Feeding Monitoring	0.5**
Sedentary Behaviours Total Time in Minutes Weekday	0.8***
Sedentary Behaviours Total Time in Minutes Weekend	0.4*

Note: Small *; Medium **, and Large ***

Table 8.3.

The Cohen's d for the Wilcoxon Signed Ranks Tests

	Effect Size (Cohen's *d*)
HbA1C	0.3**
Lifestyle Food Score	0.2*
Lifestyle Physical Activity and Situation Score	0.3**
Fruits Eaten in The Last 7 Days	0.6*
Fruits Last frequency Week	0.3**
Veg Eaten in The Last 7 Days	0.5**
Veg Last frequency Week	0.6**
Non-Core Foods Last 7 Days	0.5*
Non-Core Foods Average Daily Portion	0.2*
Water Last 24 Hours	0.5**
Fruits Eaten Average Daily Portion	0.5**
Veg Eaten Average Daily Portion	0.5**
RCADS Obsessive Compulsive	1.1***

Note: Small *; Medium **, and Large ***

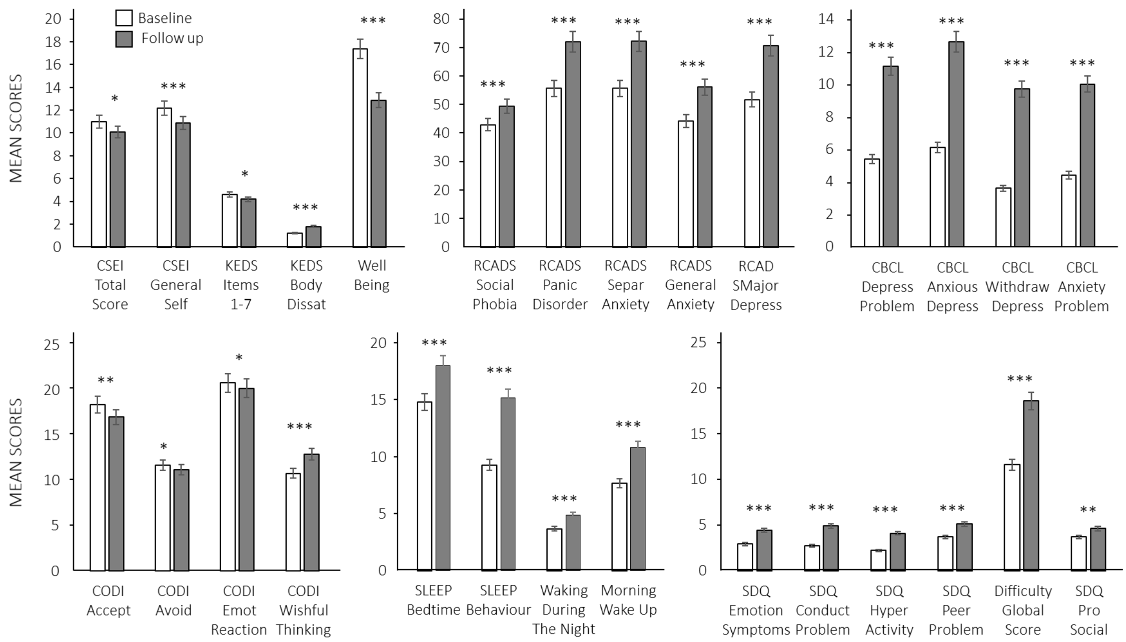


Figure 8.4. Child measures at Baseline (in white) and Follow up (in grey). Bars represent means and standard errors. The graph at the top left shows CSEI total, CSEI general, KEDS 1-7 items, KEDS body satisfaction, and child well-being. The top middle graph shows RCADS subscales. The top right graph shows CBCL subscales. The graph at the bottom left shows CODI subscales. The bottom middle graph shows sleep habits subscales. The bottom righ graph shows SDQ subscales. All the results are significant with *$p < .05$, **$p < .01$, ***$p < .001$.

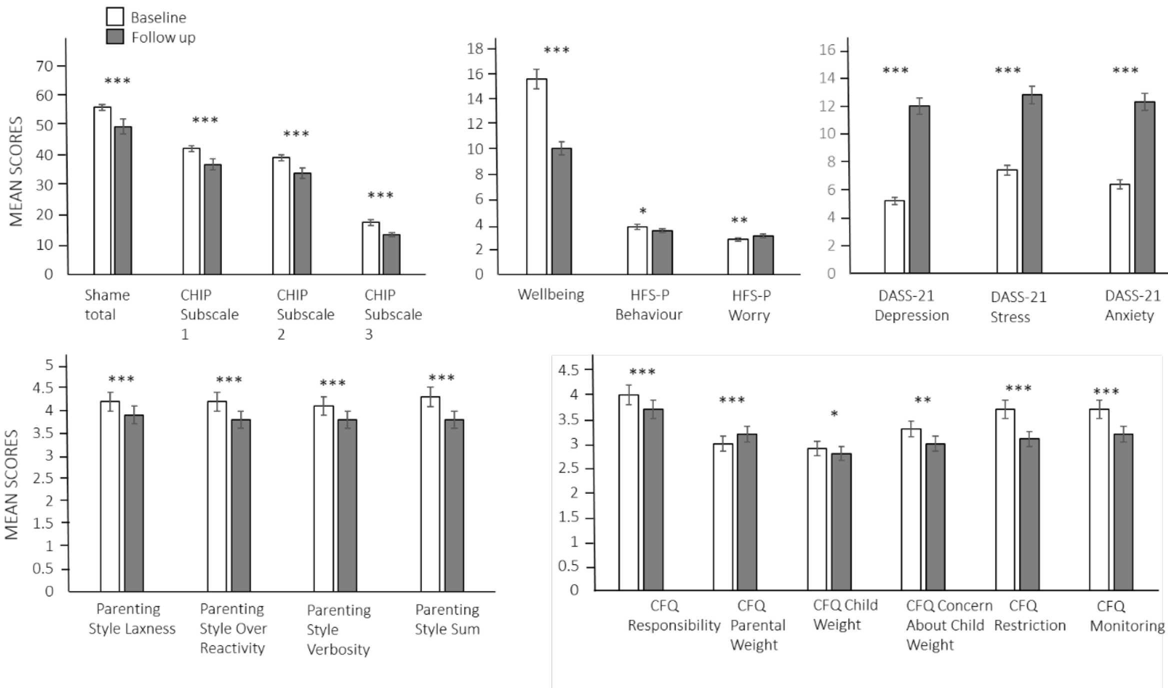


Figure 8.5. Parents Measures at Baseline (in white) and Follow up (in grey). Bars represent means and standard errors. The graph at the top left shows Shame total, and CHIP subscale. The top middle graph shows Well-being, and HFS-P subscale. The top right graph shows DASS-21 subscales. The graph at the bottom left shows Parenting subscales. The bottom righ graph shows CFQ subscales. All the results are significant with *p < .05, **p < .01, ***p < .001.

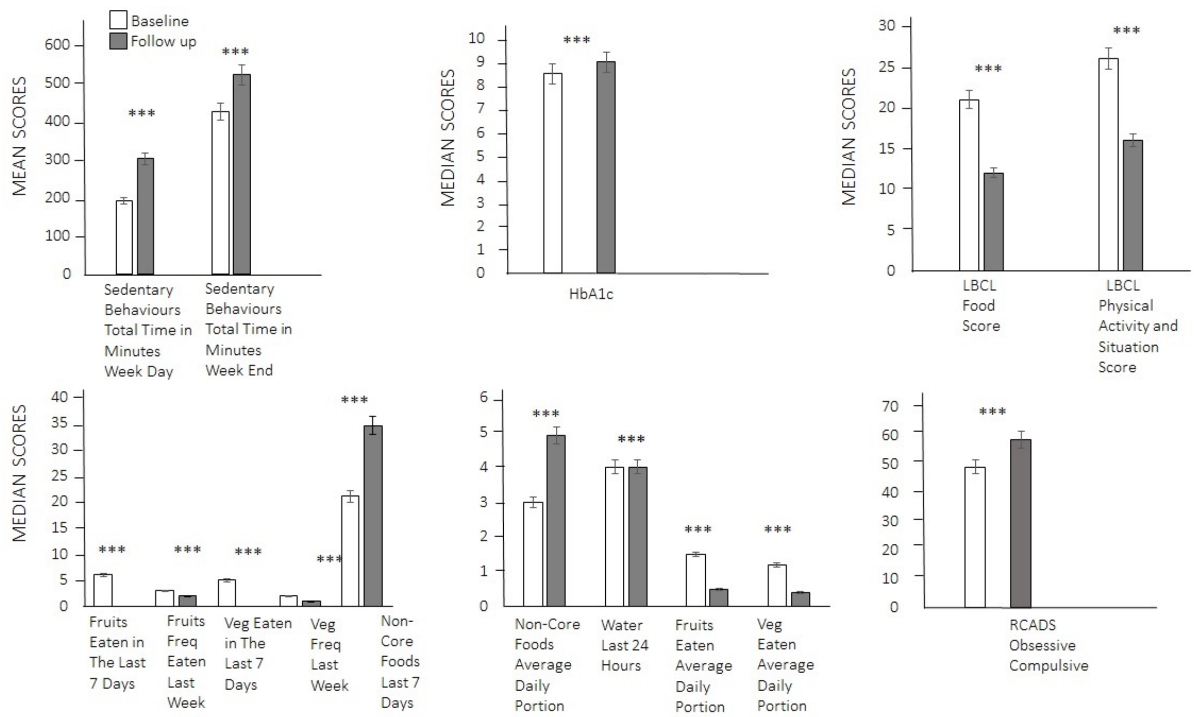


Figure 8.6. Lifestyle Measures and HbA1c at Baseline (in white) and Follow up (in grey). Bars represent means and standard errors. The graph at the top left shows children's physical activity subscales. The top middle graph shows HbA1c. The top right graph shows LBCL subscales. At the bottom left and the middle graph shows the children's dietary subscales. The bottom righ graph shows RCADS obsessive compulsive. All the results are significant with *p < .05, **p < .01, ***p < .001.

Test-retest reliability for Physiological Measures

Inspection of the data from baseline to follow up for the physiological measures with Pearson's product moment test-retest (TR) correlations indicated moderate to strong classifications: (1) HbA1C = .85, p <. 001; (2) BMI percentiles = .79, p <. 001, and Height = .99, p <. 001. Strong = .80 or above and moderate = .50 to .79 (Campbell et al., 1999; Devore & Peck, 1993).

Reliable Change Indices for Well-being and Mental Health

The findings for the repeated measures t-tests showed that the mental health and well-being of parents and children worsened during the pandemic. No notable changes were found for the lifestyle related variables so they were not explored in the regression analysis.

Children's Well-being at Follow Up

A hierarchical regression was run to predict children's well-being scores at follow up after inspecting the pattern of correlates for the RCIs and those for the follow up scores. At step one children's baseline well-being scores were controlled for and accounted for 10% of the unique variance in children's well-being follow up scores (F (1, 68) = 7.54, p = .008). The addition of the five predictor variables in step two accounted for an additional 27% of the unique variance (F (5, 63) = 5.41, p < .001) and the full model accounted for 37% of the unique variance in children's well-being follow up scores (F (6, 63) = 6.17, p < .001, post hoc power = .99 and Cohen's f-squared = 0.59). Examination of the VIF (1.00 to 1.96) and tolerance (0.51 to 1.00) values indicated that there were no violations of regression diagnostic assumptions (see Table 8.7.).

Table 8.7.
Regression Coefficients for Children's Well-being at Follow Up

Outcome variable	Predictor variables	*β*	*p*
Well-being at FU			
Step 1	Well-being at BL	316	.008
Step 2	Difficulties RCI scores	-.291	.042
	HFS worry RCI scores	-.131	.217
	Separation anxiety RCI scores	.203	.059
	Depressive problem RCI scores	-.004	.976
	Coping 3 RCI scores	-.284	.007

Parental Outcomes at Follow Up

Preliminary correlational analysis identified that the best predictors of parental outcomes were the RCIs derived from their self-report measures (e.g., DASS-21 RCI depression scores) rather than the baseline or follow up scores so these were used to build three regression models of parental outcomes (see Table 8.8.).

Table 8.8.
Regression Coefficients for Predicting Parental Outcomes

Outcome variable	Predictor variables	*β*	*p*
Shame RCI scores	Parenting style sum RCI scores	.186	.105
	DASS-21 stress RCI scores	-.201	.067
	Child feeding sum RCI scores	.334	.005
Parenting Style Sum RCI scores			
	Shame RCI scores	.188	.137
	HFS behaviour RCI scores	.153	.188
	Child feeding sum RCI scores	.240	.059
Child Feeding Sum RCI scores	Shame RCI scores	.346	.003
	DASS-21 depression RCI scores	-.182	.089
	Parenting style sum RCI scores	.225	.047

The model for predicting: (1) parental Shame RCI scores accounted for 26.5% of the unique variance (F (3, 66) = 7.93, p < .001, post hoc power = .99, Cohen's f-squared = 0.36); (2) parenting style sum RCI scores 18.5% of the unique variance (F (3, 66) = 4.99, p < .01, post hoc power = .92, Cohen's f-squared = 0.23), and (3) child feeding sum RCI scores 27.6% of the unique variance (F (3, 66) = 8.39, p < .001, post hoc power = .99, Cohen's f-squared = 0.38). No violations of regression diagnostic assumptions occurred during the modelling of parental outcomes: VIF = 1.04 to 1.15 and Tolerance = 0.87 to 0.96 (Model 1); VIF = 1.07 to 1.26 and Tolerance = 0.79 to 0.93 (Model 2), and VIF = 1.01 to 1.13 and Tolerance 0.89 to 0.98 (Model 3).

Parental Mental Health at Follow Up

Inspection of the parental mental health RCIs identified that three models could be derived from the data (see Table 8.9.). In model one, child feeding sum RCI scores accounted for 5.8% of the unique variance in DASS-21 depression RCI scores, (F (1, 68) = 4.17, p < .05, post hoc power = .56, Cohen's f-squared = 0.06.). In model two, HFS behaviour RCI scores accounted for 6.00% of the unique variance in DASS-21 anxiety RCI scores, (F (1, 68) = 4.36, p < .05, post hoc power = .56, Cohen's f-squared = 0.06), and finally; in model three, shame RCI and HFS behaviour RCI scores accounted for 16.9% of the unique variance in DASS-21 stress RCI scores, (F (2, 67) = 6.82, p < .01, post hoc power = .92, Cohen's f-squared = 0.20, VIF = 1.05, Tolerance = 0.95). Models one and two were found to have low post hoc power and Cohen's f-squared values because of the small amount of unique variance accounted for in each model in relation to the sample size (N = 70). The findings for models one and two need to be replicated with a larger sample to reliably identify the strength and direction of the relations between the predictor and outcome variables.

Table 8.9.
Regression Coefficients for Predicting Parental Mental Health RCI Scores

Outcome variable	Predictor variables	β	p
DASS-21 Depression RCI scores			
	Child feeding sum RCI scores	-.240	.045
DASS-21 Anxiety RCI scores			
	HFS behaviour RCI scores	-.245	.041
DASS-21 Stress RCI scores			
	Shame RCI scores	-.219	.059
	HFS behaviour RCI scores	-303	.010

Parents' Responses to a Questionnaire about the Impact of COVID-19 in 2020

Table 8.10. summarises the distribution of sample responses from parents who answered the questionnaire about the impact of COVID-19 in 2020. It can be seen that Covid-19 has had a negative impact on parents' lives in all aspects, except family finances, which is reflected in question number 2.

Table 8.10.
Frequencies of the Sample Responses from Parents Regarding the Impact of COVID-19 in 2020

Item	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	*N*
1- COVID-19 has had a negative impact on our family relationships.	4	53	3	10	-	70
2- COVID-19 has had a negative impact on our family finances.	-	23	3	44	-	70
3- COVID-19 has had a negative impact on me as a parent.	5	43	4	18	-	70
4- COVID-19 has had a negative impact on my mental health and well-being.	6	52	4	8	-	70
5- COVID-19 has impacted on how I manage my child's diabetes.	4	53	5	8	-	70
6- COVID-19 has impacted on how my child manages their diabetes.	3	44	11	12	-	70
7- COVID-19 has had a negative impact on my child's mental health and well-being.	7	53	3	7	-	70
8- COVID-19 has impacted on how medical services manage my child's diabetes.	1	39	7	23	-	70
9- COVID-19 has had a negative impact on my daily routines (sleep, eating, exercise).	6	50	6	8	-	70
10- COVID-19 has had a negative impact on my child's daily routines (sleep, eating, exercise).	3	55	3	9	-	70
11- COVID-19 events are making me worry about the future.	4	55	4	7	-	70
12- COVID-19 events have changed our lives in important ways.	5	53	3	9	-	70

To add more detail to the responses, each question was followed up with a prompt, asking parents if they had anything to add.

Q1- A total of 32 parents commented. Of these, 28 stated that they missed seeing their friends and attending family gatherings; two of the parent responders were divorced and one reported that his child missed her mother. One mother reported that her husband was not in Kuwait and that she was missing a family gathering as a result; another mother divulged that her only child hates her father because of his work as a policeman which keeps him away from the home.

Q2 - Of seven respondents, five answered that they had no present income and two reported that they had lost their employment.

Q3- Of the 22 parents who provided comments, five answered that they had been careless; three reported experiencing feelings of fear, whilst two others described shouting and feeling nervous regularly. Stronger anger issues were acknowledged by three of the parents; three others reported high levels of caring, concern, and associated strictness, three mothers said that they had more responsibilities in the absence of their husbands. One father said that COVID-19 had impacted negatively on the relationship between him and his child, as "he was not there when he was supposed to be." Another mother said her behaviour had bounced between being strict and careless. "Money shortages made me feel that I could not keep up with my family expenses," she explained.

Q4- A total of 29 parents commented on this question. Ten revealed they had experienced depression, weight gain, and anger issues; six reported suffering from sleep problems, stress, and nervousness. Ten had experienced anger issues, anxiousness, stress, and fear. Three of the parents said they were constantly fearful, and that life was not enjoyable anymore.

Q5- Twenty-eight parents commented on this question; 24 reported their children had suffered from high blood sugar; two children with high blood sugar had been admitted to hospital, and two reported levels of low blood sugar in their children.

Q6- Out of nine respondents, four reported being fearful of their children having high blood sugar; three revealed that their children had refused their medicine, one child was said to care more about medicine than previously, and one child insisted that they did not care about their medicine.

Q7- Of 34 parents who commented on the question, 10 reported that their children had experienced stress, nervousness, and a reluctance to go out in public. Five reported fearfulness and hyperactivity in their children related to COVID-19 and noted that most had many questions about it. Two reported that their children had lost interest in food and play and become careless as a consequence of emotional anxiety about the pandemic. Two reported child bedwetting and anger as symptoms of their children's reactions to COVID-19, while another two said their children were worried about the future. Additionally, three reported their children had experienced sleep problems, nightmares, and/or they wanted to sleep near their mothers. Two reported that their children have tended to cry a lot since the outbreak of the pandemic, have a fear of death, and are more anxious or overly sensitive. Four revealed that their children wanted to self-isolate and did not want to play outside. Three reported that their children had experienced sadness and loneliness due to the pandemic and had missed their friends.

Q8- Twelve respondents commented on the question. Five reported a lack of access to hospital appointments; four reported delays in receiving medicine, two reported sleep issues and concerns about clinic closures. Lastly, one parent reported that they or their child had experienced eye problems and been refused routine care.

Q9- Of 29 parents who commented, most reported that their children had experienced sleep issues (including insomnia), eating issues, and a decrease in physical activities. Additionally, two reported that their children had been repeatedly asking for non-healthy food. Three parents reported that their children had experienced insomnia.

Q10- A total of 32 parents commented on this question. Most reported sleep issues, lack of exercise, and eating-related issues (eating significantly less or more food or refusing it). Three parents reported their children asked for non-healthy food.

Q11- Fifteen parents commented, of which 12 reported experiencing feelings of fear about life and the future, one reported fear of death, and two revealed they did not trust the future and worried about it.

Q12- Twelve parents offered comments, of which four said that life had changed for the worse, three described the challenging effects of no school, no work, and a lack of social gatherings. Two parents said they no longer experienced enjoyment in their lives and another two reported major changes in their thoughts and beliefs about life. Only one parent reported losing their employment, and as a result, a major impact on their daily routine.

Discussion

The findings demonstrated that the COVID-19 pandemic had a significant impact on the mental health, well-being, and lifestyle of children with Type 1 diabetes, and their parents during the lockdown. Children with Type 1 diabetes at follow-up had higher scores than before the lockdown with respect to mental health issues, such as anxiety, depression, low self-esteem, and stress. These issues may be related to daily routine disruption, impairment of quality of life; moreover, children with Type 1 diabetes may be more vulnerable to developing fear, distraction and irritability (Passanisi et al., 2020). Imran et al. (2020) suggested that children in quarantine are likely to have anxiety and stress due to social isolation, fear of an unknown disease, and stigmatisation.

We also recorded higher levels of HbA1c during the lockdown, the change in diabetes unmanaged group increased by 21 child during lockdown. Passanisi et al. (2020) reported higher levels of blood sugar during the lockdown. Due to limited access to health services, patients were unable to keep scheduled outpatient follow-up appointments and were also forced to change their approach to chronic disease management.

Our study observed lower scores for well-being in both parents and children with Type 1 diabetes during the lockdown. The regression analyses showed that child well-being at follow-up could be predicted by changes in SDQ difficulities RCI scores, *T*-scored RCADS separation anxiety RCI scores, raw CBCL depressive problem RCI scores, and two parental varaibles, namely; HFS worry RCI scores, and coping 3 RCI scores after controlling for baseline well-being scores. Similarly, a study by McArthur et al. (2021) found that Covid-19 has the potential for significant negative consequences on children's mental health and well-being.

Alongside sleep disorders, changes in lifestyle, fewer physical activities and minimal consumption of healthy core food were also oberved from baseline to follow-up. Such negative health effects may be exacerbated if children are confined to their homes without access to outdoor activities or interactions with friends during the outbreak. An expected decrease in exercise and increase in sedentary behaviour could thus have a negative impact on glycemic control (Tornes et al., 2020). A previous study suggested that there is a correlation between physical health outcomes and well-being in improving immune system response, and in several ways, the lockdown is pushing children with Type 1 diabetes and their parents out of balance regarding their well-being (Howell, Kern & Lyubomirsky, 2007). The sudden change in lifestyle along with distance learning has led people to play more video games, modify their eating habits, and sleep time; this could contribute to an increase in weight gain, and to excessive consumption of snacks and unhealthy food. Di Renzo. (2020)

suggested that eating due to stress or boredom is one of the many implications of the COVID-19 lockdown.

Our study found that parents' worry increased while adaptive health coping decreased. A similar finding by Sweenie, Mackey and Streisand (2014) suggested that increasing parental stress could be associated with their child’s diabetes condition, such as fear of hypoclaecemia. By contrast, differences were observed between previous studies, and the current study, as parents’ external shame decreased during the lockdown. The regression analysis for predicting parental outcomes suggests that there is a relation between changes in shame RCI scores, parenting style RCI scores, stress RCI scores, and child feeding RCI scores. External factors are theorized to be the source of shame, due to the unique nature of lockdown and self-isolation, there is a probability that external shame was reduced to its minimum level in this study (Benedict, 1946; Wolf et al., 2010). Moreover, shame is characterised by a negative self-evaluation and is linked to avoidance behaviours or avoidance-oriented behavioural interntion (Wolf et al., 2010).

Parents of children with Type 1 diabetes also showed increased levels of depression, anxiety, and stress at follow-up compared to baseline, which fell into a clincial range. This finding is also supported by the regression analyses that show DASS-21 depression RCI scores, DASS-21 anxiety RCI scores, and DASS-21 stress RCI scores are predicted by changes in child feeding sum RCI scores, HFS behaviour RCI scores and shame RCI scores. Our finding is supported by the existing literature as it has been suggested that social restrictions, working from home, homeschooling, and changes to everyday family life increased parenting stress, anxiety, and depression (Calvano et al., 2021).

This study has two limitations. First, the data for 30 participants could not be collected due to lockdown restrictions. Second, we were unable to collect face-to-face data. However, these limitations appear to have had little or no impact on the general direction, importance and significance of the findings in relation to the sample recruited and tested or the identifiable impact of COVID-19. Comparing the results of the impact of the mental health, well-being and lifestyle before and during Covid-19 is a key strength in this study.

In conclusion, the COVID-19 lockdown experience had an impact on the mental health, well-being, and lifestyle of the parents and children with Type 1 diabetes in Kuwait. Our findings suggest that there may be a need for a psychological intervention for children and their parents to overcome the implications caused by the lockdown and restore an appropriate balance regarding their physical, psychological and mental health. This would require attention from multi-collaborative specialised teams to minimise its impact (e.g.,

Chapter 9

General Discussion

This chapter first reminds the reader of the aim of the current thesis and why we have conducted this research; it next summarises the findings and states the contribution to the literature. This is followed by brief discussions on theoretical implications, strengths and limitations, and implications for future research. The last section presents the author's reflection on the study and PhD.

The research presented in this thesis focused on both children with Type 1 diabetes and their parents. Type 1 diabetes is a chronic disease in which patients need insulin daily. Type 1 diabetes represents the most common form of diabetes among children (see Chapter 1; Diabetes UK, 2022), and the number of children and adolescents diagnosed with Type 1 diabetes is increasing yearly. Worldwide, 1.1 million children and adolescents under 20 years of age are estimated to have Type 1 diabetes (International Diabetes Federation, 2017).

The complications of diabetes affect not only the afflicted individual but can rather extend to the family and beyond. For example, diabetes can affect the child's learning capabilities (e.g., from absences due to hospital appointments) if not managed (Diabetes UK, 2022). Negative effects can also include depression, a high level of avoidance coping, and a low-grade point average (Reid et al., 1995). Moreover, diabetes can negatively impact an individual's social life; for example, some people with diabetes may feel anxious or experience hypo-anxiety (e.g., fearing situations that could lead to low blood sugar), leading them to avoid social situations or gatherings (Hedia, 2020). Parents of children with diabetes may experience parenting stress and symptoms of depression (Blankfeld et al., 1996; Patton et al., 2011).

Findings Summary and Contribution to the Literature

This thesis aimed to examine psychological functioning of children with Type 1 diabetes and their parents, and to explore why some children with Type 1 diabetes show a higher incidence of poor mental health and behavioural problems, such as depression, anxiety, and disordered eating patterns, while others do not. We additionally planned to examine how the variables identified in the existing research interact to produce these outcomes in primary school-age children, who have historically been underrepresented in sampling methods (see Chapter 5).

Chapter 3 systematically reviewed literature concerning children in primary school with Type 1 diabetes and their parents. The current thesis has identified areas for improvement in the methodological aspects of research. The purpose of the main systematic review was to elucidate the psychological and lifestyle variables that may impact the health and well-being of primary-age children and their families, by examining findings of 20 studies. The systematic review confirmed that children with Type 1 diabetes and their parents often suffer from psychological problems such as anxiety, depression, and sleep disturbance. Moreover, parents of children with Type 1 diabetes have been reported to suffer from hypocalcaemia. The review noted that most of the literature focused on teenagers (mean age was around 12 years old) rather than younger children.

The second part of the systematic review, presented in Chapter 4, was divided into four categories. The first category concerned psychological and behavioural variables in children with Type 1 diabetes and included nine studies. The findings from these studies demonstrated that children with Type 1 diabetes reported low self-esteem and depression. Moreover, there was a significant relationship between haemoglobin levels and emotional problems. The second category concerned comparing children with Type 1 diabetes to a control group and included six studies, which reported that children with Type 1 diabetes scored higher regarding aggressive problems, attention problems, and anxiety. The third category compared children with Type 1 diabetes to children diagnosed with other chronic diseases and included eight studies, which suggested that parents of children with Type 1 diabetes demonstrated higher levels of parenting stress and were more vulnerable to stress reactions compared to parents of children with other chronic diseases. Finally, the fourth category concerned the experiences of parents of children with Type 1 diabetes and included 15 studies, which reported that parents of children with Type 1 diabetes showed symptoms of posttraumatic stress disorder, a high level of burden, and low quality of life.

The paper presented in Chapter 7 aimed to fill some of the literature gaps identified in the systematic review. Our overall purpose was to explore whether primary school-age children with Type 1 diabetes experience poorer mental health, have a poorer lifestyle, or report poorer well-being than their peers without this diagnosis. We further investigated psychological factors, such as self-esteem, coping skills, and sleep habits, as well as parental fear, shame, mental health, coping skills, parenting skills, and parental relationship to child well-being. The results of Chapter 7 were divided into three sections.

In the first section, we used a difference in blood tests (HbA1c) to classify children with managed and unmanaged diabetes (children in the managed group had a lower HbA1c compared to those in the unmanaged group). We found that children in the managed group consumed more water than those in the unmanaged group. Additionally, parents of children in the unmanaged group experienced more parental shame than parents in the managed group. Next, the Body Mass Index (BMI) score for the diabetes group were used to form categories of; underweight, healthy weight, overweight and obese. Children who were classified as obese had a higher score on eating disorder items-1-7, body dissatisfaction, *T*-scored RCAD panic disorder, general anxiety, and sleep awake earlier. Overweight children had a higher score on *T*-scored RCAD obsessive compulsive. The results also suggested that children with a higher BMI are more likely to score higher than normal in assessments gauging panic disorder, depression, generalised anxiety, and body dissatisfaction, as well as more likely to score lower on a measure of academic self-esteem. There was a negative correlation between child well-being and social phobia, depression, and anxiety, but a positive correlation between parent well-being and academic self-esteem. There was a significant positive relationship between parental shame and Child Behavior Check List (CBCL) withdrawn depressed scores.

In Section 2 that considered healthy children and their parents, the findings showed a positive correlation between BMI and eating disorder items 1-7, binge eating, and body dissatisfaction. Conversely, a negative correlation was found between child BMI and peer problems, as well as between well-being and depression. Furthermore, children with a higher BMI spent more time participating in weekend activities. The BMI in the control group was also divided into four categories, similar to the diabetes group. The healthy weight children had a higher score on eating disorder items 1-7 than the other BMI classifications.

Section 3 compared the diabetes and control groups, with the findings suggesting that there were no significant differences between the parents of children with Type 1 diabetes and the parents in the control group regarding mental health, well-being, and external shame. Children with Type 1 diabetes had significantly lower mean scores across all self-esteem subscales. They additionally had lower scores in well-being and mental health subscales, such as the *T*-scored RCAD subscale and CBCL subscale, waking during the night more often than the control group. Concerning lifestyle, the control group was more likely to have a poor lifestyle (e.g., eating less fruit and vegetables), and eating more non-healthy food compared to the diabetes group. However, we identified that healthy eating and physical activity were so low in both cohorts that this presented a possible health risk for all the children.

Chapter 8 investigated the impact of Type 1 diabetes on the mental health, well-being, and lifestyle of children with Type 1 diabetes and their parents before and during the COVID-19 lockdown. The results for children with Type 1 diabetes showed that self-esteem and well-being were decreased at follow-up, while mental health variables such as social phobia, panic disorder, anxiety, depression, emotional symptoms, conduct problems, hyperactivity, and peer problems had increased to clinical ranges. Moreover, HbA1c scores were increased at follow-up, and sleep habits had also changed, including an increased frequency of waking up at night. Parents of children with Type 1 diabetes showed an increase in depression, stress, and anxiety to within clinical ranges. Furthermore, the scores on the HFS worry scale had increased, which suggests that parents were more worried about their child's hypocalcaemia status. However, well-being and shame scores decreased at follow-up. The impact of COVID-19 on children was readily observable through diet; for example, the consumption of vegetables and fruits had decreased during the pandemic, and the consumption of high fat/sugar food and soda had increased. Furthermore, physical activities decreased during COVID-19 due to restrictions, and children spent more time on sedentary behaviours, like video games. These results, taken together, present an alarming picture.

Comparisons with the existing literature

Overall, the empirical findings reported in this thesis were aligned with the existing literature in most part, and extended these findings to a younger sample of children from a different culture. Cultural effects were probably seen to influence some scores, such as lessening some of the adverse effects for children with higher weight status (as this becomes a social norm).

Children with Type 1 diabetes

The current thesis found that children with Type 1 diabetes reported depression and anxiety symptoms, which is consistent with the previously published research (Armstrong et al., 2011; Gruhn et al., 2016; Jaser et al., 2008; Jaser et al., 2010; Jaser et al., 2014; Whittemore et al., 2003). Children with Type 1 diabetes also showed symptoms of poor sleep quality (Feeley et al., 2019; Jaser et al., 2017). A significant relationship was found between higher BMI, mental health variables, and low self-esteem, similarly to the findings of Halfon et al. (2013) and Melnyk et al. (2006). Moreover, poor well-being in children with Type 1 diabetes may be associated with mental health variables and body dissatisfaction, an association similar to that found by de Wit et al. (2007).

Control group

Children with higher BMI reported more problematic eating, which is supported by a previous study by Munkholm et al. (2016). Children with higher BMI also reported less disrupted sleep and participated in more physical activities at the weekend. Moreover, a significant relationship was found between well-being and emotional problems, including depressive symptoms, similar to England's (2021) study.

Comparisons

Children with Type 1 diabetes had higher scores in mental health (such as anxiety, depression, and social phobia) than those in the control group, corresponding to studies conducted by Dahlquist et al. (2007) and Zheng et al., (2013). They also ate more vegetables/fruit, ate less unhealthy food, and had lower level of physical activity. Younk et al., (2009), found that children with Type 1 diabetes and their parents tend to avoid physical activities due to the fear of hypocalcaemia.

Parents of both groups

Unlike other literature that reported that parents of children with Type 1 diabetes showed symptoms of parental stress, anxiety, and depression compared to the control group (Gamlelaere, 2020; Malerbi et al., 2012), the results from the current research found no differences in the mental health and well-being scores between parents of children with Type 1 diabetes and the control group. This may be due to cultural values, such as stigma, embarrassment, or the potential disgrace of family reputation in Arab families (Almazeedi et al., 2013; Dalky, 2012). Moreover, no studies have reported a relationship between mental health and stigma in Kuwait (Westbrook et al., 1993).

COVID-19 study follow-up

COVID-19 pandemic has negatively impacted children and parents. Young children are typically vulnerable and have limited coping strategies, as well as a limited understanding of the pandemic (Imran et al., 2020). In Chapter 8, we investigated the impact of the pandemic. Our findings reported a decrease in child self-esteem and well-being, a finding similar to that of Alsawalqa (2021). There were increases within clinical ranges for child mental health scores (RCADS, CBCL, SDQ), the sleep habit subscale, and HbA1c results, similar to published studies (Alsharji et al., 2020; Dimeglio, 2020; Imran et al., 2020). This is alarming because, at baseline, none of the scores averaged into the clinical range.

Parents also suffered mental health impacts during the COVID-19 pandemic and lockdown, reporting an increase to clinical ranges for anxiety, depression, and stress, the same finding reported by Alessi et al. (2021); Duan et al. (2020); and Wang et al. (2020). Furthermore, external shame and parental well-being decreased during COVID-19. Regarding lifestyle (e.g., eating habits and physical activity), there was an increase in non-healthy food consumption (e.g., snacks), and parents did not report any physical activities for their children, similar to a study conducted in Kuwait during the COVID-19 by Almughamis et al. (2020), which found that people demonstrated poor eating habits, less physical activity, and weight gain. Another supportive finding comes from Di Renzo (2020), who reported a higher frequency of eating snacks and unhealthy foods during the pandemic.

Theoretical Implications

Children change as they grow, and their illnesses evolve over time; so does our understanding and treatment of diseases. The ecological model proposes that the child is at the center of a series of concentric circles that represent environments that influence the child in both directions. The concentric rings furthest away from the child represent societal values and culture, whereas the concentric rings closest to the child represent smaller-scale settings such as neighbourhood, family, and school (see Chapter 2; Bronfenbrenner, 1979). Our findings relative to ecological theory may help us understand environmental influences on the mental health and lifestyle of children and parents.

It is noteworthy that different schools of thought have developed in the study of ecology depending on the emphasis placed on analysis, including cultural ecology (Lumsden & Wilson, 1981), population ecology, and human ecology (Park, 1945). A socio-ecological perspective emphasises both individual and contextual systems, as well as their interdependent relationships, and thus provides a variety of conceptual frameworks for organising and evaluating health-promotion interventions (Stokols, 1996). According to Lakhan and Ekúndayò (2013), the socio-ecological model can make a significant contribution to the treatment and prevention of depression at both the secondary and tertiary levels. It can also be used as a useful framework for raising public awareness.

Using this ecological approach may be helpful in treating and rehabilitating people with depression in the community. However, this may also necessitate some level of community awareness, mental health advocacy, and empowerment. Windley and Scheidt,

(1982) found a link between the environment, mental health, and demographic factors. Moreover, Swearer and Hymel (2015) investigated how the socio-ecological diathesis-stress model can aid in understanding the nature of bullying, assisting in comprehending the fluid and dynamic nature of bullying as a stressful life event for both bullies and victims.

Mental health is influenced by a variety of social and environmental factors (e.g., stigma and discrimination**)**. According to Thornicroft et al. (2007), individuals experiencing stigma and discrimination in the healthcare system may receive reduced quality of care; such factors can also impact mental health outcomes, as well as augment educational, healthcare, and employment disparities (Hatzenbuehler et al., 2013). Maher et al. (2008); and Salsberry and Reagan (2005) reported the influencing factors for early childhood obesity and overweightness within the context of the microsystem and found them consistent with the ecological model of childhood obesity, in which Hispanic children were more likely to be obese or overweight than white children. Moreover, children of obese or overweight parents had a greater risk of becoming obese or overweight themselves (Dorosty et al., 2000; Dubois & Girard, 2006; Fernald & Neufeld, 2007; He et al., 2000; Jouret et al., 2007). Low household income also contributed to a higher BMI in children (Maher et al., 2008). Because mothers can have a significant impact on their children's nutrition, eating, and exercise behaviours, maternal weight issues can also impact a child's weight status (Durmus et al., 2012). Boonpleng et al. (2013) suggest that a school environment can help children achieve a healthy lifestyle when the ecological model is adopted by changing eating habits and promoting physical activities.

The ecological model approach allows for a range of environmental influences to impact and interact with a person's feelings, behaviour, lifestyle, and overall functioning. The environment, socio-ecological perspective, and family factors must all be considered when understanding the individual within a social context. It is also recommended that interventions be made at all levels to boost resilience and eliminate or reduce negative aspects of an individual's social functioning.

The findings of the present thesis show that younger, primary-age children with Type 1 diabetes could profit from help at multiple levels of the system, including psychological interventions targeting their parents' health and wellbeing, which has suffered from COVID-19 restrictions; societal drives to improve healthy eating and physical activity and improve their weight status; availability of health care and monitoring to better manage blood sugar levels; and psychological help administered to children who show elevated scores on indices of poor mental health and self-esteem as a preventative measure, before problems escalate.

Ecological Interventions to Improve Mental Health for Children with Type 1 Diabetes and Their Parents

There have been several interventions designed to improve mental health and wellbeing of children with Type 1 diabetes and their parents. For instance, Mourao et al. (2022) discusses the findings of an educational intervention designed to improve children's knowledge of diabetes in a primary school setting in Brazil. In this study, a sample group of 73 students aged seven to twelve years old, along with sixteen members of staff, attended a forty-minute theatrical production that focused on the causes and treatments of Type 1 diabetes. The production included scenes of glucometer (blood glucose meter) use, insulin shots, diet and food consumption, and physical activity, each of which have a significant impact on the health and wellbeing of children with Type 1 diabetes. Following exposure to the intervention, the sample was subjected to two structured interviews two months and two days after the play to assess knowledge about diabetes-related health behaviours. Mourao et al. (2022) discovered that children and teachers who were exposed to the intervention exhibited demonstrable improvements in knowledge across three key domains, including: (a) diabetes signs and recognition of diabetes symptoms; (b) diabetes management in the school; and (c) general knowledge of diabetes. According to Mourao et al. (2022), the most significant changes concerned diet and measures to introduce in the event that a pupil experienced a hypoglycaemic attack. These findings suggest that ecological interventions, which address the interpersonal (*microsystem*) determinants of success, can help to raise awareness about Type 1 diabetes. However, it remains to be seen how this knowledge translates into better mental and physical health for the children.

Studies have also explored the role that parents play in influencing the health outcomes of children living with Type 1 diabetes. For example, Mackey et al. (2016) evaluated the efficacy of interventions aimed at improving parents' understanding of Type 1 diabetes management. Thirty mothers of young children (aged one to six) who had recently been diagnosed with Type 1 diabetes were randomly assigned to one of two groups: the Young Child-Newly Diagnosed (YC-ND) intervention (a phone-based intervention which provided professional support to parents from trained counsellors); or a treatment-as-usual physical education intervention group. The researchers measured clinical outcomes, including children's blood glucose and insulin levels at baseline, and following the intervention, as well as child and parent measures of mental health, quality of life, stress, social support, and depressive symptomology. The researchers found that, when compared to the treatment-as-usual group, parents in the YC-ND group reported higher levels of engagement and satisfaction, greater perceived levels of social support, and lower levels of self-reported depressive symptoms. In addition, parents in the YC-ND group reported greater adjustments to parenting and disease management than parents in the control group. However, there was no observable change in clinical outcomes for the children following the intervention. These findings suggest that, while parental wellbeing is evidently a crucial determinant of a child's health outcomes, improvements to glycaemic control may be harder to achieve.

These findings have been supported by Grey et al. (2011) who randomly allocated a sample group of 186 parents of young children with Type 1 diabetes to a Coping and Skills Training (CST) intervention, or a generic educational intervention. Grey et al. (2011) assessed the mental health and coping skills of parents and children, as well as clinical outcomes, at three, six and twelve months post-intervention. Similarly, to Mackey et al. (2016), Grey et al. (2011) discovered that parents' self-reported measures of mental health were higher in the intervention group than in the control group, resulting in better coping mechanisms. However, Grey et al. (2011) also found that there were no statistically significant differences in measures of blood glucose levels prior to and following the intervention. As a result, it can be argued that addressing parental mental health and coping strategies has little impact on the child's health outcomes (Grey et al., 2011; Mackey et al., 2016).

Katz et al. (2014) used Care Ambassadors (CA) and family-focused psychoeducational interventions to improve glycaemic control in youth (median age 12.9 years). In a 2-year randomised clinical trial, three groups were compared: a standard care, monthly CA outreach, and monthly CA outreach plus a quarterly clinic-based psychoeducational intervention. There were no differences in HbA1c between treatment groups, but the authors reported that youth in the psychoeducation group maintained or improved their HbA1c and maintained or increased parent involvement more than youth in the other two groups combined, with no negative impact on diabetes-specific family conflict or youth QoL.

In two video-based telehealth interventions, Monzon, Clements, & Patton (2021) used a multidimensional conceptualisation of group engagement to help parents of children with Type 1 diabetes who were experiencing anxiety about hypoglycaemia or diabetes distress. The aim was to assess the relationship between the parents' level of group engagement and their treatment outcomes, as well as examine the variation in group engagement among parents. They discovered that parents who spent more time attending to the needs of other group members reported less hypoglycaemia fear after treatment. Moreover, parents who actively supported the group leader's goals during the session reported fewer depressive symptoms at the end of treatment. There is evidence that participants' opinions of the group dynamic influence their likelihood of attending subsequent sessions, particularly if they believe their level of engagement in the group is appropriate for the group (Paquin, Miles, & Kivlighan, 2011).

In addition to schools and parents, studies have examined the effectiveness of interventions aimed at improving a child's mental health in order to improve clinical outcomes. Much of the previous research has shown that young children with Type 1 diabetes experience higher levels of depression and anxiety than their peers and are more likely to have low self-esteem (Borus & Laffel, 2010). According to Borus and Laffel (2010), poor mental health is associated with a lack of perceived self-efficacy and an absence of motivation, which, in turn, has a negative impact on a child's capacity to adhere to the rigorous self-care regimens that children with Type 1 diabetes must regularly employ to maintain optimal blood glucose levels (such as a healthy diet and physical activities). A number of micro level interventions have been developed specifically to address this issue. For instance, some studies have explored psychosocial, cognitive-behavioural and motivational interventions to improve health outcomes for children with Type 1 diabetes (Carpenter & Cammarata, 2019). Many studies demonstrate significant improvements in treatment adherence following intervention (Carpenter & Cammarata, 2019).

Studies have also suggested that obesity prevention programs be implemented in schools. Safdie et al. (2014) applied an ecological intervention program to encourage healthy lifestyle habits and prevent overweight and obesity in school-aged children. In one setting (a school), thirty-two distinct intervention strategies were implemented to engage four different target groups (students, parents, school representatives, and government) across two domains (nutrition and physical activity) using a Social Cognitive Theory (SCT) construct. While there were no significant differences in the use of SCT constructs across domains, the results revealed a promising combination of strategies and theoretical constructs for implementing a school-based obesity prevention program.

Additionally, there have been many empirical studies that have explored the benefits of technological interventions to enhance treatment adherence and healthy lifestyle. For example, Knox et al (2019) conducted a systematic review of thirty previously published studies to examine the relationship between technological interventions (including telehealth, text messaging, interactive online support, and mobile phone apps), mental health and self-regulating behaviours, and clinical outcomes for children with Type 1 diabetes (outcomes included HbA1c levels, diet, and physical exercise). Knox et al. (2019) discovered a positive correlation between technological interventions and adherence to treatments. However, findings suggest that, while they are important, perceptions of self-efficacy have only a limited effect upon the key indicators of Type 1 diabetes self-management (Knox et al, 2019).

Finally, some studies have examined how social and cultural norms affect children's and parents' experiences of living with Type 1 diabetes. According to Elissa et al. (2017), who conducted a thematic analysis of ten parent-child interviews, a lack of knowledge and stigma pertaining to Type 1 diabetes are associated with lower levels of self-reported diabetes management and higher levels of anxiety and psychosocial distress.

However, while it is important to acknowledge the findings of research into ecological interventions, it is also essential to underline the limitations of the evidence base. Three issues are apparent: firstly, there are methodological limitations in the research that has been conducted into exploring the health of children with Type 1 diabetes. For instance, schools included in studies may not be representative of broader experiences with healthcare management across the educational sector (a school may, for instance, be situated in an area of relative wealth). Consequently, it is difficult to identify patterns of cause and effect between interventions and outcomes. Secondly, little research has been conducted to investigate the interconnectivity between the various ecological determinants of health and wellbeing. While some studies focus on the child, others will assess school settings or parental influences (Enlow et al., 2021). This is an immensely important limitation to note because the effectiveness of the ecological model can only be determined by understanding how the constituent parts of a social or environmental system interact (Enlow et al., 2021). Thirdly, much of the research on the benefits of technological and psychological interventions focuses on older children and adolescents, which further emphasises the importance of school and parental factors (Gonzalez et al., 2016), i.e. the mesosystem.

The ecological model identifies five interrelated factors that can determine the health and wellbeing of the child. This section has demonstrated that there is a range of evidence to support the application of the ecological model in interventions aimed at improving outcomes for children living with Type 1 diabetes. The vast majority of the evidence has focused on interpersonal, intrapersonal, and social factors, with limited evidence focusing on the social and cultural determinants of health. Studies have shown that parental and school-based interventions can improve children's and parents' mental health and increase understanding of Type 1 diabetes. Additionally, microlevel interventions can improve the psychological wellbeing of children while also increasing self-efficacy and treatment adherence. However, there remain a number of methodological and conceptual limitations that reduce the extent to which causal relationships between ecological interventions and outcomes for children with Type 1 diabetes can be identified.

Strengths and Limitations of the Present Research

Considering the systematic review presented in Chapters 3 and 4, typically, the authors of these studies often neither selected a representative sample size before conducting the examination nor specified the age range of the target population. Moreover, some researchers combined young children and older adolescents who could be classified as adults into a single category (e.g., 0–18 years old). Age is critical when considering phenotypic changes in health and disease. Currently, age information is used in medicine in a rather simplistic manner, with ages frequently classified into a small number of crude ranges corresponding to major stages of development and ageing, such as childhood or adolescence (Geifman et al., 2013). In addition, the discussed studies did not employ a comparison group, which is important in allowing us to account for any potential influences on the relationship in question. When a researcher includes a comparison group, many of these explanations can be ruled out (Mingle, 2018).

Regarding the methodology in Chapter 6, we selected a cross-sectional design to provide us with a snapshot of the health-related characteristics of Type 1 diabetes at a particular time. The main strength of the cross-sectional study design is that it is typically quick and affordable. For example, it is possible to study numerous results and exposures, allowing us to examine various characteristics simultaneously. However, the findings from the systematic review (Chapter 3) have revealed several limitations of most cross-sectional studies. Our goal was to improve certain aspects of the flawed methodology discovered in previous literature. Firstly, regarding sample size, effect sizes on mental health and the benefits of physical activity have been found to range from small (-.26) to moderate (.73) (Biddle et al., 2019). Moreover, when measuring parental mental health and child sleep issues in a sample of 82 preadolescent children, Hamilton et al. (2020) discovered a moderate effect size. Therefore, our sample size has been determined based on previously published research from the systematic review of the literature on childhood diabetes. Power and sample size calculations considering six predictor variables and a medium effect size, with alpha set at .05 and power at .80, indicated that 100 participants per group should be sufficient (Cohen, 1992). We aimed to recruit similar numbers of males and females. We did not anticipate excluding anyone confirming to the diagnostic recruitment criteria. Secondly, the comparison group is important because it allows us to control for any external factors that could influence the relationship (Mingle, 2018). Additionally, we have reported the therapy type. Finally, in contrast to almost all examined studies in the systematic review that did not specify an age range (i.e. 1 to 18 years old), our sample focused on a specific age range. However, as noted in Chapter 6, because of the nature of the 2020 pandemic, we amended our original design and plan for recruiting participants from Kuwait only to adapt to the current situation. Moreover, we could not devise an intervention plan.

The strength of Chapter 7 lies in the combination of mental health, well-being, and lifestyle. This present thesis is the first to address these factors for young children, as the primary focus was on primary school-age children with Type 1 diabetes, along with their parents. This study is also novel in exploring these factors using a control group and parents in Kuwait, an Arab country. However, lifestyle variables such as physical activity yielded limited results in the control group. Although these determinants are critical to a child's well-being (Jessen & LeBlanc, 2010), the data was collected in the summer season, and due to hot weather conditions at that time of year, it is critical to consider the types of activities that Kuwaiti children can engage in. It is worth noting that outside temperatures during summer in Kuwait can range between up to 50 °C and down to 40 °C, at day and night, respectively (Alenzi et al., 2020).

The current research did not find any significant differences in mental health between parents of children with Type 1 diabetes and the control group, pre-COVID, although a previous study suggested that participants may be less forthcoming with accurate information due to the stigma associated with mental health, particularly resulting from certain aspects of culture and religion (Petkari, 2015). It is possible that in-person interviews at baseline inhibited accurate reporting of problems, compared to calls that were used during follow-up, presenting a confound in the results.

The key strength of Chapter 8 was in examining the impact of COVID-19 on children with Type 1 diabetes and their parents. This helped us understand the effects of the pandemic by comparing results from before and during the event, while other studies have only examined the effects of COVID-19 during the pandemic. One limitation of this study is that we were unable to retest the control group due to the 2020 school closures and curfew restrictions in Kuwait, and because personal contact data was not available for the cohort.

Implications and Future Research

Despite the limitations discussed previously, the current research contributes significant evidence to the growing body of knowledge regarding the determinants of children's well-being, mental health, and lifestyle in those with Type 1 diabetes. This research aimed to fill the gap identified by the systematic review by exploring and elucidating the interaction between mental health, lifestyle, determinants, and well-being in children (children with Type 1 diabetes group vs. control group). As previously stated, little research exists concerning mental health and lifestyle in primary school-age children, both with and without Type 1 diabetes, in Kuwait and other Middle Eastern countries (Petkari, 2015).

The current research provides an exploratory opportunity to add to the existing literature, and the groundwork for both expanding evidence-based practice and recommending future research on child outcomes in Middle Eastern countries is thus laid. According to Thanhäuser et al. (2017), evidence-based interventions should implement proven strategies and activities through a continuum of research and evaluation that is demonstrated to effectively address the presenting problem. Moreover, they suggest that preventative methods for reducing mental health issues and increasing well-being are more effective and can improve outcomes for both children and parents, as well as across all ages.

Chapter 7 revealed a significant relationship between poorer lifestyle (such as physical activity, BMI/obesity, and eating habits) and mental health. An intervention targeting these areas/constructs/behaviours before they become established is required and should include both parents and children. Furthermore, Fuller et al. (2019) suggested that parents and caregivers are the primary influencers on behaviour development. Regarding child mental health intervention, Kuwait has limited intervention strategies for children. Kuwait's National Programme for Healthy Living is an initiative aimed at promoting the health and well-being of children with chronic disease (especially Type 1 diabetes), with the main focus of the programme centering on lifestyle determinants, such as physical activity, eating habits, body mass index (BMI), and child sleep patterns (Behbehani, 2014). However, this programme does not address parental influences, mental health, or healthy children. Future research may benefit from interventions considering the relationship between the lifestyle and mental health of children (especially young children) and their parents and promoting a healthy lifestyle that acknowledges the culture, stigma, and discrimination in Arab countries.

In Chapter 8, we conducted a follow-up during the COVID-19 pandemic and found that children with Type 1 diabetes and their parents had very negative experiences as a result of quarantine, often describing these experiences as a disaster. The impact of the event is huge compared to that of the circumstances before the event, with the ever-changing rules and restrictions only increasing difficulties. It is worth noting that in follow-up we have changed our plan from meeting participants face-to-face to contacting them via phone, the consent form and debrief was sent via an internet messaging application (WhatsApp, widely used in Kuwait), this demonstrates that data collecting can be achieved instantly even in difficult situations require social distancing between people (i.e., pandemic or a natural disaster). Parents and their children may require intervention, an emergency plan from the healthcare system, support from government agencies, and community such as family and friends. School provides an exceptional environment in which to assist children and adolescents in developing positive mental health and resilience, helps prevent mental health problems, and promotes the effective treatment of existing conditions (The Association for Child and Adolescent Mental Health, 2022). Future research should investigate the long-term psychological consequences that affected parents and children during the COVID-19 pandemic, especially in schools, and develop interventions that are tailored and targeted to increase efficacy.

At the present, it is not clear how the post-pandemic world will look, and there may be other restrictions that have to be applied in the future in case more dangerous strains of the coronavirus emerge. The results of the present research will be made available to the Kuwait Ministry of Health, and through journal publications to the wider scientific community, to aid in planning for such an event. Overall, the present thesis shows that children with Type 1 diabetes demonstrate poor mental health, including anxiety, depression, and low self-esteem, which can be detected at a younger age. It also highlights that the relationship between children's mental health and lifestyle, including diet and physical activity, was significant. Children and their parents need support from specialists, such as psychologists, teachers, medical doctors, nurses, and nutritionists to prevent the development of more serious issues in the future. They may require screening, assessment and intervention earlier than what is currently perceived, prescribed or advocated in the existing literature.

Personal Reflection

I herein present my personal reflection statement for my PhD. I hold a bachelor's degree in my field. I have served as a clinical psychologist in a hospital for over six years and have worked with children with chronic diseases and witnessed their behavioural issues, and I thought that I almost knew everything that is, until I started to ask questions and seek proper explanations. This prompted me to apply to Bangor University in 2016. I now hold an MSc in clinical and health psychology and am currently a PhD student. A PhD has been a journey for me. I had no idea of the breadth and depth of understanding I was about to acquire, let alone the level of effort required to reach such a level of understanding. Such efforts changed my thoughts and augmented my knowledge. When I started, right after my PhD proposal, I thought that I had enough information and could avoid further trouble (except statistics, of course). In writing the systematic review, I realised how much information was out there and how little I knew, as well as how weak my English-speaking and writing skills were (English is a second language to me).

The data collection was one of my favourite parts of the PhD. While collecting data in hospitals, I listened to children and parents and engaged with them rather than with paperwork. I felt they needed someone to listen to them, to understand how they feel and live every day, a specialist who could improve their daily life using techniques that are proven to be successful. The data input and analysis were not easy aspects of the PhD, and it would have lasted forever without the help and support of my supervisors.

The COVID-19 event was a disaster, and I thought that my PhD would be brought to a halt. The study plan changed, access to schools and hospitals was limited, and everything went online, such as meeting my supervisors and contacting children and parents by phone instead of face-to-face. I was worried that questionnaires would not be given to participants or returned to me. On the contrary, and to my surprise, many of the participants were very cooperative, and given their concerns about the pandemic and the health of their children, they were more than willing to talk. This gave me strength and confidence in my duty, and I realised how important my role as a psychologist is. I am confident that I have fulfilled my objective of deepening my understanding of my chosen field now, in the last year of my writing and having finished data collection and analysis. I believe that that a PhD is one step further in learning.

Training

During my PhD, I have attended training courses to learn more and to offer evidence-based help and assistance to children when I return to my clinical practice. These included:

- *Lecture on Diabetes on the 8th of May 2018, in Llandrillo Menai.* This lecture presented an overview of Type 1 diabetes, from the medical and psychological aspects.
- *Child Psychology Development Diploma, on the 30th of May 2019, in New Skills Academy.* This was a training course for anyone looking to work with children. It covered the area of development in children, and adolescents. We observed how a child interacts with their parents, themselves, and the world, to understand their mental health development.
- *Acceptance and Commitment Therapy (ACT) in Mindfulness Training in London, approved by the British Psychological Society*. This course consisted of two parts, and included theoretical and practical components.
    - Part 1: 32 hours; completion date on the 10th of May 2019. Trainers: Henry Whitfield and Martin Wilks.
    - Part 2: 32 hours; completion date on the 19th of July 2019. Trainers: Henry Whitfield and David Gillanders.

- *Acceptance and Commitment Therapy for Young People: 12 hours, on the 3rd & 4th Mach 2022*. Presenter: Dr. Louise Hayes. The course gave a detailed explanation of what ACT is all about, and introduced different ways to perform it.

- *A webinar: Is social media actually bad for adolescent mental health? On the 16th of February 2022.* This was organised by the British Psychological Society; it talked about the effect of social media on adolescent mental health and backed it up with a case study.

I have also undertaken training in teaching in higher education, offered by Bangor University, and completed the required module which included supervised practical aspects, talks, and reflection.

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Appendices

- Appendix 1: Information Sheet, Consent Form, and Debrief.
- Appendix 2: Information Sheet, and Consent Form in Arabic.
- Appendix 3: Child Self-Completed Measures.
- Appendix 4: Parent-Completed Self-Report Measures.
- Appendix 5: Parent-Completed Child Measures.
- Appendix 6: COVID-19 Questionnaire.
- Appendix 7: Descriptive statistics for Diabetes Group and Cronbach Alpha
- Appendix 8: Descriptive statistics for Control Group.
- Appendix 9: Descriptive statistics for Diabetes Group after COVID-19.
- Appendix 10: The 14th international conference on child and adolescent psychopathology on July 22-24 at the University of Roehampton London.
- Appendix 11: Bangor winter conference.
- Appendix 12; How to live with COVID-19? Sponsored by Arab Open University in Kuwait 31/07/2021.
- Appendix 13: Quality Assessment Tool for Quantitative Studies.
- Appendix 14: Prisma Checklist Guideline

Appendix 1: Information Sheet + Consent Form+ Debrief

Participant Information Sheet

Study title: Exploring the determinants of mental health and well-being of 8 to 11-year old children with Type 1 diabetes and their healthy counterparts.

Researchers: Afrah Alazmi, MSc**;** Mihela Erjavec, PhD**;** Simon Viktor, PhD

Information about the study

The aim of this study to understand the relationship between health, well-being, and lifestyle of children aged 8-11 years old and their family. We hope to learn more about young children who had been diagnosed with Type 1 diabetes, and also about children who have not had such a diagnosis. This will help us to, in the future, provide appropriate help and support for those children who may need it, and for their parents**.**

Why have I been asked to take part?

We are asking a large number of children and their families to take part in this research. Your participation is entirely voluntary, and you will help us to learn more about health, well-being, and lifestyle of children aged 8-11 years old and their parents.

What does study involve and what I will actually do?

In this study, you and your child will be asked to answer several behaviour / questionnaire measures relating to health, well-being, and lifestyle using pencil and papers. The height and weight will also be measured for the children. This session will take approximately 30 to 60 minutes of your time. This will include a welcome and brief information about the research; completing the questionnaires and measurements, and any questions you may have being answered by the researcher.

What are the possible disadvantages and risks of taking part?

There are no risks in taking part in this research. You do not have to answer any questions that you do not feel comfortable with, and you are able to withdraw at any time without giving a reason.

What will happen to my data?

All data will be kept confidential and anonymous, meaning that nobody will ever be able to identify you or your child by name (or in any other way). Full data protection regulations will be applied. Only the researchers will have access to the data, which will be stored on an encrypted and pass-worded computer in a securely locked office.

Who can I contact for further information?

You may contact the lead researcher, Afrah Alazmi, by phone on +44 7447 791349 or email at elx67e@bangor.ac.uk. or her supervisor, Dr Mihela Erjavec, at m.erjavec@bangor.ac.uk.

If you have any complaints regarding this research study, please contact Mr Huw Ellis, College Manager, Brigantia, Penrallt Road, Bangor LL57 2AS, UK; email: huw.ellis@bangor.ac.uk; phone +44 1248 383229.

Consent Form

Date of Testing: ____

Parent's name(s) and gender: ____

Child's name(s) and gender: ____

Child's age (years and months): ____________________________________

Please read the statements below and initial the boxes next to each statement:

I have read and understood the information accompanying this form ☐

I consent to participate in the study ☐

I consent to the participation of my child in the study ☐

I am aware that I can refuse to answer any question ☐

I am aware that the height and weight of my child will be measured ☐

Parent's signature: ____________________________________

Researcher name: ____________________________________

Researcher signature: ____________________________________

Date: ____

Thank you for taking part!

Study title

Exploring the determinants of mental health and well-being of 8-11 year old children with Type 1 diabetes and their healthy counterparts.

Researchers

Afrah Alazmi, MSc**;** Mihela Erjavec, PhD**;** Simon Viktor, PhD

About the study

We are hoping to learn more about health and well-being of primary school age children and their families. We are especially interested in finding out how children's mental health can be supported, and how to design effective interventions that can help their parents. To do this, we need to learn how to improve the mental health in children with no chronic illness, and in those who have been diagnosed with diabetes.

Why is this research important?

Previous research investigated these issues in adolescents, and we are hoping to learn more by looking at younger children and their parents. This study will enable us to understand the relationship between health, well-being, and lifestyle of children aged 8-11 years old and their family. Your participation in this study is much appreciated; our research relies entirely on good will and help from families like yours.

Queries

We welcome the opportunity to answer any questions you may have in relation to this study. If you think of any later, please do not hesitate to contact Afrah by phone on +44 7447 791349, via email on elx67e@bangor.ac.uk, or by writing to Bangor university, Brigantia building, Penrallt Rd, Bangor LL57 2AS.

If you have any complaints regarding this research study, please contact Mr Huw Ellis, College Manager, Brigantia, Penrallt Road, Bangor LL57 2AS, UK; email: huw.ellis@bangor.ac.uk; phone +44 1248 383229.

Appendix 2: Information Sheet + Consent Form in Arabic

Exploring the determinants of mental health and well-being in 8 - 11 years old children with Type1 diabetes.

طالبة الدكتوراه في علم النفس الإكلينيكي: أفراح سالم العازمي

المشرف على الدراسة من جامعة بانقور في بريطانيا:

Dr. Mihela Erjavec and Dr. Simon Viktor

مقدمة مختصرة للدراسة

قد يؤدي مرض السكري النوع الاول عند الاطفال الى مشاكل متشابكة مرتبطة بالسلوكيات مثل القلق والاكتئاب والقلق الاجتماعي واضطرابات الاكل وانخفاض معدل الثقة بالنفس. وغالبا ما يؤدي التشخيص للمرض في بدايته الى القلق فيما يتعلق بالخطة العلاجية للمريض مستقبلا وتقديمها من قبل مقدمي الرعاية الصحية. مما يجعل المريض قلقا بشأن كيفية إدارة المرض مع امكانية تطور الوضع الي العزلة والخوف من مغادرة المنزل أو التواصل مع الآخرين وتجنب العلاقات الاجتماعية بشكل عام. وبالإضافة لذلك، قد يؤثر مرض السكري على الاسرة بطرق عديدة مثل الناحية المالية والاجتماعية والعاطفية للأسرة، لذلك من الضروري أن تتعلم الأسرة مهارات إدارة المرض والتعامل مع الآثار التي قد تكون مصاحبة للمرض الطفل ونموه على المدى البعيد. وإلى الآن هنالك القليل من الدراسات المنشورة لمرضى السكري وخاصة الأطفال الاصغر سنا على سبيل المثال من 8 الى 11 عاما. وعليه فإن التأقلم مع المرض قد يشكل تحديا كبيرا للأسرة والطفل. تشخيص المرض والتأقلم معه يؤدي غالبا الي تغيير سلوك الطفل من خلال التأثير في نظامه الغذائي والتعليمي ونمط الحياة إذا لم تكن الاسرة تعي هذه المخاطر ومن المرجح ان يكون الوضع أكثر صعوبة للأسرة والطفل مستقبلا. من أفضل الطرق للتعامل مع هذه التحديات ألى الان هو خلق الوعي حول تأثير مرض السكري على صحة الطفل وسلوكياته و تقديم الدعم من المتخصصين القادرين على تقديمها من قبل المتخصصين في الصحة النفسية و السلوكية منذ بدايات تشخيص المرض.

الهدف من الدراسة

تهدف الدراسة الى معرفة السبب الذي يجعل بعض الاطفال المصابين بالسكري النوع الاول يعانون من سوء الصحة النفسية ومشاكل سلوكية مثل القلق و الاكتآب و اضطرابات الاكل بينما الاطفال الآخرين المصابين بالسكري لا يعانون من تلك المشاكل.

وعلاوة على ذلك تهدف الدراسة لمعرفة العلاقة بين المتغيرات في هذه المخرجات من البحث للفئة العمرية من 8 الى 11 عاما، خصوصا انه لا توجد دراسات كافية لهذه الفئة. وعليه فإنها تقدم نتائج أولية مهمة تخدم الدراسات المستقبلية لهذه الفئة العمرية. حيث أنها الدراسة الأولى التي تدرس هذه المخرجات.

المنهجية:

سوف نقوم بجمع عينه قوامها 200 طفل مع اهاليهم في الكويت تتراوح اعمارهم من 8 – 11 عاما. سيكون مجموع العينة في الكويت 200 طفل مع اهاليهم ,100 طفل مصاب بالسكر النوع الاول ويخضعون لرعاية الصحية في المستشفيات و100 طفل يتمتعون بالصحة من المدارس.

وتقرر جمع هذه الكم من المشاركين بالدراسة بعد الاطلاع على الدراسات السابقة. سوف تطبق علي الاطفال المرضى والاصحاء و اهاليهم مقاييس اكلينيكيه لدراسة التأثيرات السلوكية والنفسية ومتغيراتها للحصول علي صوره واضحه وشامله عن المرض وتداعيته.

الأخصائية

سنقوم بتحليل العينة عن طريق برنامج إس بي إس إس من شركة آي بي أم, وسنقوم بنشر النتائج في المجلات الطبية المتخصصة.

<u>معلومات عن المشاركة في الاستبيان</u>

عنوان الدراسة

Exploring the determinants of mental health and well-being in 8 - 11 years old children with Type1 diabetes.

طالبة الدكتوراه في علم النفس الإكلينيكي: أفراح سالم العازمي
المشرف على الدراسة من جامعة بانقور في بريطانيا:
Dr. Mihela Erjavec and Dr. Simon Viktor

ما هو دوري في هذه المشاركة ؟

مشاركتك في هذه الدراسة هي اختيارية بشكل كامل ومشاركتك ستساعدنا في فهم سلوك مرضي السكري والأصحاء.

ماهي محتويات الدراسة؟

سوف تجيب انت وابنك على استبيان مكون من مقاييس السلوكية بخصوص الصحة العامة ونمط الحياة هذا بالإضافة لقياس الطول والوزن للطفل. سوف تستغرق الاجابة عن هذه الاسئلة من 20 الي 30 دقيقه تقريبا.

هل هناك اي مخاطر من المشاركة؟

لا توجد أي مخاطر من أي نوع من المشاركة و تستطيع التوقف و الانسحاب من المشاركة في أي وقت تريد.

ماذا ستخدم هذه النتائج؟

هذه النتائج ستمكننا من فهم المشاكل السلوكية لمرضي السكر وغيرهم من الأطفال. هذا مع حفاظنا علي سرية المعلومات بشكل كامل. علما بأن مشاركتك غير مشروطة بالإفصاح عن الاسم او اللقب.

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<u>نموذج الموافقة</u>

التاريخ:

عمر الطفل:

جنس الطفل: ذكر انثى

بعد اطلاعي علي ورقة المعلومات : الرجاء رسم دائرة حول الإجابة:

1- أوافق على المشاركة في هذه الدراسة	نعم	لا
2- أوافق علي مشاركة ابني في هذه الدراسة	نعم	لا
3- أوافق على أخذ وزن وطول ابني	نعم	لا
4- أنا علي علم بأن أسمي ولقبي غير مطلوب	نعم	لا

توقيع ولي الأمر:

توقيع الباحث:

Appendix 3: Child Self-Completed Measures

Age:

Are you: Boy Girl Other

Which class are you in?

Nationality:

Therapy type:

Diabetic since 20…….

Weight:

Height:

Part (1) is looking at how you see yourself.

Please mark each statement in the following way:

If the statement describes how you usually feel, put a circle around "Like Me".

If the statement does not describe how you usually feel, put a circle around "Unlike Me". Example:

I spend a lot of time thinking of the future. like me unlike me

Like Me Unlike Me

❑ ❑ 1. Things usually don't bother me.

❑ ❑ 2. I find it very hard to talk in front of the class.

❑ ❑ 3. There are lots of things about myself I'd change if I could.

❑ ❑ 4. I can make up my mind without too much trouble.

❑ ❑ 5. I'm a lot of fun to be with

Part (2) is looking at your eating behaviour.

Please circle the best answer. If you not are not sure, circle the question mark.

Yes (like you) No (unlike you) ? If you are not sure

---

1) Do you want to lose weight now?

Yes No ?

2) Have you ever thought that you looked fat to other people?

Yes No ?

3) Have you ever been afraid to eat because you thought you would gain weight?

Yes No ?

Part 3: is looking at coping heath.

Please read each statement carefully and circle the number to the right of the item that indicates how often you find yourself feeling or experiencing what is described in the statement. Use the scale below.

1	2	3	4	5
Never	Rarely	Sometimes	Often	Always

1- I am able to manage my illness. 1 2 3 4 5
2- I have got used to my illness. 1 2 3 4 5
3- I cope well with my illness. 1 2 3 4 5
4- I accept my illness. 1 2 3 4 5
5- I take my illness easy. 1 2 3 4 5

Part4: Please put a circle around the word that shows how often each of these things happens to you. There are no right or wrong answers.

1	I worry about things	Never	Sometimes	Often	Always
2	I feel sad or empty	Never	Sometimes	Often	Always
3	When I have a problem, I get a funny feeling in my stomach	Never	Sometimes	Often	Always
4	I worry when I think I have done poorly at something	Never	Sometimes	Often	Always
5	I would feel afraid of being on my own at home	Never	Sometimes	Often	Always
6	Nothing is much fun anymore	Never	Sometimes	Often	Always
7	I feel scared when I have to take a test	Never	Sometimes	Often	Always
8	I feel worried when I think someone is angry with me	Never	Sometimes	Often	Always
9	I worry about being away from my parent	Never	Sometimes	Often	Always
10	I am bothered by bad or silly thoughts or pictures in my mind	Never	Sometimes	Often	Always
11	I have trouble sleeping	Never	Sometimes	Often	Always
12	I worry that I will do badly at my school work	Never	Sometimes	Often	Always
13	I worry that something awful will happen to someone in my family	Never	Sometimes	Often	Always
14	I suddenly feel as if I can't breathe when there is no reason for this	Never	Sometimes	Often	Always
15	I have problems with my appetite	Never	Sometimes	Often	Always
16	I have to keep checking that I have done things right (like the switch is off, or the door is locked)	Never	Sometimes	Often	Always
17	I feel scared if I have to sleep on my own	Never	Sometimes	Often	Always
18	I have trouble going to school in the mornings because I feel nervous or afraid	Never	Sometimes	Often	Always
19	I have no energy for things	Never	Sometimes	Often	Always
20	I worry I might look foolish	Never	Sometimes	Often	Always

Well-Being Please indicate for each of the five statements which is closest to how you have been feeling over the **last two weeks**. Notice that higher numbers mean better well-being. Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, put a tick in the box with the number 3 in the upper right corner.

	Over the last two weeks	All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
1	I have felt cheerful and in good spirit.	5	4	3	2	1	0
2	I have felt calm and relaxed.	5	4	3	2	1	0
3	I have felt active and vigorous.	5	4	3	2	1	0

Appendix 3: Parent-Completed Self-Report Measures

Part (1) is looking at your feelings or experiences about how you may feel other people see you. Please read each statement carefully and circle the number to the right of the item that indicates how often you find yourself feeling or experiencing what is described in the statement. Use the scale below.

0	1	2	3	4
Never	Seldom	Sometimes	Almost	Always

---

1. I feel that other people see me as not good enough.	0 1 2 3 4
2. I think that other people look down on me.	0 1 2 3 4
3. Other people put me down a lot.	0 1 2 3 4
4. I feel insecure about others' opinions of me.	0 1 2 3 4
5. Other people see me as not measuring up to them.	0 1 2 3 4

Part (2) is looking at your child's feeding behaviour

Please read each question carefully and circle the appropriate response.

---

1) When your child is at home, how often are you responsible for feeding them?

1= never - 2= seldom - 3= half of the time - 4= most of the time - 5= always

2) How often are you responsible for deciding what your child's portion sizes are?

1= never - 2= seldom - 3= half of the time - 4= most of the time - 5= always

3) How often are you responsible for deciding if your child has eaten the right kind of foods?

1= never - 2= seldom - 3= half of the time - 4= most of the time - 5= always

Part (3) is looking at your parenting style

At one time or another, all children misbehave or do things that could be harmful, are "wrong," or that parents, don't like. Examples include: hitting someone, forgetting homework, having a tantrum, whining, throwing food, lying, arguing back, not picking up things, refusing to go to bed, coming home late. Parents have many different ways or styles of dealing with these types of problems. Below are items that describe some styles of parenting.

For each item, fill in the bubble that best describes your style of parenting during **the PAST TWO MONTHS** with the child with you here today.

Example. At meal time...I let my child …

decide how much to eat. I ◯ ◯ ◯ ◯ ● ◯ ◯ decide how much my child eats.

IN THE PAST TWO MONTHS

1. When my child misbehaves... *I do something right away*	○	○	○	○	○	○	○	*I do something later*
2. Before I do something about a problem... *I give my child several reminders and warnings*	○	○	○	○	○	○	○	*I use only one reminder or warning*
3. When I'm upset or under stress... *I am picky and on my child's back*	○	○	○	○	○	○	○	*I am not more picky than usual*
4. When I tell my child NOT to do something... *I say very little*	○	○	○	○	○	○	○	*I say a lot*
5. When my child pesters me... *I can ignore the pestering*	○	○	○	○	○	○	○	*I can't ignore the pestering*
6. When my child misbehaves... *I usually get into a long argu-ment with my child*	○	○	○	○	○	○	○	*I don't get into an argument*
7. I threaten to do things that... *I'm sure I can carry out*	○	○	○	○	○	○	○	*I know I won't actually do*
8. I am the kind of parent that... *Sets limits on what my child is allowed to do*	○	○	○	○	○	○	○	*Lets my child do whatever he/ she wants*
9. When my child misbehaves... *I give my child a long lecture*	○	○	○	○	○	○	○	*I keep my talks short and to the point*
10. When my child misbe-haves... *I raise my voice or yell*	○	○	○	○	○	○	○	*I speak to my child calmly*
11. If saying no doesn't work right away... *I take some other kind of action*	○	○	○	○	○	○	○	*I keep talking and try to get through to my child*
12. When I want my child to stop doing something... *I firmly tell my child to stop*	○	○	○	○	○	○	○	*I coax or beg my child to stop*
13. When my child is out of sight... *I often don't know what my child is doing*	○	○	○	○	○	○	○	*I always have a good idea of what my child is doing*

Part (4) is looking at your behaviour in general

Please read each statement and circle a number 0, 1, 2 or 3, which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

Use the scale below.

0 Did not apply to me at all.

1 Applied to me to some degree, or some of the time.

2 Applied to me to a considerable degree, or a good part of time.

3 Applied to me very much, or most of the time.

1- I found it hard to wind down.	0	1	2	3
2- I was aware of dryness of my mouth.	0	1	2	3
3- I could not seem to experience any positive feeling at all.	0	1	2	3

Part 5: is looking at coping behaviours .Please Circle one number

□ 3 = Extremely helpful □ 2 = Moderately helpful □ 1 = Minimally helpful□ 0 = Not helpful. • For each coping behaviour you did not use please record your "Reason." o Please record this by checking on of the reasons: Chose not to use it or Not Possible

Coping Behaviors	Extremely Helpful	Moderately Helpful	Minimally Helpful	Not Helpful	I do not cope this way because: Choose Not to	Not Possible
1. Talking over personal feelings and concerns with spouse	3	2	1	0	☐	☐
2. Engaging in relationships and friendships	3	2	1	0	☐	☐
3. Trusting my spouse (or former spouse) to help support me and my child(ren)	3	2	1	0	☐	☐
4. Sleeping	3	2	1	0	☐	☐
5. Talking with the medical staff (nurses, social worker, etc.) when we visit the medical center	3	2	1	0	☐	☐
6. Believing that my child(ren) will get better	3	2	1	0	☐	☐
7. Working, outside employment	3	2	1	0	☐	☐
8. Showing that I am strong	3	2	1	0	☐	☐
9. Purchasing gifts for myself and/or other family members	3	2	1	0	☐	☐
10. Talking with other individuals/parents in my same situation	3	2	1	0	☐	☐
11. Taking good care of all the medical equipment at home	3	2	1	0	☐	☐
12. Eating	3	2	1	0	☐	☐
13. Getting other members of the family to help with chores and tasks at home	3	2	1	0	☐	☐
14. Getting away by myself	3	2	1	0	☐	☐
15. Talking with doctor about my concerns about my child(ren) with the medical condition	3	2	1	0	☐	☐
16. Believing that the medical center/hospital has my family's best interest in mind	3	2	1	0	☐	☐
17. Building close relationships with people	3	2	1	0	☐	☐
18. Believing in God	3	2	1	0	☐	☐
19. Develop myself as a person	3	2	1	0	☐	☐

Final part: is you:

1. **Age** (please circle):

18 - 24 years.
25 - 34 years.
35 - 44 years.
Over 44 years.

2. **Gender** (please circle):

Male Female Other

3. **What is the highest qualification that you have completed? (**Please circle**).**

None
Secondary school (GCSE, QCE, O'levels etc.)
College (A level, BTEC, HND, HNC etc.)
Bachelor's degree (BSc, BA etc.)
Master's degree
Professional degree
Doctorate degree
Other (please state)--

4. How many members are there in your household?

-- Persons

5. What is your current employment status? (Please circle**).**

Employed full time (40 hours per week).

Employed part time (below 40 hours per week).

Self-employed.

Unemployed.

Unable to work.

Working from home.

Home carer.

6. What category would best describe your total household income per year? (Please circle**).**

£ 20.000 – 30.000

£ 31.000 – 40.000

£ 41.000 – 50.000

£ 51.000 – 60.000

£ 60.000- and above

Other (please state)--

7. Nationality:--

8. **Do you have any history of mental health problems or illness in your family? If yes, which family members and what problem (please write below).**

NO

YES

Thank you very much

Appendix 5: Parent-Completed Self-Report Measures

Your child's date of birth (dd/mm/yy): …………….
Are you the child's: mother / father / guardian / other
Your child is gender: Girl Boy Other
Nationality:
Therapy type:
Diabetes since:20…….

Part (1) The following statements are about your child's sleep habits and possible difficulties with sleep. Think about the past week in your life when you answer the questions. If last week was unusual for a specific reason, choose the most recent typical week. Unless noted, check Always if something occurs every night, "Usually" if it occurs 5 or 6 times a week, "Sometimes" if it occurs 2 to 4 times a week, "Rarely" if it occurs once a week, and "Never" if it occurs less than once a week.

BEDTIME Write in your child's usual bedtime:
Weeknights _____:_____ am/pm
Weekends _____:_____ am/pm

	7 Always	5-6 Usually	2-4 Sometimes	1 Rarely	0 Never
1. Child goes to bed at the same time at night.					
2. Child falls asleep within 20 minutes after going to bed.					
3. Child falls asleep alone in own bed.					
4. Child falls asleep in parent's or sibling's bed.					
5. Child falls asleep with rocking or rhythmic movements.					
6. Child needs special object to fall asleep (doll, special blanket, stuffed animal, etc.).					
7. Child needs parent in the room to fall asleep.					
8. Child resists going to bed at bedtime.					
9. Child is afraid of sleeping in the dark.					

Part (2) is looking at your child's behaviour in general and includes any strengths or difficulties they may have. For each item, please mark the box for: Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of how things have been over the past six months.

		Not True	Somewhat True	Certainly True
1	Considerate of other people's feelings.			
2	Restless, overactive, cannot stay still for long.			
3	Often complains of headaches, stomach-aches or sickness.			
4	Shares readily with other children (treats, toys, pencils etc.).			
5	Often has temper tantrums or hot tempers.			

6	Rather solitary, tends to play alone.			

Part (3) is looking at your child's behaviour in general.
Below is a list of items that describe children and youths. For each items that describes your child now or within the past 6 month's record.
0= not true **1**= somewhat or some time true **2**= very true or often true

---

1)	There is very little he or she enjoys.	0	1	2
2)	Clings to adult or too dependent.	0	1	2
3)	Cries a lot.	0	1	2

Part (4) is looking at your child's physical activities.
Which of the following PHYSICAL activities did your child do in the PAST 7 DAYS?
Please complete this questionnaire for the following
days: ………………………… to ……………………………

Did your CHILD do the following activities in the past 7 days?		MONDAY - FRIDAY		SATURDAY- SUNDAY	
		How many times Mon–Fri?	Total hours/minutes Mon-Fri?	How many times Sat-Sun?	Total hours/minutes Sat-Sun?
EXAMPLE: Bike riding	No Yes	2	40 mins	1	15 mins
SPORTS ACTIVITIES Aerobics	No Yes				
Baseball/softball	No Yes				

Part (5) is looking at your child's life style
To what extent has this behaviour been a problem for you with your child in the last month?
Please circle the appropriate number: From 1 (not at all) to 7 (very much).

---

1) Eats too quickly.

1	2	3	4	5	6	7
not at all	a little		somewhat	much		very much

2) Eats too much.

1	2	3	4	5	6	7
not at all	a little		somewhat	much		very much

3) Complains about food.

1 2 3 4 5 6 7

part 6: is looking at your child's eating behaviour

1) **Please tick whether your child has eaten any of the following fruit (fresh, tinned or sweet) over the past 7 days. Tick every circle that applies.**

Fruit salad	Berriers	Orange	Peach
Mango	Dried fruit	Watermelon	Banana
Apple	Apricot	Melon	Pineapple

Pear	Mandarin	Avocado	Nectarine
Plum	Kiwi fruit	Grapes	Other fruit

The final part: **is looking at your fear of hypoglycaemia:**

1= Never **2= Rarely** **3= Sometime** **4=Usually** **5= Very Often**

1- Feed my child large snacks at bedtime.	1	2	3	4	5
2- Avoid allowing my child to be away from me when his/her	1	2	3	4	5
sugar is likely to be low.	1	2	3	4	5
3- Try to run a little high to be on the safe side.	1	2	3	4	5
4- Keep my child's sugar higher when he/she will be away from me.	1	2	3	4	5
5- Feed my child as soon as I feel or see the first signs of low blood	1	2	3	4	5

Appendix 6: Covid 19 questioner
Questionnaire about COVID-19 impact 2020
(Parents)

1) COVID-19 has had a negative impact on our family relationships.

Strongly agree   Agree   Neither agree nor disagree   Disagree   Strongly disagree

1a) How has COVID-19 impacted on your family relationships?

2) COVID-19 has had a negative impact on our family finances.

Strongly agree   Agree   Neither agree nor disagree   Disagree   Strongly disagree

2b) How has COVID-19 impacted on your family finances?

3) COVID-19 has had a negative impact on me as a parent.

Strongly agree   Agree   Neither agree nor disagree   Disagree   Strongly disagree

3b) How has COVID-19 impacted on you as a parent?

4) COVID-19 has had a negative impact on my mental health and well-being.

Strongly agree   Agree   Neither agree nor disagree   Disagree   Strongly disagree

4b) How has COVID-19 impacted on your mental health and well-being?

5) COVID-19 has impacted on how I manage my child's diabetes.

Strongly agree   Agree   Neither agree nor disagree   Disagree   Strongly disagree

5b) How has COVID-19 impacted on how you manage your child's diabetes?

6) COVID-19 has impacted on how my child manages their diabetes.

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

6b) How has COVID-19 impacted on how your child manages their diabetes?

7) COVID-19 has had a negative impact on my child's mental health and well-being.

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

7b) How has COVID-19 impacted on your child's mental health and well-being?

8) COVID-19 has impacted on how medical services manage my child's diabetes.

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

8b) How has COVID-19 impacted the way medical services manage your child's diabetes?

9) COVID-19 has had a negative impact on my daily routines (sleep, eating, exercise).

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

9b) How has COVID-19 impacted on your daily routines (sleep, eating, exercise)?

10) COVID-19 has had a negative impact on my child's daily routines (sleep, eating, exercise).

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

10b) How has COVID-19 impacted your child's daily routines (sleep, eating, exercise)?

11) COVID-19 events are making me worry about the future.

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

11b) How are COVID-19 events making you worry about the future?

12) COVID-19 events have changed our lives in important ways.

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

12b) How did COVID-19 change your lives? (In addition to what you have already reported.)

Appendix 7: Descriptive statistics for Diabetes Group

Table 1
Descriptive statistics for Child Self-Completed Measures

Measure	*N*	Min	Max	*M*	*SD*	Skew	Kurtosis
Level of Blood Sugar (HbA1c)	100	5.50	13.00	8.64	1.23	0.39	1.17
Child Weight in kg	100	20.00	106.00	40.93	14.7	2.40	7.49
Child Height in cm	100	125.00	164.00	141.08	9.71	0.51	-0.54
BMI percentiles	100	1.00	99.00	75.71	21.00	-1.15	1.15
Child Well-being	100	2.00	25.00	17.59	4.54	-0.42	0.14
KEDS							
Eating Disorders	100	0.00	9.00	4.47	2.59	-0.42	-1.17
Binge Eating	100	0.00	4.00	0.46	0.78	1.93	4.12
Body Dissatisfaction	100	-1.00	5.00	1.38	1.30	0.25	-0.63
Coping							
Acceptance	100	6.00	30.00	18.41	6.51	0.00	-0.67
Avoidance	100	4.00	20.00	11.75	3.66	0.22	-0.24
Cognitive-Palliative	100	9.00	25.00	18.21	3.18	-0.21	0.60
Distance	100	4.00	20.00	10.24	3.69	0.00	-0.52
Emotional Reaction	100	7.00	30.00	21.20	4.26	-0.57	0.53
Wishful Thinking	100	3.00	15.00	10.99	2.98	-0.28	-0.64
Coppersmith Self-Esteem							
General Self	100	5.00	25.00	12.20	3.26	0.36	1.46
Social Self	100	0.00	7.00	3.43	1.72	0.17	-0.64
Home Parents	100	0.00	7.00	3.08	1.43	0.59	0.41
School Academic	100	0.00	7.00	3.21	1.59	0.21	-0.58
Total Score	100	4.50	22.00	10.96	2.83	0.43	1.15
RCADS							
Social Phobia	100	27.00	64.00	42.30	7.05	0.37	0.83
Panic Disorder	100	36.00	82.00	56.25	8.84	-0.01	-0.02
Major Depression	100	32.00	83.00	52.65	9.34	0.43	0.40
Separation Anxiety	100	36.00	77.00	55.56	8.28	0.06	-0.35
Generalized Anxiety	100	29.00	64.00	44.38	7.46	0.26	-0.10
Obsessive Compulsive	100	5.00	72.00	48.72	9.59	-0.78	3.74

Table 2
Descriptive statistics for Parent-Completed Self-Report Measures

Measure	*N*	Min	Max	*M*	*SD*	Skew	Kurtosis
Parenting Scale							
Laxness	100	1.91	6.55	4.34	0.78	-0.04	1.45
Over reactivity	100	1.60	6.30	4.14	0.84	-0.16	0.37
Verbosity	100	1.00	6.57	4.16	1.06	-0.20	0.03
Parenting Scale Sum	100	2.03	6.30	4.28	0.67	-0.15	2.38
Child Feeding Questionnaire							
Responsibility	100	1.00	5.00	4.05	0.86	-1.43	2.85
Parental Weight	100	1.00	4.00	3.06	0.57	-0.82	1.00
Child Weight	100	1.33	4.00	2.91	0.59	-0.28	-0.45
Concern About Child Weight	100	1.00	5.00	3.35	0.97	-0.21	-0.53
Restriction	100	2.13	5.00	3.79	0.72	-0.32	-0.49
Pressure to eat	100	1.00	5.00	3.19	1.00	-0.05	-1.20
Monitoring	100	2.00	5.00	3.71	0.84	-0.30	-0.56
Shame Total	100	31.00	72.00	56.66	9.37	-0.43	-0.47
DASS-21							
Stress	100	0.00	17.00	7.30	3.65	0.59	-0.00
Anxiety	100	0.00	16.00	6.56	3.78	0.35	-0.38
Depression	100	0.00	19.00	5.21	3.55	0.87	1.41
Parent Well-being	100	2.00	25.00	15.95	5.55	-0.33	-0.06
Coping							
Subscale 1	100	26.00	56.00	42.58	6.87	-0.20	-0.57
Subscale 2	100	23.00	54.00	39.79	6.37	-0.64	0.23
Subscale 3	100	8.00	24.00	17.53	3.09	-0.09	-0.03

Table 3
Descriptive statistics for Parent-Completed Child Measures

Measure	*N*	Min	Max	*M*	*SD*	Skew	Kurtosis
Sleep Habits							
Sleep Bedtime	100	6.00	25.00	14.62	4.16	0.28	-0.30
Sleep Behaviour	100	4.00	22.00	9.44	3.49	0.91	0.84
Waking during the night	100	0.00	8.00	3.77	1.36	-0.17	1.39
Morning wake up	100	0.00	16.00	7.64	2.99	0.07	0.21
Fear of Hypoglycaemia							
Behaviour Scale	100	1.10	5.00	3.82	0.78	-1.21	1.92
Worry Scale	100	1.06	4.25	2.87	0.68	-0.44	0.00
Life style Behaviour Checklist							
Food	100	4.00	45.00	20.98	8.26	0.64	0.52
Physical Activity and Situation	100	0.00	45.00	12.08	7.34	1.20	3.35
CBCL							
Depressive Problem	100	0.00	15.00	5.15	2.98	0.65	0.44
Anxiety Problems	100	0.00	10.00	4.21	1.96	0.46	-0.00
Anxious / Depressed	100	0.00	12.00	5.88	2.66	0.35	-0.12
Withdrawn / Depressed	100	0.00	10.00	3.41	2.53	0.75	0.02
SDQ							
Emotional Symptoms	100	0.00	8.00	2.73	1.72	0.74	0.73
Conduct Problem	100	1.00	6.00	2.67	1.13	0.38	-0.04
Hyperactivity	100	0.00	5.00	2.11	1.41	0.37	-0.65
Peer problem	100	0.00	7.00	3.63	1.27	-0.40	0.37
Difficulties Global Score	100	2.00	20.00	11.14	3.57	0.20	0.31
Prosocial	100	0.00	10.00	3.68	2.17	0.60	0.17
Children's Dietary Questionnaire							
Fruits eaten in the last 7 days	100	0.00	19.00	6.59	3.86	0.88	1.13
Fruit last 24 hours	100	0.00	10.00	2.06	1.52	1.66	6.44
Fruit last week	100	0.00	6.00	2.97	1.41	-0.18	-0.65
Veg eaten in the last 7 days	100	0.00	14.00	5.47	3.08	0.34	0.07
Veg in evening meal in the last 24 hours	100	0.00	5.00	1.00	0.88	1.68	4.68
Veg last 24 hours	100	0.00	5.00	0.85	0.88	1.65	5.09
Veg last week	100	0.00	6.00	2.34	1.43	0.61	-0.34
Diary - last 24 hours	100	0.00	17.00	6.29	3.31	0.90	1.48
Diary Reduced - last 24 hours	100	0.00	7.00	1.87	1.46	1.00	1.32
Non-core foods past 7 days	100	6.00	53.00	22.43	8.51	1.08	1.99
Sweetened beverage last 24 hours	100	0.00	5.00	1.07	1.04	1.15	1.60
Water last 24 hours	100	1.00	5.00	4.25	0.85	-1.78	4.62
Fruit eaten average daily portion	100	0.00	4.00	1.66	0.72	0.41	0.79
Veg eaten average daily portion	100	0.00	3.57	1.38	0.60	0.28	0.98
Non-core foods average daily portion	100	0.86	7.57	3.20	1.21	1.08	1.99
Children's Physical Activity Questionnaire							
Physical activity frequency weekdays	100	0.00	6.00	2.08	1.91	0.35	-0.97
Physical activity total time in mints weekdays	100	0.00	120.00	36.71	35.08	0.54	-0.57
Physical activity weekend frequency	100	0.00	0.00	0.00	0.00		

Measure	*N*	Min	Max	*M*	*SD*	Skew	Kurtosis
Physical activity weekend total time in mints	100	0.00	0.00	0.00	0.00		
Leisure activity weekday frequency	100	0.00	3.00	0.05	0.35	7.37	55.26
Leisure activity weekday time in mints	100	0.00	50.00	0.95	6.69	6.99	48.00
School active travel	100	0.00	0.00	0.00	0.00		
School activity total time in minutes	100	0.00	45.00	0.45	4.50	10.00	100.00
Sedentary behaviours total Freq	100	0.00	3.00	1.45	0.62	0.06	-0.22
Sedentary behaviours total Freq	100	0.00	3.00	1.45	0.62	0.06	-0.22
Sedentary behaviours total time in minutes weekdays	100	0.00	500.00	194.00	119.76	0.42	-0.30
Sedentary behaviours total time in minutes weekend	100	0.00	1000.00	403.10	241.46	0.50	-0.49

Table 4: Cronbach Alpha for all Measures

Measure	Alpha at baseline
KEDS	.54
Coping	.70
Coppersmith Self-Esteem	.69
RCADS	.86
Wellbeing	.84
Parenting Scale	.64
Child Feeding Questionnaire	.87
Shame Total	.85
DASS-21	.86
Parent Wellbeing	.77
Coping	.86
Sleep Habits	.52
Fear of Hypoglycemia	.92
Lifestyle Behaviour Checklist	.89
CBCL	.75
SDQ	.47
Children's Dietary Questionnaire	.71
Children's Physical Activity Questionnaire	.38

Appendix 8: Descriptive statistics for Control Group

Table 5

Descriptive statistics for Child Self-Completed Measures

Measure	*N*	Min	Max	*M*	*SD*	Skew	Kurtosis
Child Weight in kg	100	20	55	34.00	6.54	0.41	0.19
Child Height in cm	100	122	150	133.50	5.97	0.28	-0.29
BMI Percentile	100	1.00	98.00	74.21	25.20	-1.46	1.31
Coppersmith Self-Esteem							
General Self	100	3.00	22.00	13.55	3.64	-0.11	0.24
Social Self	100	1.00	7.00	4.01	1.47	0.06	-0.31
Home Parents	100	0.00	8.00	3.91	1.63	-0.00	-0.31
School Academic	100	0.00	7.00	4.16	1.62	-0.23	-0.47
Self-Esteem total	100	2.50	19.00	12.81	3.19	-0.38	0.24
KEDS							
Eating Disorder	100	0.00	10.00	5.58	1.97	-0.89	0.12
Binge Eating	100	0.00	3.00	0.77	1.02	1.05	-0.19
Body Dissatisfaction	100	-1.00	5.00	1.54	1.50	0.35	-0.90
Child Well-being	100	10.00	25.00	21.15	3.53	-0.87	0.33
RCADS							
Social Phobia	100	27.00	55.00	35.61	5.40	0.85	1.38
Panic Disorder	100	3.00	61.00	45.56	7.20	-1.88	11.08
Major Depression	100	31.00	62.00	42.19	6.66	0.59	0.22
Separation Anxiety	100	31.00	64.00	44.89	6.09	0.30	0.39
Generalized Anxiety	100	28.00	52.00	36.71	5.40	0.80	0.21
Obsessive Compulsive	100	28.00	68.00	38.07	6.43	1.18	3.81

Table 6
Descriptive statistics for Parent-Completed Self-Report Measures

Measure	*N*	Min	Max	*M*	*SD*	Skew	Kurtosis
Shame sum	100	24.00	72.00	54.95	11.79	-0.74	-0.06
Child Feeding Questionnaire							
Perceived Responsibility	100	1.00	5.00	3.71	0.83	-0.96	1.51
Parent Weight	100	1.00	4.00	2.90	0.61	-1.03	1.07
Child Weight	100	1.00	4.00	2.89	0.49	-1.30	3.64
Concern Child Weight	100	1.00	5.00	3.19	1.05	-0.25	-0.68
Restriction	100	1.63	5.00	3.77	0.76	-0.53	-0.20
Pressure to Eat	100	1.50	5.00	3.36	0.81	-0.07	-0.37
Monitoring	100	2.00	5.00	3.46	0.74	0.32	-0.31
Parents Well-being	100	0.00	25.00	17.05	4.90	-0.65	0.99
DASS-21							
Depression	100	0.00	17.00	5.91	4.17	0.47	-0.79
Anxiety	100	0.00	19.00	6.25	4.23	0.44	-0.29
Stress	100	0.00	17.00	7.70	4.18	0.26	-0.52
Parenting Scale							
Laxness	100	2.64	7.00	4.60	0.87	0.27	0.37
Over reactivity	100	2.70	7.00	4.28	0.83	0.63	1.05
Verbosity	100	2.29	7.00	4.59	0.94	0.22	0.41
Parenting Style Sum	100	2.00	7.00	4.80	1.12	-0.14	-0.18

Table 7
Descriptive statistics for Parent-Completed Child Measures

Measure	*N*	Min	Max	*M*	*SD*	Skew	Kurtosis
Sleep Habits							
Sleep Bedtime	100	0.00	32.00	17.60	6.90	0.12	-0.19
Sleep behaviour	100	0.00	28.00	9.22	4.90	0.68	1.04
Waking during night	100	0.00	8.00	1.88	1.38	0.82	2.64
Morning wake up	100	0.00	13.00	2.84	2.78	0.81	0.68
CBCL							
Depressive Problem	100	0.00	12.00	3.02	2.22	1.51	3.64
Anxiety Problem	100	0.00	10.00	2.65	2.08	0.84	0.60
Anxious Depressed	100	0.00	15.00	3.78	2.85	1.02	1.90
Withdraw Depressed	100	0.00	7.00	1.61	1.54	0.94	0.63
SDQ							
Emotional Symptoms	100	0.00	6.00	1.77	1.39	0.73	0.08
Conduct Problem	100	0.000	7.00	2.56	1.23	0.79	1.55
Hyperactivity	100	3.00	9.00	5.28	1.37	0.34	-0.44
Peer problem	100	0.00	8.00	3.87	1.36	-0.15	1.27
Difficulties Global Score	100	7.00	22.00	13.48	2.94	0.53	0.40
Prosocial	100	0.00	10.00	2.79	1.77	1.17	2.21
Lifestyle Behaviour Checklist							
Food	100	2.00	45.00	15.53	8.21	0.92	1.17
Physical Activity and Situation	100	0.00	25.00	10.07	5.94	0.49	-0.36
Children's Dietary Questionnaire							
Fruits Eaten in the last 7 days	100	0.00	18.00	4.83	2.18	2.33	13.30
Fruit last 24 hours	100	0.00	11.00	2.39	2.30	1.56	2.70
Fruit last week	100	0.00	6.00	2.05	1.29	0.97	0.96
Veg eaten in the last 7 days	100	0.00	19.00	4.91	2.68	1.25	6.69
Veg in evening meal in the last 24 hours	100	0.00	5.00	1.21	1.23	1.17	0.95
Veg last 24 hours	100	0.00	5.00	1.06	1.17	1.46	2.01
Veg last week	100	0.00	6.00	1.87	1.25	1.57	2.59
Diary-last 24 hours	100	0.00	25.00	7.57	4.33	1.08	2.27
Diary Reduced-last 24 hours	100	0.00	10.00	2.45	2.28	1.09	0.68
Non-core foods past 7 days	100	3.00	78.00	27.46	12.52	1.081	1.81
Sweetened beverage last 24 hours	100	0.00	5.00	1.99	1.35	0.74	-0.21
Water last 24 hours	100	1.00	5.00	3.89	1.23	-0.86	-0.29
Fruit eaten average daily portion	100	0.00	3.57	1.32	0.56	1.12	2.44
Veg eaten average daily	100	0.29	3.43	1.29	0.56	1.13	2.22
Non-core foods average daily portion	100	0.43	11.14	3.92	1.78	1.08	1.81
Children's Physical Activity Questionnaire							
Physical activity frequency weekdays	100	0.00	10.00	2.67	2.26	0.67	0.19
Physical activity total time in mins weekdays	100	0.00	170.00	47.25	39.75	0.56	-0.24
Physical activity weekend frequency	100	0.00	4.00	0.23	0.69	3.35	11.76

Table 7 Continued

Measure	*N*	Min	Max	*M*	*SD*	Skew	Kurtosis
Leisure activity weekday frequency	100	0.00	8.00	0.280	1.11	4.88	26.70
Leisure activity weekday time in mins	100	0.00	70.00	4.00	14.19	3.53	11.46
School active travel	100	0.00	0.00	0.00	0.00		
School activity total time in minutes	100	0.00	180.00	5.40	28.40	5.53	30.53
Sedentary behaviours total frequency	100	1.00	5.00	1.50	0.65	2.05	8.01
Sedentary behaviours total time in minutes weekdays	100	0.00	1190.00	189.60	187.17	1.94	7.34
Sedentary behaviours total time in minutes weekend	100	0.00	1100.00	361.4	216.83	1.02	1.40

Appendix 9
Descriptive statistics for Diabetes Group before COVID-19

Table 8
Descriptive statistics for Child Self-Completed Measures

Measure	*N*	Min	Max	*M*	*SD*	Skew	Kurtosis
Child Weight in kg	70	25.00	106.00	40.06	15.18	2.67	8.68
Child Height in cm	70	125.00	163.00	140.00	9.49	0.62	-0.29
BMI percentiles	70	14.00	99.00	74.95	19.73	-0.85	0.43
Child Well-being	70	9.00	25.00	17.45	4.53	-0.12	-0.99
KEDS							
Eating Disorders	70	0.00	8.00	4.64	2.56	-0.56	-1.07
Binge Eating	70	0.00	2.00	0.40	0.66	1.42	0.74
Body Dissatisfaction	70	-1.00	4.00	1.28	1.27	0.26	-0.78
Coping							
Acceptance	70	6.00	30.00	18.42	6.35	0.04	-0.60
Avoidance	70	4.00	20.00	11.72	3.50	0.21	-0.09
Cognitive-Palliative	70	9.00	25.00	17.85	3.12	-0.34	1.10
Distance	70	4.00	18.00	10.22	3.64	-0.22	-0.84
Emotional Reaction	70	7.00	30.00	20.81	4.34	-0.61	0.72
Wishful Thinking	70	3.00	15.00	10.88	2.77	-0.26	-0.16
Coppersmith Self-Esteem							
General Self	70	6.00	25.00	12.20	3.25	0.77	2.376
Social Self	70	0.00	7.00	3.41	1.70	0.24	-0.67
Home Parents	70	0.00	7.00	3.25	1.51	0.56	0.22
School Academic	70	0.00	7.00	3.18	1.56	0.33	-0.33
Total Score	70	6.50	22.00	11.02	2.85	0.80	1.64
RCADS							
Social Phobia	70	27.00	64.00	42.91	7.73	0.25	0.53
Panic Disorder	70	36.00	82.00	55.70	9.21	0.08	0.15
Major Depression	70	32.00	83.00	51.80	9.30	0.79	1.26
Separation Anxiety	70	36.00	77.00	55.73	8.27	0.07	-0.11
Generalized Anxiety	70	29.00	64.00	44.23	7.34	0.33	0.46
Obsessive Compulsive	70	5.00	72.00	48.43	10.46	-0.82	3.59

Table 9
Descriptive statistics for Parent-Completed Self-Report Measures

Measure	*N*	Min	Max	*M*	*SD*	Skew	Kurtosis
Parenting Scale							
Laxness	70	1.91	6.55	4.32	0.82	-0.23	1.39
Over reactivity	70	1.60	6.30	4.27	0.86	-0.38	0.73
Verbosity	70	1.00	6.57	4.14	1.13	-0.32	-0.09
Parenting Scale Sum	70	2.03	6.30	4.31	0.70	-0.63	2.68
Child Feeding Questionnaire							
Responsibility	70	1.00	5.00	4.00	0.95	-1.40	2.28
Parental Weight	70	1.50	4.00	3.08	0.55	-0.53	0.17
Child Weight	70	2.00	4.00	2.92	0.55	0.01	-0.72
Concern About Child Weight	70	1.00	5.00	3.39	0.94	-0.14	-0.66
Restriction	70	2.13	5.00	3.75	0.73	-0.35	-0.36
Pressure to eat	70	1.00	5.00	3.17	0.96	-0.17	-1.07
Monitoring	70	2.00	5.00	3.70	0.84	-0.36	-0.53
Shame Total	70	31.00	72.00	56.21	10.05	-0.33	-0.63
DASS-21							
Stress	70	0.00	17.00	7.42	3.78	0.59	0.04
Anxiety	70	0.00	16.00	6.42	3.91	0.41	-0.25
Depression	70	0.00	14.00	5.20	3.30	0.43	-0.05
Parent Well-being	70	2.00	25.00	15.64	5.62	-0.39	-0.07
Coping							
Subscale 1	70	26.00	55.00	42.32	7.04	-0.23	-0.69
Subscale 2	70	23.00	51.00	39.30	6.80	-0.70	-0.08
Subscale 3	70	12.00	24.00	17.52	2.80	0.17	-0.43

Table 10
Descriptive statistics for Parent-Completed Child Measures

Measure	*N*	Min	Max	*M*	*SD*	Skew	Kurtosis
Sleep Habits							
Sleep Bedtime	70	6.00	25.00	14.82	4.32	0.28	-0.25
Sleep Behaviour	70	4.00	22.00	9.37	3.59	1.06	1.43
Waking during the night	70	0.00	8.00	3.75	1.40	-0.00	1.47
Morning wake up	70	0.00	16.00	7.70	3.08	0.21	0.24
Fear of Hypoglycaemia							
Behaviour Scale	70	1.10	5.00	3.82	0.80	-1.19	1.81
Worry Scale	70	1.06	4.25	2.89	0.69	-0.49	-0.01
Life style Behaviour Checklist							
Food	70	4.00	45.00	21.55	8.91	0.61	0.29
Physical Activity and Situation	70	1.00	45.00	12.68	7.39	1.29	4.13
CBCL							
Depressive Problem	70	0.00	15.00	5.45	3.03	0.67	0.49
Anxiety Problems	70	0.00	10.00	4.45	2.06	0.31	-0.02
Anxious / Depressed	70	0.00	12.00	6.12	2.75	0.29	-0.15
Withdrawn / Depressed	70	0.00	10.00	3.60	2.62	0.67	-0.13
SDQ							
Emotional Symptoms	70	0.00	8.00	2.91	1.80	0.63	0.56
Conduct Problem	70	1.00	6.00	2.77	1.11	0.15	-0.31
Hyperactivity	70	0.00	5.00	2.28	1.38	0.34	-0.64
Peer problem	70	0.00	7.00	3.70	1.26	-0.33	0.63
Difficulties Global Score	70	2.00	20.00	11.67	3.59	0.21	0.16
Prosocial	70	0.00	9.00	3.70	2.20	0.49	-0.22
Children's Dietary Questionnaire							
Fruits eaten in the last 7 days	70	0.00	16.00	6.05	3.45	0.37	0.07
Fruit last 24 hours	70	0.00	10.00	2.01	1.69	1.80	6.12
Fruit last week	70	0.00	6.00	2.81	1.47	-0.14	-0.93
Veg eaten in the last 7 days	70	0.00	14.00	5.17	3.10	0.54	0.57
Veg in evening meal in the last 24 hours	70	0.00	5.00	0.98	0.98	1.71	4.13
Veg last 24 hours	70	0.00	5.00	0.85	0.93	1.81	5.55
Veg last week	70	0.00	6.00	2.25	1.48	0.61	-0.55
Diary - last 24 hours	70	0.00	17.00	6.28	3.62	1.06	1.30
Diary Reduced - last 24 hours	70	0.00	7.00	1.85	1.58	1.14	1.33
Non-core foods past 7 days	70	6.00	53.00	22.38	9.09	1.21	2.19
Sweetened beverage last 24 hours	70	0.00	5.00	1.01	1.09	1.39	2.28
Water last 24 hours	70	1.00	5.00	4.28	0.83	-1.96	5.70
Fruit eaten average daily portion	70	0.00	3.00	1.55	0.67	-0.17	-0.36
Veg eaten average daily portion	70	0.00	3.57	1.32	0.63	0.46	1.41
Non-core foods average daily portion	70	0.86	7.57	3.19	1.29	1.21	2.19

Table 10 Continued

Measure	*N*	Min	Max	*M*	*SD*	Skew	Kurtosis
Children's Physical Activity Questionnaire							
Physical activity frequency weekday	70	0.00	6.00	2.22	1.99	0.31	-1.04
Physical activity total time in mints weekdays	70	0.00	120.00	39.64	37.31	0.50	-0.77
Physical activity weekend frequency	70	0.00	0.00	0.00	0.00	.	.
Physical activity weekend total time in mints	70	0.00	0.00	0.00	0.00	.	.
Leisure activity weekday frequency	70	0.00	0.00	0.00	0.00	.	.
School active travel	70	0.00	0.00	0.00	0.00	.	.
School activity total time in minutes	70	0.00	45.00	0.64	5.37	8.36	70.00
Sedentary behaviours total Freq	70	0.00	3.00	1.42	0.64	-0.05	-0.19
Sedentary behaviours total time in minutes weekdays	70	0.00	500.00	192.00	120.34	0.41	-0.03
Sedentary behaviours total time in minutes weekend	70	0.00	1000.00	515.8	211.43	0.25	-0.52

Descriptive statistics for Diabetes Group after COVID-19

Table 11
Descriptive statistics for Child Self-Completed Measures

Measure	*N*	Min	Max	*M*	*SD*	Skew	Kurtosis
Child Weight in kg	70	27.00	28.00	39.81	11.88	1.92	4.25
Child Height in cm	70	125.00	163.00	140.41	9.17	0.69	-0.26
BMI percentiles	70	20.00	99.00	71.44	20.95	-0.71	0.24
Child Well-being	70	9.00	18.00	12.9	2.22	0.10	-0.67
KEDS							
Eating Disorders	70	0.00	8.00	4.28	2.63	-0.35	-1.28
Binge Eating	70	0.00	2.00	0.41	0.67	1.36	0.58
Body Dissatisfaction	70	-1.00	5.00	1.85	1.15	-0.17	0.45
Coping							
Acceptance	70	6.00	30.00	17.04	5.90	0.37	-0.45
Avoidance	70	4.00	20.00	11.22	3.18	0.37	0.65
Cognitive-Palliative	70	6.00	25.00	16.90	3.67	-0.52	0.49
Distance	70	4.00	18.00	10.40	3.63	-0.24	-0.67
Emotional Reaction	70	9.00	30.00	20.21	4.31	-0.05	-0.25
Wishful Thinking	70	6.00	20.00	12.98	3.13	-0.06	-0.63
Coppersmith Self-Esteem							
General Self	70	1.00	18.00	10.19	3.31	-0.36	0.45
Social Self	70	0.00	7.00	3.37	1.76	-0.01	-0.78
Home Parents	70	0.00	7.00	3.12	1.59	0.15	-0.55
School Academic	70	0.00	6.00	2-97	1.48	0.13	-0.71
Total Score	70	0.50	17.500	10.18	3.12	-0.42	0.71
RCADS							
Social Phobia	70	31.00	76.00	49.58	8.48	0.34	0.56
Panic Disorder	70	49.00	96.00	72.12	10.27	0.22	-0.01
Major Depression	70	20.00	97.00	70.77	13.28	-0.76	2.27
Separation Anxiety	70	45.00	106.00	72.22	12.34	0.58	0.97
Generalized Anxiety	70	43.00	77.00	56.27	8.82	0.98	-0.04
Obsessive Compulsive	70	35.00	81.00	59.55	8.71	0.14	0.17

Table 12
Descriptive statistics for Parent-Completed Self-Report Measures

Measure	*N*	Min	Max	*M*	*SD*	Skew	Kurtosis
Parenting Scale							
Laxness	70	1.91	5.18	3.90	0.67	-0.56	0.12
Over reactivity	70	1.60	5.30	3.88	0.67	-0.44	0.78
Verbosity	70	2.00	6.57	3.80	0.84	0.21	-0.39
Parenting Scale Sum	70	1.84	5.25	3.86	0.59	-0.62	1.03
Child Feeding Questionnaire							
Responsibility	70	1.00	5.00	3.70	0.79	-1.23	1.99
Parental Weight	70	2.00	4.25	3.29	0.51	-0.71	0.63
Child Weight	70	1.80	4.00	2.81	0.50	0.08	-0.51
Concern About Child Weight	70	1.00	4.67	3.09	0.80	-0.42	-0.20
Restriction	70	1.00	4.88	3.15	0.76	-0.35	-0.86
Pressure to eat	70	1.00	5.00	3.02	0.96	-0.29	-0.14
Monitoring	70	1.00	5.00	3.25	0.93	-0.28	0.25
Shame Total	70	27.00	62.00	49.77	6.60	-0.72	0.72
DASS-21							
Stress	70	4.00	21.00	12.87	3.38	-0.18	-0.12
Anxiety	70	1.00	21.00	12.35	3.12	-0.43	2.25
Depression	70	2.00	21.00	12.02	3.31	0.04	0.82
Parent Well-being	70	2.00	16.00	10.07	3.46	-0.34	-0.94
Coping							
Subscale 1	70	27.00	55.00	37.02	5.62	0.36	0.30
Subscale 2	70	22.00	49.00	34.00	5.63	0.59	-0.18
Subscale 3	70	9.00	21.00	13.31	2.45	0.48	0.50

Table 13
Descriptive statistics for Parent-Completed Child Measures

Measure	*N*	Min	Max	*M*	*SD*	Skew	Kurtosis
Sleep Habits							
Sleep Bedtime	70	8.00	28.00	18.01	5.06	-0.24	-0.69
Sleep Behaviour	70	3.00	23.00	15.21	4.03	-0.67	0.18
Waking during the night	70	2.00	8.00	4.90	1.34	0.29	0.16
Morning wake up	70	4.00	16.00	10.82	3.04	-0.19	-0.43
Fear of Hypoglycaemia							
Behaviour Scale	70	1.60	5.00	3.54	0.58	-0.31	1.41
Worry Scale	70	1.50	4.06	3.19	0.50	-0.67	1.65
Life style Behaviour Checklist							
Food	70	2.00	44.00	26.00	7.98	-0.30	1.06
Physical Activity and Situation	70	2.00	39.00	16.28	6.41	0.88	1.69
CBCL							
Depressive Problem	70	2.00	19.00	11.10	3.77	-0.22	0.00
Anxiety Problems	70	3.00	18.00	10.00	2.96	0.40	0.23
Anxious / Depressed	70	4.00	24.00	12.60	3.85	0.34	0.45
Withdrawn / Depressed	70	1.00	14.00	9.71	3.08	-0.71	0.56
SDQ							
Emotional Symptoms	70	1.00	9.00	4.44	1.69	0.12	0.56
Conduct Problem	70	1.00	9.00	4.97	1.65	-0.20	0.12
Hyperactivity	70	0.00	8.00	4.11	1.74	-0.23	-0.27
Peer problem	70	1.00	9.00	5.11	1.69	-0.03	0.05
Difficulties Global Score	70	4.00	30.00	18.64	4.47	-0.95	1.86
Prosocial	70	1.00	9.00	4.64	1.64	0.07	0.07
Children's Dietary Questionnaire							
Fruits eaten in the last 7 days	70	0.00	1.00	0.27	0.44	1.05	-0.92
Fruit last 24 hours	70	0.00	4.00	1.80	0.91	0.29	1.23
Fruit last week	70	0.00	5.00	1.60	1.33	0.51	-0.31
Veg eaten in the last 7 days	70	0.00	1.00	0.45	0.50	0.17	-2.02
Veg in evening meal in the last 24 hours	70	0.00	3.00	1.01	0.57	0.93	3.45
Veg last 24 hours	70	0.00	3.00	0.85	0.70	0.71	0.98
Veg last week	70	0.00	5.00	1.27	0.97	1.63	3.37
Diary - last 24 hours	70	0.00	10.00	5.94	2.46	-0.17	-0.31
Diary Reduced - last 24 hours	70	0.00	6.00	1.92	1.24	0.93	0.71
Non-core foods past 7 days	70	6.00	66.00	35.84	13.92	0.26	-0.54
Sweetened beverage last 24 hours	70	0.00	3.00	0.77	0.64	0.52	1.01
Water last 24 hours	70	1.00	5.00	3.72	1.02	-1.11	1.16
Fruit eaten average daily portion	70	0.14	1.29	0.52	0.22	0.85	1.03
Veg eaten average daily portion	70	0.14	1.14	0.51	0.22	0.78	0.54
Non-core foods average daily portion	70	0.86	9.43	5.12	1.98	0.26	-0.54
Children's Physical Activity Questionnaire							
Physical activity frequency weekday	70	0.00	0.00	0.00	0.00	.	.

Table 13 Continued

Measure	*N*	Min	Max	*M*	*SD*	Skew	Kurtosis
Physical activity total time in mints weekdays	70	0.00	0.00	0.00	0.00	.	.
Physical activity weekend frequency	70	0.00	0.00	0.00	0.00	.	.
Physical activity weekend total time in mints	70	0.00	0.00	0.00	0.00	.	.
Leisure activity weekday frequency	70	0.00	0.00	0.00	0.00	.	.
School active travel	70	0.00	0.00	0.00	0.00	.	.
School activity total time in minutes	70	0.00	0.00	0.00	0.00	.	.
Sedentary behaviours total Freq	70	0.00	0.00	0.00	0.00	.	.
Sedentary behaviours total time in minutes weekdays	70	200	1000	521.57	202.50	0.44	-0.76
Sedentary behaviours total time in minutes weekend	70	0.00	750	302.42	134.77	0.67	0.98

Table 14

Cronbach Alpha for all Measures Before and After COVID-19

Measure	*Alpha* at baseline	*Alpha* at follow up
KEDS	.57	.63
Coping	.61	.74
Coppersmith Self-Esteem	.70	.73
RCADS	.86	.90
Child Well-being	.86	.56
Parenting Scale	.68	.67
Child Feeding Questionnaire	.85	.86
Shame Total	.06	.71
DASS-21	.79	.87
Parent Well-being	.77	.86
Coping	.84	.85
Sleep Habits	.32	.88
Fear of Hypoglycaemia	.91	.89
Lifestyle Behaviour Checklist	.89	.83
CBCL	.77	.78
SDQ	.50	.69
Children's Dietary Questionnaire	.74	.82
Children's Physical Activity Questionnaire	.40	.87

Table 15
Child Measure

Measure	Clinical	Children at baseline (70)	Children at follow up (70)
KEDS	-	-	-
Coping	-	-	-
Coppersmith Self-Esteem	-	-	-
RCADS	> 65 indicate borderline > 70 indicate clinical		
Social Phobia		70 normal	68 normal 2 borderlines
Panic Disorder		60 normal 5 borderlines 5 clinical	10 normal 20 borderlines 40 clinical
Major Depression		62 normal 3 borderlines 5 clinical	21 normal 16 borderlines 36 clinical
Separation Anxiety		60 normal 8 borderlines 2 clinical	15 normal 17 borderlines 38 clinical
Generalized Anxiety		70 normal	61 normal 7 borderlines 2 clinical
Obsessive Compulsive		66 normal 2 borderlines 2 clinical	60 normal 5 borderlines 5 clinical
Child Well-being	25 representing best possible quality of life 13 indicate poor well-being	54 normal 3 representing best possible quality of life 13 indicate poor well-being	26 normal 44 indicate poor well-being
Sleep Habits	-	-	-
Fear of Hypoglycaemia	-	-	-
Lifestyle Behaviour Checklist	-	-	-
CBCL			
Depressive Problem	6 subclinical 8 clinical	43 normal 11 subclinical 17 clinical	7 normal 6 subclinical 57 clinical
Anxiety Problems	6 subclinical 8 clinical	47 normal 18 subclinical 5 clinical	l 4 normal 9 subclinical 57 clinical
Anxious / Depressed	7 subclinical 9 clinical	40 normal 19 subclinical 11 clinical	4 normal 5 subclinical 61 clinical
Withdrawn / Depressed	5 subclinical 6 clinical	48 normal 6 subclinical 16 clinical	4 normal 1 subclinical 65 clinical
Children's Dietary Questionnaire	-	-	-
SDQ			
Emotional Symptoms	0-3 normal 4 borderline 5-10 abnormal	47 normal borderline 11 abnormal 12	19 normal 13 borderline 38 abnormal

Conduct Problem	0-2 normal 3 borderline 4-10 abnormal	29 normal 21 borderline 20 abnormal	6 normal 10 borderline 58 abnormal
Hyperactivity	0-5 normal 6 borderline 7-10 abnormal	70 normal	55 normal 12 borderline 3 abnormal
Peer problem	0-2 normal 3 borderline 4-10 abnormal	9 normal borderline 21 40 abnormal	4 normal 6 borderline 60 abnormal
Difficulties Global Score	0-13 normal 14-16 borderline 17-40 abnormal	49 normal 15 borderline 6 abnormal	8 normal borderline 15 53 abnormal
Prosocial	0-4 normal 5 borderline 6-10 abnormal	48 normal 9 borderline 13 abnormal	32 normal 18 borderline 20 abnormal

Table 16
Parents Measure

Measure	Clinical	Parent at baseline	Parent at follow up
Parent Well-being	25 representing best possible quality of life 13 indicate poor well-being	44 normal 3 representing best possible quality of life 23 indicate poor well-being	11 normal 59 indicate poor well-being
Parenting Scale	-	-	-
Child Feeding Questionnaire	-	-	-
Shame Total	-	-	-
DASS-21			
Depression	0-4 normal 5-6 mild 7-10 moderate 11-13 severe +14 extremely severe	28 normal 19 mild 19 moderate 3 severe 1 extremely severe	1 normal 3 mild 20 moderate 26 severe 20 extremely severe
Anxiety	0-3 normal 4-5 mild 6-7 moderate 8-9 severe +10 extremely severe	14 normal 19 mild 12 moderate 7 severe 18 extremely severe	1 normal 1 mild 2 moderate 6 severe 60 extremely severe
Stress	normal 0-7 mild 8-9 10-12 moderate 13-16 severe +17 extremely severe	39 normal 12 mild 12 moderate 5 severe 2 extremely severe	4 normal 10 mild 16 moderate 29 severe 11 extremely severe
Coping	-	-	-

Appendix 10: The 14th international conference on child and adolescent psychopathology on July 22-24 at the University of Roehampton London

SEICOLEG BANGOR PSYCHOLOGY

Psychological Variables and Lifestyle Correlates in Children with Diabetes and Their Families: A Systematic Review of the Literature.

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PRIFYSGOL BANGOR UNIVERSITY

Background

Diabetes is a serious chronic metabolic disease. It occurs either due to a lack of the pancreas-produced hormone insulin, or because the body cannot effectively use the insulin that is produced (Egan & Dinneen, 2014)[1]. The effect of inadequate insulin is an excess in blood glucose concentration (hyperglycaemia; Watkins, 1982)[2]. Diabetes places a considerable burden on the individual patient because it requires constant monitoring of blood glucose, daily treatment, lifestyle changes, and numerous visits to hospital.

Research Aim

We have conducted a systematic review from the literatures to understand the behavioural problems of children with diabetes (Type 1), aged from 8 to 11 years old, as well as those of their families using psychological variables and lifestyle measures.

Method

A literature search was carried out in five databases: ProQuest; Science Direct, Web of Science, Google Scholar and Bangor Library. This search reviewed scientific and electronic literature without specifying dates of publication.

The terms used in the search as key words or phrases described target population, as follows:

- Childhood diabetes
- Children with diabetes
- Diabetes mellitus in children
- Children with diabetes Type 1
- Parenting and diabetes Type 1 in children

Psychological variables were that were used in the search included:

- Psychological status of children with Type 1 diabetes
- Psychological problems in children with diabetes
- Depression in children with diabetes
- Psychological problems in parents of children with Type 1

This literature search yielded 420 relevant studies. In the next step, title and abstracts were read to choose studies to be included in the present review according to the following criteria:

1. They reported on children with diabetes type 1
2. They included in the sample primary school age range
3. They questioned parents of children with diabetes
4. They used psychological variables and /or lifestyle and physical activity

Studies were eliminated if:

1. Child age started at 11 years
2. Results were neuropsychology based
3. Interventions were used, or
4. Results solely reported memory problems and cognitive behaviour

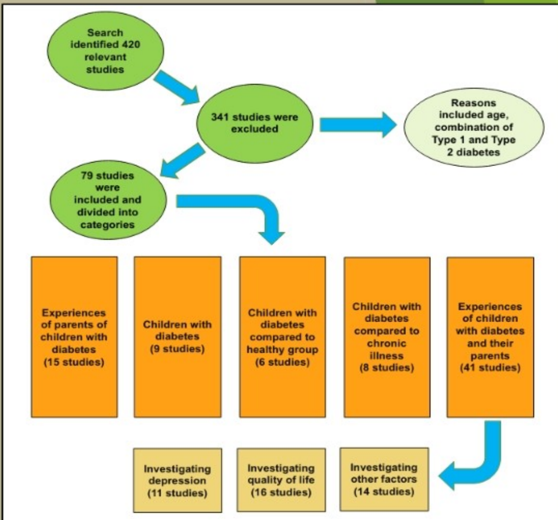

Figure 1. Literature selection process.

Results

The studies examined in the systematic review reported that children with diabetes suffered from behavioural problems such as anxiety, depression, eating disorders, emotional problems, sleep disturbance and other lifestyle issues. They also showed that diabetes can also affect the parents of the children in a life-changing situation causing parental stress, depression, anxiety and sleeping difficulties.

Conclusions

This systematic review has identified 79 studies reporting that children with diabetes and their parents may have suffered from behavioural problems. There were some limitations:

- Most of the literatures focused on the teenagers but not specifically on younger children, even though problems are likely to start before adolescence and should be investigated in primary-age children.
- Methodologically, some studies had poor sample size, did not specify the age range examined, and used no comparison group.
- Many studies did not consider the lifestyle of the children and their parents, which we know, from healthy samples, may be of relevance.

Therefore we propose to explore parenting, family, and lifestyle factors in children with diabetes in primary school age and their families. We plan to collect data in two countries, UK and Kuwait, to enable cross-cultural comparisons.

References

[1]. Egan, A. M., & Dinneen, S. F. (2014). What is diabetes? *Medicine, 42(12)*, 679-681.
[2]. Watkins, P. J. (1982). What is diabetes? British Medical Journal, 284, 1690-1692.

Appendix 10: Bangor winter conference

PRIFYSGOL BANGOR UNIVERSITY

Afrah Alazmi
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School of Psychology

Exploring the determinants of health and wellbeing in 8-11 year old children with Type 1 diabetes and their healthy counterparts in Kuwait

Diabetes is a serious chronic metabolic disease. It occurs either due to a lack of the pancreas-produced hormone insulin, or because the body cannot effectively use the insulin that is produced. Type 1 diabetes is usually diagnosed in childhood. Previous research, typically done with older children and adolescents, indicates that these children may show higher incidence of poor mental health and behavioural problems such as depression, anxiety, and disordered eating patterns, compared to their healthy counterparts.

Image: Freepik.com

The aim of the present study is to explore why some children with Type 1 diabetes maintain good physical and mental health, whilst others do not.

Procedure. Following a pilot study that tested suitability and delivery of the planned measures with parents and children, approval was received from the School of Psychology Ethics Committee, and from the Ministry of Health in Kuwait. Next, we recruited a group of 100 dyads (parents and their children with diabetes aged between 8 and 11 years old) who were in follow up care in three hospital diabetes clinics. A matched control group (n=100) was recruited from four primary schools. All dyads were asked to complete measures relating to health, wellbeing, and lifestyle, which were identified from relevant literature and translated to Arabic.

HEALTH & WELLBEING INDICES

PHYSICAL MEASURES
- HbA1c (Diabetes Group)
- Height and Weight (BMI)

MENTAL HEALTH MEASURES
- Depression and Anxiety Subscales of the Child Behaviour Checklist
- Strengths and Difficulties Questionnaire
- Anxiety and Depression Subscales of the RCADS
- The Kids' Eating Disorders Survey
- WHO (five) Wellbeing Index

CHILD VARIABLES

PSYCHOLOGICAL MEASURES
- Self Esteem via Cooper Smith Long Form
- Sleep Habits Questionnaire
- Coping Skills for Children (Diabetes Group)

LIFESTYLE MEASURES
- Lifestyle Behaviour Checklist
- Children's Dietary Questionnaire
- Physical Activity Questionnaire for Children

PARENTAL VARIABLES

PSYCHOLOGICAL MEASURES
- Coping Skills via Coping Health Scale (Diabetes Group)
- Fear of Hypoglycaemia for Parents (Diabetes Group)
- Shame via the Other as Shame Scale
- Depression, Stress & Anxiety via DASS 21

PARENTING MEASURES
- Parenting Skills via The Parenting Scale
- Parental Feeding via Child Feeding Questionnaire

We hypothesise that associated (and possibly protective) factors may include good dietary habits, levels of physical activity, and sleep quality; good self-esteem and coping skills; and sound parental mental health, coping, and parenting practices. We also plan to examine whether any patterns of associations between the putative predictors and outcomes may differ between the children with diabetes and a matched control cohort.

Demographic variables we have collected include parental age, education, nationality, marital status; and family size. For all children, we noted age, sex, gender, and any existing health conditions. For diabetes group, we also noted onset age, therapy type, and comorbidity.

Some characteristics of the present sample

	Diabetes Cohort (n=85)		Control Cohort (n=100)	
Therapy Type	pump insulin (n=14) insulin injection (n=71)		- -	
Sex	Girls (n=54)	Boys (n=31)	Girls (n=48)	Boys (n=52)
Median Age	10yrs	10yrs	10yrs	10yrs
(Range)	(8-11)	(8-11)	(8-11)	(8-11)
Median Height	141cm	138cm	134cm	131cm
(Range)	(125-163)	(125-164)	(122-150)	(122-145)
Median Weight	41kg	36kg	35kg	33kg
(Range)	(20-106)	(25-64)	(20-47)	(21-55)
Median BMI Percentiles	85	85	84	88
(Range)	(1-99)	(42-99)	(1-98)	(2-98)

- Underweight, less than the 5th percentile
- Healthy weight, 5th percentile up to the 85th percentile
- Overweight, 85th to less than the 95th percentile
- Obesity, equal to or greater than the 95th percentile

Data collection will be completed by January 2020 (15 further dyads, all boys, will be tested to complete the diabetes sample).

This study is preregistered. As Predicted #30759.

We plan to use the results of the present study to devise and pilot an intervention that would assist parents whose children are diagnosed with Type 1 diabetes. No such service is presently offered in Kuwait.

MINISTRY OF HEALTH

Funded by the Kuwait Ministry of Health
For more information about this research please contact Afrah Alazmi, School of Psychology, elx67e@bangor.ac.uk.

Centre for Activity and Eating Research
CAER BANGOR

- Appendix 12:

How to live with covid- 19? Sponsored by Arab Open University in Kuwait 31/07/2021

المتغيرات النفسية و الصحية للأطفال المصابون بداء السكر النوع الاول و ذويهم قبل و خلال جائحة كورونا

أفراح العازمي
طالبة دكتوراه علم نفسي اكلينيكي وصحي

Supervisors: Dr. Mihela Erjavec & Dr. Simon Viktor

ما هو داء السكر؟

هو مرض مزمن يحدث عندما يعجز البنكرياس عن انتاج الانسولين بكمية كافية أو عندما يعجز جسم الانسان عن الاستخدام الفعال للأنسولين

أنواع داء السكر

داء السكري من النوع الأول

داء السكري من النوع الثاني

داء السكري النوع الاول(داء السكر عند الاطفال أو اليافعين)

هو مرض يقوم الجهاز المناعي خلاله بإتلاف خلايا بيتا في البنكرياس لأسباب غير معروفة و لم يتم تحديدها حتى الان

أعراضه

العطش
الجوع الشديد
انخفاض الوزن
التعب
تشوش الرؤيا
كثرة التبول

علاج داء السكر

مضخة الانسولين

قلم الانسولين

حقن الانسولين


Position	Country	Incidence (per 100,000)
1	Finland	57.6
2	Sweden	43.1
3	Saudi Arabia	31.4
4	Norway	27.9
5	United Kingdom	24.5
6	USA	23.7
7	Australia	22.5
8	Kuwait	22.3
9	Denmark	22.2
10	Canada	21.7

الدراسات السابقة للأطفال

- الغضب
- الاكتئاب
- القلق
- علو أو انخفاض الثقة بالنفس

الدراسات السابقة بالنسبة للوالدين

- القلق
- العار من المرض
- اضطرابات في النوم

الهدف من الدراسة

مقارنة الصحة النفسية و نمط الحياة (التغذية, الرياضة) للأطفال المصابين بداء السكر و ذويهم قبل و خلال جائحة كورونا

منهجية البحث:

* العينة 70 طفل من 3 مستشفيات بدولة الكويت

* العمر من 8 الى 11 عاما

* الأدوات المستخدمة في البحث:

حزمة من المقاييس للصحة النفسية و نمط الحياة

النتائج

1- ملاحظة زيادة في القلق و الاكتئاب و الرهاب الاجتماعي

2- زيادة القلق و الاكتئاب بالنسبة للوالدين

3- زيادة الخوف من نقص أو زيادة سكر الدم بالنسبة للوالدين

4- بالنسبة لنمط الحياد, تمت ملاحظة زيادة الاكل الغير صحي, انخفاض تناول الخضراوات و الفواكه مع قضاء فترات طويلة بالألعاب الاليكترونية

مقتطفات من أقوال مرضي السكر و ذويهم:

الطفل (اشتقت للمدرسة حتى لو كان فيها تنمر على مرضي, اشتقت لأصدقائي و للألعاب)

الأم (خايف اني افقد ولدي, اشتقت لعائلتي, النوم مو منتظم, وايد قمت أصرخ على عيالي)

ألاب (بنتي قامت تكرهني لأني بعيد عنها بسبب طبيعة عملي, فقدت المتعة بالحياة, الخوف من المستقبل)

الخلاصة

جائحة كورونا أثرت سلبا على الصحة النفسية على
الاطفال و ذويهم مقارنةً بما قبل الجائحة
مما قد ينتج عنه اضطرابات نفسية على المدى البعيد

شكرا لكم على حسن الاستماع

Appendix 13: Quality Assessment Tool for Quantitative Studies

QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES

EPHPP
Effective Public Health Practice Project

COMPONENT RATINGS

A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?
1 Very likely
2 Somewhat likely
3 Not likely
4 Can't tell

(Q2) What percentage of selected individuals agreed to participate?
1 80 - 100% agreement
2 60 – 79% agreement
3 less than 60% agreement
4 Not applicable
5 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

B) STUDY DESIGN

Indicate the study design
1 Randomized controlled trial
2 Controlled clinical trial
3 Cohort analytic (two group pre + post)
4 Case-control
5 Cohort (one group pre + post (before and after))
6 Interrupted time series
7 Other specify ______________________________
8 Can't tell

Was the study described as randomized? If NO, go to Component C.
No Yes

If Yes, was the method of randomization described? (See dictionary)
No Yes

If Yes, was the method appropriate? (See dictionary)
No Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

C) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?
1 Yes
2 No
3 Can't tell

The following are examples of confounders:
1 Race
2 Sex
3 Marital status/family
4 Age
5 SES (income or class)
6 Education
7 Health status
8 Pre-intervention score on outcome measure

(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?
1 80 – 100% (most)
2 60 – 79% (some)
3 Less than 60% (few or none)
4 Can't Tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

D) BLINDING

(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?
1 Yes
2 No
3 Can't tell

(Q2) Were the study participants aware of the research question?
1 Yes
2 No
3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

E) DATA COLLECTION METHODS

(Q1) Were data collection tools shown to be valid?
1 Yes
2 No
3 Can't tell

(Q2) Were data collection tools shown to be reliable?
1 Yes
2 No
3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

F) WITHDRAWALS AND DROP-OUTS

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?

1 Yes
2 No
3 Can't tell
4 Not Applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

1 80 -100%
2 60 - 79%
3 less than 60%
4 Can't tell
5 Not Applicable (i.e. Retrospective case-control)

RATE THIS SECTION	STRONG	MODERATE	WEAK	
See dictionary	1	2	3	Not Applicable

G) INTERVENTION INTEGRITY

(Q1) What percentage of participants received the allocated intervention or exposure of interest?

1 80 -100%
2 60 - 79%
3 less than 60%
4 Can't tell

(Q2) Was the consistency of the intervention measured?

1 Yes
2 No
3 Can't tell

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?

4 Yes
5 No
6 Can't tell

H) ANALYSES

(Q1) Indicate the unit of allocation (circle one)

community organization/institution practice/office individual

(Q2) Indicate the unit of analysis (circle one)

community organization/institution practice/office individual

(Q3) Are the statistical methods appropriate for the study design?

1 Yes
2 No
3 Can't tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?

1 Yes
2 No
3 Can't tell

Appendix 13: Prisma Checklist Guidline

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	Page 1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	Page 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	Page 4
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	Pages 4-5
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	-
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	Pages 5-6
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	Page 5
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Page 5
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Pages 5-6
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	Pages 6
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	Page 5
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	QATQs Page 8
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	Pages 5-6

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SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Page 7
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Table 2 P 9 Table 3 P 12
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	QATQS/EPHPP Pages 8-9
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Table 3 Page12
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Table 2 Page 9
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Page 18
Limitations	20	Discuss the limitations of the scoping review process.	Page 19
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	Page 20
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Page 26

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.
* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.
† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).
‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.
§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.

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