Prevalence and Early Features of Depression in Children, Adolescents, and Young Adults with Diabetes

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ABSTRACT

Introduction: Children, adolescents and young adults with diabetes face a significant psychological burden, which increases their risk of developing depression. Early symptoms are often underrecognized and undertreated. This review aims to identify and highlight early markers of depression in this vulnerable population.

Methods: A lirerature review was conducted informed by Public Patient involvement The literature search explored studies assessing depression, diabetes distress, and related psychological symptoms. Screening tools and diabetes-specific distress measures were evaluated, and input from individuals with lived experience informed the review's direction.

Results: The prevalence of depression among children and- adolescents with T1DM ranged between 9.5% and 46.3%, with m-ost studies reporting rates between 14.1% and 22%. Early features of depression identified from the review include persistent low mood or sadness, irritability, loss of interest or pleasure (anhedonia), low self-esteem and feelings of worthlessness, hopelessness or pessimism, difficulty concentrating, social withdrawal, fatigue and low energy, changes in sleep and appetite, academic difficulties, and feelings of guilt. These symptoms often overlap with the features of diabetes distress, which is characterized by emotional burden, frustration with self-management, worry about complications, and low motivation. Notably, diabetes distress itself can trigger depressive symptoms and is highly prevalent, affecting up to 61% of young people with diabetes.

Conclusions: Early symptoms of depression in children, adolescents, and young adults with diabetes encompass a range of emotional, cognitive, behavioural, and physical features. These symptoms—particularly when persistent—should prompt timely psychological assessment and intervention. Routine screening for both general depressive symptoms and diabetes-specific distress is essential for optimal diabetes management and psychosocial well-being in this population.

Keywords: Adolescents; Children; Depression; Diabetes distress; Emotional burden; Mental health; Psychosocial factor; Type 1 diabetes; Young adults.

INTRODUCTION

Type 1 diabetes is a significant global health issue, affecting approximately 1.21 million children and adolescents under the age of 20 globally.[1] Diabetes has multiple physiological impacts, such as glycemic control, acute complications such as ketoacidosis, hypoglycemia and chronic complications. In addition to physiological effects, diabetes also exerts profound psychological stress on young patients. Depression and diabetes distress are well-established challenges in this population.[2] Studies have shown that poor mental health is strongly

associated with suboptimal glycemic control,[3] higher rates of complications, and lower quality of life, and evidence of the bidirectional nature of this relationship between diabetes management and mental health is also increasing.[4] Depression remains underdiagnosed and undertreated in children and adolescents and young adults with diabetes.[5] The aim of this study was to explore early markers of depression in children, adolescents, and young adults with type 1 diabetes.

METHODOLOGY

Critical review of the of existing studies to identify symptoms of depression associated with diabetes. Multiple public patients were involved from the outset, which guided the direction of review. We conducted a search for articles published between 2000 and 2024. The search focused on identifying early symptoms of depression in individuals with diabetes. Articles on the emotional aspects of living with diabetes and quality of life was also included in the review, guided by input from the PPI.

Search strategy:

Keywords: Type 1 diabetes, Depression, Psychological symptoms, Diabetes distress. The following databases were searched: PubMed and PsycINFO (This selection was determined after an initial broad search across multiple database with no additional relevant studies met the inclusion criteria elsewhere) Search Engine:"Type 1 Diabetes" AND "Depression".

Article selection process: As shown in the Prisma flow diagram (Fig 1) the initial search yielded 1591 articles from PubMed and 39 from PsycINFO. A total of 1380 records were screened for title, 214 of which were selected on the basis of title to review the abstract. A total of 98 articles were selected for review, 32 of which were selected for final review. Fifteen articles were also selected via the snowball method, and 1 article was selected from Google Scholar. A total of 49 articles were included in the primary review. However, we reviewed the initially deselected review article for the purpose of discussion only.

Prevalence of diabetes and depression

The literature review revealed wide variation in the prevalence of depression among children and adolescents with type 1 diabetes, ranging from 9.5% to 46.3%. Twenty-nine articles examined the overall prevalence of depression in children with diabetes. The highest prevalence (46.3%) was reported by Alassaf et al. in

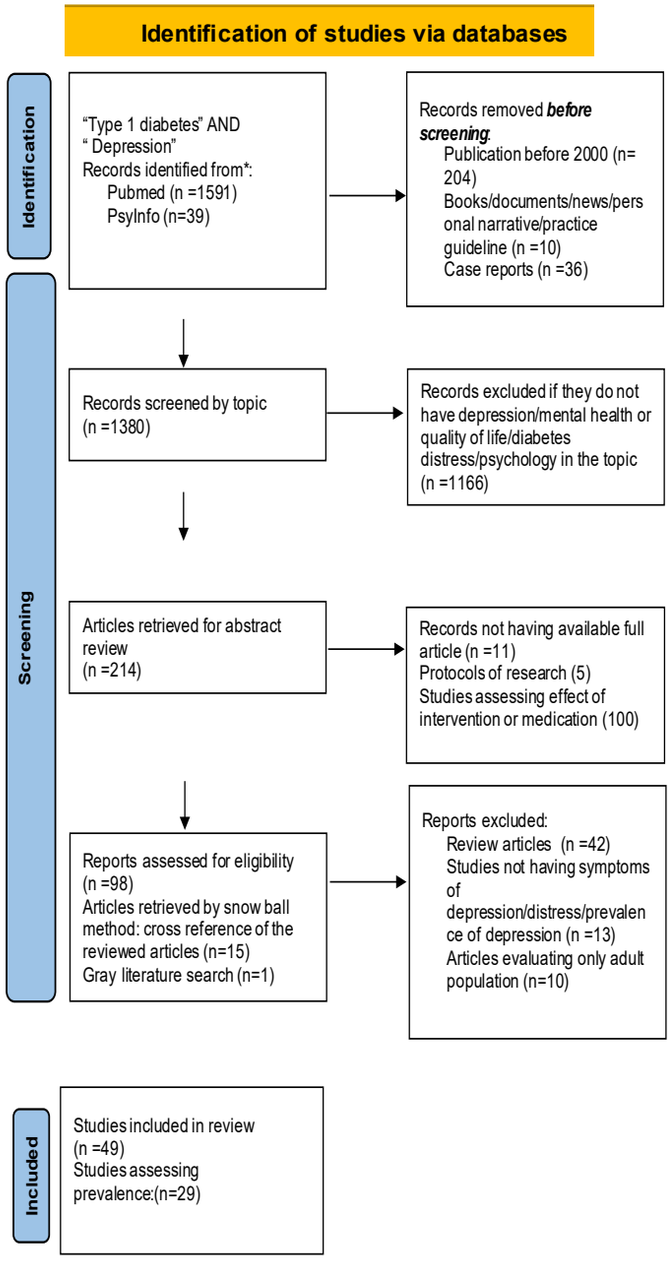

Figure 1: PRISMA flow diagram for systematic review, which included searches of databases

their study on the prevalence of depression in Patients with Type 1 Diabetes between 10 and 17 Years of age in Jordan.[6] In contrast, Hassan et al. reported the lowest prevalence (9.5%) in their study assessing the role of socioeconomic status, depression, quality of Life, and glycemic control in Type 1 diabetes mellitus.[7] However, most of the studies reported prevalence rates between 14.1% and 22%. [8-12] Compared with children and adolescents without diabetes, those with diabetes have a nearly 2-fold higher prevalence of mental, behavioral, and developmental disorders.[13] A significantly greater prevalence of psychosocial illness (55.95%) was observed in children with T1DM than in those without T1DM (20%).[14]

Five studies out of twentynine compared the prevalence of depression among genders, four of which reported a greater prevalence of depression among females than among males.[9-11,15-16] Five articles were from Asia, out of which two were from Southeast Asia, specifically one each from India and Pakistan.[6,17-20] Fifteen articles originated from North America. [10-12,16,21-34] Seven were from Europe, [9,15,35-39] one was from South America,40 and one was from Australia.[41]

The interconnection between diabetes and depression has been extensively studied at the level of symptomatology, and the bidirectional nature of the disease has also been explored.[20] A strong association was observed between depression and diabetes-related factors, such as glycemic control and the frequency of glucose monitoring.[42] Hence, it is highly important that we look for early features of depression in individuals living with diabetes. The features of depression can cover a combination of emotional, cognitive, behavioral and physical symptoms, and in people living with diabetes, all these symptoms impact their diabetes management and overall wellbeing. Conversely, the burden of managing diabetes, the fear of complications, and the impact of fluctuating blood glucose levels can exacerbate depressive symptoms, creating a vicious cycle. The diagnosis of diabetes itself, especially when newly received, can trigger or intensify depressive symptoms due to the psychological burden and need for lifestyle adjustments. Screening tools are utilized to capture early symptoms of depression to ensure that timely psychological care is provided to individuals in need. We used multiple screening tools to assess depression in these studies. Nevertheless, three major tools were used: the CDI, the CES-D and the PHQ-9. These tools capture early symptoms of depression by systematically assessing key depressive symptoms that align with diagnostic criteria.

Children's Depression Inventory: The CDI comprises 27 items assessing self-reported symptoms of depression in children and adolescents 7–17 years of age.[43] Twenty studies out of total used the CDI as a screening measure. It has a total of five subscales: negative mood, interpersonal problems, ineffectiveness, anhedonia, and negative self-esteem. Major symptoms of depression that are assessed by the CDI include sadness, irritability hopelessness, negative self-esteem, guilt, difficulty concentrating, social withdrawal, decreased interest in activity and fatigue, changes in sleep patterns, changes in appetite, academic difficulties, feelings of ineffectiveness, and loss of pleasure. [16,30-31]

CES-D: The Center for Epidemiologic Studies Depression Scale is a self-reported screening tool that focuses on depressive symptoms over the past week. It captures a continuum of symptoms from well-being to depression, which allows for the identification of early depressive symptoms before full clinical diagnosis.[44] It consists of 20 items, and responses are rated on a 4-point Likert scale. Symptoms assessed by the CES-D scale include sadness, hopelessness, irritability, loneliness, negative feelings, worthlessness, difficulty concentrating, recurrent thoughts of death, fatigue, appetite change, restlessness, sleep disturbance, social withdrawal, decreased activity level, feeling happy, cheerful, feeling hopeful about the future, and experiencing enjoyment or satisfaction with life.[6,12,44]

PHQ-9: The Patient Health Questionnaire-9 (PHQ-9) is a screening tool designed to screen, monitor and measure the severity of depressive symptoms in individuals aged > 13 years. It assesses symptoms early in time via a 9-item scale. The symptoms assessed included little interest or pleasure in doing things; feeling down, depressed, or hopeless; trouble falling or staying asleep; sleeping too much; feeling tired or having little energy; having a poor appetite or overeating; feeling bad about yourself; trouble concentrating; moving or speaking too slowly; being fidgety/restless; and thoughts of self-harm or suicide. [45--47]

The commonality of the symptoms and the specific symptoms assessed by these three tools has been compared in the table 1 below.

Table 1: Early markers of depression as assessed by three tools

Symptoms common to tools	Symptoms specifically captured by individual tool
Lack of interest or pleasure	Restlessness and slowed movement (PHQ-9)
Feeling sad or down	Crying or emotional reactivity (CES-D, CDI)
Sleep disturbances	Social withdrawal (CDI, CES-D)
Changes in appetite	Irritability (CDI, CES-D)
Feeling of worthlessness or guilt	Physical complaints (CDI, CES-D)
Trouble concentrating	
Fatigue or low energy	
Thought of self- harm	

All these are general symptoms that can occur in individuals with or without diabetes. However, people living with diabetes often face the added challenge of managing their condition every day, which can take a significant emotional toll. This emotional strain should not be overlooked, as it can contribute to early signs of depression in individuals with diabetes. Since the screening tools used for depression are not designed for specifically addressing diabetic issues, we explored the symptoms of diabetes distress as well.

Diabetes Distress:
Diabetes distress (DD) refers to the negative emotions arising from living with diabetes and the burden of self-management. It is a normal emotional reaction to the burden of self-management demands of diabetes, including frustration with treatment demands, worry about complications, feeling defeated or hopeless about one's ability to manage diabetes and low motivation for diabetes self-management. It represents a significant clinical burden in people living with diabetes and is related to both glycated haemoglobin (HbA1c) and self-management behaviours.[30] Various risk factors for elevated DD in individuals with type 1 diabetes are a longer duration of diabetes, severe hypoglycemia, and female sex. [48-50]

The prevalence of diabetes distress (DD) varies across different studies. The prevalence of diabetes distress among children was approximately 58%, with major concerns affecting family and peer relationships.[51-52] There are two main screening tools utilized for assessing diabetes distress among children, adolescents and young adults. The Problem Areas in Diabetes (PAID) scale is the Diabetes Distress Scale (DDS).[53] The Problem Areas in Diabetes Scale (PAID) is a self-report questionnaire designed to assess the emotional distress and psychological burden associated with living with diabetes. The PAID scale focuses on the emotional impact of diabetes rather than just on clinical aspects such as blood glucose levels or insulin usage. It is a 20-item questionnaire measuring diabetes-related emotional distress. It assesses emotional distress, food-related distress, social distress and treatment-related distress and hence captures both emotional reactions and practice concerns, which can be the major parameters of diabetes distress.[11,30] Diabetes distress scale: The Diabetes Distress Scale (DDS) is a tool developed to assess the emotional distress and psychological burden associated with managing diabetes. DDS focuses specifically on the emotional challenges that arise from living with diabetes and the various factors that can make diabetes management difficult. It consists of 17 items assessing distress across four primary domains: emotional burden, physician-related distress, regimen-related distress, and interpersonal distress. The symptoms assessed by the DDS-17 include worries about complications, frustration with the management of diabetes, guilt, discomfort with social situations, concerns about receiving unsatisfactory medical care, and stress due to daily self-management tasks.[54]

Depression as well as Diabetes distress are conditions that can complicate the management of Diabetes. The symptoms assessed by the depression and distress screening tools both overlap and differ. However, we need to remember that people living with diabetes can have any of these symptoms as a primary trigger resulting in depression. The Venn diagram (Fig 2) shows the overlap and distinction between the symptoms of depression and diabetes distress.

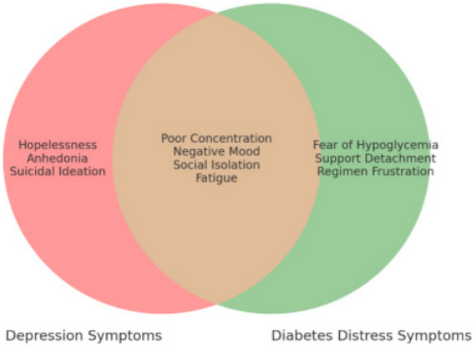

Figure 2 Distinction and overlaps between the symptoms assessed by the depression and distress screening tools

DISCUSSION

Diabetes and depression are two issues that might move together, and one might lead to or worsen the management of another. The articles we reviewed, as well as similar review articles and meta-analyses, established that youth living with diabetes have a greater risk of developing depression than do their age- and sex-matched peers. Most of the studies reported a prevalence of depression in people living with diabetes between 14.1% and 22%. However, there were two major outliers, with 46.3% coming from a lower middle-income country, Jordan, and 9.5% coming from a higher income country, the USA. These wide differences in rates could be the result of the type of assessment tool used and the study setting. A meta-analysis of diabetes and depression in children and adolescents reported a pooled prevalence of 19.1%, which matched the prevalence reported in our review.55 Another important aspect is the fact that most of the data that we are discussing in our review come from higher income countries. Hence, these prevalence

percentages cannot be extrapolated for Nepal, and it is of utmost importance that we carry out a prevalence study for our country.

Early symptoms of depression in children, adolescents and young adults living with diabetes might result from general features of depression or from diabetes-specific issues. The persistence of any of these symptoms for longer durations can trigger depression in individuals living with diabetes. The common early features of depression identified in our review are similar to those identified in other studies, such as persistent low mood, loss of interest, low self-esteem, pessimism, poor concentration and withdrawal from social interaction. Physical complaints such as poor sleep/excessive sleepiness, loss of appetite, and fatigue are overlapping features that can be observed in individuals with diabetes distress as well as depression.[56-58] Diabetes distress arises due to the stress associated with the management of diabetes and can present as anger, guilt, worry about diabetes management and potential complications.[59]
During the initial phase of diabetes diagnosis, many young patients experience features of depression or anxiety, but these symptoms usually resolve within months. However, components such as poor adjustment during this period can lead to long-term psychosocial difficulties.[60] Our review has not explored the social component of the management of diabetes, and this is one part that we must look into in further studies, as these components impact the adjustment of the new diagnosis.

Features of depression and diabetes distress in individuals living with diabetes affect the daily management of diabetes, such as glucose monitoring, impair the glycemic index and increase episodes of DKA, hypoglycemia and chronic complications. Likewise, the burden of managing diabetes can exacerbate the symptoms of depression. Moderate to severe depressive symptoms are associated with high regimen distress and emotional burden.[61] Similarly, diabetes-specific distress and emotional challenges can directly compound general depressive symptoms. Studies have shown that 70% of those with depressive features also experience diabetes distress.[62]
Therefore, it is very important that both the general depressive features and diabetes distress components are assessed regularly during clinical visits if we want our children, adolescents and young adults to take care of the psychological burden of having diabetes. Identifying and distinguishing between general depressive features and diabetes-specific stress is challenging, as the symptoms of these two conditions overlap. The literature supports the use of validated screening tools for both depression and distress. Instruments such as the PHQ-9 for general depressive features and the PAID-T for diabetes distress have shown utility in clinical practice. The International Society for Pediatric and Adolescent Diabetes (ISPAD) guidelines recommend psychosocial screening of children >12 years of age and highlight the importance of having mental health professionals on the diabetes care team.

An ideal diabetes care team would include a mental health professional to address psychosocial issues, but this is often not feasible in our setting. Therefore, screening tools usable by primary care physicians or nursing staff may be a practical alternative. Although tools assessing both depression and diabetes-related distress are recommended, time constraints in outpatient settings of lower middle-income countries like Nepal make their routine use challenging. A tailored screening tool for diabetes patients that simultaneously assesses distress and depressive symptoms and identifies those needing referral to psychiatry services would be more practical.

Initially, the research team proposed the term "predepression" to identify and assess early signs of depression among individuals living with diabetes. Predepression was hoped to be impactful in improving mental health-seeking behaviour and less stigmatizing. However, during discussions, participants voiced the lack of impact of the term Predepression, perceiving it as synonymous with depression. Nevertheless, they emphasized the importance of providing emotional support from the point of diagnosis, as living with diabetes involves significant emotional challenges. Hence, on the basis of this feedback, we removed Predepression from the study title. To better reflect the emotional experiences of individuals with diabetes, we broadened our literature search to include studies focused not only on depression but also on the emotional aspects of living with diabetes. As a result, we incorporated research on diabetes distress alongside the literature on depression. A key strength of our study lies in its integration of PPI, which shaped the direction of review, as identified by the people with lived experiences. We integrated both the general depressive features and the features of diabetes distress to identify early symptoms of depression, providing a holistic analysis. The lack of review and analysis of socioeconomic factors also limits the breadth of this analysis. Addressing these areas in future studies could further refine the understanding of depression in diabetic populations.

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