The Psychosocial Burdens of Living with Diabetes

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Novelty Statement:

What is already known:

- The prevalence of psychosocial challenges is considerably higher amongst people with diabetes than the general population, including depressive symptoms, self-harm and suicide

What this study has found:

- This large scale survey confirms high rates of self-reported psychosocial burdens, low mood and diabetes-related distress amongst adults with type 1 diabetes or type 2 diabetes. Despite this, appropriate support is lacking in routine care.

Implications of the study:

- This study highlights the ongoing failure of clinical care to adequately support the needs of people with diabetes beyond physical aspects of disease management.

- The lack of focus on psychosocial issues is a barrier to optimal diabetes self-management; it is crucial that a biopsychosocial model is integrated into routine care

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Abstract

Aim: To better understand the prevalence of self-reported psychosocial burdens and the unmet needs identified by people with diabetes in relation to routine diabetes visits.

Methods: An English language, online survey was distributed via social media, key stakeholder networks, charity and advocacy groups to adults with type 1 diabetes or type 2 diabetes. Survey items were designed by members of the FDA RESCUE Collaborative Community Governing Committee prior to pilot testing with potential participants. Descriptive statistical analyses were conducted; as well as thematic analyses on free text responses using NVivo v14.

Results: 478 participants completed the survey. 373 (78%) had type 1 diabetes, 346 (73%) identified as a woman and 433 (91%) were white. Most participants had experienced self-reported (rather than diagnosed) anxiety and depression (*n*=323 and *n*=313 respectively), as well as fear of low blood sugars (*n*=294), low mood (*n*=290) and diabetes-related distress (*n*=257). 68% reported diabetes had negatively affected self-esteem and 62% to feelings of loneliness but 93% reported friends/family/work colleagues were supportive when needed. 272 (57%) reported their diabetes team had never raised the topic of mental health. The overwhelming majority stated the best thing their diabetes team could do to help was to simply ask about mental well-being; listen with empathy and without judgement; and practice skills to understand psychosocial issues in diabetes.

Conclusion: Integrating psychosocial discussions and support within routine healthcare visits is crucial to improve outcomes for people with diabetes. Such a biopsychosocial model of healthcare has long been advocated by regulatory bodies.

Key words: Type 1 diabetes; Type 2 diabetes; psychosocial; emotional burden; RESCUE diabetes

Introduction

In those with type 1 diabetes (T1D) and type 2 diabetes (T2D), the prevalence of psychosocial issues are higher than the general population [1]. Specifically, depression rates are 2-3 times higher than the general population and suicide attempts 3-4 times more likely [2]. Mental health screening has recently begun to increase in diabetes clinics, however, this is still not widespread. Additionally, there is little knowledge of the experiences of people with T1D or T2D around the psychosocial challenges in discussion with their providers. Diabetes is a psychologically demanding condition with diabetes-related distress affecting up to 40% of individuals living with diabetes at any time [3] Furthermore, rates of hopelessness and low feelings of self-worth have been commonly reported for many years [4].

Rates of intended self-injury (ISI) and suicide are likely to be considerably under-estimated in those with T1D [5]. A study of 160 cases of insulin overdose reported 90% were suicidal or parasuicidal, with only 5% deemed accidental [3]. Talking about mental health issues remains highly stigmatized [7]. The isolation that suicidal people feel alongside feeling broken or weak, for example, can be reinforced by a judgmental approach in which their behaviour is viewed as manipulative or selfish. For every completed suicide by people with diabetes, the World Health Organization estimate there are a further twenty suicide attempts [8,9].

The purpose of this study is to determine awareness, understanding, and comfort of people with diabetes around diabetes-related psychosocial issues in order to determine potential areas for increased education and healthcare support. An additional purpose is to understand the perspectives of people with diabetes on their unmet needs to help determine how best health care providers can be supportive. This was achieved by an international survey of people with diabetes.

Methods

An English language, online survey targeting individuals in the UK and USA was distributed via social media, key stakeholder networks, and charity and advocacy groups to people with type 1 diabetes or type 2 diabetes. The survey was hosted securely through Microsoft forms and no identifying data were collected from the participants to ensure confidentiality and anonymity. The survey was designed for adults aged 18 years or over. To avoid anybody under the age of 18 years from accessing the survey, participants were required to check a box confirming their age before they could progress to survey entry. A clear message was displayed indicating that nobody under the age of 18 years should attempt to access the survey. The recruitment strategy employed targeted adults with type 1 diabetes or type

2 diabetes through adverts on social media sites and encouraging broad sharing by readers, charity and advocacy groups including Diabetes UK, Diabetes Research and Wellness Foundation, Diatribe and Close Concerns. Stringent efforts were made to repost adverts twice a week during recruitment and to encourage readers of the adverts to share amongst their networks. Recruitment remained open from 4th January 2023 to 13th March 2023.

The survey items were informed by a literature review and were initially agreed by members of the FDA RESCUE Collaborative Community Governing Committee. This represents multi-disciplinary healthcare professionals as well as key stakeholders representing people with diabetes, industry, government, charity and advocacy agencies. Items addressed psychosocial factors associated with living with diabetes. Questions were designed to provide insights into a range of psychosocial factors and how participants perceived these were considered within routine care visits. These included perceived psychological morbidity and diabetes-related burden including distress, low mood, diabetes-related anxiety and perceived depression. Space was available for participants to provide free-text responses to expand on their 'forced-choice' answers.

Several resources were provided at the beginning and at the end of the survey signposting participants to charities and helplines (both online and telephone) should they feel uncomfortable with any of the questions or feelings they may have raised. The survey draft was shared with potential participants for review and adapted as necessary prior to a final version being submitted for ethics approval. Ethics approval for the study, including international recruitment, was granted by the University of Southampton review board (ERGO II 79163).

The final survey consisted of 32 questions and took an average of 8-10 minutes to complete per participant (see Appendix for survey). Descriptive statistical analyses were conducted on survey responses. Each question response was examined for frequency of each response and variability of their spread across all unique questions. Subgroup analyses was conducted based on type of diabetes, duration since diagnosis, gender, age and other demographic variables. Thematic analysis followed the grounded theory methodological approach [10] using open coding methodology. This inductive approach avoids the imposition of pre-conceived themes, rather it allows the data to speak for itself and any new concepts to emerge. Free text data were initially independently coded and categorized using constant comparison techniques by two researchers experienced in qualitative methods (KBK and EB). Free text data were analysed both within each individual question response, but also across other questions across the survey to provide a deep, rich understanding of the responses. Regular review meetings were held to cross-compare coding and key themes and assess inter-rater reliability. Nvivo v14 software was used to support coding activities. Key themes were derived from the data.

Results

478 participants completed the survey. 373 (78%) had type 1 diabetes, 346 (73%) identified as a woman and 433 (91%) were white. Demographic data are presented in Table 1.

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Emotional distress was widely reported across many domains (Figure 1). Self-reported anxiety was the most commonly endorsed experience (69%), followed by self-reported depression (65%) and fear of low blood sugars (62%). Needle fear was not common. The ‘other’ responses were also less common, but (*n*=67) included feelings of anger, burnout/feeling overwhelmed/hopelessness, disordered eating, mental fatigue, PTSD, suicidal thoughts, fear of high blood sugars, and marriage problems. Analyses was conducted to explore any clusters of responses across the domains, however, no clear patterns emerged. Only two clusters of note were identified, namely for respondents who endorsed depression and anxiety and fear of hypoglycaemia and low mood and diabetes-related distress (*n*=48); and for respondents who endorsed all of these and fear of needles (*n*=68). Furthermore, there were no discernible differences in responses according to age range or duration of diabetes. Data analyses of free text responses is presented below, the inter-rater reliability was high with a Cohen Kappa of 0.84.

More than two thirds (n=327, 68%) participants reported that diabetes has negatively affected their self-esteem (now or in the past). More participants with T1D (70%) reported this negative impact compared to participants with T2D (63%)(p=<0.001). Free text responses to this question (*n*=444) most frequently endorsed the relentless self-management of diabetes and feelings of not doing enough; followed by discomfort about diabetes in public and lack of understanding by others. Feeling judged and the stigma of diabetes was reported by several participants, along with feeling a burden to others. In addition, loss of freedom and lack of spontaneity caused by diabetes was commonly reported; as was self-reported depression, low mood, self-reported anxiety and constant worry about living with diabetes. Several participants felt self-conscious about weight gain, often associated with insulin use, as well as scarring from injections and cannulas. Furthermore, feelings of isolation and suicidal ideation were endorsed by some participants. Example quotes include:

- “I feel separated and "special" from others. I hide my diabetes, my pump gives me away. People don't understand the disease and I get tired of explaining it.”
- “Having to inject in public, medical devices attached to body on show, people’s views on why I have the condition like it’s something that is my fault.”
- “It has control over every decision I make!”
- “Because I can’t do all the things "able bodied" people do and feel bad about myself why I can’t keep up.”
- “I have injection scars and pump scars all over my body. It has impacted my weight gain. Diabetes has not been easy on my body.”

298 (62%) reported diabetes had led to feelings of loneliness now or in the past. Again, more participants with T1D reported feelings of loneliness (68%) than T2D (44%)(p=<0.001). Free text responses (*n*=421) show the majority of participants endorsed not knowing anyone else with diabetes and lack of understanding of the challenges of the condition by others can make living with diabetes feel more isolating. Other responses included being irritable due to hypoglycaemia or hyperglycaemia which makes it difficult to keep friends; as well as always having to explain about diabetes or having to change social life activities to accommodate diabetes contributing to feelings of outsideness and loneliness. Example quotes include:

- “People don’t understand how difficult it can be, I feel like I have to deal with it on my own”
- “Close friends and family have very little understanding of T1 which can make it feel more isolating”
- “It’s difficult for non-diabetics to fully understand how many elements are involved in the care of diabetes”
- “I don’t socialise, especially in food settings because I feel awkward asking about certain foods”
- “Eating differently to others in a social situation sets you apart. People notice and ask questions. It can be embarrassing”
- “Sometimes I feel like my closest relationship, ie partner, family, friends, can never understand what it’s like to live with this day in day out. I don’t want to burden them so try and carry it alone, but in turn that can feel very lonely when it’s hard, or when you are having a bad sugar level day and can’t even say the words to try and share it”

More positively, 438 (93%) reported the people important in their life (e.g. family, friends, work colleagues) are supportive when they needed help with their diabetes; of whom 325 (69%) responded always or often to this question. Results were similar for participants with T1D and T2D at 69% and

65% respectively. In response to an additional question of ‘how their support (or lack thereof) makes you feel, 428 (90%) responses were received which described both positive and negative aspects. Positively, feeling looked after, heard, understood and listened to were endorsed by the majority of participants; as well as feeling appreciative, thankful and loved. Negative responses included feeling unloved, ignored, nagged and a lack of understanding by loved ones. Example quotes include:

- “Loved, looked out for, less afraid of having hypos or highs as they understand”
- “It’s nice to feel supported. However, support can sometimes feel a bit like nagging. Sometimes they get upset about what’s happening and it makes me feel guilty”
- “Thankful, blessed”
- “Can always rely on my partner - he’s learned a lot about diabetes and is always willing to listen”
- “Their support is great, though sometimes it borders on helicoptering around me; which is something I do not like”
- “Their support means the world to me. I owe much of my capability to stay out of DKA and my ability to manage my diabetes effectively to these people”
- “Misunderstood, lonely, angry”

When asked whether the diabetes team had ever raised the topic of mental well-being, 57% (*n*=269) participants responded that they had not. 228 (48%) participants reported ever having discussed the topic with their diabetes team, with a further 154 (32%) reporting they have had concerns but have not discussed them with their diabetes team. Of those that had discussed mental well-being, 142 (30%) said they had spoken about it in general terms, with the remaining 65 (13%) reported having discussed a specific topic or issue. Only 160 (34%) had received treatment from their diabetes team, compared with 120 (25%) who had asked but not received support. Despite this, 83% of participants reported that they would feel comfortable speaking with their diabetes team about their psychosocial issues (*n*=238 always comfortable; *n*=153 sometimes comfortable); and 386 (81%) believing that psychological support should be routinely available from their healthcare team. More participants with T2D always felt comfortable (56%) compared with participants with T1D (48%)(p=<0.001).

In response to free text questions about what the diabetes team could do to help people with diabetes feel more comfortable discussing psychosocial concerns with their diabetes team and what support would be helpful if struggling with such issues, free text responses (*n*=351) showed most participants endorsed just being asked about psychosocial issues in routine visits would be a huge improvement. In addition, listening with empathy and without judgement, having better skills to understanding issues beyond glycaemic management, having access to a therapist or mental health resources, providing peer support, or raising awareness that psychosocial challenges are common in diabetes were all endorsed. Example quotes include:

- "Ask if mental health is a problem at every appointment!"
- "Be more open to listening and do not judge"
- "Letting all people with diabetes know that mental health can be a problem"
- "Show some empathy. They are very cold and distant"
- "Just asking about mental health helps"
- "Ask me as part of the routine screening. In addition to talking about my A1c, ask about how I'm feeling"

Discussion

In this survey of 478 people with diabetes (373 T1D, 103 T2D, 2 did not state), the vast majority reported experiencing psychosocial and emotional burden as a result of their diabetes. This report confirms current literature about the high prevalence of emotional distresses amongst people living with diabetes. In this large participant sample, the most commonly endorsed experiences were self-reported anxiety and depression as well as, fear of low blood sugars, low mood and diabetes-related distress. It must be noted that no formal diagnosis information was sought. Of particular concern in this study, is the majority of participants who reported their diabetes team did not broach the topic of psychological support during clinical care, unearthing a significant gap in holistic healthcare for people with diabetes. On a positive note, the majority of participants felt well supported by friends, family and work colleagues.

The spread of data across participants and the absence of meaningful clusters of responses make it very difficult to propose recommendations for routine clinical care beyond raising and exploring the psychosocial needs of the person in the visit. The absence of differences according to age or duration of diabetes is consistent with previous research [11,12]. Hunter's analyses of two large secondary datasets, including 5,372 individuals, reported no differences on either variable. The Farooqi systematic review and meta-analysis comparing the prevalence of depression between people with and without type 1 diabetes and type 2 diabetes included 44 studies. Results showed no association between study effect size and mean age or gender. As such, it is clear that psychosocial distress is experienced across all ages of people with diabetes, irrespective of duration of disease state. Simply being asked about diabetes experience beyond glycaemic levels was frequently reported by participants as a significant step to improving the encounter. Many participants reported the acknowledgement diabetes was broader than HbA_{1c} rather than the provision of specific solutions would be beneficial to their clinical experience.

Ten years after the global Diabetes Attitudes, Wishes and Needs (DAWN2) study [7] which assessed psychosocial outcomes in people with diabetes across countries for benchmarking purposes, it is clear that there has been no discernible improvement in psychological outcomes for this population. In the DAWN2 study, the proportion of people with likely depression as measured on the WHO-5 score ≤28) was 14% compared with 16% in the current study. Diabetes-related distress was reported by 45% of participants in the DAWN2 study, whereas in the current study it was 56%. Similarly, fear of hypoglycaemia in the DAWN2 study was 56% compared to 62% in the current study.

Gonzales et al [13] reviewed the evidence of psychosocial factors implicated in diabetes self-management. They reported that emotional distress and wellbeing, as well as coping skills, are all modifiable via psychological intervention. Addressing these aspects of diabetes within routine care, alongside physical health aspects of disease management such as glycaemic management, is crucial in delivering effective healthcare for people with diabetes. Furthermore, a continuing failure to do so leaves people with diabetes vulnerable to psychological disorders. Dickinson et al [14] explored the emotional experiences of people with diabetes in the context of words and phrases previously identified as problematic and potential differences in emotional impact. A survey of 107 adults with type 1 diabetes and 110 adults with type 2 diabetes revealed that respondents reported feeling “blamed, misunderstood, hopeless, judged, not motivated and not trusting” in response to words including ‘non-compliant, unmotivated, in denial, failed’ and comments such as ‘you could end up blind or on dialysis’. Such terms reflect paternal attitudes that are inappropriate and should be avoided. Person-centred, collaborative engagement in routine care has long been demonstrated to be more effective and should be pursued in line with language matters guidance.

This study also confirms previously reported data reflecting widespread dissatisfaction by people with diabetes about the lack of psychosocial support in routine diabetes care [15]. Adults with type 2 diabetes and severe mental illness reported the level of diabetes healthcare and support received, emotional well-being, perceived ability to manage diabetes and perceived consequences of self-management were all associated factors. It was concluded that providing adequate psychological support was required through integrated action plans. Dissatisfaction with care has also been demonstrated to be significantly related to self-care behaviours amongst people with type 2 diabetes, specifically diet, poorer quality of life and worse blood glucose levels [15]. Sachar et al (2020)[16] report that psychosocial difficulties are the norm rather than the exception amongst people with type 1 diabetes or type 2 diabetes. They argue that it is necessary to embed psychological support into the entire diabetes care pathway; however, the authors recognise that in diabetes commissioning psychological services is an 'afterthought' seen as 'nice to have' rather than a crucial integral component.

It has long been recognised that the medical model of healthcare is ill-fitting to the needs of people with long-term conditions including diabetes [17]. Further, that a biopsychosocial approach is required. This is in line with the World Health Organization founding charter (1948) [18] that defines health not as the absence of disease, but the presence of physical, mental and social wellbeing. Including psychosocial support routinely within diabetes appointments, in-person or remote, is crucial to support effective management of diabetes beyond glycaemic management. Furthermore, improving healthcare professional's listening and communication skills around psychosocial issues could help. Phillips et al [19] report that physicians interrupt their patients on average 18-23 seconds after they start to describe the problem. It can be very difficult to raise difficult topics from a patient perspective, but it can also be uncomfortable for healthcare professionals to be asked such questions [20]. The National Institute of Mental Health provide a list of tips for talking with a healthcare provider about mental health [20]. Whilst helpful, this is at risk of placing the onus on the patient to take responsibility for raising what can be difficult topics, rather than the emphasis on healthcare systems to provide consultations designed with holistic healthcare in mind. As seen in the current survey, most participants simply want their healthcare team to ask about diabetes challenges beyond glycaemic management routinely in healthcare visits. Further, that healthcare providers listen with empathy and without judgement.

The strengths of the current study include that it is a large survey exploring psychosocial issues associated with diabetes from a personal perspective. It represents opinions across the UK and USA and addresses both the scale of psychosocial burdens as well as views on what can be done to address the situation. The study is limited by only being available in English language and in the USA and UK due to ethics requirements. Also, the system only recorded data of those who completed the questionnaire and not how many people opened it but did not complete it. As such, it is not possible to calculate an accurate response rate. Consequently, the sample may be biased due to the self-selecting nature of participation; however, the high response mitigates this bias. The high numbers of adults with T1D as compared to T2D may reflect the predominance of people with T1D on social media sites. To overcome this, we actively targeted charities and sites dedicated to T2D, however, albeit with limited success. The data from this survey are being used to inform development of a novel screening tool for self-harm and suicidal acts. As such, the survey was necessarily limited to adults with type 1 diabetes or type 2 diabetes. This limitation precluded the views of adults with other types of diabetes.

Further research is required to explore ways to integrate psychological support routinely in diabetes care to improve the physical and psychosocial outcomes of those living with the disease. Limited demographic data were collected in line with ethics approval and, as such, it was not possible to compare data from respondents in different countries. With different healthcare systems in the UK and USA such integration will necessarily differ, however, the burden of diabetes is experienced similarly in these comparable western cultural environments. For example, high rates of diabetes-related distress are observed in both the UK and USA, as they are across Europe [21]. As such, there will be central themes throughout which will aid standardisation of therapeutic programmes. It is also recommended that education and support are provided for healthcare providers both during their training and as continuing professional development. Fisher et al recommend practical strategies for intervention in clinical settings to assist diabetes professionals in addressing diabetes distress. Such training should include skills in empathy as well as the psychosocial aspects of diabetes and how to access and signpost support.

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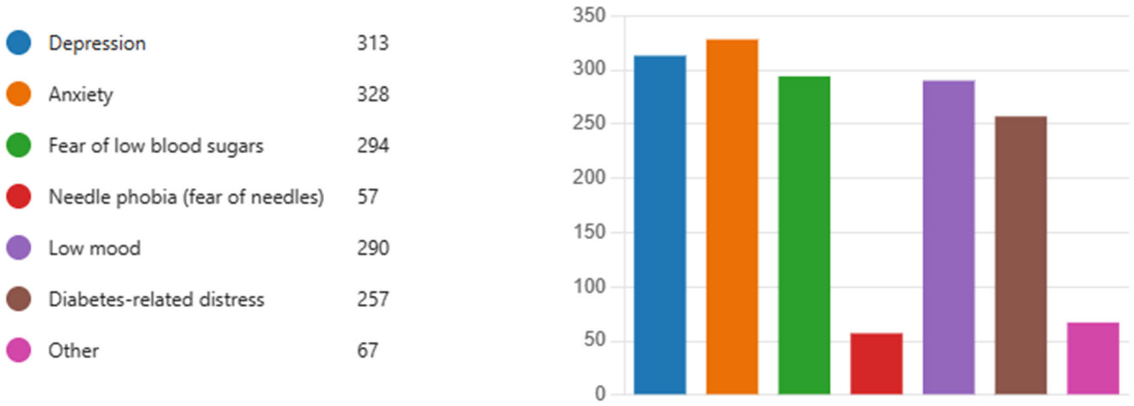
Table 1: Demographic Data

	N (%)
Gender	
Woman	346 (72.4)
Man	127 (26.6)
Non-binary	2 (0.4)
Transgender man	0
Transgender woman	1 (0.2)
Age	Mean 64 (range 20-87, SD4.16)
Race	
White	433 (90.5)
American Indian or Alaska Native	2 (0.4)
Asian	6 (1.2)
Black or African American	13 (2.7)
Hispanic, Latino or Spanish Origin	10 (2)
Middle East or North African	2 (0.4)
Native Hawaiian or Other Pacific Islander	0
Prefer Not to Say	3 (0.6)
Other	8 (1.6)
Marital Status	
Single	71 (14.8)
Married / partnered	323 (67.6)
Divorced	57 (11.9)
Widow/er	21 (4.4)
Prefer not to say	5 (1.0)
Duration of Diabetes (yrs)	Mean 28 (range <1-72, SD 13.64)
Type of Diabetes	
Type 1	373 (78.0)
Type 2	103 (21.5)
Treatment	
Diet only / lifestyle advice	12 (2.5)
Tablets / Pills / non-insulin injectable	47 (9.8)
Insulin (always since diagnosis)	327 (68.4)
Insulin only (but I used to take tables/pills/non-insulin injectable	27 (5.6)
Insulin plus tablets/pills/non-injectable	64 (13.4)
Receiving Care From …	
Primary care doctor or practice nurse	110 (23.0)
Private diabetes clinic / diabetes specialist	164 (33.4)
Diabetes clinic within a hospital or associated with a hospital	195 (40.8)
Via telehealth / video / remote provider	8 (1.7)

Figure 1: Experiences of Emotional Distress



●	Depression	313
●	Anxiety	328
●	Fear of low blood sugars	294
●	Needle phobia (fear of needles)	57
●	Low mood	290
●	Diabetes-related distress	257
●	Other	67

Depression and anxiety are self-reported rather than formal diagnoses