**Experience of Diabetes Stigma during Established Adulthood: Unpacking the Source and Impact of Stigma in People living with Type 1 and Type 2 Diabetes**

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**Highlights**

* Reflective thematic analysis of stigma experiences for people with diabetes.
* Observed similarities and differences in stigma markings between diabetes types.
* Diabetes and weight relationship is complex due to stigma-based prioritisation.
* Negative impact of stigma on management centres around visibility of diabetes.

**Structured Abstract**

*Aims:* To explore the lived experience of diabetes and weight stigma in established adults (25-45) with both type 1 diabetes (T1D) and types 2 diabetes (T2D), to better understand the nature of diabetes-related stigma.

*Methods:* A large-scale cross-sectional survey using participant-generated text design was conducted from February to April 2024. Data were analysed using inductive reflexive thematic analysis.

*Results:* The study identified 91 respondents (79 T1D; 84 female; mean age 31.9; SD 4.7 years) in the established adulthood stage. Experiences are reflected in three themes: **(1) Same yet Different**: people with diabetes (PWD) experience stigma in similar ways, as the stigma targets from those without diabetes. However, people with T2D face additional stigma marking from those with T1D. **(2) Stigma Consequences:** The intersection of diabetes and weight stigma was observed to result in detrimental psychological and diabetes-management consequences. Some PWD responded by educating others and showing resilience. (**3) Weight over Health Prioritisation**: Healthcare professionals and social networks often prioritise weight concerns resulting in PWD feeling their diabetes health and management is overlooked.

*Conclusions:* PWD share stigma experiences; comparing both highlights complexities in the intersectionality between diabetes and weight-related stigma that has important implications for psychological and diabetes health.

**Keywords:** Diabetes, Diabetes stigma, Weight stigma, Diabetes Self-management, Reflexive Thematic Analysis

**Graphical Abstract**

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1. **Introduction**

Current research indicates that four in five adults with diabetes experience diabetes stigma, with one in five facing discrimination due to their condition [1]. Psychosocial research on diabetes-related stigma has focused primarily on either type 1 diabetes (T1D) or type 2 diabetes (T2D), despite similarities in experiences such as blame, shame, rejection and misunderstanding [2, 3]. This separation in research may itself perpetuate diabetes stigma by reinforcing a narrative that associates T2D with lifestyle assumptions [4, 5]. In line with this, the misidentification of people living with T1D as having T2D is often cited as the source of stigmatisation [4]. Schabert et al. [5] describes diabetes-related stigma as driven by attitudes of blame, disgust, and the need to enforce social norms like diet and exercise – outlined in the Health Stigma and Discrimination Framework as determining the stigma marking [6]. Stigma manifests through practices such as labelling, negative stereotyping, separation and discrimination [6, 7].

Diabetes-related stigma has been associated with high diabetes distress and HbA1c levels, and lower self-esteem and quality of life, negatively impacting diabetes self-management (DSM) [8, 9, 10]. For people with T2D, internalising stigma hinders DSM by amplifying negative self-image [11]. However, in-depth exploration of stigma’s impact on DSM in individuals with T1D is lacking. Furthermore, much diabetes stigma research has focused on the adolescent and young adult (AYA) population due to their increased vulnerability to stigma [4, 12, 13, 14]. In contrast, adults in established adulthood (mid-twenties to mid-fourties) [15] are often overlooked and subsumed within general adult populations, despite facing unique changes related to health and identity [11, 16]. This lifespan experience significant life challenges such as career and parenthood navigation, which may indicate a time of increased vulnerability in the context of navigating health-related stigma [17]. However, no research has specially exploring diabetes stigma in this population.

Established adulthood is also distinct from emerging adulthood (AYA) in terms of physical health, with notable changes in metabolic rates and age-related weight gain [18, 19]. Weight-related stigma is increasingly recognised in the context of T2D, affecting over half of adults with T2D, and moderately related to diabetes stigma [20]. Healthcare professionals (HCPs) also demonstrate bias and negative stereotyping towards individuals with obesity and T2D, which may help to explain, in part, stigma perceptions as a result of mislabelling expressed by those living with T1D [21]. Similar intersecting weight and diabetes stigma-based practices are evident in T1D care, where non-supportive attitudes towards weight management have been reported amongst AYA populations [22].

The aim of this study was to explore the lived experience of diabetes and weight stigma in established adults (25-45) living with both T1D and T2D, to better understand the nature of diabetes-related stigma.

1. **Subjects, Materials and Methods**
	1. Study design

The study employed a mixed methods methodology using a large-scale cross-sectional survey and participant-generated text design, hosted on Qualtrics, to explore PWD’s experiences of stigma. The quantitative survey was designed to determine the relationship between diabetes stigma and diabetes management, and the role that weight stigma and diabetes type may play, using four validated measures – the T1D and T2D Stigma Assessment Scales (DSAS-1 [23]; DSAS-2 [24]), Weight Bias Internalisation Scale Modified (WBIS-M [25]), and Summary of Diabetes Self-Care Activities (SDSCA [26]). The qualitative research methodology enabled participants to elaborate on their lived experiences in open-ended questions relating to the focus of each validated survey instrument ([Appendix I](#Appendix)).The study was performed in compliance with relevant laws and institutional guidelines and was approved by two independent reviewers from the University of Derby College of Health, Psychology and Social Care Ethics Committee [ID: ETH2324-2041; DOI 10.01.2024].

* 1. Participant-generated Data

Data was collected from February to April 2024. Participants were recruited through social media advertisement, including that of JDRF (the type 1 diabetes research charity), and online diabetes groups following approval by relevant administrators. Inclusion criteria were aged 16 or over and a diagnosis of type 1 or type 2 diabetes. A total of 173 PWD completed the survey; the quantitative data is currently being subject to multivariate analysis for future publication. The qualitative data has been stratified to enable more focussed analysis in order to support a deep and nuanced understanding of the respondents lived experience. In accordance with Fugard and Potts [27], who advised that a sample in excess of 50 was required for analysis using participated-generated text design for thematic analysis, a total of 91 participants were identified as belonging to the established adult stage of life ([*Table 1*](#Table1)). Explicit statements of definitions were applied for sex and gender: sex referring to a binary sex categorisation of male/female designated at birth, and gender referring to socially constructed roles, behaviours and identities, categorised into identified gender of male/female/non-binary or third gender. Ethnicity categorisation followed those of the 2021 ONS consensus: Asian or Asian British/Black, Black British, Caribbean or African/Mixed or multiple ethnic groups/White/Other ethnic group.

 Data was analysed using Braun and Clarke’s framework for inductive reflexive thematic analysis within a realist/essential paradigm [28, 29]. This entailed coding guided, but not consumed, by (1) the conceptualisation of stigma through labelling, stereotyping, separation and discrimination [7]; and (2) the identification of stigma manifestations (experienced, perceived and internalised), stigma practices (stereotypes, prejudices, behaviours and attitudes), and stigma drivers and facilitators (judgement, blame, and awareness) as described in the Health Stigma and Discrimination Framework [6]. Data was also coded with those deemed relevant outside of the theoretical understanding of stigma, in line with the data-driven inductive approach of the methodology [28]. Tri-level codes were then organised into potential themes and sub-themes, and reviewed to create a conceptual map of the analysis ([Supplementary Table](#SupplementaryTable)), working both in relation to coded extracts and the entire dataset [28]. Interpretation and refinement of each theme was continued into the writing process, where the final themes presented in this manuscript were decided.

**Table 1**Participant demographics

|  |  |
| --- | --- |
| **Demographics (*N* = 91)** | ***N* (%) Mean [SD]**  |
| Sex, female | *86* (94.5%)  |
| Gender, categorised  | Female, *83* (91.2%)Male, *5* (5.5%)Non-binary/third gender, *3* (3.3%) |
| Age, years | 31.8 [4.7] |
| Ethnicity | White, *82* (90.1%)African, *1* (1.1%)Asian, *2* (2.2%)Asian British/Black, *1* (1.1%)Mixed/multiple ethnic groups, *3* (3.3%)Other ethnic group, *2* (2.2%) |
| Country, residency | UK, *32* (35.2%)US, *50* (54.9%)Canada, *1* (1.1%)Czechia, *1* (1.1%)Hawaii, *1* (1.1%)India, *1* (1.1%)Mexico, *1* (1.1%)Netherlands, *1* (1.1%)Serbia, *1* (1.1%) |
| Diabetes, type 1 | *79* (86.1%) |
| Diabetes duration, years | 14.4 [9.2]  |
| Diabetes management, categorised | IPT, *55* (60.4%)MDI, *23* (25.3%)CGM, *71* (78%)Oral medication, *9* (9.9%)Manual BG testing, *6* (6.6%)Diet, *3* (3.3%) |

1. **Results**

Three themes were identified ([*Table 2*](#Table2)):

1. Same yet Different
2. Stigma Consequences
3. Weight over Health Prioritisation
	1. **Same yet Different**
		1. **Similar Stigma Experiences for all PWD**
			1. ***Negative Stereotypes and Assumptions***

Beyond the re-occurring assumptions of “*diabetes being caused by too much sugar*”, or that PWD can’t consume sugary foods, PWD experience a greater level of judgement, dictation, and even the loss of choices, over their diet. Many are made to feel at fault for their diabetes diagnosis, based on a judgement made by a person without diabetes on their food choices either at present, or in childhood. This judgement, based on the stereotypical assumptions of diabetes, results in a dictation or lecture from people without diabetes on what they believe PWD should be consuming. For some, this is recognised as coming from a place of good intention and concern, but for many, this causes feelings of frustration and anger, particularly when it is perceived that people without diabetes think they know best about what a person with diabetes’ diet should look like. Similar feelings are expressed about food and drink choices being taken away from PWD; in some cases, particularly that of family members, smaller portions are given to PWD, regardless of previous attempts to inform them that they can eat anything, and in other cases, PWD are purposefully missed out in the dishing up of desserts, or given sugar-free alternatives, without consensus.

*“If someone is offering cakes around in work, they skip me. It makes me feel really angry that people think they understand my condition more than I do, especially as I have been living with it for 17 years”* [Participant 7, T1D].

*“Everyone always has something to say. From other kids making jokes about how they’ll get diabetes from eating too much candy to family members telling me what I can and can’t eat”* [Participant 34, T1D].

*“(People believe that) because I have T1D, I cannot have certain foods or should not have them, and if I do, that makes me irresponsible in regards to my health”* [Participant 55, T1D].

In addition, stereotypes surrounding lifestyle choices, linked with weight, are very commonly experienced by PWD; specifically assumptions that a lack of self-care, laziness, and therefore overweight is the cause of their diabetes diagnosis. Many PWD feel that this belief negatively impacts the supportiveness of their networks. These assumptions and judgements come from a variety of sources – from family and friends, but also from published and social media, which is heavily frowned upon by PWD as a source of influential misinformation. PWD who describe themselves as a ‘healthy’ weight experience reactions of

**Table 2**
Primary and secondary codes under four themes with sub-themes, and number of times quotes from the narrative were coded

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Theme** | **Sub-theme** | **Primary Code** | **Secondary Code** |  | ***N*** |
| 1. | Same yet Different | Similar Stigma Experiences for all PWD | Assignment of blame | StereotypesAssumptions  |  | 68 |
| Discrimination | At workIn healthcare |  | 10 |
| Social exclusion | Loss of social groupExcluded from social event |  | 6 |
| Lack of education in the general public | Lack of empathy about DSM activitiesComments/jokes online and in the mediaExpectation to ‘just get on with it’ |  | 12 |
| Lack of education in healthcare  | HCP colleagues misinformed on diabetesAssignment of blame/failure-based languageAssumptions all issues are diabetes-relatedFeels of mistrust between PWD and HCPs |  | 25 |
| Additional Stigmatisation of T2D | Assignment of blame to T2D by people with T1D | People with T2D caused their diabetes Vilification of T2D as the “bad” type of diabetesOffence as being mis-assumed as T2DLack of understanding about T1D because of T2DT2D portrayed as failure for overweight |  | 15 |
| 2. | Stigma Consequences |  | Psychological consequences | Negative emotionsResilience |  | 33 |
| Consequences for DSM  | Withholding insulinHiding hypoglycaemia symptoms and treatmentsOverstrict extreme management Negative relationship with foodAvoidance and lack of care about DSM |  | 13 |
| Avoiding being perceived as the stereotypical person with diabetes | Better DSM to avoid blame assignmentEngaging in damaging behaviours |  | 8 |
| Educating and advocating |  |  | 11 |
| 3. | Weight over Health Prioritisation  |  | Complexity of relationship between DSM and weight gain/lossNot wanting to “look like a person with diabetes”DSM has to be perfect for PWD living with overweight |  |  | 14 |
| Weight focus over health focus |  |  | 14 |

shock and surprise when disclosing their diagnosis to other people, whereas PWD who describe themselves as a heavier weight experience an automatic assumption that their diagnosis is of T2D, and could therefore be cured if they lost weight. For both false assumptions, frustration and annoyance is expressed at the ignorance and commonality of these experiences.

*“Because I am not extremely thin there is an added stigma that I caused my diabetes by not caring for myself properly”* [Participant 70, T1D].

*“My mum and dad will often loudly query why I might have developed it, given they've always promoted a healthy lifestyle and good diet”* [Participant 87, T2D].

* + - 1. ***Discrimination and Social Exclusion***

A number of PWD disclose experiencing denial of progression opportunities, job restriction, and job loss, believed to be due to their diabetes. There were shared experiences of being fired or pushed out of employment due to disbelief from employers that the person with diabetes was keeping up with the workload and doing their job effectively during difficult periods of diabetes management. Failure to provide reasonable adjustments, with cited reasoning such as the inconvenience and unfairness to other employees, and being “*denied opportunities that otherwise would have been given*” and “*passed up for leadership roles…on numerous occasions*”, were also experienced by a number of PWD in the workplace, demonstrating instances of disability discrimination from people without diabetes to PWD.

*“I kept waking up with low blood sugars. One morning I had a seizure, and a week later they fired me for not keeping up with the workload”* [Participant 38, T1D].

*“Had to quit my previous job that I had been in for 12 years because they believed the amount of time off I had made it not possible to do my role effectively. I had only been back 5 months after nearly dying”* [Participant 76, T1D].

This differential treatment of PWD in the workplace is also evident in social experiences of PWD; being excluded from social groups, gatherings and events is described by some, with varying reasons for the exclusion given or implied. These ranged from the group, people without diabetes, explicitly stating that the person with diabetes wasn’t “*invited because they thought it would (have been) too risky*”, to PWD feeling that they were excluded due to the interference and hinderance of their diabetes to other people’s fun and comfort. The idea that the people without diabetes are uncomfortable around PWD, particularly when food is involved, was mentioned by numerous PWD as a reason for why they believe they are excluded from particular social events.

*“I don’t get asked to do social things in work as my ‘illness’ will hold me back”* [Participant 37, T1D].

*“I have lost friendships because of T1D because they thought I was faking the bad days and/or not taking care of myself on purpose”* [Participant 75, T1D].

* + - 1. ***Limited and Lacking Education***

Many PWD cite the negative stereotyping and false assumptions as a direct iteration of a lack of knowledge and empathy from people without diabetes, both in the general population and in healthcare. A clear lack of knowledge surrounding the cause, treatment, and mental load of diabetes – both type 1 and type 2 – from people with no experience of diabetes results in stigmatising, belittling and unempathetic judgements and comments to PWD. A lack of empathy is also often displayed in regards to DSM activities - particularly insulin injections - and in the media, which PWD feel portrays all “*diabetics as being stupid, fat and lazy*” in their broadcasting of harmful misinformation surrounding diabetes. Some PWD express anger at people without diabetes who think they have a better understanding of their condition.

*“Something that comes up a lot is people saying ""oh I hate needles I can't watch or could never do that""…Do they think I want to do this? Because the choice is literally to do this or die”* [Participant 9, T1D].

*“It enrages me when I’ve been up all night trying to keep myself alive…and I then hear a throwaway comment from a member of the public implying all diabetics are reckless and should have looked after themselves better!”* [Participant 16, T1D].

Experiences of uneducated HCPs, both from patient and colleague perspectives, are very common for PWD. A general lack of knowledge and understanding of the basics of diabetes care, how this can vary between T1D and T2D, and how no two patients are the same, is experienced from a variety of HCPs. It is also a common experience that many HCPs assume that all health concerns from PWD are diabetes-related, without sufficient investigation - resulting in feelings of dismissal and frustration. For a number of PWD, the lack of education in general healthcare meant that if it wasn’t for their research and self-advocacy, there could have been dangerous consequences during hospital stays due to refusal of insulin and hypoglycaemia treatment. Many PWD therefore express feelings of mistrust and misunderstanding between themselves and HCPs, even PWD who work in healthcare themselves – many detailed experiences of having to educate their HCP colleagues, or witnessing them not knowing how best to manage the diabetes of their patients.

*“Every time I’ve been in hospital…the care by the nurses around my diabetes has made the whole experience worse… They wanted me to eat, I said I needed insulin for that, they refused to give me any because I’d had a previous dose less than 4 hours ago. They were then surprised when my blood sugars went high and refused to discharge me because of that”* [Participant 6, T1D].

*“The ultra sound technician tutted at me and said something along the lines of ‘we always get people like you who don’t listen to the Doctor and do what they are told. You should have laid off the sweets.’...I was so angry I couldn't say a single word. She had no idea how hard I was trying. She had no idea what my sugar levels actually were”* [Participant 13, T1D].

*“I’m sometimes looked at as an illness and not heard for my symptoms/concerns for something common and not diabetes related. I have had to learn to research and advocate a lot for myself, and find knowledgeable physicians”* [Participant 71, T1D].

* + 1. ***Additional Stigmatisation of T2D***

Blame is assigned to people living with T2D by both people living with T1D, the general population, and HCPs – evidencing Schabert et al.’s [5] framework of blame as a driver of diabetes stigma. For people with T1D, some express offense as being mis-assumed as having T2D, because they associate the stereotypes of poor diet and lifestyle with T2D. In conversation with HCPs, some PWD describe how T2D is portrayed as the “*ultimate failure*” for people living with overweight, and have experiences of HCPs demonstrating a lack of regard and understanding towards patients with T2D. This perpetuates the vilification and stigmatisation of T2D as the ‘bad’ type of diabetes for which individual blame can be assigned; a number of people with T1D also demonstrate frustration at their condition being under the same term as T2D, because they believe that this creates misinformation of T1D as a non-serious condition. The belief that more education and separation is required of the different types of diabetes is therefore important to some people with T1D. This in itself perpetuates the stigma of T2D as curable, controllable and self-blamed, and further highlights Schabert et al.’s [5] conceptualisation of feelings of fear and disgust driving diabetes stigma.

*“I asked the nurse how many people in the practice had type 1 diabetes, and she said ‘I'm not sure about how many type 1s, unfortunately most are type 2s’ with this awful tone in her voice of how little she thought of those patients”* [Participant 12, T1D].

*“It became overwhelming clear that the general public truly does not understand Type 1 diabetes and unfortunately, we’re grouped in this stigma of lacking self-care, proper nutrition, and poor lifestyle choices…I believe we need more education around the different forms of diabetes and how they differ”* [Participant 40, T1D].

* 1. **Stigma Consequences**
		1. ***Psychological Consequences***

Stigma experiences leave many PWD feeling shameful, embarrassed, and misunderstood. Many PWD feel a lot of shame surrounding their diabetes diagnosis, diabetes technology, and their food choices as a person with diabetes - which can make it even more difficult to accept their diagnosis and carry out DSM activities. This causes significant feelings of isolation, whereby some PWD have – or had previously - not told friends, family, class mates or colleagues about their diabetes. For some, this is recognised as stemming from worries about negative reactions and judgements; for others, this decision reflects their lack of self-worth and confidence regarding their diabetes.

*“Because of the stigma, it took me an extremely long time to accept my condition”* [Participant 7, T1D].

*“I don’t tell anyone I have it because I am ashamed. Not even my parents know”* [Participant 61, T2D].

*“There are very few people outside of my family and friends who I even tell that I have type one…My thoughts are constantly consumed with negative self-talk and guilt”* [Participant 70, T1D].

*“When you're feeling low it's really easy to think you're not worth taking care of. Stigma exacerbates that”* [Participant 87, T2D].

There is some notion that the longer people have been diagnosed with diabetes, the more resilient they become to judgement from others. A number of PWD express a development of resilience that helped them to build confidence to not let stigma and negative reactions affect their diabetes self-management and wellbeing. For some, this involves putting their health above other people’s stigma-based judgements, engaging with the diabetes community, and working on embracement of progress. However, other PWD detail still struggling with the upset caused by stigmatisation, despite being diagnosed for what they considered to be a lengthened amount of time.

*“It’s taken me a long time to build the confidence to not let stigma affect how I act and how I manage my diabetes”* [Participant 7, T1D].

*“You’d think after 6 years, my feelings wouldn’t get so hurt from the stigma but they definitely do”* [Participant 66, T1D].

*“Despite the stigmas from diabetes and weight, I know my health is important so I will always take care of my diabetes to the best of my ability…I will never not take care of myself for fear of being judged. My life and health are more important than someone’s judgement/discomfort”* [Participant 75, T1D].

* + 1. ***Diabetes Self-Management Consequences***

The most commonly experienced consequence centres around insulin misuse, stemming from weight-related stigma, or from avoidance of visible DSM activities such as taking insulin. In terms of weight stigma, a number of PWD detailed previous experiences of misusing insulin, ranging from complete withholding to reducing dosages, in order to reduce their weight or avoid potential weight gain caused by insulin. For some, this is recognised as wanting to avoid being perceived as the stereotype of a person with diabetes, to reduce the blame attributions and judgements associated with diabetes stigma. For similar reasons, many PWD feel they have to maintain an even tighter control over their diabetes, to the extremes of eating a certain way/not eating in public; no-carb/limited intake dieting; and overexercising. This overstrict engagement with DSM behaviours often led to long-term negative relationships with food, including experiences of disordered eating, and feeling completely restricted in life. Furthermore, the lack of sustainability meant that some PWD then experienced the opposite extreme of not engaging with DSM behaviours at all. This avoidance of all DSM activities, however, is also experienced by PWD from the offset, without a period of overstrict management – a number of PWD detailed past and present experiences of hiding their diabetes, meaning disengagement with DSM to at least some extent, of which some cited diabetes stigma and blame assignment as the direct reasoning for this. For many PWD, not taking their insulin in front of others is the main way of hiding their diabetes, which feels necessary due to negative experiences such as worries about others’ perceptions, public stares and comments, accusations of drug-taking or overreaction, and requests not to inject in public. Other ways PWD hide their diabetes to avoid these include choosing to stop using diabetes technology in order to make diabetes less visible, and hiding hypoglycaemia and hyperglycaemia symptoms at the detriment of recovery.

*“I do not want to look what people think a person with diabetes looks like... I want to be conventionally attractive (ie thin) .. and also want to be strong/fit”* [Participant 63, T1D].

*“There are many times when I’m dealing with low or high blood sugars and try to hide it so as not to inconvenience people around me. This is often at a detriment to myself because I don’t give myself the time I need to recover from a low or to feel better when having high blood sugars”* [Participant 67, T1D].

*“There have been many times in my life that I've actively chosen to make poor decisions about my diabetes management simply to avoid needing to tell people about my diagnosis (skipping injections, not testing my blood sugar, eating carbs in excess of what my body can handle, choosing not to use my insulin pump)”* [Participant 72, T1D].

*“While my control is multifaceted and fuelled by many aspects, I do find that the stigma has contributed to me trying to do even more to make sure I am well controlled as I don’t want to be perceived as someone who doesn’t do everything she can do control her T1D”* [Participant 77, T1D].

* + 1. ***Educating and Advocating***

In addition to the development of resilience to stigma, a number of PWD take an educational approach as a response to stigmatising events, in order to correct false stereotypes and assumptions. For many of these PWD, education is important because they believe most of these false assumptions are genuine misunderstandings as opposed to malice; and most experience positive reception and appreciation for the correction. Education is also seen as crucial to minimising the stigma around diabetes. However, taking this approach is often an exhausting experience, particularly when PWD find themselves explaining the same things to people on countless occasions, or when the reception is continually ignorant.

*“I now educate as much as I can every time someone makes a comment (often genuine misunderstandings and not malicious)”* [Participant 20, T1D].

*“It is so important to educate people on the disease and stop vilifying”* [Participant 48, T2D].

*“I’ve tried really hard to take the educational approach when people notice or ask me about diabetes. It can be exhausting because sometimes I find myself explaining the same things to the same people time and time again”* [Participant 49, T1D].

* 1. **Weight over Health Prioritisation**

For PWD, the relationship between DSM and weight change is complex – having diabetes is perceived to make discussions of weight more uncomfortable with HCPs and support networks, and makes PWD feel even more vulnerable to weight stigma. The complicated relationship between insulin and weight is often misunderstood, leading to false assumptions and negative comments about weight gain due to insulin use upon diagnosis, which are often upsetting and cause feelings of isolation for newly diagnosed PWD. Most commonly, PWD experience a greater focus – from HCPs as well as support networks – on their weight, as opposed to their diabetes management and general health. For many, this is through praise surrounding weight loss caused by insulin mis-use, undiagnosed diabetes, or diabetes complications such as diabetes ketoacidosis. Being complimented on their appearance, without any concern for their diabetes health, often causes ongoing issues with negative body image for the PWD. For PWD who self-identified as living in a larger body/with a BMI above “normal”, this focus on weight over DSM is experienced in healthcare through negative, stereotypical assumptions of their lifestyle as lazy and unhealthy (*see section 3.1.1.1*). HCPs consequently base their consultations on weight loss and lifestyle improvement, without consideration of diabetes management – and in many experiences, PWD felt as though their diabetes management was worthless to HCPs because of their weight stigma-based practice.

*“Because my BMI is above normal, I’m regularly told to exercise more and eat more fruit and veg to lose weight and manage my diabetes. I eat a Mediterranean diet, walk 4 miles every day, weightlift 3 x per week and have an excellent hba1c”* [Participant 16, T1D].

*“I omitted insulin to lose weight. They (HCPs) didn’t know how much weight I had lost and because I was still a healthy BMI they didn’t see it as a problem. It’ not until I stopped restricting insulin and started restricting food did they take notice”* [Participant 18, T1D].

*“I wasn’t on insulin for a year which made my life miserable due to strict diet and over exercising to keep BG in check. And first thing my family was worried about when I mentioned that I will have to start using insulin was ‘oh but you will gain so much weight from it’”* [Participant 30, T1D].

*“Prior to my diagnosis I dropped about 20 pounds (~20% of my body weight). Everyone told me how fantastic I looked. Even when I expressed I was concerned this was pathological, people would reassure me it probably wasn’t... Naturally, when I began treatment I put all that weight back on…The result was that I hated my body”* [Participant 56, T1D].

1. **Discussion**

This study presents an advancement in our understanding of diabetes stigma, particularly focused on the established adulthood population and encompassing both T1D and T2D populations – it is the first to highlight similarities and differences in stigma markings of diabetes types, and to explore the consequences of stigma for the self-management behaviours of PWD.

Whilst previous research has separately explored stigma experiences in people living with T1D and T2D, by including both diabetes type together in one study, this analysis provides insights into how stigma manifests with similarities and differences between T1D and T2D. Despite only 13.9% of participants living with T2D in this study, the experiences reported support that of previous research exploring diabetes stigma in people with T2D, which implies wider population generalisability is possible [2]. PWD, regardless of diabetes type, experience stigma in similar ways, as the targets for stigma from those who do not have diabetes. Commonalities in stigma practices such as negative stereotypes, discrimination and social exclusion are experienced by both people with T1D and T2D. This supports previous findings of similar manifestations - shame, rejection and misunderstanding - in separate T1D and T2D research [2, 3]. However, for people living with T2D, analysis revealed additional stigma marking from those living with T1D, as well as those without diabetes. One possible explanation for this is due to the fear of being mislabelled as having T2D in those living with T1D, reinforcing the blame narrative due to perceptions of poor lifestyle and diet choices. For those without diabetes, this additional stigma marking may be due to the known possibility of prevention and/or reversibility of T2D, which again reinforces assignment of blame.

Previous research has demonstrated detrimental consequences of diabetes stigma on psychological wellbeing, self-image, and diabetes self-management [10]. This study supports these findings with individuals living with both T1D and T2D, demonstrating a universality of stigma consequences across both diabetes types. However, this analysis highlights the complexity of the relationship between weight management and diabetes management in the presence of stigma. Previous diabetes stigma studies and weight-focused research suggested the established adulthood population may be at a greater vulnerability to stigma experiences [14, 20]. Stigma-based healthcare practices and societal attitudes prioritise weight over diabetes health as manifestations of these intersecting stigmas, affecting eating, exercise and insulin-taking behaviours among PWD during established adulthood. With the age of T2D onset reducing, due in part to increases in overweight and obesity, understanding the intersectionality between diabetes and weight stigma, especially in the context of healthcare and DSM, during established adulthood is of increased importance [30].

Furthermore, the study also reported resilience and advocacy roles observed among PWD, which have not previously been explored in diabetes-related stigma research – in HIV-related stigma studies, resilience to stigma experiences has been reported, and found to positively predict treatment adherence [31, 32]. Further exploration of how some PWD build resilience, advocate for the diabetes community, and how this can mitigate the consequences of stigma, is needed.

The study’s methodology includes a range of participants using various diabetes management strategies such insulin pump therapy, injections and continuous glucose monitors - this diversity ensures that stigma experiences related to different DSM behaviours are adequately represented, enhancing applicability across the diabetes community. Furthermore, the findings suggest that a universal strategy to address diabetes stigma across both types of diabetes and DSM activities could be effective - the Health Stigma and Discrimination framework [6] could serve as a useful guide for developing interventions to reduce this stigma. However, caution is advised due to the additional stigma faced by individuals with T2D identified in the study. Despite its strengths, the study acknowledges certain limitations. For instance, the participant pool primarily consists of PWD from the UK and US, which may limit the generalisability of findings to non-Westernised cultures – however, given the evidence of stigma-based healthcare practices, this cross-country pool does suggest that these practices are not specific to country or medical training. Nevertheless, there is also underrepresentation of ethnic minorities; with a 90.1% white participant pool, understanding intersecting stigma experiences in non-white PWD should therefore be a high prioritisation for future research, given differential prevalence rates of both diabetes and overweight, particularly in South Asian, Middle Eastern and North African groups [33].

**Declaration of Competing Interest**

The authors declare they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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**Appendices**

Appendix I – Supplementary Data

(Following question block 2: Diabetes stigma)

Thinking about the questions you've just answered we would be really grateful if you could tell us in your own words a bit more about any of your experiences of stigma?

You can share as much or as little information as you like.

You may want to draw on experiences with GPs, nurses, at hospital appointments; with family or friends; at work; in school; in public places; in the media.

If you can, try to explain how these experiences made you feel, both at the time, and now looking back on them.

(Following question block 3: Weight stigma)

Thinking about the questions you've just answered we would be really grateful if you could tell us in your own words a bit more about any of your experiences of weight stigma?

Again, you may want to draw on experiences with GPs, nurses, at hospital appointments; with family or friends; at work; in school; in public places; in the media.

If you can, try to explain how these experiences made you feel, both at the time, and now looking back on them.

(Following question block 4: Diabetes self-management)

Thinking about the questions you've just answered do you think the way in which you manage your diabetes, this could include your diet, exercise, blood testing and or medication/insulin use, has been impacted by any experience of stigma?

Yes or No responses to offer the following prompt:

If yes - Could you tell us a little more about how the experience of stigma has influenced the way you feel about yourself and your diabetes and what role it has had in how you are able to manage your diabetes?

If no - continue to next question block.

Final question block:

How, if at all, have these experiences impacted the way you manage your diabetes? This could include your diet, exercise, blood sugar testing and or medication/insulin use.

Is there anything else you'd like to tell us about your experience of stigma or about how you manage your diabetes?

Appendix II -**Supplementary Table**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Theme** | **Sub-theme** | **Primary code** | **Secondary code** | **Tertiary Code** | ***N*** | **Illustrative quotes** | **Participant Profile** |
|  | Same yet Different | Similar Stigma Experiences for all PWD | Assignment of blame through stereotypes and assumptions | Diabetes and diet  | Sugar causes diabetesPeople without diabetes judging PWD dietsDictation of what PWD should/shouldn’t drinkPeople without diabetes making choices for PWD | 37 | Most people I chat to assume that type 1 diabetes is caused by poor diet, now or when I was younger. They often think it was my fault for my diagnosis and feel they can monitor or judge what I eat. | White male (sex and gender) aged 29 from the UK, with T1D for 1.5 years, managed with CGM and MDI Other ethnic group female (sex and gender) aged 33 from the US, with T1D for 10 years, managed with CGM and IPT |
| Diabetes and age | Diabetes happens to older peopleT1D is for kids, T2D is for older adults | 7 | My GP initially tried to tell me I was “too old” for Type 1 despite the fact that I have no family history or risk factors for Type 2. It took me advocating for myself and an extreme toll on my mental health to get an accurate diagnosis and appropriate treatment. | White female (Sex and gender) aged 31 from the US, with T1D for 1 year, managed with CGM and IPT |
| Diabetes and lifestyle | Not looking after yourself/poor lifestyle choices cause diabetesPWD are lazy | 6 | A business unit of the company I worked for was looking into digital ways to tackle health challenges. Their strapline was something like ""80% of people die due to personal choices"" and then referred to diabetes, suggesting you'd made poor choices which resulted in your diagnosis and this was therefore your fault | White female (sex and gender) aged 38 from the UK, with T2D for 6 years, managed with oral medication and diet |
| Diabetes and weight | Overweight causes diabetesPWD of a ‘healthy’ weight used to be overweight Losing weight will fix diabetesPWD who are overweight automatically assumed to have T2D as opposed to T1D | 18 | I was misdiagnosed with type 2 diabetes for 2 years because of family history of it and weight bias.It’s mostly just “you don’t look diabetic” | White female (sex and gender) aged 33 from the US, with T1D for 8 years, managed with CGM and IPTWhite male (sex and gender) aged 42 from the UK, with T2D for 2 years, managed with CGM |
| Discrimination | At work | Job lossNo reasonable adjustment Denied/passed up for progression and opportunities | 7 | Having been denied of opportunities that otherwise would have been given simply because you are a diabetic (type-1) makes it a smidge harder to digest  | Asian female (sex and gender) aged 28 from the US, with T1D for 26 years, managed with CGM and IPT |
| In healthcare | Refusal of servicesAccess to services/treatment denied | 3 | My first endocrinologist used shame to motivate me, and ended up firing me from her practice because she claimed I ""wasn't trying hard enough""  | White female (sex and gender) aged 34 from the US, with T1D for 18 years, managed with CGM and IPT |
| Social exclusion | Loss of social groupExcluded from event |  | 6 | Being cut off from your social circle because diabetes interferes with every one’s fun time is preposterous.. But it allows you to weed out shallow people from your life and leaves you with quality friendships and relationships that will definitely last a lifetime | Asian female (sex and gender) aged 28 from India, with T1D for 16 years, managed with CGM and DMI |
| Lack of education in the general public | Lack of empathy about DSMExpectation to just get on with itComments/jokes online and in the media |  | 12 | I was told that T1D management is not difficult and the illness doesn’t prevent me from doing anything/affect my life negatively. (Of course from someone who had no experience with T1D or diabetes management) | White female (sex and gender) aged 26 from Czechia, with T1D for 5 years, managed with CGM and MDI |
| Lack of education in healthcare | HCP colleagues misinformed on diabetesHCPs unknowledgeable about the everyday of diabetesAssignment of blame/telling-off language/failure-based narrativeAssumption all issues are diabetes-relatedFeelings of mistrust between PWD and HCPs | Specialised HCPs preferred over GPs Dangerous experiences with unknowledgeable HCPs | 25 | I have had an anesthesiologist ask if I ate an entire cake right before bed (assuming jokingly in her mind) right before going into a procedure because my number was high the night before. Most of the diabetic professionals that I have seen who do not directly have type 1 diabetes involved in their family have been a combination of disrespectful and not knowledgeable. Nurses from other specialties have made rude or uninformed comments about my diabetes, which made me uncomfortable in their care | White male (sex and gender) aged 29 from the US, with T1D for 17 years, managed with manual BG testing and IPTAsian female (sex and gender) age 28 from India, with T1D for 16 years, managed with CGM and MDI |
| Contrasting support networks | Supportive, knowledgeable and non-stigmatising support network  |   | 10 | I’m grateful I work in a medical field and am surrounded by people who either have some understanding, or are willing to invest in understanding my disease so that I have a strong, relatively stigma-free support network | White female (sex and gender) aged 31 from the US, with T1D for 1 year, managed with CGM and IPT |
|  | Lack of effort/understanding/empathy from support network, making stigmatising comments/judgements |   | 16 | My experience lately with type 1 Diabetes is that friends and family members just don't want to hear about it, and/or think it's not a problem and doesn't come with struggles. I notice less views and social media engagement when I spread awareness on Instagram and Facebook  | Mixed/multiple ethnic group female (sex and gender) aged 36 from the US, with T1D for 28 years, managed with CGM and IPT |
| Additional Stigmatisation of T2D |  | Blame assignment | People with T2D caused their diabetes Vilification of T2D as the “bad” type of diabetesOffence as being mis-assumed as T2DLack of understanding about T1D and severity because of T2DHCPs perpetuating T2D blame T2D portrayed as the ultimate failure for people with overweight  | 15 | I am not overweight /obese nor have I ever been obese or overweight so I don’t look like someone who should have diabetes. Even though I have type 1 and of course there is no certain look to diabetes.I asked the nurse how many people in the practice had type 1 diabetes, and she said ""I'm not sure about how many type 1s, unfortunately most are type 2s"" with this awful tone in her voice of how little she thought of those patients.  | African female (sex and gender) aged 31 from the US, with T1D for 3 years, managed with CGM and IPTWhite female (sex and gender) aged 30 from the UK, with T1D for 19 years, managed with CGM and IPT |
|  | Stigma Consequences |  | Psychological consequences | Negative emotions | Hopeless, shame, guilt, embarrassment, feeling less than for having diabetes | 33 | I often feel hopeless. And unworthy of a full, healthy lifeThere are very few people outside of my family and friends who I even tell that I have type one. Because I am not extremely thin there is an added stigma that I caused my diabetes by not caring for myself properly. My thoughts are constantly consumed with negative self-talk and guilt.it can be awkward sometimes to need to eat in public when others aren't eating, or to need to take time away from an activity to manage diabetes, but in my current situation in life I don't feel any pressure to hide what I need to do. | White non-binary individual (female sex) aged 36 from the UK, with T1D for 24 years, managed CGM and IPTWhite female (sex and gender) aged 33 from the US, with T1D for 13 years, managed with CGM and IPTWhite female (sex and gender) aged 30 from the UK, with T1D for 19 years, managed with CGM and IPT |
| Lack of self-worth/self-confidence |
| Worry | Worry about employmentWorry about future complications of diabetes |
| Isolating | Feeling misunderstood, different, isolated |
| Resilience  |  |
| Consequences for DSM | Withholding insulin/medication | For weight | 5 | I withheld insulin for 7 years. No one picked up on it. Uniformed comments like this one (why do you have diabetes when you’re so skinny) are probably part of the reason why I continued to do so. | White female (sex and gender) aged 30 from the UK, with T1D for 20 years, managed with CGM and IPT |
| Not taking insulin in front of others/in public | 12 | I believe the only thing that concerns me is people thinking I take drugs. I do get stares, and sometimes i go to the bathroom stall to avoid being looked at  | Asian British/Black female (sex and gender) aged 28 from the US, with T1D for 10 years, managed with CGM and MDI |
| Hiding hypoglycaemia symptoms and treatments Overstrict, extreme managementNegative relationship with foodLack of care about DSMAvoidance of all DSM activities  |  | 13 | I am self concious of eating anything with sugar in it as I feel negatively judged. I often have to fight old eating disordered ways of thinking which was ingrained in me from diet culture. I will often not eat rather than make a poor choice.When I have a low blood sugar and am out with friends, I try not to be an inconvenience so much so that I try to hide the fact that I’m having a low and try to hide how I treat my low. I feel like people will think I’m overreacting or exaggerating the feeling of having a low so I try to appear as normal as possible.  | White female (sex and gender) aged 45 from the UK, with T2D for 2 years, managed with oral medicationOther ethnic group female (sex and gender) aged 33 from the US, with T1D for 10 years, managed with CGM and IPT  |
| Avoiding being perceived as the stereotypical person with diabetes  | Doing more to maintain good DSM to avoid opportunities for blame and to avoid being perceived as the stereotypeEngaging in damaging behaviours to avoid being perceived as the stereotype  |  | 8 | I also felt that I needed to eat a certain way so people would not think that I caused my diabetes/made it worse.While my control is multifaceted and fuelled by many aspects, I do find that the stigma has contributed to me trying to do even more to make sure I am well controlled as I don’t want to be perceived as someone who doesn’t do everything she can do control her T1D.  | White female (sex and gender) aged 26 from Czechia, with T1D for 5 years, managed with CGM and MDIWhite female (sex and gender) aged 36 from the US, with T1D for 20 years, managed with CGM and IPT |
|  | Educating and Advocating  |  |  | 11 | I’ve tried really hard to take the educational approach when people notice or ask me about diabetes. It can be exhausting because sometimes I find myself explaining the same things to the same people time and time again, but for the most part people are really receptive to my explanations and find it really interesting. I get more frustrated with people who are not receptive and, though they mean well, will insist there is something I can do to reverse my type 1 diabetes or manage it without insulin.  | White female (sex and gender) aged 29 from the US, with T1D for 12 years, managed with CGM and IPT |
|  | Weight over Health Prioritisation  |  |  |  | Complexity of relationship between DSM and weight gain/lossNot wanting to “look like a person with diabetes”DSM has to be perfect for PWD living with overweight | 14 | I have found my weight detrimentally increase since starting insulin and I hate that. I have found it so much harder to lose weight as a result, because I literally need to eat refined sugars to stay conscious when I hypo.  | White male (sex and gender) aged 29 from the UK, with T1D for 1 year, managed with CGM and MDI |
| Weight focus over DSM/health focus | Praise of weight loss due to poor DSM | 14 | I was diagnosed with LADA and wasn’t on insulin for a year which made my life miserable due to strict diet and over exercising to keep BG in check. And first thing my family was worried about when I mentioned that I will have to start using insulin was “oh but you will gain so much weight from it” | White female (sex and gender) aged 26 from Czechia, with T1D for 5 years, managed with CGM and MDI |
|  | Unthemed/miscellaneous codes |  | Understanding weight stigma | Weight cannot equal health | Childhood anti-obesity campaignsSkinny meant healthy for women in childhoodPhysical ability doesn’t matter | 5 | Our society puts so much pressure to be skinny. Skinny = Beautiful in our society. I grew up in the late 90s/early 2000s when the tabloids scrutinized women for being anything other than stick thin. Everywhere you went, you'd see magazines calling major pop stars fat. Being fat was treated like you were evil. There was no representation for folks in bigger bodies.  | White non-binary individual (female sex) aged 25 from the US, with T2D for 20 years, managed with CGM, MDI and oral medication |
|  |  | HCP approach to PWD | Number focusedDisinterest/disregard for patientScare tactics | 7 | Many doctors and nurses scold me, telling me that if I don't take care of myself I'm going to go blind, they're going to cut off a limb, I'll have kidney failure. But they were not clear enough about periodic check-ups with specialists and how much they help to avoid certain complications. | Mixed/multiple ethnicity male (sex and gender) aged 40 from Mexico, with T1D for 25 years, managed with CGM and MDI |

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