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DIABETIC Medicine

RESEARCH: EDUCATIONAL AND PSYCHOLOGICAL ASPECTS

A cognitive behavioural model of the bidirectional relationship between disordered eating and diabetes self care in people with type 1 diabetes mellitus

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Abstract

Aims: This qualitative study aimed to develop the first cognitive behavioural therapy model outlining the development and maintenance of disordered eating in type 1 diabetes and report on recovery strategies and resilience factors to improve previous theoretical models of type 1 diabetes and disordered eating.

Methods: Twenty-three women ($n = 9$ with type 1 diabetes and disordered eating, $n = 5$ with type 1 diabetes recovering from disordered eating, and $n = 9$ with type 1 diabetes without disordered eating) participated in semi-structured interviews. Data were analysed using grounded theory and individual cognitive–behavioural formulations were developed for each participant to inform the development/maintenance and resilience models.

Results: The development/maintenance model summarises commonly experienced vicious cycles of thoughts, feelings and behaviours in type 1 diabetes and disordered eating. The resilience model summarises strategies and knowledge acquired by those with type 1 diabetes in recovery from disordered eating and individuals with type 1 diabetes who did not develop disordered eating. Early adverse life events, past psychiatric history, perfectionist personality traits, difficult experiences around type 1 diabetes diagnosis and its relentless daily management sensitise individuals to eating, weight and shape cues. Alongside physical symptoms/complications, unhelpful interpersonal reactions and inadequate healthcare, vicious cycles of thoughts, feelings and behaviours develop. '*Good enough*' psychological adaptation to type 1 diabetes,

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integrating type 1 diabetes into one's identity, self care and compassion around eating, weight and shape were key protective/post-traumatic resilience factors.

Conclusions: This first cognitive behavioural therapy model of type 1 diabetes and disordered eating informed by personal experience will inform an intervention for type 1 diabetes and disordered eating.

KEYWORDS

type 1 diabetes mellitus, disordered eating, cognitive behavioural therapy, qualitative

Novelty statement

- *What is already known?* Comorbid disordered eating is twice as common in individuals with type 1 diabetes than peers without type 1 diabetes. However, there are no established treatments for this population. Thoughts, feelings and behaviours related to eating, shape and weight and the daily management of type 1 diabetes might perpetuate this form of disordered eating.
- *What this study has found?* After interviewing 23 adult women with personal experience of type 1 diabetes and disordered eating, a new cognitive behavioural therapy conceptualisation of type 1 diabetes and disordered eating was developed.
- *What are the clinical implications of the study?* The new model will now be used to develop an intervention for people with type 1 diabetes and disordered eating.

1 | INTRODUCTION

Psychiatric comorbidity in type 1 diabetes is high.[1,2,3] Comorbid disordered eating is twice as common in type 1 diabetes than peers without type 1 diabetes.[4] A specific behaviour—only possible in type 1 diabetes—is the deliberate restriction of insulin to avoid weight gain, or with the intention of losing weight, resulting in higher HbA_{1c} and more severe diabetes complications than those with type 1 diabetes without disordered eating.[5] However, to date, there are no effective treatments specific to disordered eating in type 1 diabetes and disordered eating.[6] This may be due to inadequate conceptualisations of the nature and complexity of these intertwined conditions in this heterogeneous group. One suggestion is that similar to eating disorders, predisposing traits of perfectionism, low self and body-esteem[7] increase vulnerability to disordered eating in those with type 1 diabetes. Interpersonal and emotion regulation difficulties[7,8] then interact with the necessary focus on eating in type 1 diabetes, a mechanism also discussed in an earlier conceptualisation of type 1 diabetes and disordered eating.[9] This provokes strict dieting behaviours, difficulties administering appropriate insulin and binge eating, leading to neuroadaptive changes like addictive patterns of loss of control over eating and fluctuations in plasma glucose.[10] This model has been further developed to specify maintenance cycles involving dietary restriction leading to hypoglycaemia, binge eating and hyperglycaemia and purging or insulin restriction.[11]

These models elucidate relevant maintenance factors for type 1 diabetes and disordered eating, but as adaptations of the transdiagnostic model for eating disorders,[8] their formulation of vicious cycles of thoughts, feelings, behaviours and physiology may be limited. Although informed by literature reviews, they do not fully account for personal experience, lack detail on diabetes self care behaviours and neglect valuable knowledge acquired through recovery from disordered eating, or resilience to disordered eating. Also, they may not reflect the wide range of behaviours observed in disordered eating in type 1 diabetes.

Our previous work on glucose monitoring in individuals with personal experience of type 1 diabetes and disordered eating highlights a complex interaction between glycaemia, negative emotion and self care behaviours in this cohort.[12] Therefore, we aimed to develop a cognitive behavioural therapy model of type 1 diabetes and disordered eating informed by personal experiences, obtained by semi-structured interviews. This involved using a novel analytic approach which combined categories derived from qualitative methodology (grounded theory), and individual cognitive behavioural therapy formulations to identify and describe the psychological processes that predicate disordered eating and insulin omission and strategies adopted to aid recovery. Our aims were to produce two models, a cognitive behavioural therapy model of the development and maintenance of disordered eating in Type 1 diabetes and a cognitive behavioural model of recovery from and resilience to disordered eating in type 1 diabetes.

2 | PARTICIPANTS AND METHODS

2.1 | Design

This qualitative, semi-structured interview study used a cross-sectional design.

2.2 | Participants

Inclusion criteria were participants with type 1 diabetes, with and without current disordered eating, aged ≥18 with type 1 diabetes for ≥1 year, HbA1c<15.0% (140 mmol/mol), who could respond in English and provide informed consent. Exclusion criteria were severe mental illness requiring intensive psychiatric treatment, intellectual disability or cognitive impairment, current or planned pregnancy, body mass index <15 or >40 kg/m^2, advanced diabetes complications or other physical or mental health conditions requiring inpatient admission. Eligibility was confirmed through a clinical assessment with a consultant physician and clinical psychologist who confirmed the presence or absence of disordered eating. Purposive, opportunity sampling was used to obtain this volunteer sample. Participants were recruited via King's Health Partners, Royal Free and Royal Bournemouth Hospitals, UK, and on social media (Twitter; Diabetics with Eating Disorders website). Participant groups were matched as closely as possible for age and duration of type 1 diabetes as a means of reducing possible confounders.

2.3 | Measures

Current disordered eating was corroborated using the Diabetes Eating Problem Survey–Revised,[13] a 16-item self report screening tool for disordered eating in type 1 diabetes. The nine-item Patient Health Questionnaire[14] provided background data on the sample. Diabetes-related distress was measured by the 17-item Diabetes Distress in type 1 diabetes scale[15] with subscales of emotional burden, care regimen, interpersonal factors and physician care. Higher scores indicate greater symptoms on all measures. Anthropometric and psychometric characteristics for the sample are well described elsewhere should readers require more information about the clinical features of the sample.[12]

Two semi-structured interviews (Supporting Information S1 and S2) were developed iteratively after a review of online blogs by people with type 1 diabetes and disordered eating,[16] and discussions with an expert advisory board with personal and professional experience (psychiatrists, clinical psychologists, clinical researchers, physicians and diabetes specialists including a diabetes nurse specialist).

2.4 | Procedure

Ethical approval was obtained from the East of England Cambridge Central Research Ethics Committee, ref: 17/EE/0490. Having provided informed consent, participants attended a face-to-face, audio-recorded individual interview lasting around 90 min at King's College Hospital conducted by a health psychologist with specialist training in conducting semi-structured interviews (NZ). This researcher was not known to participants nor involved in their clinical care. Height and weight were measured and used to calculate body mass indices. Participants were not informed of their weight. Glycated haemoglobin Hba1c was obtained from participants' last clinic letter.

2.5 | Data analysis

2.5.1 | Grounded theory qualitative analysis

Interviews were transcribed verbatim and analysed using a social constructionist grounded theory approach.[17] This systematic methodology involves the construction of theories through the methodical gathering and analysis of data and uses inductive reasoning, producing theories from participants' narratives. A constructivist epistemology was selected as we wanted to draw on cognitive behavioural theory with the aim of developing a model which could inform treatment. First, data were analysed line-by-line to produce a descriptive picture of participants' experiences. Following initial coding, data were analysed through focused coding, applying a method of constant comparison. Here, data within and across participants were compared for similarities and differences, and emerging ideas and themes were tested, explored and discussed.[17] Third, focused codes were grouped into theoretical categories to explain large segments of data, including conceptual definitions, working towards an analytic level of abstraction. This analysis was conducted independently by AH and MS and corroborated through discussions with the wider research team.

2.5.2 | Individual cognitive behavioural therapy formulations

An experienced clinical psychologist expert in eating disorders and cognitive behavioural therapy (AH) and a consultant diabetologist (MS), independently reviewed the 23 audio recordings and corresponding transcripts.

First, each researcher independently noted key themes pertaining to possible predisposing and precipitating factors for the onset and maintenance of type 1 diabetes and disordered eating. Second, each researcher noted thoughts, feelings and behaviours related to type 1 diabetes and disordered

eating. Third, each researcher produced individual cognitive behavioural formulations[18] for all participants which focused on predisposing factors (associated with the possible origins of the disordered eating) and triggers, thoughts, feelings and behaviours hypothesised to maintain disordered eating in the here and now. For participants with type 1 diabetes without disordered eating ($n = 9$), and participants with type 1 diabetes in recovery from disordered eating ($n = 5$), alternative recovery and resilience formulations were also produced, focussing on coping mechanisms and protective factors. Fourth, researchers discussed their individual illness and recovery formulations and key cycles and patterns from each participant's narrative. Next, researchers worked independently on draft models, summarising the narratives and experiences of the 23 participants. Following this, they agreed on final versions of the models.

These models were discussed with an advisory board of experts in diabetes and EDs and shared at a co-design workshop with participants with professional or personal experience of type 1 diabetes and disordered eating. This feedback was used to further clarify and refine the models. This novel approach combining grounded theory and the development of complex cognitive behavioural therapy informed formulations was particularly useful because it allowed us to derive key categories from participants' narratives and then use the cognitive behavioural therapy model to show how these categories interact in the development and maintenance of disordered eating.

3 | RESULTS

The final sample consisted of 23 women. Eighteen were white British (78%). Nine participants with type 1 diabetes reported no past or current history of disordered eating; nine participants had type 1 diabetes and five were in recovery from disordered eating alongside type 1 diabetes. Due to the complexity and varied presentation of type 1 diabetes, the research team engaged with a final sample of 23 participants with personal experience to reach data saturation over a 9-month period. In the sections below, we first explain the categories obtained from the grounded theory analysis which informed an initial model of the development and maintenance of disordered eating in type 1 diabetes. We then explain the findings of the individual cognitive behavioural therapy formulations which informed us further on how the categories were related in the genesis and perpetuation of the disordered eating.

3.1 | Grounded theory findings

Six theoretical categories and two potential variants of type 1 diabetes and disordered eating were identified. Figure 1 details the categories and suggested relationships between the categories.[17] The white boxes contain the six categories and the light grey shaded boxes reflect the proposed variants. Within each category, bold italics are used to highlight the focused coding underpinning these categories. *Predisposing factors* relate to historical factors discussed by participants as playing a role in causing or protecting against disordered eating. First *encounters with diabete*s reflects the range of positive and negative experiences participants had at initial diagnosis. *Impact of type 1 diabetes on food, eating, weight and shape* relates to how the necessary focus on eating and food in type 1 diabetes self care and weight changes related to using insulin sensitised individuals to eating and weight cues and the range of responses including dietary restriction or self compassion. *Type 1 diabetes impacts my physical health* encompasses the physical impact of diabetes, including complications and fatigue. *My relationship with diabetes* reflects experiences around integrating diabetes into participants' identity and their positive and negative feelings towards diabetes. *Others' reactions to my type 1 diabetes* reflects the range of supportive and misinformed attitudes and interventions from others around diabetes self care. Further information on the categories and quotations from the transcripts are provided in Supporting Information S3.

3.2 | A cognitive behavioural therapy model of the development and maintenance of disordered eating in type 1 diabetes

Informed by the grounded theory categories and the individual cognitive behavioural therapy formulations, Figure 2 outlines the development and maintenance model of type 1 diabetes and disordered eating, providing common examples of each element of the formulation derived from the interviews in italics. The longitudinal aspect of this model which indicates possible origins of the disordered eating (boxes A–E in Figure 2) posits that predisposing vulnerability factors, like early life events, important transitions, past psychiatric history (e.g. depression, anxiety, trauma, EDs) and personality factors (e.g. perfectionism) (Box A, Figure 1) interact with and contribute to how participants' first encounter and experience type 1 diabetes diagnosis (Box B, Figure 2). Experiential factors at diabetes diagnosis include: timing of the diagnosis, family involvement, health care professionals and peers supporting the person to come to terms with the diagnosis and cope with type 1 diabetes, physical signs and symptoms of type 1 diabetes, including weight loss before, and rapid weight re-gain on commencement of insulin and initial training around diabetes self care. For some, there is a 'double-hit' hypothesis, where pre-existing vulnerability to disordered eating, or pre-existing eating disorders are exacerbated by type 1 diabetes diagnosis.

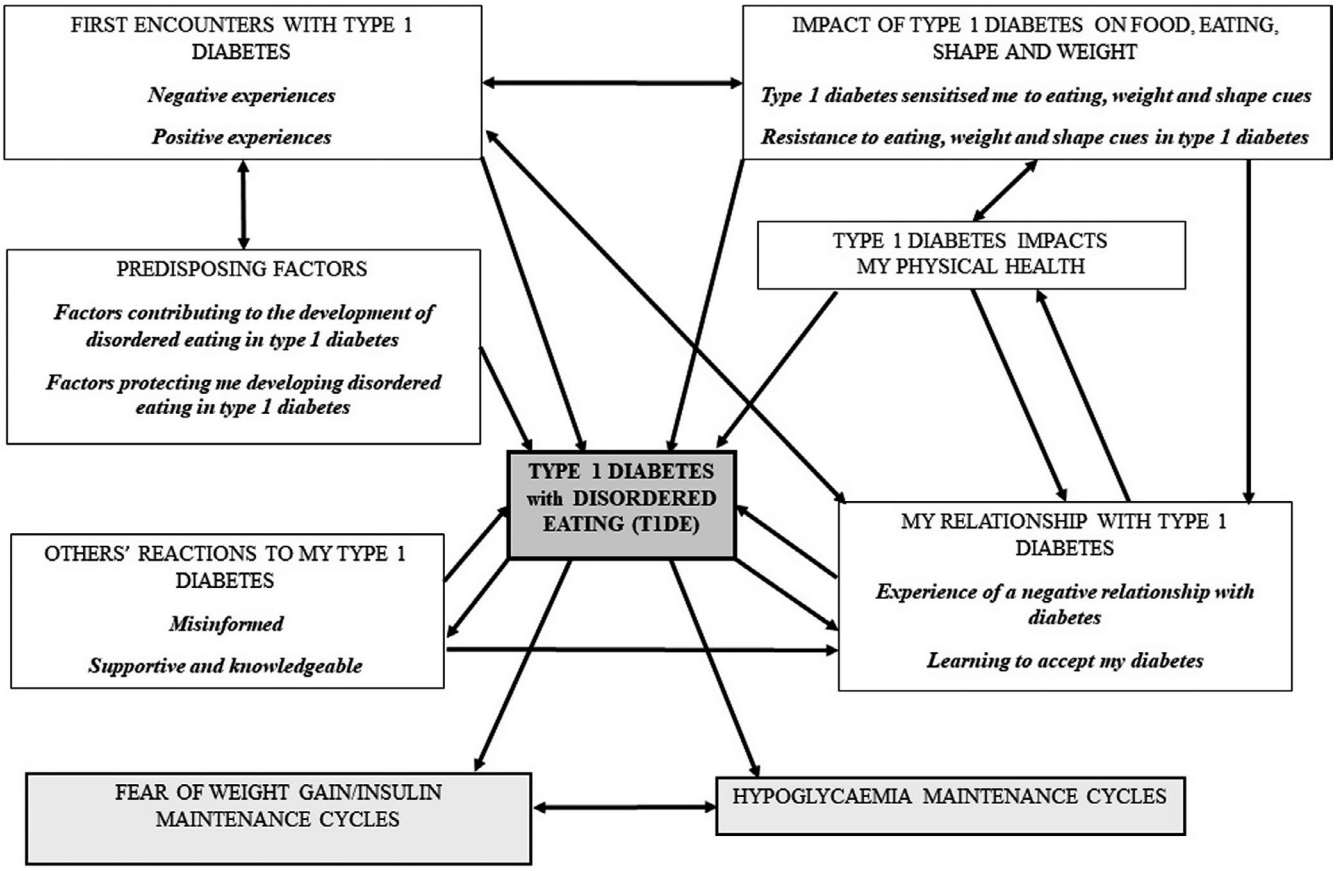

FIGURE 1 Six categorical themes identified by Grounded Theory analysis of semi-structured interviews with people with type 1 diabetes mellitus and current or historical disordered eating

Initial experiences of type 1 diabetes contribute to the experience of the physical symptoms of type 1 diabetes (e.g. tiredness, weight gain and physical symptoms of hyper and hypo-glycaemia) and the ongoing daily intervention required to manage type 1 diabetes ('diabetes is a 24 h job and you do not get a day off') (Box C, Figure 2). For example, a negative experience around rapid and severe weight loss prior to diagnosis, poor diabetes education, an inflexible regime and problems accessing diabetes technology may contribute to greater difficulties regulating plasma glucose levels. This may be reinforced by hyper or hypoglycaemia being experienced as addictive states providing a numbness to negative emotions and the experience of '(brain) fogginess' because of hyperglycaemia.

Vulnerability factors, first encounters with type 1 diabetes and its management, physical symptoms (particularly the impact of insulin on weight) and the relentlessness of type 1 diabetes self care also evoke negative thoughts about type 1 diabetes, eating, weight and shape (Box D, Figure 2), which further exacerbate sensitisation to eating, shape and weight cues (Box E, Figure 2). Examples of these negative thoughts are, in relation to type 1 diabetes: 'I hate diabetes, diabetes makes me different or defective' how diabetes/insulin affect weight and shape: 'keeping my blood sugar high prevents weight gain and aids weight loss,' self-critical thoughts associated with perfectionism: 'I've made a mistake in my management, therefore, I've got it all wrong' which provoke a loss of control, e.g. 'what the hell…. I just want a day off diabetes' and acceptance of feeling unwell as normal: 'I would rather feel unwell than be fat; I am always like this.'

Box F (Triggers), Box G (Thoughts), Box H (Feelings) and Box I (Behaviours), all in Figure 2, represent the vicious cycles which maintain type 1 diabetes and disordered eating:

3.3 | Triggers

Precipitating factors include environmental factors like a culture of dieting and the thin ideal, physical cues like weight loss or gain (due to type 1 diabetes), life events and stressors.

3.4 | Thoughts

Participants gave examples of negative thoughts related to managing weight in the context of type 1 diabetes: 'my weight is out of control; no matter what I do, I cannot manage my diabetes; I'm a bad diabetic, others will think badly

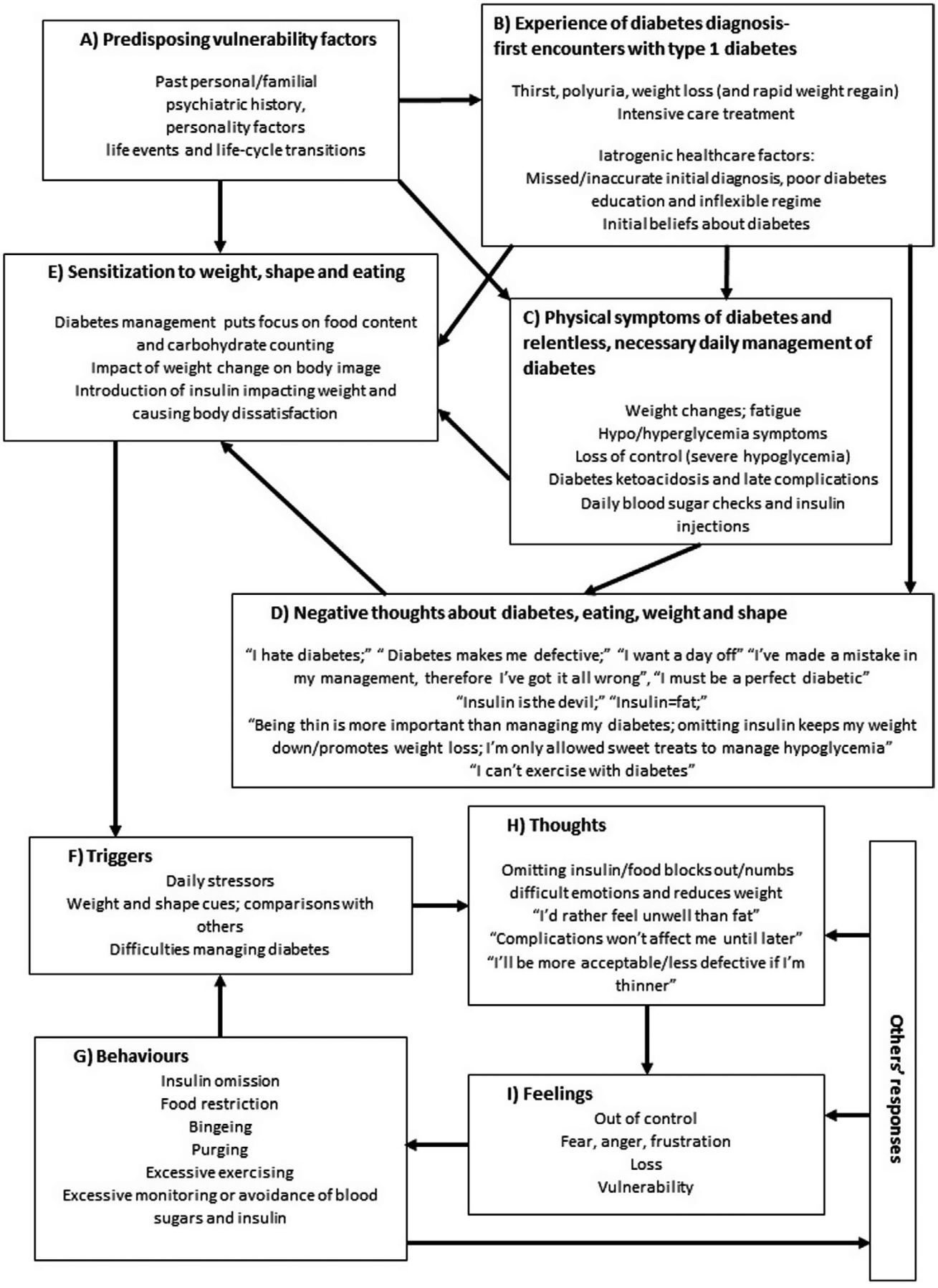

FIGURE 2 A development/maintenance model of disordered eating in type 1 diabetes

of me because of weight gain, not giving insulin is a way of keeping my weight down; I mustn't let my blood sugar go too low'. Other examples related to thoughts about perceptions of personal safety: 'I'm invincible—I don't care; I can take risks; Complications won't affect me until later in life.' Other thoughts showed a relationship between mood and blood sugar: 'I can manage my mood difficulties by being hyper or hypo.' Additionally, there were negative thoughts related to hypoglycaemia: 'I can't allow my blood glucose to drop (whilst restricting to lose weight) because it makes me feel too anxious about having a hypo; if I binge, I will hypo and feel guilty, so I must restrict.'

3.5 | Feelings

Examples include anger, frustration, depression, anxiety, guilt, shame, anticipation of danger ('I'm riding a burning unicycle on a tightrope'), loss (of health, spontaneity, freedom, imagined future), feeling out of control, fear of insulin as fat gaining, stigma (from the self and others).

3.6 | Behaviours

1. Examples of behaviours involving insulin: Bolus insulin omission to avoid weight gain; Basal insulin omission to induce a katabolic state and glucosuria for weight loss; Keeping blood glucose high ('so I feel numb… the feeling is addictive'); Inducing hypoglycaemia by over-injecting ('so I am allowed sweet treats');
2. Examples of diabetes self care behaviours: Avoiding checking blood glucose ('this allows me to avoid diabetes and having to give insulin'); Avoiding injecting in front of others ('this is how I avoid stigma'); Self-harm via diabetes care self-neglect ('for me it was like a slow suicide or deliberate self-harm'); over injecting bolus insulin later;
3. Examples of food-related behaviours: Omit carbohydrates ('I take this to the extreme of not eating at all so I don't have to inject'); Nutritional restriction;
4. Eating disorder behaviours: Binging (with and without insulin), purging
5. Examples of behaviours related to hyper and hypoglycaemia: 'I don't allow my blood glucose to drop (whilst restricting to lose weight) because it makes me feel too anxious about having a hypo;' 'if I binge, I will have high blood sugar levels and then feel guilty.'

These vicious cycles of thoughts, feelings and behaviours are further maintained by systemic factors like others' responses to diabetes including misinformed advice (e.g. 'take cinnamon; should you be eating chocolate?', stigma alongside difficulties accessing well-informed, flexible diabetes care regimes and mental health support (Box J, Figure 2).

3.7 | Variants of type 1 disordered eating

Reflecting the complexity of type 1 diabetes and disordered eating, two variants were discussed in-depth by participants. It is important to note that these variants are not mutually exclusive, as some participants had experienced both maintenance cycles, and for some, fear of hypoglycaemia was the key reason for insulin omission. However, for 64.3% ($n = 9$,) the key driver of disordered eating was a fear of weight gain and insulin and fear of hypoglycaemia was the key driver for disordered eating in the remaining five participants (35.7%).

3.7.1 | Fear of weight gain and insulin maintenance cycles

Participants discussed beliefs that omitting insulin (and often, also restricting nutritional intake) will result in weight loss, or the maintenance of low weight. The principal disordered eating behaviour involves partial or complete omission of short and/or long-acting insulin. Through experiences of weight loss due to hyperglycaemia or diabetic ketoacidosis, participants discussed learning that omitting insulin produces rapid and significant weight loss and believe this to be a genuine reduction in weight (as opposed to severe dehydration). Omitting insulin also produces a numb and foggy experience which temporarily alleviates negative affect. Participants reported avoiding testing blood sugars, binge eating and omitting short-acting insulin to avoid weight gain. These behaviours were maintained by negative thoughts about diabetes and insulin like 'insulin makes me fat;' positive beliefs about insulin manipulation providing supreme control over one's weight and shape, and a form of diabetes burnout, where participants felt they had failed at diabetes management and gave up entirely, restricting food intake and/or not taking insulin. These behaviours were also maintained by negative emotional states experienced due to the relentless challenge of diabetes self care and in response to internal and external stigma about diabetes and disordered eating. Figure S1 provides an example of a vicious cycle of thoughts, feelings and behaviours present in this variant using quotations from participant interviews.

3.7.2 | Hypoglycaemia-related maintenance cycles

The aversive and traumatic cognitive, physical and emotional experience of hypoglycaemia can lead to the belief

that hypoglycaemia is terrifying and dangerous and must be avoided at all costs in some. Catastrophic thoughts about losing control during hypoglycaemia and also physical hypoglycaemia symptoms at high or blood glucose levels within range maintain this cycle.

Another reason to avoid hypoglycaemia is the experience of hypoglycaemia triggering binge eating. The consequential negative emotions of anger, depression, frustration and anxiety and feeling out of control around food intake provoke food restriction (to aid weight loss).

Over-dosing insulin to drop into hypoglycaemia and experience emotional numbness which temporarily reduces negative affect, or allowing oneself 'sweet treats' and exercising instead of giving insulin to manage blood sugar were also patterns that were described. Figure S2 provides an example of a vicious cycle of thoughts, feelings and behaviours present in this variant using quotations from participant interviews.

3.8 | A cognitive behavioural model of recovery from and resilience to disordered eating in type 1 diabetes

This alternative model (Figure 3) focuses on thoughts, feelings and behaviours involved in recovery from and resilience to disordered eating in type 1 diabetes and includes perspectives of those with type 1 diabetes who had recovered from disordered eating and those with type 1 diabetes who did not develop disordered eating.

Individuals either manage and learn to overcome early difficult experiences and challenging aspects of personality like perfectionism or inflexibility, or experience an early life with good transitions, few negative life events and weight and shape are not stigmatised in family conversations.

These early experiences interact with experiences of type 1 diabetes diagnosis, which either occurs in a supportive way with effective and supportive management strategies in place from the start, or, in the case of a more 'traumatic' diagnosis, individuals draw wisdom and develop resilience and use their learning to inform how to take care of their diabetes in future. This may result in fewer negative experiences of the physical symptoms of type 1 diabetes and fewer difficulties with its day-to-day management. This makes it less likely that the individual will become so strongly sensitised to eating, weight and shape cues. Another way in which individuals discussed being less vulnerable to weight, shape and eating cues as sensitising factors for disordered eating was learning to take 'good enough' care of diabetes. This involved 'doing my best' rather than 'feeling under pressure to do it perfectly' and this seemed to be associated with a more compassionate approach to eating weight and shape and allowed the integration of diabetes into their identity ('I am different, special and that's okay; diabetes is my identity; it is part of my identity; 'I have a defective pancreas and that doesn't mean I am a defective person;' I can accept that diabetes means my weight might fluctuate'). This approach appeared protective of disordered eating because it resulted in neutral or positive thoughts about diabetes (e.g. 'it is my job to take care of my diabetes; I embrace diabetes') and allowed participants to arrive at a place of acceptance ('I have good enough acceptance.') which meant they were less bothered by diabetes and felt more able to manage it on a daily basis ('diabetes can be challenging to manage but I have a future; insulin is no longer an enemy'). These factors then provoke virtuous cycles of thoughts, feelings and behaviours.

3.9 | Thoughts

1. Positive or neutral thoughts about health and type 1 diabetes: 'Diabetes and my weight and shape aren't the only things that define me; I am responsible for others (at home or work) so I have to take care of myself; I have found ways to eat out with friends by selecting options that work for me; If the same meal affects my blood sugars differently on different days. I am able to adapt to this and do my best to manage my health when this happens; I don't care if others see me check my blood sugars or inject my insulin—others support me with this;'
2. Thoughts indicating health being prioritised over shape and weight: 'Taking the right amount of insulin does not mean I will balloon in size, being thin is not the most important thing in my life; I am mostly OK with my weight; health is more important; I can resist the urge to omit my insulin. I don't want to feel unwell anymore. I am concerned about late complications. Any weight loss I might experience would largely be due to dehydration. I can manage my emotions and have different coping strategies;'
3. Acceptance of life with type 1 diabetes: 'I live with diabetes and I need to get on with it; I can accept my diabetes and I have found a way to tolerate it; I can educate others and help them to understand. If people say misinformed things, I can challenge them and explain the truth;'
4. Acceptance of diabetes self care tasks: 'Insulin is the key to managing my blood sugars and to me feeling well; Diabetes is a normal part of my daily routine; My relationship with diabetes and my body is an ongoing task I have to work on in order to stay well;' and;
5. Being 'good enough' at diabetes self care: 'I am allowed treats and can inject insulin to manage the impact of these on my blood sugars; I do not have to have perfect diabetes management – I will have bad days and that's OK. I don't need to be a perfect diabetic. I am able to

FIGURE 3 A cognitive behavioural model of recovery from and resilience to disordered eating in type 1 diabetes

manage hypoglycemia and I am less afraid of going low and have strategies to manage this if it happens.' Those endorsing this 'good enough' perspective appeared to endorse a thinking style which was outward (as opposed to inward) looking and rather than being focused on small details such as calories or minutes of exercise, they endorsed a bigger-picture approach to health and well-being.

3.9.1 | Feelings

Empowerment, good enough self-esteem and body image, positive self-evaluation, a positive sense of self in which type 1 diabetes is integrated into ones' identity, contentment and positive emotion, interest in activities and hobbies which can be done in spite of type 1 diabetes.

3.9.2 | Behaviours

1. Diabetes self care: Checking blood sugars and injecting in front of others; giving adequate insulin to prevent tiredness, fatigue and fogginess; using insulin effectively and flexibly; resting after having high or low blood sugars; a stepwise rebuilding of the ability to give and tolerate background insulin, and then growing confidence at giving short-acting insulin; having a balance of structure and flexibility in diabetes management
2. Eating strategies: finding a way of eating that works for the individual (e.g. a low carb approach); eating a range of food groups and allowing treats and regular eating;
3. General self care behaviours: 'I nurture the body and give it the food and insulin it deserves and needs'; going for walks, spending time with others, doing interesting hobbies, using distraction to manage emotions; and
4. Seeking support: working collaboratively with trusted practitioners; involving others who accept and support diabetes self care routine and using online forums for social support and information.

These factors are maintained further by useful interactions with systemic factors including 'accessing structured diabetes education, working collaboratively with an understanding and knowledgeable practitioner, having access to support from teams with both type 1 diabetes and eating disorders expertise and rapid and easy access to well-informed, flexible care and diabetes technology, and biomedical parameters, including body weight are discussed by professionals in compassionate and supportive manner.' Individuals' thoughts, feelings and behaviours were less affected by daily triggers such as stressors and weight, shape and eating cues when supported by these interactions.

4 | DISCUSSION

This is the first model of type 1 diabetes and disordered eating to offer an initial conceptualisation informed by personal experiences of a diverse group of experts by experience. The development and maintenance model shares some features with Treasure et al's.[10] Both highlight the negative thoughts experienced around type 1 diabetes management and care. Mood dysregulation is also present in both ours and Treasure et al.'s models: In Treasure et al.'s, emotion dysregulation has a recursive relationship with binge eating; in our model, the belief that manipulating insulin and blood sugars is a mood regulation strategy that provokes insulin omission and nutritional restriction. Both highlight the recursive relationship between diabetes and others' interpersonal responses. Cultures focused on weight, shape, dieting and thinness may be systematic maintaining factors also reported elsewhere[19] because they stigmatise food, idealise thinness and promote dieting and body dissatisfaction, impacting the ability to care for type 1 diabetes and recover from disordered eating.

There are some important differences between our development and maintenance model and Treasure et al.'s. Our model elaborates on multiple ways that insulin might be used to influence weight and shape, like omission of basal insulin to induce a katabolic state and glucosuria to provoke rapid weight or fluid loss; omission of bolus insulin to avoid weight gain and the use of nutritional or carbohydrate restriction to prevent needing to give insulin to lead to weight loss. Clinicians should be aware of these behavioural variants in type 1 diabetes and disordered eating and our development and maintenance model also explains how these behaviours exacerbate the physical symptoms and complications of diabetes which further enhance negative beliefs about diabetes and its impact on shape and weight. Our development and maintenance model does not emphasise the neuroadaptive changes hypothesised by Treasure et al[10] to be caused by insulin mismanagement and fluctuations in plasma glucose, possibly because our model draws largely on patient experience and these individuals may not be aware of neuroadaptive changes. However, possible neuroadaptive changes as a result of difficulties managing plasma glucose levels are discussed in our new model in the context of the behaviours that people use to either manage emotions or influence shape and weight, because the feeling of hyper or hypoglycaemia is described as addictive by some.

This new development and maintenance model also corroborates components from De Paoli and Rogers'[11] model. Both highlight a sense of difference due to type 1 diabetes and report on type 1 diabetes and disordered eating subtypes. De Paoli and Rogers[11] suggest some individuals experience dietary restriction leading to hypoglycaemia and/or disinhibition; binge eating and hyperglycaemia; and purging and insulin restriction. Our model better clarifies possible type

1 diabetes and disordered eating sub-variants (*fear of weight gain and insulin* and *hypoglycaemia* maintenance cycles), explaining the nature of the thoughts experienced by people with type 1 diabetes and disordered eating and shows how these thoughts influence behaviours related to diabetes care and weight, shape and eating.

Neither Treasure et al.'s,[10] nor De Paoli and Rogers'[11] models provide a clear idea of how people learn to look after their type 1 diabetes and recover from disordered eating and the resilience model we constructed based on personal experience is a novel and important contribution to understanding type 1 diabetes and disordered eating. However, overall, synergy exists between our new development and maintenance model of type 1 diabetes and disordered eating informed by personal experience and Treasure et al.'s[10] and De Paoli and Rogers'[11] models derived from clinical experience, case studies and systematic reviews. In comparison to cognitive behavioural therapy models of eating disorders like Fairburn's,[7,8] there are shared factors, like perfectionism, emotion regulation difficulties and body image distress. However, this work highlights that initial diagnosis and management of diabetes, its physical health impacts and demanding self care regimes are unique and important in sensitising individuals to eating, weight and shape cues. It also clarifies the types of disordered eating behaviours observed in type 1 diabetes which are not well explained in other eating disorder models.

4.1 | Limitations

As voluntary sampling was used, we may have missed people who may have been unaware their relationship with eating, weight and shape may be pathological, which biases our sample towards those with insight into their difficulties. No men opted to participate. It would be helpful to develop strategies to encourage participation from more diverse gender and ethnic groups because there is no evidence that this form of disordered eating affects any one group in particular. The sample size was limited and future work should test the validity of these initial conceptualisations in a larger, more heterogeneous sample.

4.2 | Conclusions

The development and maintenance model highlights the early experiences and psychological factors that interact with a diagnosis of type 1 diabetes which, alongside the physical symptoms of type 1 diabetes, contribute to vicious cycles of thoughts, feelings and behaviours, which, exacerbated by systemic factors, maintain type 1 diabetes and disordered eating. The National Institute for Health Research funded Safe management of People with Type 1 Diabetes and Eating Disorders project will now use these models to develop and test a cognitive behavioural therapy intervention for type 1 diabetes and disordered eating aimed at using psychoeducation to support people with diabetes self care, treating disordered eating using cognitive behavioural therapy interventions to improve quality of life and reduce diabetes complications. Other clinical implications for diabetes professionals are (1) we should be aware of sensitising elements when giving advice (e.g. using appropriate language when discussing weight and shape and diabetes complications, and avoiding emphasising perfection in diabetes education); and (2) ask patients their feelings about weight and shape to normalise these discussions in clinic and avoid them struggling alone with body image distress.

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CONFLICT OF INTEREST

None to declare.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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