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The Detection and Management of Diabetes Distress in People With Type 1 Diabetes

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Abstract Diabetes distress (DD) represents a significant clinical burden in which levels of DD are related to both glycated haemoglobin (HbA1c) and some self-management behaviours. DD is related to, but different from, depression. Differences in DD experienced in people with type 1 and type 2 diabetes have been observed. Commonly measured using the Problem Areas in Diabetes Scale (PAID) and the Diabetes Distress Scale (DDS), rates of elevated DD in research study participants range from 20 to 30 %. Risk factors for elevated DD in type 1 diabetes are longer duration of diabetes, severe hypoglycaemia, younger age and being female. A systematic review of intervention studies assessing DD identified eight randomised controlled trials (RCTs) and nine pre-post design studies. Only three studies targeted DD with the intervention. Intervention types were diabetes self-management education (DSME), psychologically informed self-management and devices. DSME pre-post studies, namely the Dose Adjustment For Normal Eating (DAFNE) programme, produced more consistent improvements in DD and HbA1c at follow-up. Psychologically informed self-management was more heterogeneous, but several RCTs were effective in reducing DD. Group interventions offered the greatest benefits across intervention designs.

Keywords Diabetes distress · Type 1 · Review · Interventions · Correlation

Abbreviations

DD	Diabetes distress
RCT	Randomised controlled trial
HbA1c	Glycated haemoglobin
DAFNE	Dose Adjustment For Normal Eating
DSME	Diabetes self-management education
PAID	Problem Areas in Diabetes Scale
DDS	Diabetes Distress Scale
SD	Standard deviation
CGM	Continuous glucose monitoring
CBT	Cognitive behaviour therapy

Introduction

Diabetes distress (DD) has been increasingly recognised in research practice for two decades but has only recently achieved a sharper focus in clinical practice. Much of the research attention has been in type 2 diabetes. This paper is the first to review the evidence for DD in type 1 diabetes. We present a definition of DD and consider its associations with the important diabetes endpoints of glycaemic control, self-management behaviours and depression. Rates of elevated

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DD in research populations and the relative merits of screening for DD are considered. We present a systematic review of interventions for managing DD in clinical environments. The paper concludes with a number of research priorities to further our understanding of DD in people with type 1 diabetes.

Definition of Diabetes Distress

DD reflects a range of different emotional response to patient's perceptions of health threats balanced against an appraisal of available coping resources, and it is content related necessitating a focus on distinguishing amongst the different sources of distress in diabetes so that specific interventions can be initiated [1•]. Esbitt et al. [2] explain that DD is "predicated on a variety of medical, contextual and individual factors, not on the presence of a psychiatric condition" (p. 35).

Manifestation of Diabetes Distress in Type 1 and Type 2 Diabetes

Some studies suggest that DD does not discriminate by diabetes type [3, 4], but it cannot be presumed that emotional problems are similarly experienced and have the same consequences in type 1 and type 2 diabetes. Indeed, the most commonly reported emotional problems in type 1 diabetes relate to hypoglycaemia and complications, worry about the future and complications, feeling burnt out/overwhelmed and worrying about low blood sugar reactions [5–7], whereas in type 2 diabetes, emotional distress relates more to goal setting and food restrictions [7]. Qualitative work confirms stressors unique to type 1 diabetes: realisation of the possible consequences of previously poor self-management as adolescents, apprehension about pregnancy, anxiety about being perceived to have type 2 diabetes, frustration competing for resources with type 2 diabetes and many great concerns specific to insulin use [8••, 9]. Our own case note documentary analysis observed differences in the manifestation of DD in the two populations [10]. Type 1 diabetes case notes revealed core issues resulting in elevated DD being lack of diabetes control and fear of associated complications with common behavioural manifestations resulting in the maintenance of high blood glucose levels, low levels of blood glucose monitoring and medication non-concordance. In contrast, type 2 diabetes case notes indicated the following: isolation, work-related issues, family demands, obesity and lack of knowledge. We found some diabetes distress themes reported in both type 1 and type 2 diabetes: neuropathic pain, fear of complications, fear of hypoglycaemia, poor sleep, loss of medication or diet control, dietary control (calorie restriction in type 2 diabetes and carbohydrate counting in type 1 diabetes), loss of independence and lack of support. It is clear from this early understanding of differences in DD that different management foci may be required.

Diabetes Distress Related to Depression

Previous psychological research in diabetes has focussed on depression, but it is now apparent that there has been a lack of clarity and precision in the measurement of depression in diabetes [1•, 11•]. Depression and DD are strongly associated not only in type 2 diabetes [12] but also in type 1 diabetes [9, 13]. Prospective research in mixed diabetes samples suggests a bidirectional association [7, 14, 15], with emerging evidence in type 1 diabetes that DD exacerbates the risk of incident-depressive symptoms by twofold [16]. Depression assessment constitutes to symptom count irrespective of cause or context, whereas DD reflects an emotional response to the adversity associated with living with and managing diabetes [11•], and Fisher et al. [1•] explain that "exclusively symptom based depression scores most likely capture the affect component of DD" (p. 769). Qualitative studies suggest that where a person with type 1 diabetes has depression, it is often related to their experience of diabetes [9, 17]. Fisher et al. [1•] explain that emotional distress in diabetes should be considered "a single continuous dimension that has two primary characteristics: content and severity; that the primary content of emotional distress among these individuals include diabetes, it's management, other life stresses and other contributors (e.g. personal characteristics, life history and genetics)" (p. 764). There is, therefore, a need to move beyond conceptualising *distress* in diabetes as diagnosable depression and recognise the impact of disease-related factors on emotional well-being [18].

Measurement of Diabetes Distress

The concept of DD emerged alongside the development of the Problem Areas in Diabetes Scale (PAID) [19], with later revisions resulting in the Diabetes Distress Scale (DDS) [20]. We recently completed the work to distinguish between measures of DD (unpublished data). The PAID was developed with a sample predominantly comprised of people with type 1 diabetes [19], and the psychometric properties of the DDS for adults with type 1 diabetes has recently been established [21]. These measures have been extensively psychometrically evaluated in type 1 and type 2 diabetes [22], parents [23], adolescents [24] and languages and cultures [21, 25, 26]. Qualitative work, however, suggests that additional aspects of DD important in type 1 diabetes are omitted from these measures: fear of hypoglycaemia, problems maintaining a normal work-life balance, fatigue [21] and guilt about social burden, for example the possibility of an emergency [9]. As a result of these

concerns, the Type 1 Diabetes Distress Scale (DDS-T1) was recently developed [27]. The DDS and DDS-T1 are comprised of empirically established sub-scales such as the DDS emotional burden and regimen distress sub-scales [20, 27] and have been employed in research studies [28••]. Short forms and screeners such as the DDS-2 and PAID-5 are also available [3, 29–31].

Relationship to Endpoints in Type 1 Diabetes

Glycated Haemoglobin

Cross-sectional evidence has consistently shown that, any point in time, someone with elevated DD is likely also to have high glycated haemoglobin (HbA1c) in type 1 diabetes [5, 32]. However, DD is not prospectively related to HbA1c when baseline HbA1c is controlled for; someone experiencing higher DD is not apparently at risk of increasing their HbA1c, or indeed developing high HbA1c, as a result of this initial distress at follow-up [33••, 34]. However, some evidence in type 1 diabetes suggests that intervention-related changes in DD are associated with changes in HbA1c with a marginally significant trend, suggesting that these concurrent changes are related, although causality cannot be inferred [35]. This mirrors findings in type 2 diabetes [36]. Furthermore, Weinger and Jacobson found that high baseline DD hampers improvement in HbA1c, suggesting that interventions must address existing DD to evidence improvement in clinical outcomes [35]. Some unpublished studies have failed to support an association between DD and HbA1c in type 1 diabetes though [37, 38], suggesting a complex relationship between these variables that requires further exploration. DD has been shown to explain the relationship between depressive symptoms and HbA1c [3, 39]. This mirrors evidence in mixed and type 2 diabetes samples [7, 40–42].

Self-Management Behaviours

Cross-sectional evidence suggests that DD impacts self-management behaviours in type 1 diabetes, namely less physical activity, poorer diet [21] and eating styles that are associated with overeating and high HbA1c [6] and insulin restriction [43, 44]. Other studies suggest that DD is not associated with self-monitoring of blood glucose, smoking and alcohol consumption, and that its association with physical activity may be explained by more general emotional distress [13]. This evidence base is very much underdeveloped at present, though. Martyn-Nemeth et al. identified that there may be a level at which DD becomes immobilising, resulting in fewer behaviours to avoid hypoglycaemia at very high levels of DD [6]. Sturt et al. found that in type 1 and type 2 diabetes, people with elevated diabetes distress alongside psychological morbidity, including low mood, were unable to convert strongly desired self-care intentions into actions [10]. Conversely, individuals with diabetes distress *only* were more successful at initiating self-care behaviours and developing self-efficacy, indicating that DD alone is easier to target [10]. Other mixed type and type 2 diabetes-only studies have found that it is the co-morbidity of DD and depression that is associated with the highest levels of HbA1c [45–47]. This suggests that when you have both DD and depression, it impacts the most on self-management behaviours that aim to control glycaemia and becomes most difficult to resolve.

Regimen Distress and Diabetes Endpoints

Research in type 1 diabetes has explicitly demonstrated that the element of DD that appears to drive the aforementioned associations with HbA1c, and self-management behaviour, is regimen distress [6, 21, 33••, 35, 39, 48]. The smallest change in regimen distress which can be subjectively realised by individuals, 0.5 standard deviation (SD) change, is associated with a difference of 7 mmol/mol (0.6 %) in HbA1c [39].

Thresholds for, and Rates of, Clinically Relevant DD

No epidemiological studies have assessed for DD; therefore, all data on degrees of DD amongst people with diabetes and proportions of people with diabetes experiencing elevated DD are derived from interventional or cross-sectional research studies which, in itself, results in a likely population bias. Investigators have used a range of thresholds across type 1 and type 2 diabetes populations to define elevated DD from PAID scores in the population aged below 30 years [49, 50] to 45–50 years [51, 52]. Studies in type 1 diabetes have endeavoured to establish the curvilinear relationship which has been observed in type 2 diabetes between DD and HbA1c, diet and physical activity [53]. In type 2 diabetes, the shape of these relationships indicated thresholds for low (a DDS mean score of 1–2), moderate (a DDS mean score of 2–3) and high (a DDS mean score over 3) clinically relevant DD; each successive increase in DD is associated with a 0.5 SD increase in HbA1c or decrease in self-management behaviour. However, the studies in type 1 diabetes found no evidence of these relationships [21, 39], suggesting that emotional problems have different implications in type 1 and type 2 diabetes and that, in type 1 diabetes, interventions can be applied, and will be effective, at any non-zero level of DD [21].

The majority of empirical studies to date have used thresholds of PAID ≥40 and a DDS score >3 to indicate elevated DD [28••]. In scoping the literature, we identified 11 studies which have reported proportions of type 1 diabetes populations with elevated DD [2, 21, 38, 47, 54–60]. These proportions range from 8 % [57] to 65 % [2]. Nearly half of these studies

(combined population of 875 participants) reported proportions of participants with elevated DD between 17 and 31 % [38, 47, 58, 60, 61]. The mean ages of participants in these studies were between 37 and 52 years with the largest study reporting on 466 participants, mean age 37 years, finding 28 % to have elevated DD [47]. A large international study with 8500 participants (DAWN2 study), of which 16 % of them have type 1 diabetes, found that 44.6 % of the study population has elevated DD on the PAID-5 [62]. The evidence suggest that 20–30 % of people with type 1 diabetes will be experiencing elevated diabetes distress that will be affecting their self-management behaviours and their glycaemic control. Given that the majority of the evidence we have observed did not have psychological morbidity inclusion criteria and that those with psychological morbidity would be regarded as hard to reach and unlikely to volunteer for research participation, it is likely that this is an underestimation of the true picture.

Specifically in type 1 diabetes, risk factors for DD include a longer duration of diabetes [21, 63] and episodes of severe hypoglycaemia [5]. Age is also negatively correlated with DD [5, 21] with adolescents and younger adults endorsing feeling scared when thinking about living with diabetes, guilty about getting off track with diabetes management, unsatisfied with their diabetes physician, discouraged with their diabetes routine and experiencing uncomfortable interactions about diabetes with family/friends as more serious concerns than do older adults with type 1 diabetes [5]. DD is greater for women than men [21, 49, 63, 64] with women also exhibiting higher prevalence of subcutaneous insulin infusion, greater self-monitoring of blood glucose and a higher level of motivation, yet no difference in HbA1c level, perhaps suggesting that greater effort in maintaining HbA1c is at the cost of higher DD [49]. Interestingly, women, but not men, with type 1 diabetes have been shown to experience greater DD when they live without a partner, an effect that is partly explained by social support albeit the precise mechanisms of this association have yet to be established [65].

The Pros and Cons of Screening

Routine psychosocial screening for DD and depression has been recommended at key time points in the care pathway, including diagnosis, annual reviews, inpatient episodes, new complications and when issues of glycaemic control, self-management and quality of life arise [66]. The incorporation of psychosocial assessment and treatment into routine care, through a collaborative team approach, is recommended [11•, 66, 67]; however, no screening studies involving only the assessment for DD have been conducted solely in type 1 diabetes populations. These recommendations assume, firstly, that the screening process is effective in detecting vulnerable people; secondly, that psychosocial care pathways are routinely available; and thirdly, that these services are acceptable to patients. Fleer et al. found in a mixed type 1/type 2 diabetes sample that only 36 of the 104 participants found to have elevated DD accepted further referral to psychological services [57]. With limited resources, Byrne et al. argue that individuals likely to benefit the most should be targeted for intervention, including those with higher DD at baseline [50]. Ironically, the hard-to-reach group that does not respond to screening has the most to benefit from it [57]. Conflicting evidence exists concerning diabetes health-care professionals' capacity to clinically detect DD. Pouwer et al. report under detection of DD by diabetes nurse specialists in 75 % of patients with established distress [68]. Conversely, Sturt et al. found that clinicians were able to detect elevated DD during their routine consultations [10]. Clinicians may not seek to uncover DD if local psychological care services and care pathways do not exist for the management of elevated DD. Fleer et al. suggested that, where integrated systems are not available, we should not screen [57]. Undertaking service audit to identify local prevalence of elevated DD may have greater merit enabling business cases to be developed for the provision of psychological care pathways in diabetes.

The Treatment and Management of Diabetes Distress: a Systematic Review

Methods

Given the relative novelty of clinical detection and management of DD in clinical practice outside of research studies, we sought to undertake a systematic approach to the identification and appraisal of effective treatment and management strategies. We updated a previous review of effective interventions for reducing DD in type 1 and type 2 diabetes populations [28••]. We searched Medline, PsycINFO and Embase from March 2013 to March 2015, for additional research studies reporting DD outcomes using the full PAID or DDS. From our previous review [28••], 14 type 1 diabetes studies were included. Figure 1 illustrates our combined flow diagram of included studies. The updated search identified 293 citations, and two people assessed each. Mixed diabetes population studies were included where the type 1 diabetes population data could be reported separately. One further unique experimental study was included. Two papers, published post March 2015, were identified through personal contacts. Due to heterogeneity in both intervention and research design, we undertook a narrative synthesis.

Managing Diabetes Distress

Seventeen studies reporting DD-related intervention outcomes specifically for adults with T1DM were identified; of

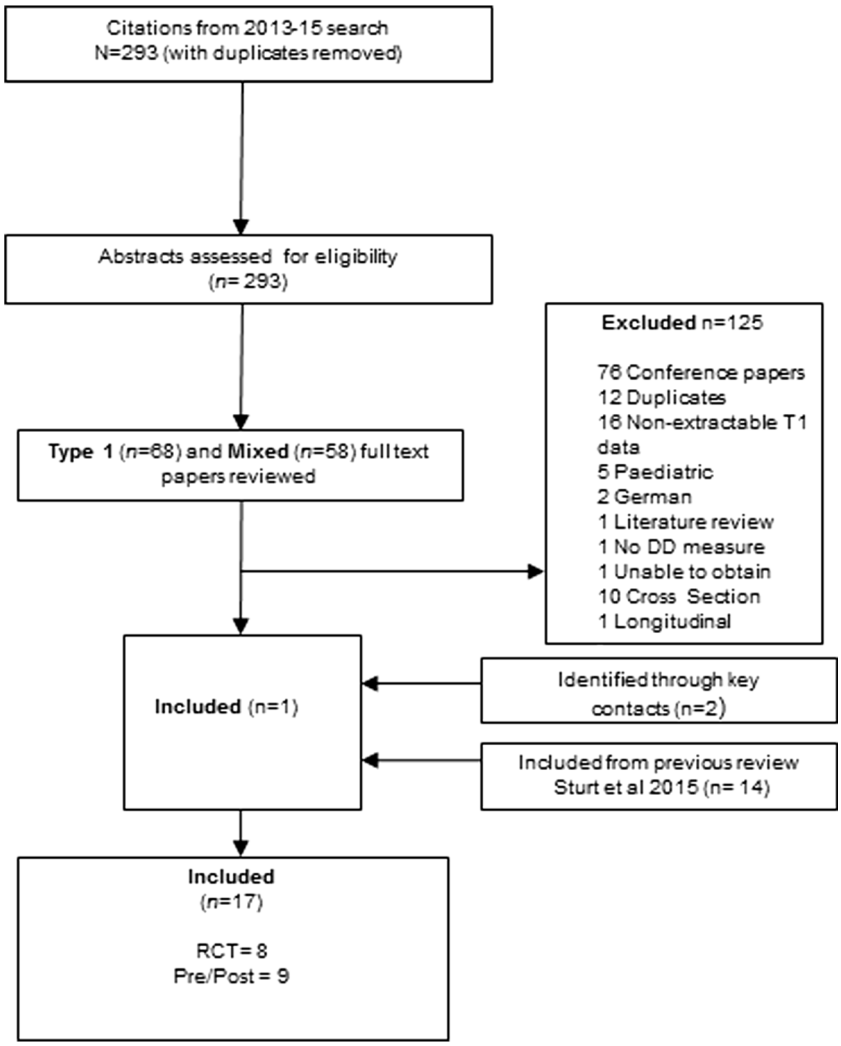

Fig. 1 Flow diagram of included studies

these, eight were randomised controlled trials (RCTs) and nine were pre-post studies. The PAID was used in 15 studies and the DDS in 2 studies. These studies are described in Table 1. Reduction of DD was the sole or co-primary outcome in two studies [56, 69] and a secondary outcome in the remainder. This indicates that the majority of studies are not targeting DD but rather determining whether an intervention targeting another outcome worsens or improves DD. Reduction of DD was reported in all studies, however not always significantly. Our synthesis has categorised interventions into three groups: diabetes self-management education (DSME), self-management with a psychological component and devices.

Six studies investigated DSME interventions which aimed to reduce HbA1c by providing knowledge about diabetes and the technical skills needed to manage the condition and may include goal setting and problem-solving. All DSME intervention studies but one [50] (who did not report significance levels) reported significant reductions in DD [35, 70–73] and in HbA1c when reported [35, 71, 72]. The DSME intervention studies were pre-post design, and five of the six evaluated the Dose Adjustment For Normal Eating (DAFNE) programme and thus are generally more homogeneous which may account for the consistent positive impact on DD across these DSME interventions. The RCT studies of DAFNE [74] did not report DD as an outcome, and so, it is not possible to be definitively convinced that DSME, and DAFNE in particular, improved DD compared to controls. A study to evaluate the impact of the DAFNE programme on people with elevated DD would be an important next step in the evaluation of both DAFNE and elevated DD.

Nine studies comprised our second category, self-management interventions with a psychological component. In addition to some degree of self-management education, these studies have a psychological component focusing on the multidimensional aspects and perceptions of living with diabetes. These interventions aim to develop strategies to cope with the emotional stress of managing the disease and modify unhelpful cognitions. In addition, knowledge provided by the

Table 1 Characteristics of intervention studies

Reference, year, country, methodology	Recruited, I/C group size, length of follow-up, intention-to-treat (Y/N), primary outcome, diabetes distress measure	Mean age, male%, T1DM%, diabetes duration (years)	Baseline diabetes distress (I/C)	Baseline HbA1c (I/C)	Intervention description Speciality of therapist *Control group*	Outcomes
Randomised control trials						
Zoffman, 2006, Denmark, RCT [78•]	61, I=61/C=25, 12 months, N, NR, PAID	36 years, I=46/C=50, T1DM=100 %, NR	I=32 (3.4)/C=40.9 (4.0)	I=9.01 (0.2)/ C=9.05 (0.2)	Empowerment theory-based self-determination theory (SDT), self-directed written materials encouraging reflection-oriented goal setting and problem-solving, supportive listening, motivational focus Group face-to-face session, by diabetes educator, 7×2-h sessions over 8 weeks *Waiting list control*	PAID: I=25.6 (2.7); C=36.7 (4.5) ($p<0.05$) The intervention group did better than controls re: increased autonomy support perceived from HCPs, higher frequency of self-monitored blood glucoses, increased perceived competence in managing diabetes, reduced diabetes distress (total score and generally consistent for sub-scales esp. treatment-related social support distress) HbA1c reduced (0.41 %) between I and C groups showing a modest but long-term effect of the intervention
Snoek, 2008, Dutch, RCT [76]	86, I=45/C=41, 12 months, Y, HbA1c, PAID	I=38 years/C=37 years, I=49/ C=34, T1DM=100 %, I=17.8 (10.1)/C=18.8 (10.9)	I=44.4 (22.4)/C=49.0 (17.2)	I=8.8 (1.3)/C=9.1 (1.1)	Theory-based CBT, addressing psychological barriers to diabetes self-management, reframing of negative beliefs, written homework assignments 6× group sessions delivered weekly by a psychologist *Six blood glucose awareness training sessions delivered weekly*	PAID: I=43.4 reduced to 38.3; C=49.0 reduced to 45.4 (intervention×time, 6 months, $p=0.99$; 12 months, $p=0.68$) Significant effect for HbA1c reduction in subgroup of depressed patients with CBT but not the BGAT group No significant changes of HbA1c
Hermanns, 2009, German, RCT crossover [62]	50, 50 crossover, 12 weeks, N, CGM satisfaction, PAID	42 years, 53 %, T1DM=100 %, 14.75 (11.9)	30.7 (18.8)	I:8.1 (1.5)	Glucose monitoring device education, single inpatient stay averaging 42 h, individual face-to-face session, delivered by a diabetes specialist, continuous glucose monitoring with real-time access to results *Same group with retrospective analysis of glucose data. Order of condition randomised*	PAID baseline=30.7 (18.8), RA=28.5 (19.2), RTA=29.2 (21.2) (NS) No significant reduction in distress from baseline in either group, nor between group differences. Continuous glucose monitoring was less desirable compared to baseline, and the real-time or retrospective analysis of data made no difference to this outcome
Amsberg, 2009, Sweden, RCT [77]	74, I=36/C=38, 48 weeks, Y, HbA1c, PAID	41 years, 49, T1DM=100 %, 21.6 (10.8)	I=31.1 (20.4)/C=33.4 (17.3)	≥7.5	Theory-based CBT, basic programme of 8×2-h weekly group sessions, plus 2× maintenance group sessions, 2× individual sessions and 5 phone calls Log book for self-care activities and emotions, homework to enhance reflection upon self-care behaviours, supportive counselling delivered by a diabetes nurse specialist and a psychologist *Usual care*	PAID: I=22.92; C=29.8 ($p=0.004$) Significant differences in DD between groups were observed at 24 weeks and maintained throughout the study to week 48 Change in HbA1c was significant between groups at 48 weeks, I=7.72; C=8.21 ($p=0.012$)
Hermanides, 2011, European, RCT [83]	83, I=22/C=21, 26 weeks, Y, HbA1c, PAID	I=39 years/C=37 years, I=50/ C=54, T1DM=100 %, I=16.9 (10.7)/C=21.0 (9.4)	I=32.4 (18.8)/C=26.5 (18.4)	I=8.45 (0.95)/ C=8.59 (0.82)	Sensor-augmented insulin pump treatment, 26 weeks. First 13 weeks: no specific instructions given; 2nd 13 weeks: advised to carbohydrate count *Control group on multiple daily injections received standard care. First 13 weeks: no specific instructions given; 2nd 13 weeks: advised to carbohydrate count*	PAID: I=21.0 (19.3) ($p=0.03$) in favour of sensor-augmented insulin pump group. Sensor-augmented insulin pump therapy was associated with an improvement in diabetes-related distress HbA1c: I=7.23 (0.65), C=8.46 (1.04) ($p<0.001$)

Table 1 (continued)

Reference, year, country, methodology	Recruited, I/C group size, length of follow-up, intention-to-treat (Y/N), primary outcome, diabetes distress measure	Mean age, male%, T1DM%, diabetes duration (years)	Baseline diabetes distress (I/C)	Baseline HbA1c (I/C)	Intervention description Speciality of therapist *Control group*	Outcomes
Hermanns, 2013, German, RCT [81••]	160, I=81/C=79, 6 months, Y, HbA1c, DDS	I=45 years/C=46 years, I=51/C=62, T1DM=100 %, I=19.3 (13.4)/C=19.6 (12.8)	I=1.3/C=1.2	I=8.3 (1.1)/C=8.1 (1.0)	Empowerment/self-management theory-based education programme (PRIMAS), written materials, homework, problem-solving, goal setting, addressing emotional problems, 12×90-min group sessions twice weekly over 6 weeks. Family members or other close relations were invited to attend one session on social support, delivered by diabetes educators *Control: usual DSME programme: written materials, health professional delivered, 12× 90-min group sessions*	DDS: I=−0.3 (0.7), C=−0.1 (0.4) (p=0.032) The intervention was superior in reducing diabetes distress, HbA1c and increasing empowerment, self-efficacy and satisfaction with insulin therapy. Both groups improved awareness of hypoglycaemia, diabetes knowledge and self-care behaviour and reduced severe hypoglycaemia incidents with no significant differences between groups HbA1c in I compared to C (−0.4±1.0 vs. 0.0±0.6 %) (p=0.012)
Hermanns, 2015, German, RCT [82]	214, I=106/C=108, 12 months, Y, depressive symptoms, PAID	43 years, 43, T1DM: I=59 %/C=72 %, 14.2 (10.5)	40.3 (3.4)	8.9 (1.8)	Empowerment/self-management theory-based CBT, diabetes motivation strengthening (DIAMOS) for patients with subclinical depression, 5×90-min group sessions plus telephone support. Coping with diabetes-related challenges, goal setting and problem-solving, motivational strategies, self-directed written materials. Delivered by diabetes psychologist *Control group 5× 90-min group education intervention delivered by a health-care professional*	PAID: I=−13.0 (18.9) (p=0.001); C=−4.2 (16.9) (p=0.022) Type 1 diabetes specific: more T1DM in control group; analysis stratified by diabetes type indicates no significant interaction effects observed except diabetes acceptance (less impact on diabetes acceptance in T1DM than T2DM). DIAMOS efficacious in treating sub-threshold depression and elevated diabetes distress si more effective than education alone. Additionally, it prevents deterioration from sub to major depression HbA1c: I=−0.5 (2.0), p=0.018; C=−0.7 (1.7), p=0.001
Zoffman, 2015, Denmark, RCT [79]	200, I=134/C=66, 18 months, Y, HbA1c, PAID	26 years, 50, T1DM=100 %, 13.7 (6.8)	I=36.4 (21.0)/C=35.2 (22.7)	I=9.5 (1.3)/C=9.7 (1.5)	Empowerment theory-based SDT, self-directed written materials encouraging reflection-oriented goal setting and problem-solving, supportive listening, motivational focus. 7× either 1-h individual sessions or 2.5-h group sessions, over max of 12 months Delivered by diabetes nurse specialists *Control group received usual care (3–4 monthly appointments with diabetes specialist)*	PAID: difference between I and C (p<0.001); I: men=−2.6; women=−15.3 (p=0.0024) The flexible self-guided determination intervention benefitted younger adult women by significantly improving glycaemic control and decreasing diabetes-related distress. No effect was seen amongst men HbA1c: I=−0.4 %, C=−0.1 % (p=0.073)
Pre/post intervention studies						
Weinger, 2001, American, pre/post [36]	55, NA, 8 weeks, N, emotion/attitude barriers, PAID	NR, 44, T1DM=100 %, NR	PAID 40.0 (3.4)	9.0	Medical/education programme, 8 weeks with monthly diabetes clinic MDT, weekly phone contact from a diabetes nurse to optimise glycaemic control in additional 8 weeks of educational programme either BGAT or cholesterol education (no information on group or individual provided)	PAID reduced from 40 to 31 (p<0.01) Newly learned self-management needs assistance to be incorporated into lifestyle. Intervention needs to help identify potential barriers and the necessary steps to achieve self-management goals. PAID is particularly useful as a screening tool for patients attempting to improve glycaemic control HbA1c=9.0 to 7.8 % (p=0.0001)

Table 1 (continued)

Reference, year, country, methodology	Recruited, I/C group size, length of follow-up, intention-to-treat (Y/N), primary outcome, diabetes distress measure	Mean age, male%, T1DM%, diabetes duration (years)	Baseline diabetes distress (I/C)	Baseline HbA1c (I/C)	Intervention description Speciality of therapist *Control group*	Outcomes
Snoek, 2001, Dutch, pre/post [70]	24, NA, 6 months, N, HbA1c, PAID	35 years, 38, T1DM=100 %, NR	39.9 (16.0)	9.3 (1.2)	Theory-based CBT, group session to improve coping with diabetes, cognitive restructuring, stress management, behavioural strategies and homework; 4×1.5-h sessions weekly, delivered by a diabetes nurse specialist and a diabetes psychologist	PAID reduced from 39.9 (16.0) to 31.2 (17.4) (p=0.06) CBGT is feasible in a poorly controlled group; perceived barriers were decreased significantly; general well-being was maintained HbA1c reduced from 9.3 % (1.2) to 8.5 % (0.91) (p=0.04)
McIntyre, 2010, Australia, pre/post [73]	145, NA, 12 months, N, HbA1c, PAID	43 years, 66, T1DM=100 %, 16.7 (11.5)	25.0 [15–27, 28••, 29–32, 33••, 34–45]	8.2 (1.2)	DAFNE programme, theory based, 5 consecutive whole days delivered in groups, to increase diabetes knowledge and self-management skills relating to insulin dose adjustment according to food intake aiming at patient autonomy, delivered by MDT of diabetes specialists	PAID reduced from 25 [15–27, 28••, 29–32, 33••, 34–45] to 16.25 [10, 11•, 12–27, 28••, 29, 30] (p<0.0001) Improved glycaemic control, reduced severe hypoglycaemia incidents, improved QOL HbA1c reduced from 8.2 to 7.8 %
Engle, 2011, Australia, pre/post [71]	144, NA, 12 months, N, well-being and coping, PAID	45 years, 35, T1DM=100 %, 17.7 (12.42)	I=31.94 (18.27), MDI=28.12 (20.94); continuous subcutaneous insulin infusion (CSII)=28.92 (17.11)	NR	DAFNE programme (see McIntyre [73]) *Usual care comparison to two groups, multiple daily injections (MDIs) and CSII*	PAID: I=−10.37 (14.67) (p<0.001); MDI=−2.14 (11.38); CSII=−3.98 (9.77) OzDAFNE provides a powerful mastery experience and positively influences subjective well-being and diabetes-related distress
Keen, 2011, UK, pre/post [73]	124, NA, 12 months, N, HbA1c, PAID	43 years, 56, T1DM=100 %, 17.8 (11.0)	20 (12.5–33.8)	8.6 %	DAFNE programme (see McIntyre [73])	PAID reduced from 25 [15–27, 28••, 29–32, 33••, 34–45] to 16.25 [10, 11•, 12–27, 28••, 29, 30] (p<0.0001) DAFNE reduced diabetes-related distress, improved glycaemic control, reduced severe hypoglycaemia and improved QOL HbA1c: only the group with ≥9.6 % had significantly lower follow-up at 12 m (p=0.004)
Byrne, 2012, UK, pre/post [51]	437, NA, 18 months, N, predictors of QOL outcomes, PAID	41 years, 46, T1DM=100 %, 15.9 (10.8)	PAID ≥33=166/423 PAID <32=257/423	8.3 (1.4)	DAFNE programme (see McIntyre [73])	PAID=21.5 (17.92) participants with higher HbA1c, and anxiety scores at baseline exhibited the greatest reduction in PAID score. There are no differences between groups on any measure
Due-Christensen, 2012, Denmark, pre/post [57]	54, NA, 12 months, Y, diabetes-related distress, PAID	44 years, 20, T1DM=100 %, 21 (11.7)	37.36 (16.16) ≥40: 29	8.2 (1.3)	Empowerment theory-based, 8×2-h and 15-min group sessions over 3–4 months, peer-directed themes, e.g. fear of complications, role of the social network, acceptance of diabetes Motivational strategies, homework sheets to enhance reflection, goal setting and problem-solving Delivered by MDT	PAID reduced from 37.36 (16.16) to 27.92 (17.88) (p≤0.001; Cohen's D=0.55) Participation in group support leads to reduced diabetes-related distress in participants with good and poor glycaemic control. Glycaemic control did not improve at any time point
Hopkins, 2012, UK, pre/post [72]	639, NA, 12 months, N, impact in routine practice, PAID	42 years, NR, T1DM=100 %, 18.0 (12.1)	25.2 (17.4)	8.51 (1.41)	DAFNE programme (see McIntyre [73])	PAID reduced from 25.2 (17.4) to 16.7 (14.1) (p<0.001) DAFNE reduces diabetes-related distress, improves well-being, reduces hypoglycaemic rates and restores hypoglycaemia awareness HbA1c fell by 0.27 % (p<0.001)

Table 1 (continued)

Reference, year, country, methodology	Recruited, I/C group size, length of follow-up, intention-to-treat (Y/N), primary outcome, diabetes distress measure	Mean age, male%, T1DM%, diabetes duration (years)	Baseline diabetes distress (I/C)	Baseline HbA1c (I/C)	Intervention description Speciality of therapist *Control group*	Outcomes
Esbitt, 2014, American, pre/post [79]	11, NA, 3 months, N, feasibility of group CBT, DDS	40 years, 50, T1DM=100 %, 22.38 years (11.69)	3.19 (0.97)	8.56 (1.04)	Theory-based CBT, group-based intervention for depression and adherence; 10× 60–90-min sessions over 10 weeks: self-management, depression and diabetes-related distress in an integrative manner including problem-solving, goal setting, motivational consultation, education, written materials and self-management education Delivered by a diabetes psychologist	DDS: pre=3.19 (0.97), post=2.82 (0.98) (Cohen's d=0.34) Participation in a group CBT was acceptable, associated with reductions in diabetes distress and depressive symptoms HbA1c mean: pre score=8.56 %, post score=8.73 % (Cohen's d=−0.08)

C control group, *CBT* cognitive behavioural therapy, *CGM* continuous glucose monitoring, *DAFNE* Dose Adjusted for Normal Eating, *DDS* Diabetes Distress Scale, *DSME* diabetes self-management education, *HCP* Health care professional, *I* intervention group, *MDT* multidisciplinary team, *NR* not reported, *NA* not applicable, *PAID* Problem Areas in Diabetes Scale, *QOL* quality of life, *T1DM* type 1 diabetes mellitus, *T2DM* type 2 diabetes mellitus

self-management components is utilised by focusing on experiential learning that influence behaviours, psychological adaptation and glycaemic control [56, 69, 75–77, 78•, 79, 80, 81••]. The results of these were less clear regarding significant changes in DD. Four studies showed significant reductions of DD in addition to significant reductions in HbA1c [76, 77, 80, 81••]. Zoffmann et al. showed significant reductions of both DD and HbA1c in women but not in men [78•]. In two pilot studies, Snoek et al. showed significant reductions in HbA1c and marginally significant reduction in DD (p=0.06) and Esbit et al. reported an effect size of 0.34 relating to DD but no effect on HbA1c [69, 79]. Likewise, Due-Christensen et al. reported an effect size of 0.55 relating to reduction in DD ($p\leq$ 0.001) but no change in HbA1c was seen [56]. Interventions were primarily delivered by diabetes educators. Psychologists or psychiatrists were part of the intervention in six studies [56, 69, 75, 76, 79, 81••]. The psychological intervention components were empowerment and supportive counselling, use of self-determination approaches and cognitive behaviour therapy (CBT).

Two studies tested the efficacy of devices: continuous glucose monitoring [61] and sensor-augmented pump therapy [82]. Pump initiation with three individual sessions focusing on blood glucose control reduced DD as compared to multiple daily injection (MDI) treatment [82]. DD was not affected negatively by use of continuous glucose monitoring (CGM) with either real-time or retrospective bio-feedback [61].

The most common feature of effective interventions across the 17 studies was the group format which likely taps into natural social support, social learning theory and social comparison theory enabling people to establish a sense of normalcy and acquire positive vicarious learning experiences which successfully aid in breaking isolation and feelings of loneliness in living with type 1 diabetes [83]. Groups aimed to share how participants addressed emotional or cognitive problems in relation to performing diabetes-specific behaviours and challenges in coping with the demands of diabetes. Problem-solving, goal setting, focus on motivational barriers and facilitators were also utilised. Homework sheets were used to develop person-specific knowledge of illness perception and to enhance reflection on beliefs and attitudes towards diabetes that might need to be changed or reinforced. Studies using a group format and goal setting, problem-solving, reflection, written homework, motivational focus, supportive listening, cognitive restructuring and addressing emotional challenges seem to offer greater reductions in DD and HbA1c.

The populations under study were predominantly mid-40s with diabetes duration of more than 13 years displaying levels of DD ranging from 20 to 44.4 on PAID with the majority scoring >30. The review has identified a lack of interventions targeting elevated DD, aiming at emerging adults and also older adults. As it seems DD is present throughout the

lifespan, it would be important to address this during the early years of adulthood and also in the early stages of diabetes to prevent long-standing DD. In addition, interventions targeting older adults with DD relating to a more severe disease because of complications might be beneficial.

To summarise, the management of DD in type 1 diabetes is in its infancy, in relation to both research evidence and clinical practice. DSME appears to reduce DD in type 1 diabetes. Psychologically enhanced self-management interventions reviewed were more heterogeneous than the DSME, predominantly DAFNE, studies that we have reviewed. Nonetheless, these theory-based interventions may have the potential to address elevated DD. Group-based interventions appear to have merit.

Conclusions

Summary of Evidence

This comprehensive review of the topic has identified that elevated DD is experienced by 20–30 % of people with type 1 diabetes and that there are well-validated scales for assessing DD, and whilst many intervention studies have assessed for it, few have targeted elevated DD. There is a rising imperative to clinically consider the role of elevated DD when providing routine care for type 1 diabetes populations. There is growing, albeit currently underdeveloped, evidence of a relationship between DD, self-management behaviours and glycaemic control. There is enough evidence though to warrant the further exploration of the role of elevated DD in influencing HbA1c and self-management behaviours crucial to good diabetes health such as blood glucose monitoring and insulin administration or restriction.

Controversial Issues

Cross-sectional evidence developed in type 2 diabetes is contradictory and ambiguous; investigators have found DD to be independently associated with some self-management behaviours, and to explain some, albeit not all, of the associations of depressive symptoms with these outcomes [42, 84], others have shown that it is depressive symptoms, not DD, that exhibit an independent association with self-management behaviours [40, 85]. Whilst prospective research has found self-management behaviours specifically related to diabetes, and which directly influence HbA1c (i.e. medication adherence), are influenced by DD, only depressive symptoms impact other more lifestyle-oriented behaviours including those that are recommended in diabetes [40]. This evidence is not available in type 1 diabetes.

Recommendations for Further Research

As the focus of DD research has shifted to type 1 diabetes only very recently, many important questions remain. Much of the extant research is in younger adults, for example those aged 18–35 years. Most of the research in type 1 diabetes has been done in Scandinavian countries, namely Norway and Denmark potentially limiting the generalisability of the findings. It remains unclear whether diabetes specialists are able to detect DD clinically within their routine consultations and, more so, what is the impact on detection rates when a clear care pathway for elevated DD exists? Diabetes population screening, using the available validated tools, is not appropriate in the absence of effectiveness and cost-effectiveness evidence related to caseness. Research in these areas has not yet commenced.

People with DD and without co-morbid depression may be more responsive to intervention which presents a case for research to detect and manage DD. The prevalence and natural history of DD and DD with co-morbid depression is unknown at the diabetes population level. DSME appears to reduce DD in type 1 diabetes, and many national diabetes policies recommend the routine provision of DSME. People experiencing elevated DD are likely to need greater support to achieve DSME participation, but the benefits to them may well out way the additional resource required to engage them in DSME. Research to evaluate the impact of DSME in patients with elevated DD is warranted. Evidence of one to one or ehealth/mhealth interventions, and research in older-age participants, is lacking.

Work delineating the prospective, time-varying, associations between DD and HbA1c and self-management behaviours, whilst accounting for depressive symptoms, is required in type 1 diabetes. Should these relationships be confirmed, it is critical to then establish the causal linkages between these variables; the pace of the associations; the complex interactive biological, behavioural and affective mechanisms/third variables involved; and the contextual and individual difference variables that determine these associations and their causal pathways (e.g. stage of disease, age, gender, burden of disease, presence of co-morbidities) [86••]. Once this evidence base has been established, there is a need to then develop and test interventions targeting DD, the mechanisms that underpin the association of DD and HbA1c and specific sub-groups at risk of high DD and for whom the DD/HbA1c association is particularly strong, in order to maximise outcomes in type 1 diabetes. Such studies should also elicit the mechanisms, mediators and moderators of any improvement in DD and other endpoints.

A few of these questions have been explored in type 2 diabetes, and there is a need to continue to understand the similarities and differences in the causes and consequences

of, and treatment options for, DD as they relate to type 1 and type 2 diabetes populations.

Compliance with Ethics Guidelines

Conflict of Interest Jackie Sturt, Kathryn Dennick and Kate McCarthy declare that they have no conflict of interest.

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- •• Of major importance

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