

What characterises diabetes distress and its resolution? A documentary analysis

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Objective: Cross-sectional studies show that diabetes distress (DD) is associated with HbA1c and depressive symptoms in individuals with Type 1 and Type 2 diabetes. Evidence of association with self-management behaviour is contradictory. Little qualitative evidence exists to understand the manifestation of DD. Our objective was to understand the documented experience of DD and its resolution.

Methods: A psycho-social care clinic using evidence-based approaches was developed in a hospital diabetes centre serving Type 1 and Type 2 diabetes populations. People were referred by specialist diabetes clinicians when they were 'struggling to cope' with their diabetes. Detailed clinical notes captured the origins, characteristics and process of resolution of referred patients' DD. Documentary clinical notes retrospective analysis used directed content analysis. DD was assessed by the Problem Areas in Diabetes Scale (PAID) at referral.

Results: Eighty-two people were referred and 70 people attended 202 consultations. Forty-one sets of case notes were included where people attended ≥ 2 appointments; of whom, 24 experienced elevated DD, 13 had elevated DD plus established psychological morbidity and 4 had general distress unrelated to their diabetes. Mean PAID score was 53. Individuals with DD *only* experienced mastery of their diabetes, using the psycho-social care service to increase self-care behaviours. Individuals with DD plus established psychological morbidity were unable to increase their self-care.

Conclusions: People 'struggling to cope' are most likely to be experiencing elevated DD *only*. People with DD *only* were able to resolve this through access to clinic-run psycho-social care.

Practice Implications: Health professionals should routinely assess for coping and distress in their care planning. Psycho-social care pathways are important for people with elevated DD.

Key words: Diabetes distress, psychological morbidity, self-management behaviours, documentary analysis

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Introduction

The prevalence of psychological morbidity in people living with diabetes is rising across age groups, Type 1 and Type 2 and those with complications.¹ Forty-one per cent report poor psychological health.² Research has focused on co-morbid depression and, to a lesser extent, co-morbid anxiety.^{1,3–5} Major depressive disorder and depressive symptoms both negatively impact self-care concordant behaviours^{6–8} with only the latter adversely impacting glycaemic control.^{8,9} Diabetes distress (DD) has recently gained prominence in the literature and the evidence suggests that only DD, not depression, exhibits an independent, bidirectional association with glycaemic control in which variations in DD correspond with changes in HbA1c over time.¹⁰

The evidence base relating to self-care concordant behaviours is less well developed and more ambiguous. Cross-sectional analyses have shown DD to be independently associated with these behaviours explaining some of the associations depressive symptoms shares with them,^{8,9} whilst others indicate that depression, not DD,

uniquely impacts them.^{11,12} Emerging prospective evidence suggests a complicated picture in which depression largely impacts self-care concordant behaviours, yet DD is still uniquely associated with some of these behaviours.¹² These authors do agree, however, that measurement issues have been complicating our understanding of major depressive disorder, depressive symptoms and DD and their relationship with important diabetes outcomes.^{9,13} Whilst cross-sectional^{8–12} evidence surrounding DD and its associations with depression, glycaemic control and self-care behaviours is reported, there is limited published evidence of the patient experience of DD and how elevated DD impacts on daily diabetes management.

In view of the size of the emotional burden in diabetes and the dearth of dedicated psychological services in diabetes clinics, a psycho-social care service employing person-centred counselling^{14,15} and motivational interviewing^{16,17} techniques was implemented in a hospital diabetes clinic for people identified by clinicians as 'struggling to cope' with their diabetes. We conjectured that

people 'struggling to cope' would be experiencing elevated DD. The delivery of this clinical service between May 2010 and November 2011 resulted in a collection of case notes documenting the patients' experience of DD, its natural history and its resolution. This paper reports on a documentary, qualitative analysis of these case notes to address the research question 'How do people experience DD, what are the factors associated with its elevation and how is it resolved?'

Methods

Data set description

Detailed clinical notes were written following each psycho-social care consultation by the health professional delivering the service who is also one of the authors (JS). These clinical notes were treated as documentary evidence which detailed the origins, experience and impact of the person's emotional struggles with diabetes and, over the duration of the person's engagement with the service, any resolutions to these struggles. All referred people completed the Problem Areas in Diabetes Scale (PAID), a validated 20-item measure of DD,¹⁹⁻²² prior to the first appointment to assess their eligibility for the service, the extent of their distress and which aspects of their diabetes were presenting the greatest struggles.

Research governance

Permission was granted by the UHCW NHS Trust R&D department for the use of clinical notes as data for the purpose of retrospective case note analysis. A service user worked with us to provide patient and public involvement. All consultation notes were anonymised by an NHS Trust Research Nurse from the diabetes clinical team prior to analysis. Analysis was undertaken on Trust premises by one of the authors (KM), a clinical academic at the UHCW Trust.

Analysis methods

Clinical notes were treated as documents and directed content analysis methods²³ were employed. The clinical notes were read in their entirety by a researcher not involved in the clinical service delivery (KM) and from

this overview, an analysis framework was developed.^{23,28} Four sets of clinical notes were independently analysed by two health science researchers and our public and patient involvement collaborator to establish inter-rater reliability. Because we were interested in temporal data, clinical notes were included if the person had a recorded attendance at two or more consultations with the psycho-social care service. The analysis framework initially included the DD items identified by the PAID^{18,19} and the closely related Diabetes Distress Scale (DDS)²⁴ which has sub-scales of emotional burden, regimen-related distress, diabetes-related interpersonal distress and physician-related distress. These four sub-scale domains have reliability, validity and have been employed in research.^{25,26} Informed by the literature^{1,2,4} and our initial review of the clinical notes, we expected to find other psychological co-morbidities reported by people and so our framework also included: general distress (not directly related to diabetes) and established psychological morbidity. The initial goal of the analysis was to identify, and categorise, all documented experiences of DD, general distress and established psychological morbidity. These categories are defined in detail in Table 1. Viewing the clinical notes as living purposeful documents²⁷ enabled a theory generating approach to analysis described first by Glaser and Strauss in relation to documentary research (p. 67) during their development of grounded theory.²⁸

Once cases (people) had been allocated to one or more of these descriptor categories, analysis of the case notes identified the characteristics of the emotional burden experienced according to the domains of DD²⁴ and person-level activation, intentional and/or actual, over the course of the person's engagement with the psycho-social care service. Intentions, behaviours and functioning were also recorded, by case and chronologically.

Results

Case note population characteristics

Clinic case notes recorded that 82 people had been referred to the psycho-social care service; of which, 70

Table 1 Category descriptors.

Descriptor	Categorisation method
Established psychological morbidity	The categorisation of established psychological morbidity was founded on the clinician's documented identification of previously diagnosed clinical depression or detection/diagnosis of depressive illness in the medical records. Where no depression-related illness was documented, key case note phrases included depression, suicide, poor sleep, crying, anxiety and discussion of antidepressant medication was taken as indicating depressive illness. Individual words were not used in isolation to categorise established psychological morbidity but in the context of the individual's wider case note documentation
Diabetes distress	The categorisation of DD was founded on their PAID score ≥ 40 and the service users' identification of specific issues, directly resulting from their diabetes, which was causing them distress. Key issues included isolation, lack of support, loss of diabetes control, fear of hypoglycaemia, fear of future diabetes complications, neuropathic pain, and diabetes associated work and financial worries
General distress	The categorisation of general distress was founded on the person's identification of a specific issue, not directly related to their diabetes, which was resulting in a distressed state. These included dysfunctional family relationships, history of sexual abuse, loss of autonomy and bereavement

Table 2 Case note population characteristics.

	Included in case note analysis (n = 63)	Excluded from case note analysis (n = 7)	Single attenders (n = 22)	Attended 2+ appointments (n = 41)		
				DD (n = 24)	DD and established psychological morbidity (n = 13)	General distress (n = 4)
Type 1 diabetes ^a	23	4	9	8	5	1
Type 2 diabetes ^a	31	2	8	14	6	3
Single attenders	22	N/A	22	12	3	7
PAID at 1st consultation ^b : mean (range)	53 (6–99)	45 (25–66)	33 (13–72)	54 (15–99)	80 (49–99)	44 (13–74)
PAID \geq 40 = % ^b	69%	60%	40%	78%	100%	50%
Taking insulin ^c	47 (75%)	5 (71%)	14 (64%)	18 (75%)	10 (77%)	4 (100%)

^aDiabetes type missing data n = 9.

^bMissing data PAID score n = 11.

^cMissing data insulin n = 8.

attended at least one appointment resulting in 202 individual consultations. Seven sets of case notes were excluded from analysis because the person either did not have diabetes or they reported that their diabetes management was not impacted by their current concerns. The average number of appointments attended was three (range 1–8). The participants' were aged 17–91 (mean 49 years). Case notes of 41 people who attended two or more consultations were included. Twenty sets of individual case notes recorded attendance of more than four appointments. Using the category descriptors mentioned in Table 1, 24 cases were identified as experiencing DD *only*, 13 DD + established psychological morbidity and four general distress. Table 2 presents the population characteristics.

Characteristics of the emotional burden of living with diabetes

Table 3 illustrates where the characteristics of the emotional burden experienced according to the domains of DD converged (in bold) or diverged in accordance with the presence or absence of additional established psychological morbidity. All domains of DD are represented as concerns for those with both DD and DD+ established psychological morbidity. Physician-related concerns appear to contribute less where people also have established psychological morbidity. The clinical note analysis indicating elevated DD is confirmed by the PAID scores detailed in Table 2. Single attendees had sub-threshold DD and those with DD+ established psychological morbidity, the highest levels. The experience of DD and DD+ established psychological morbidity was proportionally represented in people with Type 1 and Type 2 diabetes and the common factor may be that the majority of people were being treated with insulin.

General distress encapsulated the experience of four participants, indicating that their distress was not associated with their diabetes although still affecting their self-management. This group will not be discussed further in this paper.

Response to intervention

The case notes record that the struggle to cope with diabetes was expressed by both groups experiencing DD with and without established psychological morbidity although the origins, experience and impact of this struggle exhibited subtle difference as early as appointment 2. An example is presented in Table 4 where two individuals expressed their DD similarly in appointment 1, by appointment 2 a difference is observed in how the individuals progress. All 24 people with DD *only* demonstrated mastery of diabetes self-management as documented in the clinical notes. Conversely, those individuals with DD + established psychological morbidity, 11 of the 13 individuals made no changes in their diabetes-related behaviours. Those with DD *only* found motivation and were able to re-engage with their diabetes self-management.

The case notes identify that as psycho-social care appointments continued, the impact on the two groups experiencing DD *only* or DD + established psychological morbidity became increasingly diverse. This was evidenced by differences in the content and progression of the consultations. Individuals with DD *only* were able to identify specific issues, explore ways to make changes, verbalise motivation and intentions, and subsequently follow them through. By the third appointment the consultations were having little behavioural impact on individuals with DD + established psychological morbidity. They were unable to engage with their expressed intentions. A number of these individuals were referred to more appropriate agencies for support, assessment and treatment (n = 8). Others declined further appointments or failed to attend as planned (n = 5). In contrast, for 12 (50 per cent) with DD *only*, by the third appointment they were able to address their DD, regain some mastery of their diabetes and consequently no longer required the focus offered by the psycho-social consultations.

Changes observed in people with DD *only*

Successful mastery appeared to enhance self-efficacy and individuals were able to build on their success and move

Table 3 Character of the emotional burden.

	DD (n = 24)	DD plus established psychological morbidity (n = 13)
Emotional burden	Obesity > reduced mobility/exercise > weight gain Neuropathic pain Fear of complications Fear of hypoglycaemia Poor sleep Loss of medication/diet control Loss of routine Not prioritising diabetes/hiding diabetes Sleep apnoea > refused surgery Comfort eating/grazing/cravings Work sickness levels distress Self-blame Poor concentration	Obesity Neuropathic pain Fear of complications Fear of hypoglycaemia Poor sleep Suicidal/crying/anxiety History of depression/psychotic episodes Self-harm/negative thought processes Low self-worth/low confidence Binge eating/bulimia Withdrawn/mood swings Poor organisation Poor memory
Regimen-related distress	Poor blood glucose level control Poor blood glucose monitoring Medication non-concordance Diabetic Keto-acidosis Omission of doses/yo-yoing blood glucose levels Fear of insulin/guessing insulin doses Volume of medication > side effects/interactions Diet control/carb counting Not a priority	Poor blood glucose level control Poor blood glucose monitoring Medication non-concordance Diabetic Keto-acidosis Multiple appointments Avoiding appointments due to fear Failure to eat > Lucozade substitute
Diabetes-related interpersonal distress	Isolated Self-isolating/hidden diabetes Lack of support Loss of routine Work sickness/financial concerns Loss of independence Prioritising family/social function Not burdening others Forced disclosure Others poor diabetes experience	Isolated Self-isolating/hidden diabetes Lack of support Loss of routine Work sickness/financial concerns Childhood abuse Still birth Death in immediate family Dysfunctional family relationships Bullied/feels unwanted Dependent on others Disengaged from life Guilt/self-blame
Physician-related distress	Lack of confidence in GP/change of GP Prefers GP input to hospital Expectation of more hospital monitoring Poor consultation with surgeon Blames GP for condition Avoiding HCPs who 'nag' about smoking	Poor engagement with healthcare providers Change of consultant without warning

Bold indicates convergence of emotional burdens.

forward as illustrated by the people mentioned in Table 5. Case 1 indicates that the psycho-social care service may be helpful in arresting the potential elevation of DD. Case 2 typifies the therapeutic benefit for people overwhelmed by a more complex range of issues.

Discussion and conclusion

Discussion

Analysis of the documented clinical notes identified three types of emotional burden experienced by people struggling to cope with their diabetes; people with DD, people with DD plus an underlying established psychological morbidity and people with general distress unrelated to their diabetes. For people with DD, these recorded experiences mapped onto the domains of the DDS²⁴ and almost two-thirds had DD *only* related to living with diabetes. Clinical notes revealed many areas of convergence and divergence in the manifestation of DD when established psychological morbidity is, and is

Table 4 Example of early temporal differences in self-care.

Person characteristics	1st appointment	2nd appointment
Woman, aged 34, Type 1, PAID score 54: DD	Fear of complications/hypoglycaemic episodes, isolation, poor dietary control, high BG readings, avoidance of BG monitoring	Commenced BGM, discussed diabetes with husband, socialising in the evening to avoid comfort eating, contemplating exercise
Man, aged 48, Type 2, PAID score 88: DD and established psychological morbidity	Neuropathic pain/fear of complications, isolation, BG levels 20–22. Missing insulin doses	BG remains high, no BGM, run out of medication, not attending other healthcare appointments

Table 5 Documented examples of temporal changes in self-care and mastery.

Case study 1	
Case characteristics	Man, aged 58, Type 2, PAID score 32
Consultation 1 Month 1	<i>Issues:</i> Frustration with yo-yoing BG levels <i>Discussion:</i> The role of anxiety/stress in altering BG levels discussed. Identified potential over-reaction to BG level of 3 mmol/L, by taking Lucozade and 2–3 digestive biscuits <i>Goal Setting:</i> Over the next 4 weeks to take a slower, more measured response to low BG levels. Use his record book and comment on meals/activities or stress which may account for unexpected BG readings
Consultation 2 Month 2	BG levels improved and person feels things are a bit better. Only two readings of 3 mmol/L in the past month, in the mornings. Actively trying not to overreact to low BG levels. Twenty-five per cent of readings are in double figures: person suggested an increase in insulin by one unit occasionally
Consultation 3 Month 4	Fewer swings in BG levels. Now reports not over-reacting to hypos. Person feels confident and settled with his new management approach
Case study 2	
Case characteristics	Woman, aged 56, Type 2, PAID score 70
Consultation 1 Month 1	<i>Issues:</i> Family's denial of her diabetes. Feels isolated. Feels angry and concerned about her temper. Commenced on insulin 3 weeks earlier
Consultation 2 Month 2	<i>Issues:</i> Needs more information on food intake as now on insulin. Final warning at work for sickness absence <i>Discussed:</i> Diet and insulin and written information provided. The level of importance for keeping her job: 3/10. Discussed the role of the DLS: available when individuals are ready to make changes towards active role in diabetes management. Current BG levels ranging 10–20 mmol/L
Consultation 3 Month 6	Requested re-referral as ready to make changes. Has instigated walking 10–20 minutes daily: discussed walking routes and companions to achieve 30 minutes Has discussed diabetes and diet with her sister-in-law and she has helped her to develop eating plans BG levels 10–14 mmol/L and goal is to achieve 9–11 mmol/L Feels more supported by her husband Stopped working and this has reduced her stress levels
Consultation 4 Month 7	Continued support from her sister-in-law with diet BG levels 7–8 mmol/L Walking has been sporadic: discussed the importance of good footwear and how to afford them Has taken a computer course and has another planned
Consultation 5 Month 9	Everything is going well Husband is now interested and supportive of her diabetes Continued support for meal planning BG levels 6.5–8.5 mmol/L almost all of the time Walking more by getting off the bus two stops early Planning to commence a diabetes weight management group Has successfully completed another computer course

DLS: Diabetes Listener Service (the name used locally for the psycho-social care service).

not, additionally present. Only people experiencing DD *only* demonstrated increased activation of their self-care. People with DD + established psychological morbidity were unable to convert strongly desired intentions into action. For those with DD *only* who initiated more self-care behaviours successively during their contact with the psycho-social care service, we proposed a mechanism of effect related to developing self-efficacy as people (re)mastered their diabetes.

Study findings placed in context of wider literature

People attending this service were not typical of a diabetes outpatient population, they were specifically identified as 'struggling to cope' with their diabetes. Hermanns *et al.*²⁰ assessed depression, sub-clinical depression and DD in a population of 376 people attending diabetes clinics in Germany. The mean PAID score for the whole population was 30.6 (SD 18.1), for those with additional sub-clinical depression DD rose to 41.3 (SD 19.6) and for those with a diagnosis of depression it

was 50.0 (SD 17.4). Our population, with and without established psychological morbidity, scored significantly higher ranging from 54 with DD *only* to 80 with co-existing established psychological morbidity. This suggests that the referring clinicians were skilled in identifying people who were not coping with their diabetes and who were experiencing distress directly related to it.

The literature continues to debate the evidence relating to the relationship of depression and DD to glycaemic control and self-care.^{10,11,29,30} Interestingly though for a population of 234 US participants attending a diabetes education programme, every 10-point reduction in DD was found to be associated with a 0.25 per cent improvement in HbA1c.³¹ Changes in depressive symptoms were not associated with changes in HbA1c. Our analysis contributes to aspects of this conversation by demonstrating qualitative and therapeutic differences between the experiences of DD with and without coexisting established psychological morbidity, and suggesting that a psycho-social care service intervention with an apparent

ameliorating effect on DD may promote concurrent changes in self-care concordant behaviours. Individuals experiencing the highest levels of DD attended more consultations. We hypothesise that the individuals represented by these case notes recognised the source of their struggle to cope and appointment attendance was evidence of their motivation to resolve it. Those only attending one consultation had a lower, sub-threshold, PAID score and may have self-selected not to attend a subsequent appointment because either the struggle was resolved or not sufficiently elevated to be a priority for them. Almost two-thirds of people attending had distress *only* related to living with diabetes and the case notes record their progress in resolving their distress with a consequent positive affect on their diabetes-related health behaviours. This evaluation suggests that a methodologically robust psycho-social intervention targeting elevated DD *only* in people with Type 1 and Type 2 diabetes is warranted to observe the impacts on DD, self-care and glycaemic control.

Strengths and weaknesses of the study

This documentary case note analysis is the first to attempt to qualitatively characterise the nature of the DD experienced by individuals and to distinguish this from the experience of established psychological morbidity co-existing with DD. The use of early grounded theory documentary analysis approaches was helpful in generating theory from this analysis. Service user involvement validated the analytical methods and the findings. The study is limited in the retrospective nature and use of the case note document as the evidence. Audio-recording the actual consultations would have strengthened the qualitative characterisation of DD and may have resulted in different theorisation. DD scores were available at referral to the service but not at the end and other psychological burdens such as depressive symptoms or anxiety were not assessed. The lack of any diagnostic or screening psychological assessment of mood is therefore limiting and will affect certainty regarding the target population for a future well-designed study. The characterisation of underlying psychological morbidity represents our attempt to distinguish this group, without specific diagnoses, because the case note analysis found them to be different.

Conclusions

People 'struggling to cope' are most likely to be experiencing elevated DD *only*. Only those with DD *only* were able to re-master their diabetes self-management.

Practice implications

Health professionals should routinely include an assessment of coping or distress in their care planning and have psycho-social care pathways available. The PAID and the DDS are appropriate tools for assessing these states formally. Future research recommendations

include well-designed qualitative study to understand the live experiences of elevated DD and longitudinal studies of the associations, and causality, of DD with glycaemic control, self-management behaviours and depressive symptoms.

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Disclaimer statements

Contributors JS delivered the psychosocial intervention, wrote the case notes and developed the manuscript. KM developed the analysis framework, analysed the case note data and contributed to the development of the manuscript. KD contributed to developing the analysis framework, the interpretation of the findings and to the development of the manuscript. MN, SS and SK identified clinic patients who were struggling to cope with their diabetes, referred them to the psychosocial care service and contributed to the development of the manuscript.

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