Deconstructing distress: the contribution of cognitive patterns to elevated distress among people with type 2 diabetes

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Introduction

Results from the Diabetes Attitudes, Wishes and Needs (DAWN) programme clearly demonstrated evidence of suboptimal psychological well-being among many people with diabetes.[1] This concurs with patient narratives reported in previous research, which show that frustration, guilt and anger are common experiences for people with diabetes.[2–4] Research from New Zealand has that shown that 67% of people with type 2 diabetes worry about the future and the possibility of complications; 20% describe these worries as 'serious'.[5] Thus one of the most salient features of such research is the emotional burden of having diabetes.[6]

Elevated levels of diabetes-related distress may have serious consequences. Research has shown that high distress about diabetes is associated with poor diabetes self-management[7] and adverse clinical outcomes, including elevated HbA_{1c}.[8,9] Research has shown that emotional distress can compromise diabetes self-care because people are 'robbed of the energy and motivation they need to follow their treatment plan';[10] consequently, metabolic control may suffer. However, the impact of distress is not limited to behavioural and metabolic parameters.

High diabetes-related distress may present a significant compromise to quality of life. To summarise, the impacts of emotional distress about diabetes are pervasive. These can include compromised self-management behaviour, lowered metabolic control and reduced quality of life.

Efficacious interventions are premised on a good understanding of underlying causal mechanisms. At present, we do not have a good understanding of the mechanisms responsible for producing high levels of distress about diabetes; particularly the role of cognition in diabetes-related distress. We can identify *general* sources of distress (e.g. diagnosis of diabetes, onset of complications), but research has yet

Abstract

Background: While the prevalence of diabetes-related distress is now well recognised, less is known about how best we might intervene to reduce distress. Effective clinical interventions require a good understanding of the factors responsible for creating elevated distress about diabetes. At present there is a dearth of scientific information in this area.

Aims: The aim of the present study was to identify cognitive patterns that may contribute to elevated distress among people with type 2 diabetes. It was predicted that cognitive illness perceptions would explain variance in diabetes-related distress.

Participants: Research participants were randomly selected from a medical database held in Wellington, New Zealand.

Method: Data was collected via mailed questionnaire survey (n=113).

Results: It was hypothesised that cognitive illness perceptions would account for a significant proportion of the variance in diabetes-related distress. Results supported this hypothesis. Cognitive variables were found to explain approximately 34% of the variability in diabetes distress (p<0.001), when controlling for age.

Conclusions: Research findings highlight two cognitive variables that may play an important role in diabetes distress: (1) a perception that diabetes symptoms fluctuate in cycles, and (2) an expectation that diabetes will have serious life consequences. These findings identify particular cognitive patterns that could form the basis for intervention targets, and might be useful for clinicians and researchers with an interest in reducing the incidence of diabetes-related distress. Findings also highlight the need for careful discussion of diabetes complications in clinical practice.

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Key words

Self-regulation; emotional distress; diabetes

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to identify *specific* cognitive patterns that may spawn and sustain high emotional distress about diabetes. Without this detailed level of information, it is difficult to design interventions that effectively reduce distress. Leventhal's self-regulatory model[11,12] suggests that the way people see their diabetes (illness representations) can influence health behaviour; this model also proposes that cognitive patterns may contribute to psychological outcomes such as illness-related distress.

Aim of the present study

The aim of the present study was to examine the relationships between personal views about diabetes (illness representations) and distress, and to identify cognitive patterns that may underpin elevated psychological distress among people with type 2 diabetes in New Zealand. It was hypothesised that cognitive illness perceptions would explain a significant proportion of variability in diabetes-related distress.

Methods

Participants

Participants were randomly selected from a medical database held in Wellington, New Zealand. Inclusion criteria were a diagnosis of type 2 diabetes, in participants aged over 18. In total, 4857 people in the database met these inclusion criteria. A mailed questionnaire survey was the primary mode of data collection. Of the participants, 51% were male, mean age 62 (SD=9.2). The average time since diagnosis was 7.7 years. Educational status varied; one-third of participants had no secondary school qualification, 18% had a university qualification. Three-quarters of participants lived with a spouse or partner. Most (86%) respondents were of New Zealand European ethnicity; the remainder were identified as Maori (indigenous to New Zealand) (2%),

Chinese (2%), Indian (3%) or European (7%). A total of 113 completed questionnaires were returned, providing a 33% response rate. Clinical data collected by diabetes healthcare professionals was obtained from medical notes, with participants' permission. The mean HbA_{1c} among participants in this study was 7.2% (SD=1.4).

Instruments

Diabetes-specific psychological distress was measured using the Problem Areas In Diabetes scale (PAID).[13] Illness representations were measured using a diabetes-specific version of the revised Illness Perception Questionnaire (IPQ-R).[14] This contains seven sub-scales measuring cognitive illness representations. Illness *consequences* taps into the personal impact of diabetes (for example, effect on functional capacity, or compromise to quality of life); *timeline chronic* refers to the agreement that diabetes is an ongoing condition; *timeline cyclical* assesses a belief that symptoms fluctuate (come and go in cycles); *treatment control* refers to the expected efficacy of recommended medical regimens in controlling diabetes; high *personal control* suggests that individual self-care behaviour is effective in providing control of illness symptoms; *illness coherence* assesses the extent to which diabetes is understandable; diabetes *identity* is an appraisal of symptoms that are connected with diabetes. Six sub-scales showed evidence of acceptable internal reliability (Cronbach's alpha ≥0.65); one subscale showed low internal consistency (treatment control Cronbach's alpha=0.52). The PAID scale showed high internal reliability in the present study (Cronbach's alpha=0.93).

Data analysis

The Statistical Package for the Social Sciences (SPSS) PC version 11.5 was

used for all statistical analyses. Three stages of analysis were undertaken. First, data was screened for inaccurate entry, missing values and fit with the assumptions of multivariate analyses. Second, bivariate relationships between key variables were computed. Third, hierarchical regression analysis was used to investigate the relationships between study variables at the multivariate level. Alpha was set at 0.05; two-tailed tests were used for all analyses.

Ethics

Ethical approval for this study was obtained from the Massey University Human Ethics Committee, protocol number 02/140. Participation was voluntary, with no financial reward.

Results

Table 1 shows bivariate correlations between the seven IPQ-R subscales and diabetes-related emotional distress. Results show that five cognitive variables were related to differences in diabetes distress. The direction of observed relationships suggests that greater distress about diabetes shows a moderately strong positive relationship with diabetes identity, timeline cyclical and diabetes consequences. Diabetes-related distress also showed significant negative associations with treatment control and diabetes coherence.

Hierarchical multiple regression analysis was utilised to further examine the relationships between cognitive variables and distress. Multivariate analysis is recommended because this enables a greater degree of statistical control. Specifically, hierarchical regression allows for control of (1) the impact of demographic and medical characteristics, and (2) relationships *among* cognitive variables included in the regression model. As such, it represents a more stringent test of the observed bivariate relationships presented in Table 1. Only variables

Illness representation scale	PAID
Diabetes identity	0.37***
Timeline acute/chronic	0.12
Timeline cyclical	0.46***
Consequences	0.48***
Personal control	-0.08
Treatment control	-0.22*
Coherence	-0.21*
* p<0.05 ** p<0.01 *** p<0.001	

Table 1. Bivariate relationships between illness representation scales and diabetes-specific distress (n=113)

showing a significant bivariate relationship with the dependent variable (distress) were entered into the regression equation.

First, the associations between distress and four demographic/medical characteristics were considered. Diabetes distress showed no significant relationship with educational status, length of diabetes diagnosis or gender in the present study. However, a significant correlation with age was present (r=-0.26; p<0.01). Therefore age was entered at step 1 of the regression as a control variable. At step 2, five cognitive representation variables were entered into the regression equation. By examining R^2 change for each block, it is possible to observe the relative contributions of age, and cognition, to the explanation of differences in distress. Age was shown to account for 6% of variance (adjusted R^2) in distress (F[1,99]=7.44; p<0.01). The addition of five cognitive variables at step 2 resulted in a significant change in explained variance. R^2 change statistics show cognitive representations of diabetes were found to contribute an additional 34% to explained variance in this model, when controlling for age.

As shown in Table 2, age and cognitive factors together accounted for approximately 38% of the variance (adjusted R^2) in diabetes-specific emotional distress. Total adjusted R^2 at step 2 was found to be

significantly different from zero (F[6,94]=11.01; p<0.001). It is concluded that results support the study hypothesis. Cognitive patterns were found to explain a significant proportion of the variance in diabetes-related emotional distress among people with type 2 diabetes. Through examination of beta coefficients it is possible to observe the effects of individual variables on diabetes distress, while controlling for the impact of all other variables in the regression model at that point. At step 2, with all variables entered into the regression equation, three variables were significantly related to distress. Observed relationships showed lower age is associated with greater distress about diabetes (beta=-0.18, p<0.05). A strong perception that diabetes symptoms come and go in cycles (beta=0.33, p<0.001), and higher belief that diabetes has serious life consequences (beta=0.32, p<0.01), were both related to greater emotional distress about diabetes in the present study.

Discussion

It was hypothesised that cognitive illness perceptions would account for a significant proportion of the variance in diabetes-related distress. Results of the current study supported this hypothesis. As evident in Table 2, cognitive variables were found to explain approximately one-third of differences in diabetes distress, when controlling for age.

Examination of bivariate correlations shown in Table 1, and standardised beta coefficients evident in Table 2 enable identification of specific cognitive variables that may be most important in explaining differences in diabetes distress. Bivariate relationships reported in Table 1 show greater diabetes distress is associated with strong diabetes identity, a belief that diabetes has serious life consequences and a perception that diabetes symptoms come and go in a cyclical manner. Higher distress was also related to lower perceived efficacy of prescribed treatments, and a belief that diabetes was difficult to understand. Multivariate analysis using hierarchical regression was employed to examine these associations in greater detail. When controlling for the relationships among cognitive variables, it appears that cognitive patterns characterised by (1) a strong belief that diabetes has serious consequences, and (2) a perception that diabetes symptoms come and go in cycles, may contribute to elevated emotional distress about diabetes.

In summary, results from the current study demonstrate that cognitive variables are able to explain variance in diabetes distress. Findings from the present research also suggest greater emotional distress about diabetes is related to specific cognitive patterns; namely, a strong belief in serious consequences, and cyclical timeframes. Other cognitive variables may contribute to elevated distress (diabetes identity, treatment control and coherence), however multivariate results suggest their role is likely to be of subordinate importance to the impact of consequences and timeline cyclical.

Clinical implications
Results from the current study could be useful for clinicians and researchers interested in reducing emotional distress among people

with type 2 diabetes. First, results provide information on the type of people who may be most at risk for developing high diabetes distress. Among adults with type 2 diabetes, there is evidence that younger age is linked to greater distress. On average, younger adults will have less previous experience with chronic illness in comparison with older adults, as the relative risk for many common chronic diseases increases with age (for example, coronary heart disease). Because experience provides an opportunity to build up coping skills, older adults may be better able to adjust when faced with a serious health threat; it is possible that younger people may be less well-equipped, and as a result diagnosis of diabetes has a greater impact on their life. It is useful for clinicians to be aware that younger people may be at greater risk of experiencing high emotional distress about diabetes and may therefore require assistance in managing the emotional impact of living with diabetes.

The importance of perceived consequences and fluctuating symptoms was emphasised in results from the present study. A belief that diabetes has serious life consequences was linked to higher diabetes-related distress. Results imply a need for care when discussing the possible consequences of diabetes in clinical practice. Healthcare professionals may emphasise the health complications that can arise from diabetes, in an attempt to motivate active self-management behaviour. Previous diabetes literature suggests that this is perceived as a useful clinical tool.[15] While some people may benefit from a discussion that emphasises the seriousness of diabetes complications, for others this could result in a significant elevation in diabetes-related emotional distress.

Many people with diabetes will be aware of (and often frightened

Predictors	Step 1	Step 2
Control		
Age	-0.26*	-0.18*
Illness/treatment representations		
Symptoms		0.07
Timeline cyclical		0.33***
Consequences		0.32**
Treatment control		0.00
Coherence		-0.06
Multiple R	0.26**	0.64***
Total R^2	0.07	0.41
Adjusted R^2	0.06	0.38
R^2 change	0.07**	0.34***
* $p<0.05$ ** $p<0.01$ *** $p<0.001$		

Table 2 Hierarchical multiple regression of diabetes-specific distress on age and illness representations showing standardised regression coefficients R, R^2, adjusted R^2, and R^2 change (n=100)

by) the negative health consequences that can accompany diabetes. Clinical styles that strongly emphasise complications may elevate emotional distress to a level that is maladaptive. Previous psychological literature suggests that high emotional distress is related to the use of coping strategies such as denial and avoidance.[16] Diabetes research shows that the employment of denial as a coping strategy is associated with poor metabolic control.[17] Potentially, excessive emphasis of diabetes complications may overburden the systems that self-regulate emotional arousal. This is likely to have a negative impact on self-care behaviour,[16,18] and may impair metabolic control. Findings from the present study suggest that when discussing the consequences of diabetes, a carefully balanced, emotionally intelligent approach is required.

High distress about diabetes results in compromise to psychological well-being and quality of life. Evidence has also shown distress is linked to poor self-management[7] and higher HbA$_{1c}$.[8,9] There is a strong need for interventions that are shown to be effective in

decreasing distress about diabetes. Interventions that explicitly seek to moderate cognitive patterns may prove efficacious in reducing emotional distress. Results reported in the current study suggest (1) a perception that diabetes symptoms come and go in cycles, and (2) an expectation that diabetes will have serious life consequences, and may contribute to elevated levels of diabetes-related emotional distress. Thus findings from the present study identify particular cognitive patterns that could form the basis for intervention targets.

Limitations and directions for future research

The present research sought to examine cognitive variables that may underpin elevated emotional distress among people with type 2 diabetes in New Zealand. The sample size (n=113) was modest, and further research is necessary to validate reported findings. The response rate (33%) is likely to reflect the response burden of a large mailed questionnaire survey (24 pages) without follow-up. The response rate could be improved in

future studies by including follow-up of non-respondents, for example, a second mail contact reminding them of the research and re-offering the invitation to participate. Replication using a larger, cross-national sample is recommended.

Previous literature has identified a positive association between serious consequences and negative emotional outcomes among people with type 2 diabetes.[19] However, there has been limited previous discussion of a possible relationship between symptom perception and distress. Results from the present study imply that a perception that diabetes symptoms fluctuate (come and go in cycles) is related to elevated emotional distress about diabetes. This constitutes an interesting empirical finding. Further research into the relationship between symptom appraisal and diabetes distress is warranted.

Recent research has emphasised the need to consider potential *interactive* relationships between cognitive variables as determinants of diabetes outcomes.[20] In the present study, bivariate correlations provide evidence of associations among illness representation variables. Timeline cyclical showed a significant relationship with diabetes identity ($r=0.33$, $p<0.001$), treatment control ($r=-0.25$, $p<0.01$), and coherence ($r=-0.29$, $p<0.01$). Diabetes consequences also showed significant associations with diabetes identity ($r=0.59$, $p<0.001$), and treatment control ($r=-0.31$, $p<0.01$). Formal testing of interactive hypotheses is recommended in future research.

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Conflict of interest statement:

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