

Using the Common Sense Model of illness self-regulation to understand diabetes-related distress: The importance of being able to 'make sense' of diabetes

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This study examines the relationships between illness perceptions and illness-related distress among adults with type 2 diabetes. Research participants ($N = 615$) were randomly selected from a primary care database in New Zealand. Data were collected through a mailed questionnaire survey and review of medical records. The primary outcome was diabetes-related psychological distress measured using the Problem Areas in Diabetes (PAID) scale. Multiple regression analyses controlling for age, clinical characteristics, and mental health showed that illness perceptions accounted for 15% of differences in distress about diabetes (F change (4,462) = 35.37, $p < .001$). Poor mental health and illness severity alone do not explain differences in diabetes-related emotional adjustment. Results suggest that 'making sense' of diabetes may be central to successfully managing the emotional consequences of diabetes.

The emotional burden of diabetes is significant (Fisher, 2006; Matthews & Lloyd, 2005; Polonsky, et al., 2005; Rubin, 2005; Samuel-Hodge, et al., 2000; Skovlund & Peyrot, 2005) and research shows that greater emotional representation of diabetes is associated with poorer self-care (Barnes, 2000), and impaired metabolic control (Weinger & Jacobson, 2001). Co-morbid depression is also a problem for many people with diabetes. Adults with diabetes are twice as likely to be depressed than similar individuals without diabetes (Anderson, Freedland, Clouse, & Lustman, 2001); and depression is associated with poor glycaemic control (Lustman, et al., 2000). Findings from a cross national study revealed 41% of people with diabetes had poor psychological wellbeing; further, the majority of health professionals believed that psychological problems affected their patients' self-management behaviour (Peyrot, et al., 2005).

The Common Sense Model (CSM)

of illness self-regulation (Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steele, 1984) suggests that beliefs about illness have five core dimensions: cause; identity; perceived control; severity of illness consequences; and time line. Subsequent research has added further dimensions including illness coherence – a belief that the illness 'makes sense' – to this core set of illness beliefs (Moss-Morris, et al., 2002). The CSM predicts that illness perceptions (e.g., perceived control of diabetes, or severity of illness consequences) will influence emotional outcomes such as illness-related distress (Hagger & Orbell, 2003).

Previous diabetes research has demonstrated a positive relationship between the number of symptoms attributed to diabetes and poor emotional adjustment (Edgar & Skinner, 2003; Paschalides, et al., 2004) perceived consequences and depression/anxiety (Law, Kelly, Huey, & Summerbell, 2002; Skinner & Hampson, 1998); and a

negative association between perceived control and depression (Eiser, Riazi, Eiser, Hammersley, & Tooke, 2001; Paschalides, et al., 2004). However research findings are inconsistent and previous studies have been limited by small sample sizes.

The purpose of this study is to investigate the relationships between illness perceptions and diabetes-related distress among adults with type 2 diabetes in New Zealand.

METHODS

The research sample ($N = 1015$) was randomly selected from a database of primary care records for people with diabetes ($N = 4857$) held in Wellington, New Zealand. The inclusion criteria for this study were diagnosis of type 2 diabetes by a qualified physician, and age ≥ 18 years. A mailed questionnaire survey was used to collect psychological data with a response rate of 62% providing 629 completed questionnaires. Of these, 615 (98%) gave permission for clinical records pertaining to their diabetes (including current treatments and physician assessed HbA_{1c}) to be released to the researcher.

Participants

On average, length of diagnosis with diabetes was 8.1 years ($SD = 5.8$), and 13% of the respondents used insulin to treat their diabetes. Mean HbA_{1c} was 7.5% ($SD = 1.5$), with a

range from 4.5 to 13.5. The goal for people with diabetes is to achieve an HbA_{1c} below 7% (New Zealand Guidelines Group, 2003). Participants' average age was 63 years ($SD = 11.6$) and 47% were female. The ethnic composition of participants (57% New Zealand European, 30% Maori, 6.4% Pacific Island) matched closely with the proportional representation of the three main ethnic groups that comprise the New Zealand diabetes population as reported by the New Zealand Ministry of Health (PricewaterhouseCoopers, 2001). Mean score on the Short Form-12 mental component summary was 50.5 ($SD = 9.8$), and 15% of participants reported a previous diagnosis of depression by a medical professional. Chi-square tests and ANOVA showed no significant difference in gender, or length of diabetes diagnosis between respondents and non-respondents.

Instruments

A diabetes specific version of the Illness Perception Questionnaire-Revised (IPQ-R) (Moss-Morris, et al., 2002) was used to assess illness

perceptions across seven dimensions: consequences, timeline chronic, timeline cyclical, treatment control, personal control, illness coherence, and illness identity. Response options were provided on a five point rating scale: (1) strongly disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, and (5) strongly agree, with the exception of the identity subscale which measures the number of symptoms attributed to diabetes.

Higher scores on the IPQ-R consequences, timeline chronic, and timeline cyclical subscales represent a greater perception, respectively, that diabetes will have serious consequences; that diabetes is an ongoing illness; and that the symptoms of diabetes come and go. A higher score on the treatment control subscale represents a stronger belief that medical treatments will be effective in controlling diabetes. A higher score on the personal control subscale represents a stronger belief in one's ability to personally influence illness outcomes. All subscales showed acceptable internal reliability (Cronbach's Alpha $\geq .65$), with the exception of treatment control

(Cronbach's Alpha = .52).

The Problem Areas In Diabetes (PAID) scale (Welch, Weinger, Anderson, & Polonsky, 2003) was used to assess diabetes-related distress. This 20-item measure assesses emotional problems encountered among people with diabetes (e.g., feeling overwhelmed by your diabetes) with responses given on a five point rating scale: (1) not at all, (2) minor, (3) moderate, (4) somewhat serious, (5) serious. The sum of all item responses is multiplied by 1.25 to provide a final score ranging from 0 to 100 with higher scores representing greater diabetes-related distress. Cronbach's alpha for the PAID in the present study was .96.

Length of diabetes diagnosis and current treatments were extracted from medical records along with glycosylated haemoglobin (HbA_{1c}), a measure of glycaemic control in the preceding six to eight weeks. The presence of diabetes complications was assessed using a five-item self-report checklist. Four items assessed microvascular

Table 1. Means, standard deviations, and bivariate correlations among clinical, demographic, and psychological variables ($n = 615$)

Demographic and clinical variables	Mean (sd)	1	2	3	4	5	6	7	8
Age	63 (11.6)	-.06	-.13**	-.21***	-.14**	-.13**	-.10*	-.21***	-.37***
Gender (% female, number)	47 (289)	.00	-.02	.03	-.02	-.07	-.02	.09*	-.06
Body Mass Index (BMI)	31.9 (7.1)	-.10*	.13**	.10*	-.04	.11**	-.08	.10*	.18***
Length of diabetes diagnosis (years)	8.1 (5.8)	.09*	.08	.11**	-.05	-.07	.00	.01	-.06
Prescribed insulin (% Yes, number)	13 (79)	.04	.20***	.29***	-.07	.01	-.07	.21***	.12**
HbA_{1c}	7.5 (1.5)	-.08	.26***	.23***	-.09*	-.03	-.14**	.21***	.24***
Psychological Variables									
1. Timeline chronic	24.04 (3.86)								
2. Timeline cyclical	11.19 (3.37)	-.17***							
3. Consequences	18.17 (4.41)	.22***	.43***						
4. Personal control	23.96 (3.24)	.43***	-.19***	.12**					
5. Treatment control	17.98 (2.53)	-.04	-.04	-.04	.38***				
6. Coherence	18.29 (3.60)	.31***	-.42***	-.16***	.44***	.30***			
7. Identity	3.58 (3.60)	-.01	.41***	.39***	-.03	.06	-.13**		
8. Diabetes-related distress	20.57 (19.11)	-.07	.51***	.48***	-.11	-.08	-.34***	.37***	

* $p < .05$ ** $p < .01$ *** $p < .001$

complications (neuropathy, retinopathy, and nephropathy), one item assessed macrovascular complications. Responses were provided as yes or no. History of clinical depression was assessed using a single self-report item, and general mental health was assessed using the Short Form-12 mental component summary score (SF-12 MCS) (Ware, Kosinski, & Keller, 1998).

Statistical Analyses

First means, *SDs*, and Pearson's product-moment correlation coefficients between key variables were computed. Second, hierarchical linear regression analysis was used to investigate multivariate relationships. Only variables showing a significant bivariate relationship ($p < .01$) with the dependent variable were entered into the regression analysis. Demographic and clinical characteristics entered at Step 1 of the regression analysis to control for their effects were age, treatment regimen, HbA_{1c}, and self-reported microvascular complications. Mental health variables (self-reported depression, and SF-12 MCS) were entered at step 2. Illness representation variables were entered at Step 3.

RESULTS

Means and *SDs* for the main study variables, and bivariate correlations among clinical, demographic, and psychological variables can be seen in Table 1. On average the level of diabetes-related distress was low (mean score on the PAID was 20.57, *SD* 19.11) and this is in line with results reported in previous research among people with diabetes (Pouwer, et al., 2005; Snoek, Pouwer, Welch, & Polonsky, 2000).

Collectively variables in this study accounted for 51% (adjusted R^2) of the variance in diabetes-related distress $F(10,462) = 50.07, p < .001$. Results from the hierarchical linear regression analysis (Table 2) show that illness perceptions explained 15% of the variance in emotional distress (R^2 change = .15, $p < .001$) when controlling for age, clinical characteristics, and general mental health. Variables demonstrating significant standardised regression

Table 2. Hierarchical Multiple Regression of Diabetes-related Distress on Age, Clinical Characteristics, Mental Health, and Illness Perceptions Showing Standardised Regression Coefficients, R , R^2 , Adjusted R^2 and R^2 change ($n = 462$)

Predictors	Step 1	Step 2	Step 3
Demographic and Clinical Characteristics			
Age	-.35***	-.28***	-.26***
Treatment Regimen	.06	.01	-.08*
HbA _{1c}	.13**	.11**	.04
Microvascular complications	.22***	.10*	.03
Mental health			
SF-12 MCS		-.38***	-.25***
Depression		.05	.07
Illness perceptions			
Timeline cyclical			.13*
Consequences			.22***
Coherence			-.21***
Identity			.07
Multiple R	.48***	.61***	.72***
Total R^2	.23	.37	.52
Adjusted R^2	.22	.37	.51
R^2 change	.23***	.14***	.15***
* $p < .05$ ** $p < .01$ *** $p < .001$			

coefficients (β) at step 2 of the analysis include: age, treatment regimen, mental health, timeline cyclical, consequences, and coherence.

DISCUSSION

Elevated distress about diabetes is associated with a perception that diabetes has serious consequences, difficulties 'making sense' of diabetes, and a belief that diabetes symptoms come and go in cycles. These results support previous work demonstrating a relationship between greater perceived diabetes consequences and poor emotional adjustment (Law, et al., 2002; Paddison, Alpass, & Stephens, 2007; Skinner & Hampson, 1998). These results are also consistent with a systematic review suggesting that symptom perception may influence emotional responses to the diagnosis of type 2 diabetes (Thoolen, De Ridder, Bensing, Gorter, & Rutten, 2008), and concur with an

earlier pilot study showing a relationship between cyclical symptoms and distress (Paddison, et al., 2007).

Our results show that people who report that their diabetes is puzzling and difficult to make sense of are more likely to experience higher distress about diabetes. This is the first study to our knowledge showing that problems 'making sense' of diabetes might be a risk factor for illness-related distress among people with type 2 diabetes. Our findings are in line with previous research showing a positive relationship between illness coherence and quality of life in an intervention pilot study (Skinner, et al., 2006).

A perception that diabetes symptoms come and go in cycles was also associated with greater diabetes distress and further research is needed to explain why. It may be that there is an indirect relationship, whereby cyclical

symptoms that are difficult to make sense of cause distress. This suggests that illness coherence may partially mediate the relationship between cyclical symptoms and illness-related distress among adults with diabetes.

Greater perceived seriousness of diabetes has shown a significant positive relationship with HbA_{1c} in research controlling for baseline HbA_{1c} measured six months previously (Lange & Piette, 2006). In analyses controlling for HbA_{1c} in this study we found that greater perceived consequences of diabetes was associated with higher diabetes related distress. Together, these findings suggest a need for prospective research to disentangle the causal relationships between the physiological progression of type 2 diabetes (indexed by HbA_{1c}), perceived seriousness, and the emotional impact of diabetes over time.

In this study general mental health and self-reported depression together explained 14% of differences in distress about diabetes. However, illness perceptions accounted for a further 15% of differences in diabetes-related distress. It is worth noting here that mental health is an important aspect of illness-related emotional well-being, but that poor mental health alone does not explain differences in diabetes-related distress. These results suggest that the CSM constructs have an impact on illness-related distress in addition to the effects of general mental health.

We observed a negative relationship between age and diabetes-related distress, consistent with the findings from an earlier small study (Paddison, et al., 2007). Younger age may be associated with greater illness related distress because, on average, younger adults have less experience with other common chronic illnesses such as coronary heart disease in comparison with older adults. As a result, younger adults may have had less opportunity to develop coping skills that could assist them in managing the emotional consequences of a serious, ongoing health threat.

Implications for diabetes education and opportunities for intervention

Illness-related anxiety is likely to influence the formation of illness representations, particularly perceived symptoms and consequences (Cameron, 2003). Further, the Common Sense Model of illness self-regulation (Leventhal, et al., 1980; Leventhal, et al., 1984) implies that illness representations are constantly being reappraised and modified, and high emotional distress about diabetes may also influence this reappraisal process. High diabetes distress could make it difficult for people to develop accurate perceptions of diabetes. For example, directed processing strategies aimed at reducing distress may interfere with substantive cognitive processing strategies that aim to create an accurate understanding of the health threat (Cameron, 2003).

It may be important to deliver diabetes education differently for adults with high diabetes-related distress. People who are very worried about their diabetes may have more difficulty learning about diabetes, or processing and retaining information provided by health professionals (Cameron, 2003). A brief written summary of key information could be helpful. Diabetes educators and clinicians should also consider the possible negative effects on psychological well-being (and diabetes self-care) of an unmoderated emphasis on the negative consequences of diabetes, particularly for people who already have high levels of diabetes-related distress.

There is some evidence that Pacific people show greater emotional representation of diabetes (Bean, Cundy, & Petrie, 2007) and higher diabetes distress (Paddison, 2010a) in comparison with New Zealand Europeans. Diabetes educators working with Pacific peoples may need to take levels of diabetes-related distress into account when designing education programmes for this group.

Few intervention studies have explicitly focused on building a coherent understanding of diabetes, and this may be a fruitful direction for future research.

Interventions that help people to explore inconsistencies in their beliefs about diabetes, address any misunderstandings about diabetes, and enable people to feel confident that they can 'make sense' of their diabetes could help promote positive emotional adjustment to life with type 2 diabetes.

Many medical professionals recognise the effect emotional distress has on people with diabetes but, as Rubin (2005) states, "fewer providers feel able to treat these problems, and very few patients are referred for treatment" (p. 172). Greater collaboration between clinicians, psychologists, and services managers appears necessary in order to improve psychological care for people with diabetes.

Limitations and directions for future research

This study focused on adults with type 2 diabetes living in New Zealand. Examining the relationships between illness representations and emotional distress in other populations including adolescents with type 1 diabetes is recommended. The modest response rate (62%) could be improved, and our study was limited by the self-reported diagnosis of depression and diabetes complications. Prospective cohort studies are recommended in future research as the cross-sectional design of this study precludes interpretation of causal relationships. In particular, we encourage research that explores the associations between illness representations, diabetes-related distress, and glycaemic control over time.

In this study approximately half of the variance in scores on the PAID was unexplained and future research could benefit from including other psychological variables in addition to those specified in the CSM. Personality factors may have a protective impact (e.g., dispositional optimism), or increase vulnerability (e.g., neuroticism) to illness-related distress, and could moderate observed associations. For example, the relationship between perceived consequences and distress about diabetes may be stronger for those with a stable disposition towards

high negative affect. Assessment of interpersonal relationships should also be considered as family conflict over behavioural self-management choices may increase illness-related distress (Paddison, 2010b). Future research could consider examining variables (for example modification of the treatment regimen, or onset of complications) that account for *change* in diabetes-related distress over time.

ACKNOWLEDGEMENTS

Ethical approval for this study was obtained from the Massey University Human Ethics Committee (02/140). The authors gratefully acknowledge support from the Wellington Regional Diabetes Trust, Palmerston North Medical Research Foundation, and the Economic and Social Research Council (UK), and thank Professor Stephen Sutton (University of Cambridge) for his helpful comments on an earlier version of this manuscript.

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2010