THE NEW ZEALAND MEDICAL JOURNAL
Vol 117 No 1188 ISSN 1175 8716

Illness beliefs and adherence in diabetes mellitus: a comparison between Tongan and European patients

Lucy Barnes, Rona Moss-Morris and Mele Kaufusi

Abstract

Aims The aim of this study was to determine whether there are cultural differences in the way in which Tongan and European people with Type 2 diabetes conceptualise their illness and treatment. The relationships between patients' illness and treatment perceptions and their adherence to self-care regimens were also assessed.

Methods Participants completed either a Tongan or English version of a questionnaire, which included standardised measures of personal beliefs about diabetes and medication, and self-reported adherence. Information about the severity of patients' diabetes was obtained from patients' notes.

Results Comparisons of glycosylated haemoglobin levels showed that Tongan patients had significantly poorer control over their diabetes than did European patients. They were also significantly more likely than European patients to perceive their diabetes as acute and cyclical in nature, uncontrollable, and caused by factors such as God's will, pollution in the environment, and poor medical care in the past. Tongan patients perceived less necessity for medication, and exhibited higher emotional distress related to their diabetes. The beliefs that characterised the Tongan patients tended to be associated with poorer adherence to diet and medication taking.

Conclusions This study highlights the need for assessment of patients' personal and cultural beliefs about their illness. Understanding patients' perceptions may provide an avenue for improving adherence to self-care regimens.

Diabetes mellitus is a major health problem in New Zealand. There are approximately 115 000 people known to have diabetes and an estimated 40 000–60 000 undiagnosed cases.[1] The Ministry of Health predicts that diabetes rates will increase by 78% in the next ten years. Maori and Pacific Island people are particularly affected. Rates of diabetes are three times more common in these groups and are forecast to rise by 130–150% by 2011 compared with 58% in European people.[1] Diabetes-related mortality rates are also 10 times higher in Maori and Pacific Island people than in Europeans, and Pacific Island people have higher admission rates to hospital for diabetes than any other ethnic group.[1]

These dramatic statistics suggest that more needs to be done to understand diabetes-related morbidity, particularly in high-risk groups. Studies have shown that barriers such as cost, lack of knowledge, and limited access to and utilisation of healthcare all contribute to the high incidence of diabetes-related morbidity in Pacific Island people.[2–4] The increased rates of the illness itself are believed to be due in part to a shift from a traditional physical environment to an urbanised and westernised lifestyle.[5] A shift towards a diet high in protein, sugar, salt and animal fat has led to an increase in blood sugar, obesity, and cholesterol levels.[6] Clearly more needs to be done to encourage people to alter their diets. However, Pacific Island people's cultural

beliefs may play an important role here. For instance, traditional Tongan culture accepts that there is a cure for every illness and that healers and spirituality can effect cures.[7] Therefore, Tongan people may focus on spiritual aspects of treatment and on recommendations presented by traditional healers, rather than on medical advice to alter diet, exercise and take medication.

Research based on psychological theory has highlighted the importance of patients' personal beliefs about their illness and treatment in their self-management of a range of chronic illnesses.[8,9] Work by Leventhal and colleagues has shown that patients' beliefs about their illness cluster around five dimensions: (1) Identity: including the disease label and associated beliefs about the symptoms of the disease; (2) Timeline: beliefs about the course and duration of the disease; (3) Consequences: the effects of the disease; (4) Cause: the perceived cause(s) of the disease; (5) Cure/control: including beliefs about recovery from the illness or controllability of an existing condition.[8] Patients' beliefs regarding these dimensions are often different to those held by their healthcare practitioner, and unless specifically asked patients may not reveal the details of their personal beliefs. However, these beliefs have been shown to be important in understanding the ways in which patients choose to cope with their illness. For instance, research on illness beliefs and diabetes has indicated that patients who believe they have control over their illness are more likely to seek treatment and engage in healthcare behaviours.[10,11]

In addition to holding their own personal model of their illness, patients have their own ideas about the necessity of taking their prescribed medication and concerns about the possible long-term effects of medication regimens. Research on a variety of illness groups has suggested that these beliefs are strong predictors of medication adherence.[12,13]

Adherence to prescribed treatment is essential for the avoidance of complications and for quality of life in diabetes.[14,15] The management of diabetes lies predominantly in the hands of the patient. A lack of knowledge and barriers to care have been identified as key factors contributing to poor management of the disease among Pacific Island people.[2,4,16] However, little research has been conducted looking specifically at the different dimensions of these patients' illness and medication beliefs. The aim of the present study was to identify cultural differences in illness perceptions and medication beliefs among European and Tongan people with diabetes. The relationships between these beliefs and adherence to diabetes self-care regimens were also examined.

Methods

Sample Tongan and European patients with diabetes were recruited from the Auckland Diabetes Centre and affiliated satellite clinics over a six-month period. Patients were invited to participate in the study while waiting for clinic appointments. The study and its rationale were described to the subjects by the researcher or if necessary a translator or by the Tongan nurse. One hundred and ninety people were asked to participate in the study. These included 72 Tongan patients and 118 European patients. One hundred and thirteen people consented to participate and returned the questionnaire – a response rate of 59%. Patients' clinic records were then accessed to confirm that subjects fitted the inclusion criteria: patients who had Type 2 diabetes, who were of either Tongan or New Zealand European decent and who were at least 18 years of age. Seventeen of the European patients had Type 1 diabetes and 14 failed to return the consent form giving their personal details, so their information could not be accessed from the files. These patients were excluded from the analysis. The final sample included 43 Tongan patients and 39 European patients.

Measures The demographic section of the questionnaire included questions relating to age, ethnic group, unemployment due to health, financial compensation due to diabetes, duration of diabetes, hospital admissions, and feet condition. Diabetes severity was measured by gathering the most recent total glycosylated haemoglobin (HbA1c) information from clinic records. HbA1c levels were grouped according to the Gill criteria as non-diabetic range (4–5.9%), excellent control (6–6.9%), good control (7–7.9%), indifferent control (8–8.9), poor control (9–9.9%), and exceptionally poor control (>10%).[17] For the purpose of this study the participants who fell within the non-diabetic range were still classified as having diabetes as they had been diagnosed as having Type 2 diabetes and were being treated for the condition.

Illness perceptions were assessed using the Revised Illness Perceptions Questionnaire (IPQ-R),[18] which is a psychometrically sound, standard measure of patients' perceptions of their condition. In accordance with Leventhal's model,[8] the IPQ-R measures beliefs surrounding illness identity, timeline, consequences, personal and treatment control, and cause. It also measures the degree to which patients feel they have a coherent understanding of their condition (illness coherence) and their distress in relation to their illness (emotional representations). Two causal items relevant to this population group 'God's will' and 'punishment' were added in accordance with the Tongan researcher's recommendations.

The Beliefs about Medications Questionnaire (BMQ)[12] was used to measure beliefs about diabetes medication. It consists of two subscales labelled 'need' and 'concern'. The former measures patients' beliefs about the necessity for taking medication and the latter patients' concerns about the negative effects of taking medication.

Adherence to diet was measured using the dietary subscale of the Summary of Diabetes Self-Care Questionnaire (SDSCA),[19] which is a brief self-report scale of eating habits over the past week. The Medication Adherence Representation Questionnaire (MARS)[20] was used to measure adherence to diabetes medication. This scale consists of statements of adherent and non-adherent behaviour. Two items relevant to the Tongan group were added to this questionnaire, including questions pertaining to taking traditional medicines and behaviour relating to religious beliefs. The internal reliability of this modified scale measured by Cronbach Alpha was 0.79.

A Tongan translation of the questionnaire was available for those who required it, which all Tongan participants utilised. This version was translated through the Middlemore translation service.

Statistical methods Data were analysed using SPSS version 11.0. Chi-square and t tests were used to assess whether differences existed in the demographic and illness-severity data between the two groups. Differences in illness and medication perceptions and self-reported adherence across the groups were assessed utilising independent samples t tests and Mann-Whitney U tests. The data from the IPQ-R identity subscale had to be dropped from the study as most of the Tongan patients failed to fill in this part of the questionnaire. It appears that the translated version of the identity subscale was confusing for these patients.

Pearson and Spearman correlations were used to establish the relationship between illness perceptions and self-reported adherence in the patient groups. All the data met the basic assumptions necessary for parametric statistics except for the MARS scale measuring medication adherence. Consequently, non-parametric tests were used in the analysis of the MARS data.

Results

Demographic and diabetes-severity data Table 1 presents the demographic and diabetes-severity data of the two patient groups. Tongan patients had significantly higher unemployment due to their health, higher rates of hospital admissions, and higher HbA1c levels. There were no significant differences between the groups with regards to duration of diabetes, feet condition (sores or black spots on the feet), and smoking.

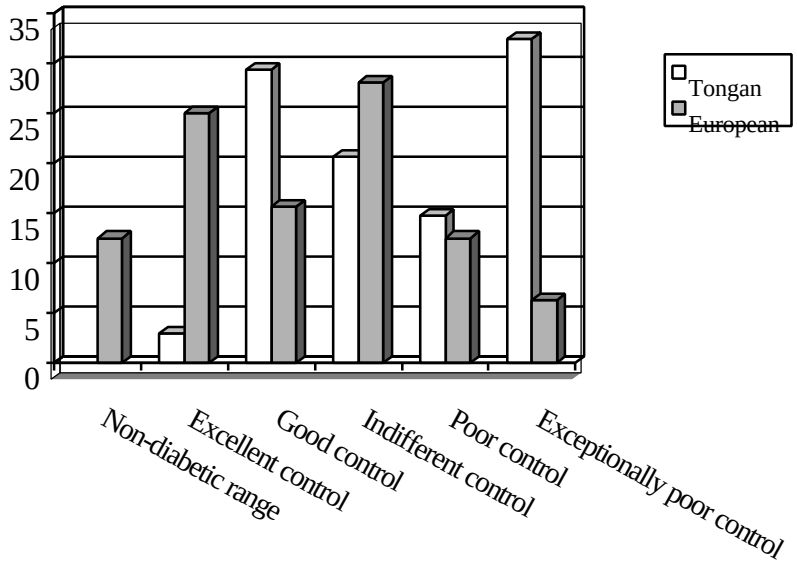
Table 1. Demographic and illness-severity features across groups

	Tongan	European	
Age, mean years (SD)	59.2 (11.2)	59.6 (12.7)	t = -0.16 p = 0.87
Duration of diabetes, mean years (SD)	8.0 (7.4)	6.3 (5.7)	t = 1.11 p = 0.27
Sores and ulcers on feet (yes)	14.0%	5.1%	χ^2 =1.81 p = 0.18
Admitted into hospital due to diabetes (yes)	59.5%	17.9%	χ^2 =15.36 p = 0.004*
Cigarette smoker (yes)	46.5%	64.1%	χ^2 = 2.56 p = 0.11
HBA1c, mean (SD)	9.2 (2.0)	7.8 (2.0)	t = 2.77 p = 0.01*
Unemployment due to health (yes)	66.7%	23.1%	χ^2 = 15.48 p =0.00†

*p <0.01; †p <0.001.

Figure 1 shows the HbA1c data across the patient groups as a function of control category. Of the European patients, 37.5% fell into the categories of non-diabetic range or excellent control compared with only 2.9% of the Tongan patients. Of the Tongan patients, 32.4% had exceptionally poor diabetes control compared with 6.3% of the European patients.

Figure 1. Percentage means for HbA1c control categories across ethnic groups (n = 66)



Group differences in illness perceptions, medication beliefs and adherence Table 2 shows the results of the t tests and Mann-Whitney U tests for the group differences

in perceptions of illness, medication beliefs, and adherence. Significant differences were found within several of the illness perception IPQ-R dimensions. With regards to timeline, Tongan patients had a more acute perception of their illness and perceived their disease to be more cyclical in nature than did European patients. Tongan patients were significantly more emotionally distressed by their illness and were less likely to believe that their treatment could control their diabetes. Three of the 19 causal items of the IPQ-R were different between the groups at the level of $p < 0.01$ and are included in Table 2. Tongan patients were more likely to believe in external causes for their diabetes including 'poor medical care in the past', 'environmental pollution', and 'God's will'. The two groups did not differ in their perceptions of the severity of the consequences of diabetes, beliefs about personal control, and perceptions of how much they understand their illness.

Table 2. Comparisons between the groups of illness perceptions, medication beliefs and adherence

	Tongan Mean (SD)	European Mean (SD)	t value
IPQ-R			
Timeline (acute/chronic)	18.8 (3.0)	21.0 (4.6)	-2.44*
Timeline (cyclical)	13.8 (3.2)	11.2 (3.4)	3.48†
Consequences	18.1 (5.5)	17.7 (4.5)	0.39
Personal control	21.9 (4.5)	22.4 (3.8)	-0.56
Treatment control	17.2 (3.7)	15.7 (2.9)	2.08*
Illness coherence	17.0 (4.2)	15.9 (4.6)	1.13
Emotional representations	20.4 (5.0)	15.7 (5.0)	4.17†
Causes (poor medical care in the past)	3.3 (1.3)	1.9 (0.8)	5.44†
Causes (environmental pollution)	2.7 (1.4)	1.9 (0.9)	2.80‡
Causes (God's will)	2.9 (1.5)	2.0 (1.2)	2.89‡
BMQ			
Need	8.4 (3.0)	14.3 (6.2)	-5.17†
Concern	16.8 (3.7)	19.0 (4.3)	-2.44*
Medication adherence§	26.9	42.3	-3.25† (Z)
Diet adherence	-1.6 (3.7)	0.8 (3.3)	-3.08‡

IPQ-R = Revised Illness Perceptions Questionnaire;[18] BMQ = Beliefs about Medications Questionnaire[12]

*$p < 0.05$; †$p < 0.001$; ‡$p < 0.01$

§data analysed using Mann-Whitney U test

With regards to beliefs about medication, Table 2 shows that Tongan patients exhibited less concern about the effects of medication (BMQ, Concern) than European patients and were less likely to see the need for medication (BMQ, Need) than the European patients. Tongan patients also reported significantly lower levels of adherence to diet recommendations and their medication regimen than did European patients.

The correlations between illness and medication beliefs and adherence are presented in Table 3. The beliefs that diabetes is a cyclical illness and that the illness was caused by poor medical care in the past were correlated with poorer adherence to diet recommendations. Adherence to medication was correlated with high scores on the BMQ Need subscale. Non-adherence to medication was associated with the beliefs

that environmental pollution, God's will and poor medical care in the past were causes of diabetes. A perception of a cyclical timeline and that the consequences of diabetes were serious were also correlated with lower medication adherence.

Table 3. Correlations between illness and medication perceptions and adherence

	Adherence to diet	Adherence to medication (r_s)
IPQ-R		
Timeline (acute/chronic)	-0.05	0.03
Timeline (cyclical)	-0.23*	-0.27*
Consequences	-0.11	-0.28*
Personal control	-0.11	0.06
Treatment control	-0.14	-0.03
Illness coherence	-0.06	0.01
Emotional representation	-0.14	-0.13
Causes (poor medical care in the past)	-0.31†	-0.29*
Causes (environmental pollution)	-0.20	-0.33†
Causes (God's will)	-0.17	-0.40‡
BMQ		
Need	0.05	0.36†
Concern	-0.07	0.14

*p <0.05, †p <0.01, ‡p <0.001

Discussion

The findings from this study suggest that perceptions of diabetes differ between the ethnic groups included in it, and that the perceptions that characterise Tongan patients tend to be associated with lower adherence to dietary and medication recommendations. Tongan patients believed their diabetes to be a more cyclical, acute illness than did European patients, who tended to view their illness as chronic. Tongan patients were also more likely to attribute their illness to external factors including the beliefs that poor medical care in the past, environmental pollution and God's will caused their diabetes. They were more emotionally distressed by their diabetes and had less confidence in the ability of their treatment to control their illness. Finally, Tongan patients saw less necessity for diabetes medication than did European patients.

Of particular significance was the finding that one third of the Tongan group had exceptionally poor control over their diabetes compared with only 6% of European patients. Tongan patients were also more likely to be hospitalised for their diabetes, to be less adherent to dietary and medication regimens, and to be unemployed because of their condition. These data highlight the importance of effective clinical interventions for these patients. Exploring patients' illness beliefs may be one way of addressing this problem. In this study, patients who saw the necessity for medications were more likely to adhere to their medication regimen. On the other hand, those who believed that their diabetes was cyclical, and caused by external factors such as pollution, God's will, and poor medical care in the past were less likely to adhere to medication and diet recommendations.

The data from this study are in accordance with previous work emphasising the importance of addressing diabetic patients' illness perceptions. In previous studies accurate beliefs about the effectiveness of treatment, the necessity for medication, and disease course have been found to be predictive of adherence.[10,12] Accurate knowledge of causal beliefs has also been shown to be predictive of both better adjustment and adherence in diabetes.[10,21,22] The finding that Tongan patients had a stronger belief in external causes is also consistent with previous research, which has shown that that Pacific Island people are strongly influenced by 'powerful others' including spirituality and family.[23] These beliefs may preclude patients from feeling a sense of personal control over their illness.

It is interesting to note that although the Tongan patients held less accurate beliefs about the causes and time course of diabetes, there was no difference between Tongan and European patients' perceptions of the degree to which they understood their condition. Perceptions of understanding were generally unrelated to adherence behaviour. This emphasises the importance of uncovering specific beliefs rather than just asking patients whether they feel they have a good knowledge or understanding of their diabetes.

Certain limitations of this study should be noted. Although the self-reported measures of adherence in this study are validated questionnaires they may not always provide accurate data.[24] There may be a retrospective bias as patients are asked to report their adherence over the last seven days. Social desirability may also influence patients' responses as they may wish to appear more adherent to the researcher. The questionnaire did, however, clearly state that the information that the patient provided would be confidential and would not be seen by staff at the clinic. Comparing data from the questionnaire translated into Tongan with the original English version may have revealed some discrepancies in the way in which questions were phrased. As mentioned earlier, the identity subscale of the IPQ-R did not appear to translate well and Tongan patients largely left this section unanswered.

Despite these limitations this is one of the first studies to provide a quantitative comparison of illness beliefs in Tongan and European patients. The data confirm that Tongan patients have less accurate medical perceptions of their condition. Some of these beliefs may be culturally determined, such as the beliefs that illness is largely acute and curable, and that spiritual factors may play a role in causing the illness itself. Asking patients about their beliefs may provide medical practitioners with an avenue to address poor adherence to self-care. Explanations can be offered that build on rather than contradict existing beliefs. For instance, it can be acknowledged that 'God's will' may be a factor in the illness, but that other aspects, such as taking appropriate medication or changing one's diet, are also important and can be addressed. Studies have shown that interventions that target patients' illness beliefs are effective in improving self-management behaviours in diabetes.[25]

This study has focused on illness and medication beliefs and how these may contribute to adherence behaviours. However, there are other factors that are likely to be important. People's expectations about their ability to engage in exercise and dietary change have also been shown to play an important role in adherence and these expectations may differ across cultural groups.[26] Future research should focus on expectations of personal competence in changing behaviours, and on social aspects that may affect adherence, such as ease of access to clinics.

Author information: Lucy Barnes, Health Psychology Intern; Rona Moss-Morris, Senior Lecturer in Health Psychology, Health Psychology, The University of Auckland; Mele Kaufusi, Diabetes Nurse Specialist, The Auckland Diabetes Centre, Auckland Hospital, Auckland

Acknowledgements: We thank the Auckland Diabetes Centre for their support of the study and the participants for taking the time to complete the questionnaire. This study was supported in part by a grant from Diabetes New Zealand.

Correspondence: Rona Moss-Morris, Health Psychology, Faculty of Medical and Health Sciences, The University of Auckland, Private Bag 92019, Auckland. Fax: (09) 373 7013; email: r.moss-morris@auckland.ac.nz

References:

1. Ministry of Health. Modelling diabetes: a summary. The Public Health Group. Wellington: New Zealand; 2002.
2. Simmons D, Weblemoe T, Voyle J, et al. Personal barriers to diabetes care: lessons from a multi-ethnic community in New Zealand. Diabet Med. 1998;15:958–64.
3. Simmons D, Voyle J. Psychological and behavioural aspects of NDDM among Pacific Islanders in South Auckland. Pacific Health Dialog. 1995;3:100–6.
4. Simmons D, Shaw L, Kenealy T, et al. Ethnic differences in diabetes knowledge and education: the South Auckland Diabetes Survey. NZ Med J. 1994;107:197–200.
5. Zimmet P, Dowse G, Finch C, et al. The epidemiology and natural history of NIDDM – lessons from the South Pacific. Diabetes Metab Rev. 1990;6:91–124.
6. Bathgate M, Alexander D, Mitikulena A, et al. The health of Pacific Islands people in New Zealand. Wellington: Public Health Commission; 1994.
7. Moata'ane L, Muimui-Heata S, Guthrie B. Tongan perceptions of diet and diabetes mellitus. J NZ Diet Assoc. 1996;50:52–6.
8. Leventhal H, Meyer D, Nerenz D. The common sense representation of illness danger. In: Rachman S, editor. Contributions to medical psychology. Oxford: Pergamon Press; 1980. p. 7–30.
9. Petrie KJ, Weinman J, Sharpe N, Buckley J. Role of patients' view of their illness in predicting return to work and functioning after myocardial infarction: longitudinal study. BMJ. 1996;312:1191–4.
10. Hampson SE, Glasgow RE, Foster, LS. Personal models of diabetes among older adults: relationship to self-management and other variables. Diabetes Educ. 1995;21:300–7.
11. Kavanagh DJ, Gooley S, Wilson PH. Prediction of adherence and control in diabetes. J Behav Med. 1993;16:509–22.
12. Horne R, Weinman J, Hankins M. The beliefs about medications questionnaire: the development of a new method for assessing the cognitive representation of medication. Psychol Health. 1999;14:1–24.
13. Horne R. Treatment perceptions and self-regulation. In: Cameron LD, Leventhal H, editors. The self-regulation of health and illness behaviour. London: Routledge; 2003. p. 138–154.
14. Cox DJ, Gonder-Frederick L. Major developments in behavioral diabetes research. J Consult Clin Psychol. 1992;60:628–38.
15. Diabetes Control and Complications Trial Research Group. The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. N Engl J Med. 1993;329:977–86.

16. Mitikulena A, Smith RB. Views of Pacific Islands people with noninsulin dependent diabetes: A Wellington survey. NZ Med J. 1996;109:467–9.

17. Gill M, editor. Diagnostic handbook: a handbook for the interpretation of laboratory tests. Auckland: Adis International; 2001.

18. Moss-Morris R, Weinman J, Petrie KJ, et al. The Revised Illness Perception Questionnaire (IPQ-R). Psychol Health. 2002;17:1–6.

19. Toobert DJ, Glasgow RE. Assessing diabetes self-management: the summary of diabetes self-care activities questionnaire. In: Bradley C, editor. Handbook of pscyhology and diabetes: a guide to psychological measurement in diabetes research and practice. Switzerland: Harwood Academic Publishers; 1994. p. 351–73.

20. Horne R, Weinman, J. Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. J Psychosom Res. 1999;47:555–67.

21. Bradley C, Lewis KS, Jennings AM, Ward JD. Scales to measure perceived control developed specifically for people with tablet-treated diabetes. Diabet Med. 1990;7:685–94.

22. Hampson SE, Glasgow RE, Toobert DJ. Personal models of diabetes and their relations to self-care activities. Health Psychol. 1990;9:632–46.

23. Simmons D. Diabetes and its complications in New Zealand: an epidemiological perspective. NZ Med J. 1996;109:245–7.

24. Johnson SB. Methodological issues in diabetes research. Measuring adherence. Diabetes Care. 1992;15:1658–67.

25. Petrie KJ, Broadbent E, Meechan G. Self-regulatory interventions for improving the management of chronic illness. In Cameron LD, Leventhal H, editors. The self-regulation of health and illness behaviour. London: Routledge; 2003. p. 257–77.

26. Williams KE, Bond MJ. The roles of self-efficacy, outcome and expectancies and social support in the self-care behaviours of diabetics. Psychol Health Med. 2002;7:127–41.

