

## Diabetes distress and related factors in South African adults with type 2 diabetes

Samantha Ramkisson<sup>a\*</sup>, Basil Joseph Pillay<sup>a</sup> and Benn Sartorius<sup>b</sup>

<sup>a</sup>Department of Behavioural Medicine, School of Nursing and Public Health, College of Health Sciences, University of KwaZulu-Natal, Durban, South Africa

<sup>b</sup>Department of Public Health Medicine, School of Nursing and Public Health, College of Health Sciences, University of KwaZulu-Natal, Durban, South Africa

\*Corresponding author, email: [samantha.ramkisson@gmail.com](mailto:samantha.ramkisson@gmail.com)

**Background:** In South Africa, the prevalence rate of diabetes is 9.27%, with an estimated 2.6 million people living with the disease. Diabetes-related distress has been described as encompassing the patient's concerns about the self-management of diabetes, perception of support, emotional burden and access to quality health care. There has been little or no research done in South Africa regarding diabetes-related distress.

**Objectives:** The aim of this paper was: (1) to identify the level of diabetes-related distress in a cohort of diabetes type 2 patients in KwaZulu-Natal and (2) to identify the factors that contribute to diabetes-related distress.

**Methods:** This cross-sectional study was conducted at two public facilities and five private medical practices on the north coast of KwaZulu-Natal, South Africa. The Diabetes Distress Scale was administered, together with a demographic questionnaire, to 401 participants.

**Results:** In total, 44% of the sample reported having moderate to high levels of distress. The mean scores of the Emotional Burden dimension ( $M = 2.6$ ;  $SD = 1.42$ ) and the Regimen Distress dimension ( $M = 2.33$ ;  $SD = 1.29$ ) suggested moderate levels of distress. Factors that significantly contributed to high levels of distress were younger age, high HbA1C levels, female gender, attending the public health sector, unemployment and being a person of colour.

**Conclusion:** Healthcare providers need to pay particular attention to the psychological needs of the patient, which impact on the medical outcomes of the disease.

**Keywords:** adults, depression, diabetes-related distress, glycaemic index, South Africa, type 2 diabetes

### Introduction

Diabetes-related distress is described as encompassing the patient's concerns about the self-management of diabetes, perception of support, emotional burden and access to quality health care.<sup>1</sup> Patients who have diabetes often feel overwhelmed and 'burned out' by the daily demands of the disease.<sup>2</sup> Rubin and Peyrot<sup>3</sup> state that distress created by problems associated with living with diabetes can cause a decrease in motivation, poor self-care, higher blood glucose levels, increased risk of complications and a poorer quality of life.

Research has suggested that the prevalence of clinical depression in patients with diabetes is almost twice that of the general population.<sup>4–6</sup> Other researchers have found that diabetes-related distress, rather than depression, is more closely linked to self-care and glycaemic control.<sup>7,8</sup> Diabetes-related distress is described as an emotional response to a demanding health condition which should not be confused with clinical depression in patients with diabetes.<sup>9</sup>

In South Africa, the prevalence of Type 2 diabetes in people aged 20–79 is 7%, with an estimate of 2.28 million people who have the condition. There are also 1.39 million people who have not yet been diagnosed.<sup>10</sup> According to Statistics South Africa,<sup>11</sup> in 2012 diabetes mellitus (DM) was the fifth leading cause of death in South Africa and the third leading cause of death in KwaZulu-Natal. Although DM is a debilitating chronic disease that has high mortality rates, there has been little or no research done in South Africa regarding diabetes-related distress. The aim of this

paper was: (1) to identify the level of diabetes-related distress in a cohort of diabetes type 2 patients in KwaZulu-Natal and (2) to identify the factors that contribute to diabetes-related distress.

### Method

The study was conducted at two public facilities and five private medical practices on the north coast of KwaZulu-Natal, South Africa.

### Participants

The total sample comprised 401 participants, 200 from the private sector and 201 from the public sector. Patients 18 years and older, diagnosed with type 2 diabetes at least six months previously, and who were able to speak either English or isiZulu, were included in the study.

### Procedures

Patients awaiting their scheduled appointments were approached by trained research staff who explained the study to them and requested voluntary participation. Patients who volunteered and met the inclusion criteria were requested to sign informed consent forms.

### Ethical considerations

The Biomedical Research Ethics Committee of the University of KwaZulu-Natal provided ethical approval for the study. The Provincial Department of Health provided consent for the study to be conducted at the public health facilities. Written permission

was sought and obtained from doctors in the private sector to conduct the research at their practices.

### Instruments

A comprehensive questionnaire, which included biographical details, was administered to participants; however, this paper focuses on the data from the Diabetes Distress Scale (DDS) developed by Polonsky *et al.*<sup>12</sup> This 17-item scale measures four dimensions: Emotional Burden (EB), Physician Distress (PD), Regimen Distress (RD) and Interpersonal Distress (ID). Patients had to rate the degree to which an item was problematic for them on a 6-point Likert scale ranging from 1 (no problem) to 6 (serious problem). A mean item score of < 2.0 indicates little or no distress, 2.0–2.9 indicates moderate distress and  $\geq 3.0$  indicates high distress.<sup>13</sup> The Cronbach's alpha reliability for the study done by Polonsky *et al.*<sup>12</sup> was 0.93 for the total 17-item scale (EB = 0.88; PD = 0.88; RD = 0.90; ID = 0.88). The Cronbach's alpha for this study was 0.93 for the total scale (EB = 0.86; PD = 0.87; RD = 0.86; ID = 0.80).

### Data analysis

STATA® version 13.0<sup>14</sup> was used to analyse the data. The following statistical tests were used when identifying factors potentially associated with distress: t-test and Wilcoxon rank-sum test for comparing means of continuous data across two groups (e.g. public vs. private sector), and the chi-square test or Fisher's exact for association between categorical variables. Bivariate and multivariable logistic regression was also employed to adjust for potential confounding covariates. An adjusted *p*-value of < 0.05 was considered statistically significant. Relative importance (attributability) of the identified factors was assessed using Shapley decomposition values.<sup>15</sup>

## Results

The demographic characteristics of the sample are given in Table 1. The mean age of the study sample was 53.70 years (SD = 10.7). The average HbA1c was 12.02% (SD = 5.00), which is higher than the generally accepted target of  $\leq 7\%$ .<sup>16</sup> There was a significantly higher mean HbA1c level in the public sector (M = 13.90, SD  $\pm$  5.50) compared with the private sector (M = 10.35, SD  $\pm$  3.80) (*p* < 0.001). This suggests that participants in the public sector had poorer metabolic control compared with the private sector. The average duration of the disease for the sample was 10.3 years (SD = 7.9; *p* = 0.390). A majority of the participants were female (243; 60.60%); 304 (75.81%) had attended high school or had a Grade 12 education and 276 (68.80%) were married. Fewer than half the participants were employed (183; 45.64%). Two-thirds of the participants were of Indian ethnicity (274; 68.33%).

The DDS mean score for the whole sample was 2.1 (SD = 1.10), which is indicative of moderate distress.<sup>13</sup> Some 44% of the sample reported having moderate to high levels of distress (DDS mean  $\geq 2$ ). The mean scores of the Emotional Burden dimension (M = 2.6; SD = 1.42) and the Regimen Distress dimension (M = 2.33; SD = 1.29) suggest moderate levels of distress.

Table 2 shows the characteristics of the proportion of participants who had moderate to high levels of distress. In terms of participant variables as shown in Table 2, there were significant gender differences, with 50% of the females reporting higher levels of distress compared with 34.81% of males (*p* = 0.003). Participants who were unemployed (60; 52.63%) had higher levels of distress compared with those who were employed (87; 47.54%) and with those who were homemakers/retired (29; 27.88%); this difference was highly statistically significant (*p* < 0.001). Compared with White

participants, high levels of distress were reported by participants from the Coloured (66.67%), the Indian (45.62%) and the Black (45.00%) groups, respectively (*p* = 0.041). Participants who were separated or divorced (62.50%), never married (56.60%) or widowed (45.83%) had significantly higher levels of distress compared with those who were married (39.49%) (*p* = 0.028). Participants in the public sector (50.25%) had significantly more distress compared with those in the private sector (37.50%) (*p* = 0.010). Those who attended high school or had a matric educational level demonstrated non-significantly higher levels of distress compared with those who had a post-matric level of education (*p* = 0.712).

After multivariable adjustment (Table 3), the following factors remained significantly associated with elevated distress levels: the Indian ethnic group (odds ratio [OR] = 2.14; 95% CI 1.22; 3.77), female gender (OR = 1.55; 95% CI 0.95; 2.54) and HbA1c (OR = 1.05; 95% CI 1.00, 1.09). Factors that contributed to lower levels of distress were increasing age (OR = 0.96; 95% CI 0.94, 0.98), being married (OR = 0.55; 95% CI 0.32, 0.95) and being employed (OR = 0.50; 95% CI 0.28, 0.88).

The decomposition/attribution analysis assigns each variable a relative contribution, the total of which sums to one (i.e. the larger fraction or percentage a variable assumes, the more important/attribution it is with regard to the outcome concerned). Based on an attribution analysis (Figure 1), age (younger) was the most important factor (38.83%), followed by being retired/homemaker (17.04%) (less distressed), female (13.13%) (more distressed), HbA1c (11.93%) (higher levels lead to more distress) and being married (7.09%) (less distressed).

**Table 1:** Demographic characteristics of the total study sample

Factor	n	%
Educational level		
Some high school or Grade 12	304	75.81
Post Grade 12	97	24.19
Employment		
Employed	183	45.64
Unemployed	114	28.43
Retired or homemaker	104	25.94
Ethnic groups		
White	24	6.00
Black	100	24.90
Coloured	3	0.75
Indian	274	68.33
Gender		
Male	158	39.40
Female	243	60.60
Marital status		
Never married	53	13.20
Married	276	68.80
Separated/divorced	24	6.00
Widowed	48	12.00
Sector		
Public	201	50.12
Private	200	49.88

**Table 2:** Characteristics of the Diabetes Distress Scale by gender, sector, marital status, educational level, ethnic group and employment

Factor	DDS n (%)	p-value*
<b>Educational level</b>		
Some high school or Grade 12	135 (44.41)	0.712
Post Grade 12	41 (42.27)	
<b>Employment</b>		
Unemployed	60 (52.63)	0.001
Employed	87 (47.54)	
Retired or homemaker	29 (27.88)	
<b>Ethnic groups</b>		
White	4 (16.67)	< 0.001
Black	45 (45.00)	
Coloured	2 (66.67)	
Indian	125 (45.62)	
<b>Gender</b>		
Male	55 (34.81)	< 0.001
Female	121 (49.79)	
<b>Marital status</b>		
Never married	30 (56.60)	< 0.001
Married	109 (39.49)	
Separated/divorced	15 (62.50)	
Widowed	22 (45.83)	
<b>Sector</b>		
Public	101 (50.25)	< 0.001
Private	75 (37.50)	

\*Pearson's chi-square test or Fisher's exact test used to compare categorical variables.

Younger age was linked to higher distress, which is consistent with other studies.<sup>12,19,20</sup> An unexpected diagnosis of diabetes at an early age and the lack of coping mechanisms in dealing with a debilitating chronic condition contribute to high distress levels.<sup>20</sup> Additional stressors are financial, family and work related.<sup>19</sup> Health care providers should therefore take cognisance of the younger patient's needs for support in terms of accepting and coping with the emotional distress accompanying the disease.

Increasing levels of HbA1c were associated with higher levels of diabetes distress, which is in keeping with the growing body of literature that supports this view.<sup>8,21,22,23</sup> Fisher *et al.*<sup>8</sup> conducted a cross-sectional and longitudinal analysis and found that distress displayed both as well as time-concordant relationships with HbA1c. They suggest a bidirectional relationship between distress and HbA1c. In some patients, high diabetes distress can negatively influence self-management and adherence to medication, with consequential effects on glycaemic control, while in other patients poor glycaemic control can lead to distress and can influence disease management.<sup>8</sup> An important goal in the management of DM is to achieve good glycaemic control to prevent complications; this emphasises the need to decrease emotional distress.

Females comprised 60% of the study sample; of these, half endorsed higher levels of distress compared with just over one-third of the male participants. Many studies have demonstrated similar findings.<sup>18,19,24,25</sup> Given that females have more gender-role responsibilities and in South Africa are often the breadwinners in the home, a chronic condition like diabetes, which requires strict self-management and medication regimes, adds to the daily demands already placed on females. These results emphasise the need for clinical services and the use of intervention strategies to cater for the needs of women. The lack of resources for women in South Africa hinders and prevents early treatment and access. Maternal health significantly impacts on the health of family and children.<sup>26</sup>

**Table 3:** Factors affecting diabetes-related distress

Characteristic	Crude (univariate)			Adjusted (multivariable)		
	OR	95% CI	p-value	OR	95% CI	p-value
Female	1.77	[1.02; 3.09]	0.041*	1.55	[0.95; 2.54]	0.081
Age	0.98	[0.96; 1.01]	0.250	0.96	[0.94; 0.98]	0.001*
Duration	0.99	[0.96; 1.03]	0.792	1.03	[1.00; 1.01]	0.037*
Married	0.47	[0.28; 0.79]	0.005*	0.55	[0.32; 0.95]	0.032*
Employed	0.64	[0.37; 1.12]	0.116	0.50	[0.28; 0.88]	0.017*
Indian ethnic group	0.65	[0.38; 1.09]	0.103	2.15	[1.22; 3.77]	0.008*
HbA1C	1.05	[1.00; 1.11]	0.041*	1.04	[1.00; 1.09]	0.062

Notes: OR = odds ratio; CI = confidence interval.

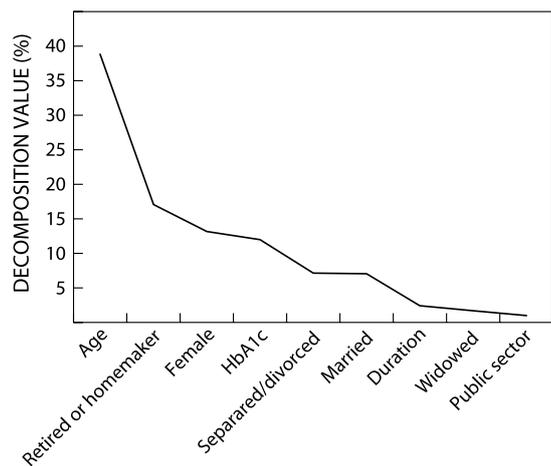
\*p < 0.05.

## Discussion

In this study, 44% of participants had moderate to high levels of diabetes-related emotional distress. Factors that significantly contributed to high levels of distress were younger age, high HbA1C levels, female gender, attending the public health sector, unemployment and being a person of colour.

Similarly, in the cross-national Diabetes Attitudes, Wishes and Needs second study (DAWN2), 44.6% of patients reported having diabetes-related distress.<sup>17</sup> Our findings are also similar to other studies which found that younger age, female gender and high HbA1c were linked to high levels of distress.<sup>18,19</sup>

Participants who attended the public health sector facilities had higher levels of distress and poorer metabolic control compared with those who attended the private facilities. The public health care sector is already overburdened and has limited resources but has to meet the demands of the majority of the population.<sup>27</sup> Due to the large demands placed on the public health care sector, patients often do not receive consistent, quality, individualised holistic care.<sup>28</sup> Often they are seen by different healthcare practitioners who manage the condition of diabetes but given their high workload do not have time to be empathic or responsive



**Figure 1:** Shapley decomposition (attributability) values for identified factors in descending order (decreasing relative importance based on the regression model).

to the patient as an individual.<sup>29</sup> However, this phenomenon is not specific to the South African context but has been reported in other countries such as the Netherlands.<sup>30</sup> In contrast to the public sector, the private sector patients are seen by a health care practitioner of their choice<sup>28</sup> and are also referred to specialists such as endocrinologists, podiatrists and ophthalmologists. The patient is therefore managed consistently by his/her health care practitioner of choice who ensures continuity of care. In a study done it was found that patients expressed the need to be informed about and involved in treatment decisions.<sup>31</sup> This further highlights the need for individualised care.

Another finding in this study is that the White ethnic group had the lowest diabetes-related distress levels. The past unjust racial practices in South Africa left all racial groups other than Whites disadvantaged in terms of their access to health care and these groups still have little access to specialised health care.<sup>28,32</sup> Barriers to health care, such as costs, time and transport, play an important role, while numerous complex social, moral, personal and situational beliefs affect adherence to treatment.<sup>26,32</sup> With the current socio-economic factors, priority is given to daily demands (e.g. providing for the family's needs), instead of placing emphasis on the strict diet and medication regimes required to manage diabetes. Furthermore, many previously disadvantaged patients do not understand that poor self-management and regime adherence result in long-term complications.<sup>27</sup>

As expected, participants who were unemployed had higher levels of diabetes-related distress than those who were employed. Interestingly, participants who were homemakers/retired had considerably lower levels of distress, possibly indicating they had fewer stressors to deal with and had more time to adhere to the strict medication and self-care regimes. In the same vein, being married was linked to low levels of distress, probably due to having spousal support. Literature supports these findings.<sup>33</sup> However, it has been found that males with diabetes have more support from their female partners.<sup>34</sup>

Contrary to other studies,<sup>35,36</sup> we did not find educational level and duration of disease to be significantly related. However, educational level is important in terms of understanding the nature of diabetes, regime adherence and self-care.

Other factors to take into consideration are general life stressors, which may not be diabetes specific but may contribute to higher levels of distress. The burden of diabetes is projected to increase in South Africa, which emphasises the urgent need to address the holistic management of the patient with diabetes and prevent other consequential medical conditions and/or minimise the complications of diabetes.

## Conclusion

In this study, participants had high levels of diabetes-related emotional distress. Factors that significantly contributed to high levels of distress were younger age, high HbA1c levels, female gender, attending the public health sector, unemployment and being a person of colour. Although diabetes-related distress impacts on medical outcomes, it is seldom taken into consideration when treating the patient. Healthcare providers need to pay greater attention to diabetes-related distress and actively address the psychological needs of patients. Addressing diabetes-related distress will assist the patient in self-management and regime adherence.

**Limitations** – The cross-sectional design limits any causal inferences. The sample sizes of the White and Coloured racial groups are too small to reach any conclusions regarding differences between racial groups in terms of diabetes distress.

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**Conflict of interest** – The authors declare that there was no conflict of interest.

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