THE IMPACT OF DIABETES DISTRESS IN YOUNG PEOPLE

Diabetes distress is an important psychosocial issue, yet little is known about how it affects those with early-onset Type 1 diabetes. A new study explores the prevalence and impact of diabetes distress in this population, who have been living with the condition for most of their lives. The findings indicate that interventions to alleviate diabetes distress should target women, young adults with lower socio-economic status and those with poorer mental and physical health.

However, little is known of the prevalence of diabetes distress among young adults with early-onset, long-duration Type 1 diabetes – those who have lived with diabetes for most of their lives. Furthermore, there have been few longitudinal studies on whether diabetes distress is prospectively related to HbA1c in adults.

A new study from Germany addresses these gaps in our knowledge about the impact of diabetes distress. Anna Stahl-Pehe from the German Diabetes Centre, Düsseldorf, carried out a nationwide population-based prospective study in adolescents and young adults with onset of Type 1 diabetes during the first five years of life.

The specific aims of the study were to:
- estimate the prevalence of diabetes distress
- determine whether diabetes distress was associated with demographic, diabetes-related and psychosocial characteristics
- examine whether diabetes distress at baseline was prospectively related to HbA1c and health status at follow-up.

**Study details**
Data for this study were drawn from two sources: (1) standardised self-
administered questionnaires from the prospective national population-based cohort study ‘Clinical Course of Type 1 Diabetes in Children, Adolescents and Young Adults with Disease Onset at Preschool Age and (2) Clinical data collected in the nationwide diabetes prospective follow-up registry. Baseline surveys were carried out in 2009 to 2010 and 2012 to 2013, and included those where onset of Type 1 diabetes was before the age of five years, during 1993 to 1999 and 2000 to 2002. Follow-up surveys were carried out three years later in 2012 to 2013 and 2015 to 2016. The final dataset consisted of three samples, as follows: 

- **sample 1a**: 208 participants with diabetes onset in 1993 to 1999 and follow-up in 2012 to 2013
- **sample 1b**: 303 participants with diabetes onset in 1993 to 1999 and follow-up in 2015 to 2016, of whom 142 participants also took part in the 2012 to 2013 survey
- **sample 2**: 73 participants with diabetes onset in 2000 to 2002 and follow-up in 2015 to 2016.

Diabetes distress was evaluated on the PAID scale, where scores range from 0 to 100, with the higher scores indicating more severe distress. A score of 40 or higher is generally considered to indicate seriously elevated diabetes distress. Health status was assessed with the 12-Item Short Form Health Survey, which ranges from 0 to 100 for physical and mental components, with higher scores indicating better health. The Patient Health Questionnaire was used to assess the level of depressive symptoms – this ranges from 0 to 27, with higher scores being a sign of more severe depression. Cross-sectional and longitudinal statistical analyses were carried out on this data.

**Prevalence and impact of diabetes distress**

There was a greater proportion of women in all three samples, mean age was 19 to 22 years and diabetes duration was between 15 and 19 years. Roughly half of participants were of intermediate socio-economic status. Mean HbA1c was 63 to 65mmol/mol and 56 to 72% of participants used an insulin pump.

The proportions of participants with diabetes distress were 13.9% in sample 1a, 12.1% in sample 1b and 16.4% in sample 2. And 6.4% in sample 1a, 6.6% in sample 1b and 5.6% in sample 2 were affected by elevated depressive symptoms. Overall, around 5% of participants were affected by both diabetes distress and elevated depressive symptoms.

Higher diabetes distress was noted among women than men. And a 1mmol/mol increase in HbA1c was associated with a 0.28 point increase in diabetes distress. Meanwhile, reduced satisfaction with treatment or care was associated with higher PAID scores. Scores were lower among those of higher socio-economic status and those with better mental and physical health. Individuals with elevated depressive symptoms scored 23 points higher on the PAID scale than those without.

However, scores on the PAID scale were not linked with age, household composition, diabetes duration, BMI, number of late diabetes-related complications, insulin pump therapy, diabetes passport use or participation in diabetes management programmes.

Longitudinal analyses showed links between the baseline PAID score in 2012 to 2013 and health status at follow-up in 2015 to 2016. Put simply, those with higher PAID scores had higher HbA1c three years on and worse health. Similar findings were reported for those with elevated depressive symptoms.

**Discussion & analysis**

Diabetes distress prevalence in these samples of 18 to 27 year-olds was lower, at 12 to 16%, than that observed earlier among older adults with later onset of the condition. The authors say that this difference is at least partly due to the early childhood onset of Type 1 diabetes. It was good to discover that diabetes distress and elevated depressive symptoms was also been previously reported. This new study confirms all these observations in a group that had not been previously investigated.

It is also one of the few to look at the longitudinal association between diabetes distress and glycaemic control in Type 1 diabetes. An earlier study, in older adults, did reveal a link between baseline diabetes distress and glycaemic control at two-year follow-up (but after adjusting for baseline Hba1c, the results were not statistically significant). Another study found that elevated diabetes distress at baseline predicts more missed insulin boluses. But, again, no significant prospective association was found between baseline diabetes distress and Hba1c.

In contrast to the findings of these two studies, this new study shows that diabetes distress is associated with Hba1c at follow-up even when adjusting for baseline Hba1c. The authors comment that this finding is surprising, as the Diabetes Distress Scale, which was used in the earlier studies, is generally thought to be more indicative of problems with diabetes self-management than is the PAID scale. They used the PAID scale as it covers more emotional concerns, stressing the importance they put on such psychosocial factors in Type 1 diabetes.

**Targeting interventions**

The researchers carried out this study to look at the impact of diabetes distress upon the course of early-onset Type 1 diabetes. It was good to discover that only one in 10 of the young adults participating was affected by serious diabetes distress. The cross-sectional analysis identified groups most at risk of diabetes distress, towards whom interventions should be specifically targeted. These are women and those with:

- lower socio-economic status
- higher Hba1c
- impaired satisfaction with their care
- worse health status
- depressive symptoms.

Simply improving the integration of diabetes care and promoting self-management could reduce some of the worries, concerns and fears associated with the condition, say the authors. They also note that higher levels of diabetes distress were associated with higher Hba1c at follow-up (a 10-unit increase...
in PAID score was linked with a 2mmol/mol increase in HbA1c). There was also a connection between higher diabetes distress and lower self-rated health status three years later. Put simply, diabetes distress has a negative impact on health. It could be worthwhile for healthcare professionals to use the PAID scale to assess diabetes distress – if they do not already do so – in order to identify those at risk of suboptimal glycaemic control and poorer outcomes at an earlier stage.

This study covered a diverse nationwide sample of young adults with Type 1 diabetes who had been living with the condition for most of their lives – a group not previously investigated in depth. Another strength was the standardised assessment of all variables using well-established psychometric tools. Cross-sectional analysis was applied to better understand the participants’ circumstances. Thus, the study was set up to identify those most at risk of developing diabetes distress. The findings could be used to inform interventions to alleviate diabetes distress and potentially improve the health and wellbeing of those living with Type 1 diabetes.


Rosanna Flury, Senior Policy Officer at Diabetes UK, says “The emotional and psychological impact of diabetes is often overlooked – through our research, people living with diabetes have told us that it is an area they would like to be considered more in their care. We know that tailored interventions can help improve both physical outcomes and mental wellbeing, and welcome research exploring these links further. We are also campaigning for diabetes care that supports emotional and mental health, to help everyone with diabetes to live well with the condition.”

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