

Psychosocial Aspects of Diabetes Study Group

Proceedings from the 8th Spring Scientific Meeting
9–11 May 2003



Editorial



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Over the past decades, psychological aspects of diabetes have been gaining interest from clinicians and researchers. This is well illustrated by an increasing body of literature on psycho-behavioural and social issues related to diabetes and its management. Nevertheless, in Europe psychosocial research in diabetes has a short history, and it was not until 1997 that the Psychosocial Aspects of Diabetes (PSAD) study group of the European Association for the Study of Diabetes (EASD) was officially established. Since then much has happened, and it makes me proud to share with you some of the findings reported at the 8th Scientific Annual Spring Meeting of the PSAD study group, held in Hvidøre, Denmark. Typically, PSAD Spring Meetings are attended by about 40 members from Europe and the USA, who present and discuss their scientific work in an atmosphere of openness and constructive criticism. Abstracts are presented orally or as posters, including both finished studies and work-in-progress.

This year's PSAD Spring Meeting chose "Lifestyle" as its core theme, and was privileged to have Dr Östenson as the keynote speaker. In this report you will find a summary of his interesting talk on stress as a risk factor for type 2 diabetes, along with other highlights in the field of European psychosocial diabetology.

Psychosocial and socioeconomic stress are risk factors for type 2 diabetes

Claes-Göran Östenson, Karolinska Institutet, Stockholm

Stress is a well known risk factor for several conditions including cardiovascular disease and depression. Recently, it has been suggested that stress may also contribute to the development of type 2 diabetes in addition to traditional risk factors such as obesity, diet, lack of exercise and low birth weight. There is good physiological basis for this suggestion – Dr Östenson highlighted that during long-term stress, increased cortisol secretion may contribute to hyperglycaemia by decreasing insulin secretion and glucose uptake while also increasing hepatic glucose production.

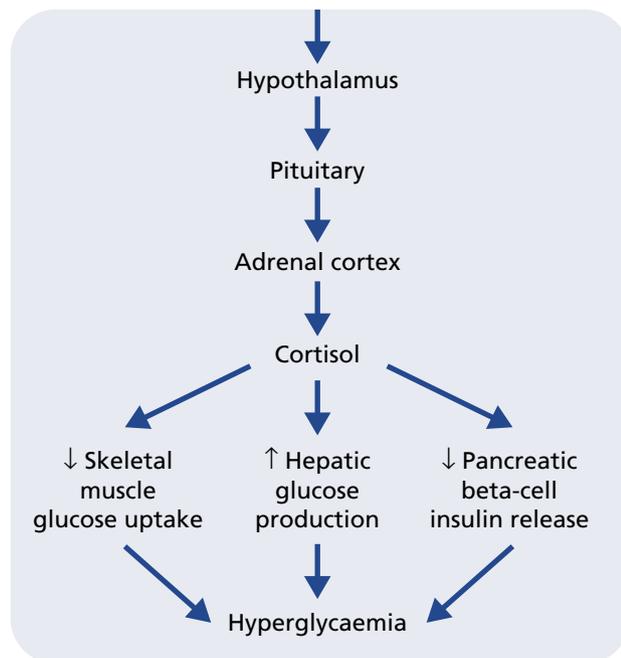
A recent study of 4821 women also suggests that stress is a risk factor for type 2 diabetes. After adjusting for traditional confounds such as smoking, family history and obesity, two measures of psychosocial stress (sense of coherence and work stress) were associated with type 2 diabetes. The relative risk of type 2 diabetes in women who felt that they had little control of or meaning in

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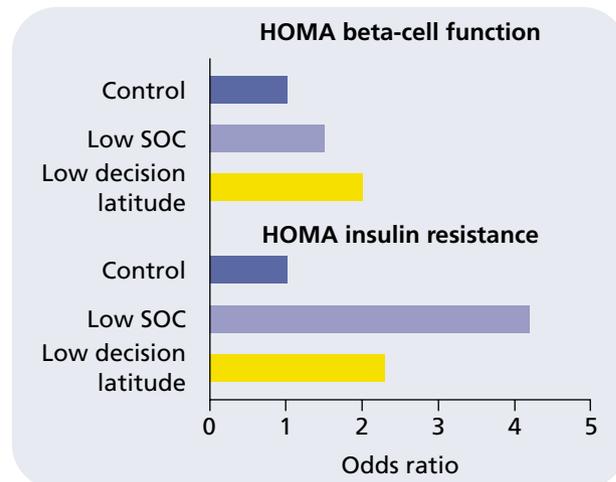
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their lives (i.e. a low sense of coherence¹) was 3.7 relative to patients with a high sense of coherence. Similarly, in women with high degrees of work-related stress (according to Karasek and Theorell's demand-decision latitude model²), the relative risk of type 2 diabetes was 2.2. Physiologically, low sense of coherence and high work stress were associated with insulin resistance and decreased beta-cell function in this patient group. Other psychosocial risk factors have also been implicated as risk factors for type 2 diabetes including death of a partner (OR = 1.9) and moving house (OR = 1.6)³.

Low sense of coherence and high work stress are associated with type 2 diabetes



During long-term stress, cortisol contributes to hyperglycaemia via a number of different mechanisms



In women, psychosocial factors such as low sense of coherence (SOC) and high work stress (as indicated by low decision latitude) are associated with insulin resistance and beta-cell function. HOMA = homeostasis model of assessment

Dr Östenson continued that socioeconomic status can itself be a risk factor for type 2 diabetes. In both men and women, type 2 diabetes is increased in the low and middle socioeconomic strata. In women, this increased risk is better accounted for by psychosocial factors such as low sense of coherence and high work stress than traditional risk factors. Interestingly however, in men of low socioeconomic status, psychosocial factors do not appear to be associated

The Psychosocial Aspects of Diabetes (PSAD) study group is an official study group of the European Association for the Study of Diabetes (EASD). For further information on PSAD, visit www.emgo.nl/psad

The Spring Meeting 2003 was made possible by an educational grant from Novo Nordisk as part of the DAWN programme.



with type 2 diabetes; instead, traditional risk factors such as obesity, smoking and lack of exercise appear to play a greater role.

With the incidence of type 2 diabetes continuing to grow at an alarming rate, it is becoming increasingly

important to understand the factors that influence its onset and progression. Dr Östenson concluded by suggesting that the reduction of psychosocial stress or circulating cortisol may be valid targets for the prevention of type 2 diabetes, particularly in women at risk of the disease.

Is the assessment of psychological health empowerment realistic?

Mirjana Pibernik-Okanovic, Vuk Vrhovac University Clinic, Croatia

The attention paid to empowerment as a factor important for the effective management of several chronic conditions has increased dramatically over the last decade. Dr Pibernik-Okanovic highlighted that research has focused on whether all patients benefit from increased empowerment, to what degree physicians encourage it and the psychological and social factors that affect its development. Despite this research, there is a discrepancy between theoretical support for empowerment and evidence of its clinical benefit. Additionally, there is little consensus over the exact definition of empowerment or how it should be assessed. Recently, Menon published a detailed definition of empowerment that may improve our understanding of this psychological state⁴. Three key aspects were defined: perceived control, perceived competence and goal internalisation.

To address the degree of empowerment felt by individuals with diabetes, Dr Pibernik-Okanovic presented the initial findings from a recent study in which 85 patients completed a questionnaire assessing the aspects of empowerment outlined by Menon. In general, patients felt highly empowered,

demonstrating low scores on only a few factors including insufficient finances to cover the cost of care and lack of time. Do these results mean that patients with diabetes feel completely in control of their own treatment? Dr Pibernik-Okanovic suggested that this is unlikely as the findings were not consistent with group therapy with the same patients. Instead, it seemed more probable that the assessment protocol required adaptation; an interview-based study design may be more appropriate for measuring empowerment. Despite these preliminary results, empowerment is likely to be an important factor in the successful treatment of diabetes because patients play such an important role in their own therapy. The continued study of empowerment in clinical settings should improve our understanding of this concept, facilitating better management, individualised patient care and highlighting patient education needs.

Empowerment is important in successful diabetes treatment because patients play such a significant role in therapy

Patient education programmes can improve hypoglycaemia awareness

Thomas Kubiak, Diabetes Zentrum Mergentheim, Germany

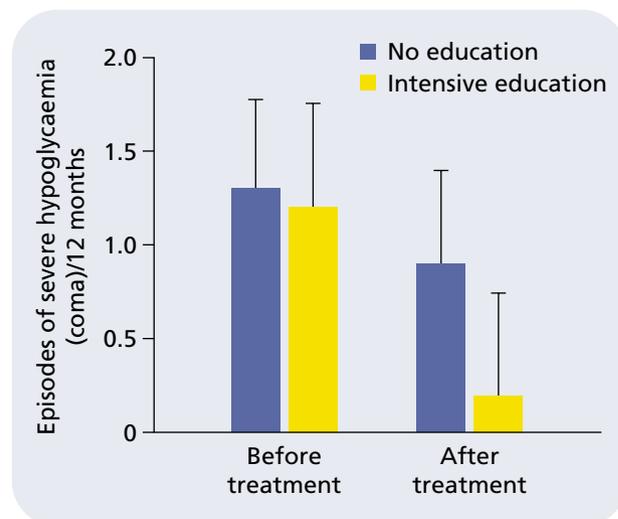
Over 40% of patients with type 1 diabetes are typically unaware of hypoglycaemia symptoms according to the findings of the Diabetes Centre Mergentheim survey 1999. However, as Dr Kubiak continued, it is possible for hypoglycaemia awareness to be improved through the use of training programmes. In a study of inpatients with type 1 diabetes, an educational programme reduced the number of patients with problems relating to hypoglycaemia from 42 to 22% ($p < 0.05$); in the control group, who did not receive intensive education, the percentage of patients with these problems remained stable (42 to 49%)⁵. Episodes of severe hypoglycaemia were also reduced in patients enrolled in the educational programme despite unaltered HbA_{1c}.

The educational programme reduced the number of patients with hypoglycaemia-related problems from 42 to 22%

Owing to the success of this inpatient training scheme, Dr Kubiak and his colleagues are evaluating an educational programme for use in outpatient care. This ongoing, 6-month, controlled study will involve approximately 200 patients with either type 1 or type 2 diabetes treated with multiple daily insulin injections or CSII and with a history of severe hypoglycaemia; patients at high risk of hypoglycaemia such as those with

self-reported impaired hypoglycaemia awareness and low HbA_{1c} (< 6.5%) will also be included. Patients will receive either a six-lesson training programme covering topics including optimum target HbA_{1c}, causes of unawareness, strategies to avoid hypoglycaemia and individual goals, or a two-lesson programme providing information on diet (control group). Mild, detected and undetected hypoglycaemic events will be assessed along with the incidence of severe hypoglycaemia. Data will also be collected concerning HbA_{1c}, self-reported hypoglycaemia awareness, hypoglycaemia-related knowledge and perceived control.

The results, expected in the next few years, will provide additional insight into the optimal



Episodes of severe hypoglycaemia were reduced in inpatients receiving education on hypoglycaemia awareness



management of insulin treatment in patients with diabetes. The study hopes to establish whether impaired awareness of hypoglycaemia can be reversed before it results in frequent episodes of

severe hypoglycaemia and whether patients with type 1 diabetes differ from those with type 2 diabetes in terms of hypoglycaemia awareness and its management.

Poster session

The poster session, held in the afternoon of the first day, presented an additional opportunity to discuss the latest findings of studies investigating psychosocial aspects of diabetes. Four posters explored the effects of diagnosis and factors influencing the overall well-being of diabetes patients. Two further posters examined aspects of diabetes care in Russian populations.

Using the 12-Item Well-Being Questionnaire (W-BQ12) and the Medical Outcomes Study Short Form 36 (SF-36), Adriaanse *et al.* from The Netherlands showed that emotional well-being and perceived health status during the first year after diagnosis were similar between patients with type 2 diabetes diagnosed in general practice and screening-detected patients.

Combining psychosocial support and medical care can improve glycaemic outcome in poorly controlled patients

The benefit of a holistic approach to diabetes treatment was illustrated in a case history presented by Ravnik-Oblak *et al.* from Slovenia. Citing the case of a 42-year-old man with long-standing type 1 diabetes in poor glycaemic control and suffering from anxiety and depression, they reported that with the combined help of a clinical psychologist, psychiatrist and diabetologist the patient was able to regain control of his life and his diabetes. This study therefore supports the DAWN recommendations that

combining psychosocial support and appropriate medical care may improve outcome.

Zoffman *et al.* from Denmark showed that patients with long-standing, poorly regulated type 1 diabetes benefited from training in Guided Self-determination (GS). GS can enable patients to change health-related behaviour on the basis of self-determined decisions. Following GS training, patients reported significant improvements in their situation, especially regarding support from health professionals. Reduced diabetes-related problems in daily life (assessed by PAID) and a significant improvement in HbA_{1c} were also reported.

A study by Johansson (UK) showed that more than 60% of diabetes healthcare providers report moderate to high emotional exhaustion. Emotional exhaustion was highly correlated with job frustration and organisational factors, suggesting that these factors should be considered in future policy-making and structuring of staff in diabetes clinics.

The Russian diabetes population was the subject of two studies. The first study examined the validity of the Russian-Audit of Diabetes-Dependent Quality of Life (Ru-ADDQoL), a questionnaire developed by Bradley (UK) and adapted for use in Russian-speaking adults with diabetes (Starostina & Shavrikova), showing it to be a valuable psychometric tool. In a second study, dietary barriers were shown to be highly prevalent in Russian patients with type 2 diabetes, irrespective of their current therapy (Starostina). These may negatively influence both self-care behaviours and glycaemic control.

European differences in physician and patient attitudes suggest that education and psychosocial support may facilitate the timely initiation of insulin

Mark Peyrot, Loyola College & Johns Hopkins University, USA

Søren E. Skovlund, Head of the DAWN programme, Novo Nordisk

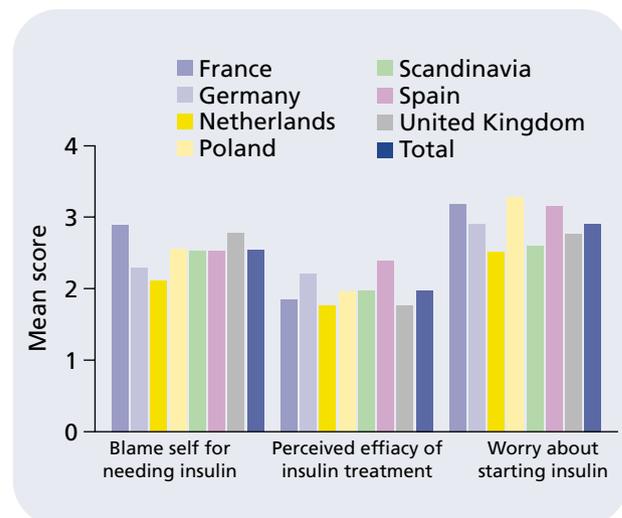
The DAWN survey showed that negative perceptions of insulin therapy among both patients and healthcare professionals may prevent the timely initiation of insulin therapy in type 2 diabetes. Dr Peyrot reported that 42% of physicians interviewed indicated that they delayed insulin until it was absolutely necessary. Physicians in all of the European countries involved in the study believed that more than half of their patients worried about starting insulin. They also believed that less than half considered themselves to blame for requiring insulin treatment.

Dr Peyrot highlighted that the biggest predictor of whether a physician would delay insulin was their attitude to treatment in general; if they delayed oral blood glucose-lowering agents, they were also likely to delay insulin. In contrast, perceiving that insulin was effective increased the likelihood of its initiation. Overall, specialists, opinion leaders, and younger physicians were less likely to delay insulin initiation.

42% of physicians delayed insulin until it was absolutely necessary

The perceptions of patients questioned in the DAWN study were generally consistent with the physician findings. However, Søren Skovlund reported that the number of patients who feel they are to blame for

requiring insulin is greater than physicians estimate. In general, 48% of patients not yet on insulin believed that starting insulin would imply their failure to follow treatment protocols. Furthermore, the majority of patients were very worried about starting insulin. Despite some country differences in the perception of insulin, negative attitudes were typically more common than positive ones among patients not yet using insulin. Patients from Germany and Spain had the most positive perception of the efficacy of insulin; interestingly, it was also these two countries in which physicians engaged in the most



Patients' perceptions of the reason for insulin initiation and their attitudes to insulin and diabetes in general differ from country to country. Higher score = greater belief

DAWN: a global initiative to improve psychosocial support for people with diabetes

The DAWN programme began with the DAWN study in 2001. It was the largest global survey of the psychosocial aspects of diabetes care and self-management, involving more than 5000 people with diabetes and 3800 healthcare professionals in 13 countries.

The DAWN survey produced a wealth of information about the wishes and needs of people with diabetes and their healthcare professionals. The results were used to identify critical gaps in the healthcare support for people with diabetes. The key finding is that increased focus must be placed on psychological issues to improve treatment outcomes in diabetes.

Today, the DAWN programme aims to translate the many findings from the DAWN survey into concrete

actions that will improve the lives of people with diabetes. It does so by facilitating dialogue between all stakeholders in diabetes and by promoting concrete initiatives that help overcome the psychosocial barriers to effective self-management and good quality of life.

The DAWN programme is a global Novo Nordisk initiative in collaboration with the International Diabetes Federation and an expert advisory panel.

For more information on the DAWN programme visit: www.dawnstudy.com

dawn
Diabetes Attitudes, Wishes and Needs



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patient education. In patients, diabetes-related stress and self-blame were the strongest predictors of worry over insulin initiation. These two factors appeared to be the mediating variables for several other predictors such as diet and appointment adherence.

48% of patients not on insulin felt they would be to blame for requiring insulin

The results from the European arm of the DAWN study indicate that patients in Europe are more

worried about starting insulin than physicians may realise. Educating patients and physicians about specific concerns including self-blame, needle phobia, weight gain and hypoglycaemia may be key to reducing psychological resistance to insulin initiation. Furthermore, emotional support for patients with pronounced diabetes-related distress may be a worthy goal in reducing the emotional barrier to insulin initiation in those patients requiring insulin but failing to accept it. The DAWN programme aims to facilitate the development of expert driven initiatives in order to help patients and physicians overcome the main barriers to timely insulin initiation.

Depression is increased two-fold in adults recently diagnosed with type 1 diabetes

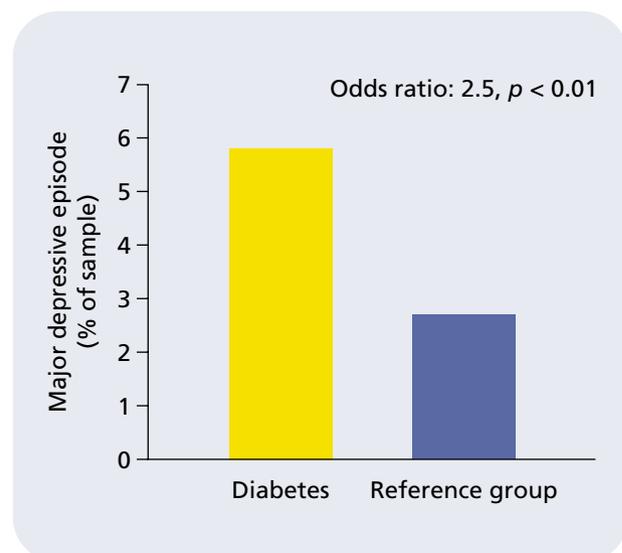
Frank Petrak, Johannes Gutenberg University, Germany

Associations between diabetes and psychiatric disorders have been documented in several studies, began Dr Petrak. However, the underlying mechanisms and exact nature of these associations are not fully understood; four different hypotheses regarding the chronological nature of the associations can be formulated; psychiatric disorders could precede the onset of diabetes, follow shortly after diagnosis, be delayed until further into the course of the disease or be no more prevalent than in the normal population. In his discussion of these issues, Dr Petrak presented data from the longitudinal, German Multicentre Diabetes Cohort (GMDC) study, investigating the factors that affect long-term adaptation to type 1 diabetes. This study assessed the prevalence of psychiatric disorders (as defined in DSM-IV) in adults aged 17–40 years with newly diagnosed type 1 diabetes (n = 313). Data from a national, representative population sample without diabetes (aged 17–40 years, n = 2046) were used as a reference group⁶.

Patients with type 1 diabetes had a two-fold increase in major depressive episodes relative to the reference group, suggesting that depression is evident prior to diagnosis or triggered shortly after. There was no significant between-group difference in mood, eating, or anxiety disorders indicating that these may develop later in the course of the illness or that they are no more prevalent than in the general population. (The long-term follow-up of this study cohort may clarify this issue.) Additionally, patients with diabetes had significantly lower prevalence of somatoform and substance disorders. Dr Petrak concluded that clinicians treating newly diagnosed

adults should be attentive to depressive symptoms as they may serve as a marker for vulnerability and help identify patients at risk of complications. As the DAWN study indicated, under diagnosis and lack of treatment of depressive symptoms may contribute to suboptimal diabetes care.

Clinicians treating adults with newly diagnosed diabetes should be attentive to depressive symptoms



The risk of major depressive episodes is more than doubled in patients newly diagnosed with type 1 diabetes compared with a reference group sample

Diabetes-related emotional distress is often evident in depressed patients

Frans Pouwer, Vrije Universiteit Medical Centre, The Netherlands

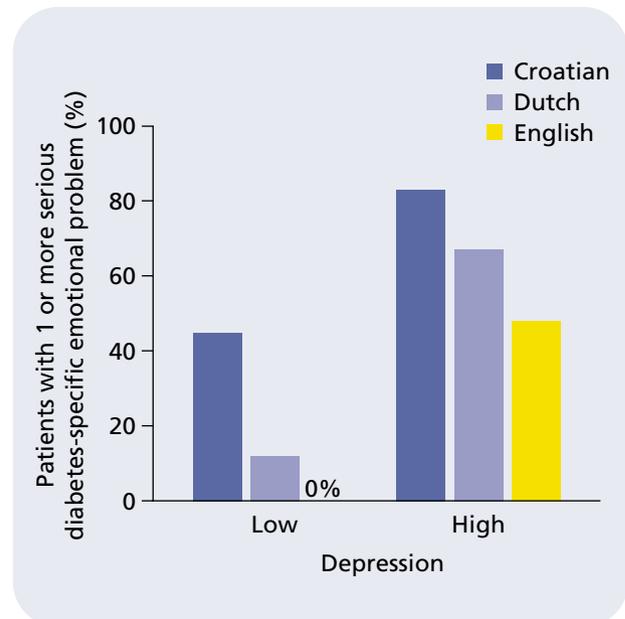
As discussed by Dr Petrak, diabetes doubles the risk of depression. Depression is associated with poor glycaemic control, impaired quality of life, diabetes-related outcomes and increased healthcare costs. While tricyclic antidepressants and SSRIs lead to remission from depression in approximately 50% of patients with diabetes^{7,8}, cognitive behavioural therapy (CBT) appears to offer greater success, said Dr Pouwer. He continued with literature showing that remission can be achieved with CBT in as many as 80% of patients, and that this success is maintained over the longer-term with 70% of patients in remission 6 months after treatment⁹. CBT is less successful, however, in patients who have high levels of diabetes-related emotional distress. Addressing diabetes-specific issues during CBT may therefore facilitate its success.

Despite this suggestion, it is unclear how often diabetes-specific emotional distress and depression co-exist. Dr Pouwer presented new findings indicating that these two aspects do frequently co-occur. Patients with high levels of depression (as assessed by CES-D) frequently presented with one or more serious diabetes-related issues as determined by the problem areas in diabetes scale (PAID). The most typical emotional concern for these patients was worry over their future and the risk of complications. Concerns over failure to comply with diabetes treatment and anger over living with diabetes were also commonly cited.

Given that the success of CBT may be diminished in patients with diabetes-specific concerns, Dr Pouwer

concluded that therapists may want to address these issues to optimise the effectiveness of CBT in the management of diabetes-related depression.

Diabetes-related emotional distress may compromise cognitive behavioural therapy



Patients with high levels of depression report diabetes-specific emotional problems to a greater extent than those with low levels of depression

Cognitive behavioural group training for type 1 diabetes patients with poor glycaemic control

Nicole van der Ven, Vrije Universiteit Medical Centre, The Netherlands

As many as 25% of patients with type 1 diabetes have poor glycaemic control, began Dr Nicole van der Ven. Given that self-care practices such as injecting and adjusting insulin, monitoring blood glucose and eating healthily form the basis of treatment, psychosocial factors are likely play a pivotal role in glycaemic control and, as the DAWN study showed, are often overlooked.

Demoralisation may be particularly important in poorly controlled patients. Through the application of the cognitive behavioural model originally developed as an explanation for depression and anxiety, Dr van der Ven highlighted that failing to attain glycaemic targets may promote negative attitudes and beliefs towards diabetes. These may affect the performance of self-care practices, leading to a negative cycle promoting poor glycaemic control. Cognitive

The European Depression in Diabetes Research Consortium: investigating diabetes-related depression throughout Europe



Immediately before the PSAD meeting, members of the European Depression in Diabetes Research Consortium (EDID), met to review current activities and plan future efforts. EDID, a multidisciplinary group of European scientists working within PSAD and EASD, aims to enhance the understanding of clinical depression in diabetes, one of the most costly mental health problems associated with this disease.

As the DAWN study showed, psychological aspects of diabetes management are often overlooked. Consequently, improvements in diabetes management may be achieved by combining specific psychosocial support with appropriate medical care.

The EDID aims to enhance the understanding and treatment of clinical depression in diabetes

The European collaborative framework of the EDID provides an ideal opportunity to investigate differences in the prevention, screening, assessment and treatment of depression throughout Europe, and to recommend future actions to improve understanding, detection and treatment of depression in routine care.

For further information on the EDID, visit www.bham.ac.uk



behavioural training (CBT) could therefore improve the outcome of at least some of these patients by replacing negative attitudes with positive ones.

A controlled clinical trial is currently underway investigating whether CBT will improve the glycaemic control and well-being of patients with HbA_{1c} over 8.0% who have had type 1 diabetes for a mean of 18 years. The preliminary data presented by Dr van der Ven demonstrate that at baseline, patients do accept that diabetes is a serious condition and worry about complications. They also realise that self-care behaviours are important, but have low confidence in their ability to perform these practices relative to the diabetes population in

general. Additionally, they consider that several of these practices such as monitoring blood glucose, maintaining a strict eating plan and exercising are burdensome. These maladaptive beliefs may be ideal targets for CBT. Consequently, the remaining trial results investigating the effectiveness of CBT in improving glycaemic control in poorly controlled patients are eagerly awaited.

Patients with poor glycaemic control often have low confidence in their self-care abilities

Women with diabetes: a preliminary study into their relationship with stress

Julie Smith, Open University, UK

Stress may have a direct negative effect on glycaemic control. It can also affect daily functioning and patient management of symptoms. Ms Julie Smith presented preliminary research concerning the causes and consequences of stress in women with diabetes, which may differ from those of men. This research involved both qualitative and quantitative assessment techniques to maximise our understanding of the relationship between stress and diabetes in women.

Following a preliminary focus group, a questionnaire was developed targeting specific concerns and experiences of women with diabetes. Women also completed the Perceived Stress Scale (PSS¹⁰) and the Problem Areas in Diabetes Scale (PAID¹¹). Initial results indicated that 63% of women found living with diabetes stressful, women reporting stress had

significantly higher scores on PSS and PAID, 69% of women said diabetes affected their daily lives and 73% believed stress affected their diabetes management. Nevertheless, 95% felt in charge of their diabetes and reassuringly, 92% said they would seek help from their healthcare provider if they had a diabetes-related problem. Twenty-three women were also involved in face-to-face interviews and journal keeping, which focused on the experiences of women in relation to stress and diabetes. This ongoing research should provide valuable insight into the unique problems faced by women with diabetes.

63% of women found living with diabetes stressful

Selected references

1. Antonovsky A. *Unraveling the mystery of health*. Jossey-Bass, San Francisco (1987).
2. Karasek R, Theorell T. *Healthy work: stress, productivity, and the reconstruction of working life*. Basic Books, New York (1990).
3. Mooy JM, De Vries H, Grootenhuis PA, et al. *Diabetes Care* 2000;23:197–201.
4. Menon ST. *Nurse Educ Today* 2002;22:28–39.
5. Kubiak T, Hermanns N, Kulzer B, et al. *Diabetologia* 2002;45(Suppl 2):832.
6. Petrak F, Hardt J, Wittchen H-U, et al. *Diabetes Metab Res Rev* 2003;19:216–22.
7. Lustman PJ, Griffith LS, Clouse RE, et al. *Psychosom Med* 1997;59:241–50.
8. Lustman PJ, Freedland KE, Griffith LS, Clouse RE. *Diabetes Care* 2000;23:618–23.
9. Lustman PJ, Griffith LS, Freedland KE, et al. *Ann Int Med* 1998;129:613–21.
10. Cohen S, Kamarck T, Mermelstein R. *J Health Soc Behav* 1983;24:385–96.
11. Polonsky WH, Anderson BJ, Lohrer PA, et al. *Diabetes Care* 1995;18:754–60.

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