

## UNIT NO. 2

## PSYCHOSOCIAL ASPECTS OF DIABETES CARE – LESSONS FROM THE DAWN STUDY

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## ABSTRACT

Addressing the individual educational and psychosocial barriers to effective self-management and optimal quality of life is key to improving the outcomes of diabetes care. This was one of the findings of the global DAWN (Diabetes Attitudes, Wishes and Needs) study, involving more than 5,000 people with diabetes and 3,800 healthcare professionals in 13 countries.

Improvements in the organisation and delivery of diabetes care with the aim to improve self-management must be based on deep insight into the unique needs and perspectives of people with diabetes and those close to them, as well as on evidence-based methods of self-management, education and support.

People with diabetes are at significantly greater risk of depression and anxiety disorders than the general population and psychiatric co-morbidity is associated with significantly worse clinical outcomes. Screening and care for psychological disorders in diabetes is recommended in international treatment guidelines and shown to be cost-effective, yet is rarely implemented according to evidence-based standards.

Psychosocial functioning of people with diabetes is a critical determinant of their clinical outcomes. Evidence-based psychological treatment guidelines, strategies and dialogue tools are becoming increasingly available to help patients overcome the psychosocial barriers to effective self-management. The challenge is still to ensure their usability in primary care.

The global DAWN Call to Action published by IDF in 2004 provides a practical evidence-based framework for effective person-centred care built on a psychosocial model of diabetes management. It specifies 5 goals for improvement of diabetes care agreed on by leading diabetes experts and organisations from 31 countries: To improve outcomes, we must: 1) Continuously enhance the relationship between people with diabetes and their healthcare professionals; 2) Promote collaboration and communication within the diabetes care team; 3) Promote active self-management; 4) Overcome psychosocial barriers to effective therapy; and 5) Provide better psychological support.

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## INTRODUCTION

The DAWN (Diabetes Attitudes, Wishes and Needs) Study in 2001 demonstrated that a significant gap exists between the psychosocial needs of people with diabetes and the general availability of psychosocial and self-management support in health care systems across several different countries (*Peyrot et al, Diabetic Medicine 2005, Peyrot et al, 2006*).

The study was conducted by Novo Nordisk in partnership with the International Diabetes Federation (IDF) and an international expert advisory board including representatives of leading diabetes nurses, diabetes psychologists, diabetologists, public health experts and patient ambassadors.

Following the study, several international summits were held involving major international organisations including the International Diabetes Federation (IDF), the Federation of Nurses in Diabetes (FEND), Primary Care Diabetes Europe (PCDE), the Psychosocial Aspects of Diabetes Study Group of the EASD (PSAD), the International Society for Pediatric and Adolescent Diabetes (ISPAD) and the World Health Organisation (WHO) (*Wroe 2002, 2004, 2006*).

A key outcome from the 2nd DAWN Summit was the global DAWN Call to Action published in 2004 by the International Diabetes Federation (*Wroe 2004, IDF 2004*). The DAWN Call to Action specifies 5 concrete goals for improved diabetes care based on international behavioural diabetes research and the findings from the international DAWN study. The continuing DAWN programme facilitates sharing of strategies, tools and better practices to implement and support person-centred diabetes care (*Skovlund et al, 2005*).

This article summarises clinically relevant findings from the DAWN study and related psychosocial diabetes research, and introduces simple practical strategies and tools to facilitate implementation in daily practice.

## SUMMARY OF THE FINDINGS FROM THE DAWN STUDY

## Background

The DAWN study was undertaken by Novo Nordisk and the International Diabetes Federation in 2001 in response to evidence that less than half of people with diabetes achieved adequate glycaemic control despite the availability of effective medicines.

The aim of the study was to create new insights into the attitudes, wishes and needs of people with diabetes and their healthcare professionals with particular focus on understanding determinants of active self-management.

This insight and understanding would be used to identify new avenues for improvement of the psychosocial management of diabetes (*Peyrot et al, Diabetic Medicine 2005*).

## Methodology

Focus groups and qualitative research studies with people with type 1 and type 2 diabetes and diabetes care providers in 8 countries were used to identify all the individual, healthcare and social factors impacting diabetes self-management.

DAWN questionnaires were developed from the qualitative study and used to conduct 45 minute structured interviews either face-to-face or by telephone in 11 survey regions representing 13 countries (India, Japan, Spain, United Kingdom, United States, France, Spain, Germany, Netherlands, Poland, Sweden, Denmark, Norway). A total of 5,104 people with type 1 or type 2 diabetes, and 3,800 diabetes healthcare professionals were interviewed.

## Key findings

The results from the DAWN study have been published in numerous articles (*Peyrot et al, Diabetic Medicine 2005, Rubin 2006, Peyrot et al, Diabetologia 2006*), and some key findings are summarised briefly here.

### Self-management

Only 18% of people with diabetes reported they were successfully managing their diabetes as recommended by their physician. Healthcare professionals estimated the self-management success of their patients at a substantially lower level. 85% of people with diabetes reported feeling shocked, guilty, angry, anxious or depressed at diagnosis, and negative emotional reactions at diagnosis consistently predicted self-management problems later on.

### Psychosocial challenges to self-management

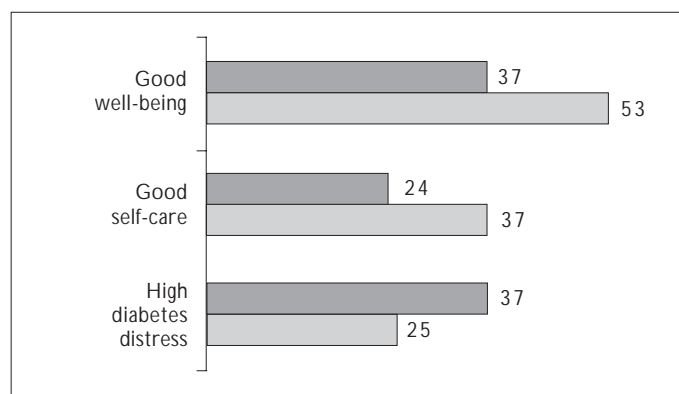
74% reported significant fears or psychological stressors of one or several kinds due to their diabetes, and 41% had poor psychological well-being according to the WHO-5 Well-Being Index (*Bech, 2003*); indicating a double risk of depression compared to the general population. Common psychosocial concerns reported by both type 1 and type 2 diabetes patients are shown in Table 1.

**Table 1. Data from the DAWN study, Novo Nordisk. (n=5,104 patients with diabetes)**

I feel very anxious about my weight	50.0%
I am very worried about the risk of hypoglycaemic events	42.5%
I feel that diabetes is preventing me from doing what I want	35.9%
I feel stressed because of my diabetes	32.7%
Diabetes has had a positive effect on my life	31.2%
I feel burned out because of my diabetes	18.1%
The community I live in is intolerant of diabetes	13.6%

Overall, patient-reported access to diabetes care providers, and quality of communication with physicians, was associated with improved glycaemic control and self-management and reduced level of diabetes related distress (Figure 1) (*Skovlund et al Diabetes Spectrum 2005*).

**Figure 1.** Percentage of diabetes patients in the DAWN study reporting good well-being, good self-care and high diabetes distress according to perceived quality of communication with physician (*Adapted from Skovlund et al 2005*)



### Barriers to use of effective therapy

The DAWN study revealed that psychosocial barriers to the use of effective therapy such as insulin is widespread and common across countries.

Among the 2,061 type 2 diabetes patients who were not using insulin, 57% were *very* worried about starting insulin therapy, 48% would blame themselves for having failed to manage their diabetes adequately if they were told they needed to begin insulin therapy, and only 27% believed that insulin could help them manage their diabetes better.

Half of the diabetes physicians said they used insulin as a threat to encourage their patients to follow their existing diabetes treatment plan; which may contribute to the problem of self-blame. Diabetes physicians were generally not aware of the magnitude of the problem of self-blame associated with progression of the disease and initiation of insulin therapy (*Peyrot et al, Diabetes Care 2005*).

### The healthcare professionals' perspective

Only 51% of people with diabetes felt the healthcare professionals they see for their diabetes talked with each other about their condition, and 60% expressed a significant need for more team care.

Healthcare professionals were generally well aware of elevated psychological distress in the diabetes population and recognised its relationship to impaired self-management. Two-thirds of them expressed a need to understand better the psychological aspects of diabetes. However, less than half of the diabetes healthcare professionals felt adequately resourced to identify and address the psychological problems affecting their diabetes patients.

### PRACTICAL IMPLICATIONS OF THE DAWN STUDY

Based on the global DAWN study results and reviews of international applied psychosocial and behavioral diabetes research, leaders in diabetes care from 31 countries joined to develop the global DAWN Call to Action for improving care for people with diabetes. Five universal goals of critical importance to all the countries were defined, and their key

aspects are discussed below. Tools and evidence-based strategies relating to each were developed and disseminated to help healthcare professionals address these goals in their daily practice (Skovlund et al 2005).

**Goal 1: Enhance communication between people with diabetes and their healthcare professionals**

Effective communication and dialogue is the foundation for provision of adequate person-centred diabetes care. Listening to patients is vital for development of viable self-management plans, and to identify individual strategies to overcome barriers to optimal self-management and quality of life. Treatment guidelines for chronic disease increasingly emphasise the significance of effective person-centred communication in all aspects of chronic care (IDF 2005).

Use by healthcare professionals of techniques such as active listening, open-ended questions and motivational interviewing build a strong therapeutic alliance with the patient, and promotes patient satisfaction and constructive engagement in the care process. Equally, people with diabetes can be helped to communicate more effectively with their healthcare team by peer mentors, coaches or lay educators.

Due to competing demands, many healthcare professionals are not offered adequate training opportunities to improve listening and dialogue skills. Sustainable improvement in communication by healthcare professionals can be facilitated by interactive training programmes with individual feedback, simple practical tools for daily use, and adequate support through practical, evidence-based guidelines and local resources.

The DAWN Experiment (Figure 2), developed by Martha Funnell and Bob Anderson, encourages diabetes healthcare professionals to explore the potential benefits of use of active listening in a diabetes consultation.

**Figure 2. The DAWN Experiment – a listening exercise for healthcare professionals (Anderson and Funnell 2003)**

1. Ask your patient with diabetes: What has been most difficult for you in managing or coping with your diabetes since your last visit?

2. Listen actively for at least 3 minutes without interrupting or providing advice in any way. If there is a pause, try to encourage more information by saying: Tell me more about that? Or why do you think that is?

3. Follow-up to address important issues that may have emerged and complete the consultation taking this new information into account

Repeat the experiment with 2 more of your patients and for each experiment, write down your answers to the following questions.

1. How did it feel to not interrupt or give advice for 3 minutes?

2. What did you learn from your patient that you didn't know before?

3. How will you use this knowledge in your future care for this patient?

The healthcare professional is encouraged to make his or her own judgment on whether the use of this experiment helps to improve the patient relationship and thereby the therapeutic

alliance with patients. On that basis, the healthcare professional may choose to continue practising effective communication skills, including effective use of questions, motivational dialogue and methods for confirming understanding of the patient's perspective.

**Goal 2: Promote team-based care and in particular facilitate improved use of diabetes educators**

The DAWN study and other recent studies confirm that people with diabetes do better when they are treated by a multidisciplinary team of health professionals who communicate well with each other. Furthermore the DAWN study showed that the diabetes educator is well positioned to facilitate improved communication between the patient and the team regarding psychosocial issues; yet is often underutilised (Siminerio 2007). A systematic, organised approach is needed to support self-management of people with diabetes, regardless of whether the care takes place in primary or secondary care. Effective coordination and collaboration is vital among all personnel within the practice, and especially with external resources needed such as psychologists, educators and other disciplines.

A multidisciplinary diabetes team involves a diabetes specialist, a primary care physician, a nurse, a dietician, a psychologist, and other relevant healthcare professionals. The team can be physically connected, or functioning as a virtual team. Primary care physicians can take many simple steps to facilitate delivery of quality team care, to enhance patient self-management and treatment outcomes. They can also involve local resources outside their clinic such as local specialists, psychologists and educators using local networks, web systems and professional societies. A local professional support network of resources (a virtual diabetes team) can be identified to provide a broader palette of support depending on individual needs. New information technologies provide powerful opportunities for effective collaboration among diabetes team members, as well as empowering the person with diabetes through improved access to all information regarding the treatment.

The 5 A framework outlined in Table 2 provides an overview of the key steps involved in an evidence-based approach to facilitating self-management. The framework can be very helpful in facilitating clear division of responsibilities of the diabetes team in providing collaborative diabetes self-management education and support.

**Table 2. Adaptation of the 5A framework for primary care practice (adapted from Glasgow 2002)**

Assess the patient's key priorities and needs for support

Advise about test results, provide tailored relevant information and resources

Agree on self-management goals through collaborative dialogue with the patient

Assist the patient in identifying barriers to self-care and ways to overcome them

Arrange that the patient also has access to support between visits.

### Goal 3. Promote active self-management

Diabetes is a very demanding chronic and predominantly self-managed condition. The person with diabetes has the constant responsibility of managing his or her diabetes 24 hours a day, 7 days a week, 365 days a year, for life. To succeed, the person has to have adequate problem-solving and self-management skills, as well as social and emotional coping skills. The DAWN study revealed that only a minority of patients with diabetes feel able to follow their doctor's treatment regimens and that many blame themselves if the disease progresses. Poor psychological well-being, diabetes worries and burn-out are strong predictors of passive self-management.

To facilitate active self-management, the healthcare professional has a vital role to play to motivate and stimulate self-confidence and enable the patient to actively take part in shared decision-making and goal-setting. Given the central role of self-management in diabetes care, it is important to have explicit goals for self-management education that can be used to design individual education plans and evaluate the outcome of educational activities. Key goals of self-management education for each patient include: taking medication as recommended, monitoring blood sugar, eating healthily, being physically active, avoiding the risk of complications, coping well and having problem-solving skills. Progress toward these important self-care goals for any person with diabetes can be evaluated over time so additional self-management support can be provided where and when relevant.

### Goal 4. Overcome psychosocial barriers to effective therapies

A key barrier to optimal glycaemic control for people with diabetes is any delay in the initiation of effective therapy, such as oral medication and insulin therapy when needed. Despite treatment guidelines and availability of effective therapies, initiation of insulin therapy is delayed for several years for many patients. Delayed insulin treatment can result in a prolonged period of avoidable poor control, resulting in a risk of severe long-term complications, disability and premature death (*Funnell 2004*). Often barriers to timely insulin initiation are found both among patients and their healthcare team. These barriers can include a lack of basic training in insulin initiation, basic knowledge about insulin, and lack of financial and educational support.

The global DAWN study was the first study to demonstrate the magnitude and geographical spread of psychological barriers to use of insulin therapy in people with type 2 diabetes, and the need for improved awareness and attention to these issues among health care professionals.

Following the DAWN study, the first insulin treatment appraisal questionnaire (ITAS) was developed to enable further quantification and reliable assessment of a patient's psychological barriers to insulin therapy (*Snoek, Skovlund, Pouwer, 2007*). Insulin-naïve patients consistently expressed more negative perceptions and psychological concerns about insulin than insulin-treated patients and less positive perceptions. As an example, 47% of insulin-naïve type 2 diabetes patients were fearful about injections, whereas only

6% of insulin-treated and otherwise comparable patients expressed the same concern.

By creating an emotionally supportive environment in the clinic, the physician or diabetes team can facilitate effective dialogues with patients about personal concerns related to starting new therapy. Being attentive to the psychological concerns that most patients have and asking open ended questions is a fundamental approach to supporting patients (*Funnell 2004*).

When time in the clinic is very limited, simple dialogue support tools can be a vital aid for the physician and nurse as well. Dialogue tools using patient reported forms and scripted dialogue examples for the professional can help the diabetes care team identify and address misbeliefs and misunderstandings that the patient may have. The aim is to enable a fully informed decision about the use of new therapy and to ease the transition to insulin therapy for those who decide to begin new therapy.

The ITAS can be used in daily practice to facilitate dialogue between the patient and the healthcare team about perceptions of insulin therapy. As the patient can complete the tool before the consultation, valuable time is saved so the patient and the nurse or physician can spend the consultation time discussing only the areas that are most relevant for that patient.

Examples of some of the psychological barriers that can be addressed through a person-centred dialogue using the ITAS questionnaire are shown in Table 3.

**Table 3. Examples of patient concerns assessed by the Insulin Treatment Appraisal Scale (Snoek et al 2007).**

- |     |  |
|-----|--|
| 1.  | Insulin signifies failure with pre-insulin therapy       |
| 2.  | Insulin signifies diabetes has worsened                  |
| 3.  | Insulin will make others perceive greater sickness       |
| 4.  | Insulin will make life less flexible                     |
| 5.  | Fear of needle injection                                 |
| 6.  | Insulin will increase the risk of hypoglycaemia          |
| 7.  | Insulin will cause weight gain                           |
| 8.  | Insulin will be demanding to administer                  |
| 9.  | Insulin means I have to give up activities I enjoy       |
| 10. | Insulin means my health will deteriorate                 |
| 11. | Injecting insulin is embarrassing                        |
| 12. | Injecting insulin is painful.                            |
| 13. | It is difficult always to inject insulin correctly       |
| 14. | Insulin makes it difficult to fulfil my responsibilities |
| 15. | Using insulin causes family/friends to be more concerned |

The physician can play a pivotal role to prevent psychosocial barriers to insulin therapy in type 2 diabetes by informing and educating about insulin therapy already from the time of diagnosis. At the time of initiation, psychosocial barriers can be identified through use of open ended questions and dialogue support tools such as the ITAS followed by a patient-centred dialogue. The aim of such dialogues is to ensure the patient is able to take a fully informed decision about starting new therapy and to ensure that there are no psychological concerns that could hinder effective insulin self-management following insulin start.



Goal 5. Promote psychological care for people with diabetes

The DAWN study found that people with diabetes are about twice as likely to have poor psychological well-being than people without diabetes. This confirms clinical studies which reveal a double risk of depression for people with diabetes (*Peyrot et al 2005, Anderson et al 2001*). Depression in diabetes is associated with a dramatic reduction in quality of life and can lead to impaired self-management and poor glycaemic control (*Lustman et al 2007*).

Depression in people with diabetes can be detected using validated assessment tools, and treated effectively with both non-pharmacological and pharmacological therapies. Quality improvement programmes which incorporate screening and treatment for depression in type 2 diabetes have been shown to be highly cost-effective (*Katon et al 2006*). Furthermore, monitoring the psychological well-being and quality of life of people with diabetes as part of ongoing care has been shown to affect positively the quality of life of the patients (*Pouwer et al 2001*).

For these reasons, global treatment guidelines from IDF and ISPAD and also a growing number of national treatment

guidelines recommend the routine evaluation of psychosocial functioning of people with diabetes (*IDF 2005, Delamater et al 2007*).

The DAWN study revealed that many diabetes healthcare professionals are not resourced to adequately address psychological aspects of diabetes, but very few are able to refer patients to diabetes psychologists.

With adequate training and mapping of local resources, the diabetes team can play a key role in preventing and addressing diabetes-related psychological problems. The provision of person-centred self-management and psychosocial support as part of all routine visits is crucial, and tools are available to assist healthcare professionals. The diabetes nurse or physician can quickly assess the patient’s psychological well-being at each visit using the WHO-5 questionnaire (Table 4) to identify signs of subclinical or clinical depression. The WHO-5 questionnaire, recommended by the DAWN programme (*Wroe 2004*), uses only positive questions, takes less than 2 minutes to complete and is very well accepted by both patients and healthcare professionals. Many patients with poor psychological well-being can also benefit from access to peer support and cognitive behavioral self-help techniques.

Table 4. The WHO-5 Wellbeing Index. Recommended by the International DAWN Programme. Reproduced with permission.

Please indicate for each of the five statements which is closest to how you have been feeling over the last two weeks. Notice that higher numbers mean better well-being.

Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, put a tick in the box with the number 3 in the upper right corner.

Over the last two weeks...	All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
1. I have felt cheerful and in good spirits	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
2. I have felt calm and relaxed	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
3. I have felt active and vigorous	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
4. I woke up feeling fresh and rested	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
5. My daily life has been filled with things that interest me	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0

Clinical use of the WHO-5 questionnaire

Patients can fill out the form in the waiting room or at the beginning of the consultation. Scores for the five items are summed to yield a score from 0-25. The total raw score can be multiplied by 4 to obtain a standard range from 0-100. A score of 50 or below indicates low mood, though not necessarily depression. A score of 28 or below indicates likely depression and warrants further assessment (a diagnostic interview) to confirm depression. In order to monitor possible changes in well-being in response to an intervention, a 10% difference can be regarded as a clinically significant change.

Feeding back the well-being score to patients in an open way is important to validate the patient’s perception of importance of well-being in the process of diabetes self-management. The aim of discussing the score is not to diagnose, but to feed back and discuss the information in a

constructive and non-judgemental manner. The patient is invited to comment on the finding and reflect on the need for help (*Snoek 2007*).

CONCLUSIONS

The global DAWN study, spanning 13 countries and involving 5,104 patients and 3,800 healthcare professionals, as well as a range of other smaller behavioural and psychosocial research studies, provide the foundation for a new evidence-based approach to diabetes care which focuses on optimisation of self-management and quality of life for people with diabetes. The DAWN Call to Action sets out five practical goals for improving care from the patient’s perspective. Evidence-based strategies and tools are available to support healthcare professionals in primary and secondary care improve their

communication skills, establish improved team coordination, support active self-management, address emotional barriers to use of effective therapy, and ensure access to psychological care for those requiring this.

Key tips to primary care physicians based on experiences from diabetes professionals involved in the DAWN initiative include:

1. Use open ended questions and active listening. For example, ask patients what they found most difficult in regard to managing their diabetes since the last visit.
2. Help each patient develop a realistic treatment plan with clear goals
3. Help locate relevant local professional and peer support resources to ensure the patient has ongoing support also in between visits.
4. At insulin initiation, carefully evaluate the patient's perceptions about insulin and address major worries and gaps in knowledge thoroughly.
5. Monitor patient's well-being and diabetes related distress on an ongoing basis to identify individual barriers to active self-management

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#### LEARNING POINTS

- o Know about the key findings of the global DAWN study and the main practical implications of the study for diabetes healthcare professionals.
  - o Understand practical strategies to achieve the five key goals for improvement of diabetes care: Effective communication, team-based care, active self-management, psychosocial barriers to use of effective therapy and psychological care for people with diabetes.
  - o Know about simple practical tools to facilitate dialogue and identification of psychosocial needs of people with diabetes
  - o Identify new opportunities for providing improved educational and psychological support for people with diabetes in diabetes care.
-