



Putting people centre stage

Highlights from the 4th International DAWN Summit, Budapest, 6 November 2008.

As part of the global DAWN (Diabetes Attitudes, Wishes and Needs) programme, led by Novo Nordisk, the International Diabetes Federation (IDF) and the International Society for Pediatric and Adolescent Diabetes (ISPAD), this Summit presented the exciting results of the DAWN MIND initiative and DAWN Youth surveys, and focused on patient-centred care.

The Summit was included in the 2nd Congress on Therapeutic Patient Education that welcomed around 600 participants from 53 countries involved in chronic care.

Introduction

After welcoming words by the Chairman, David Matthews (UK), and Lise Kingo (Novo Nordisk Executive Vice-President), IDF President Martin Silink (Australia) described the message for the day: the recognition that psychosocial well-being is as of equal importance as striving to prevent or delay vascular complications. This is illustrated by the World Health Organization (WHO) 2008 report that acknowledges social determinants of health, empowerment and patient-centred management as significant elements of chronic care. Citing WHO Director Chan in saying 'What is not measured will not be funded', he concluded that this extends beyond HbA_{1c} to psychosocial issues.

Global update of DAWN activities

Søren Skovlund (Director of the DAWN programme at Novo Nordisk) emphasised that to improve outcomes we must address the person behind the diabetes. He recalled the 2004 DAWN Call to Action that identified five goals to improve real-life outcomes and six strategies to achieve these goals at a local, national or global level (Table 1).

Key elements for sustainable improvement are measuring progress, and sharing achievements and effective tools. He gave examples of recent implementation

Table 1. Summary of the 2004 DAWN Call to Action that identified five goals to improve real-life outcomes and six strategies to achieve these goals at a local, national or global level. (S Skovlund)

Goals of the DAWN programme

- Promote active self-management
- Enhance psychological care
- Enhance communications between people with diabetes and health care providers
- Promote communication and coordination between health care professionals
- Reduce barriers to effective therapy

Strategies to achieve DAWN goals

- Raise awareness and advocacy
- Educate and mobilise people with diabetes and those at risk
- Train health care providers and enhance their competencies
- Provide practical tools and systems
- Drive policy and health care systems change
- Develop psychosocial research in diabetes

activities, e.g. the distribution of a special *Diabetes Voice* issue, dedicated to DAWN Youth,¹ to stakeholders in 150 countries.

In an attempt to gauge progress since 2004, a 'snapshot' was taken through an interactive voting system during the Summit. When asked 'which of the six DAWN action points has been most successfully implemented in your country/region?' the highest percentage (30%) said training health care providers (HCPs) and enhancing their competencies had proved most successful. Raising awareness and advocacy was the next largest response with 25% of voters, and 19% said educating and mobilising people with diabetes and those at risk was the most successful action point. Less success was recorded for the provision of practical tools and systems (12%), driving policy and health care systems change (8%), and developing psychosocial research (5%). When the question was flipped to ask which had been the most difficult to implement, unsurprisingly the converse of these results were shown with the largest score (46%) against the 'drive policy and health care systems change' action point highlighting this as one of the main stumbling blocks.

Focusing on the DAWN goals 37% of voters said promoting active self-management was the one they spent most time advocating, with 23% opting for enhancing communication between people with diabetes and health care professionals.

Perspectives on implementing the DAWN Call to Action England: overcoming the barriers

Despite the evidence and existence of education programmes, such programmes remain unavailable for most individuals in the UK, Simon Heller stated. Barriers include lack of understanding and commitment from doctors, the old belief that HCPs are responsible, and unwillingness to provide funding despite evidence of cost effectiveness. Diverting a fraction of the money spent in pursuit of new treatments could transform the care of many patients. There is a need for more adequate research to improve the effectiveness of existing programmes, for funding of quality assurance and educator training, and last, but not least, doctors must come to understand that educational programmes are the basis for quality care and good long-term



outcomes, rather than optional extras provided by 'their' nurses and dietitians.

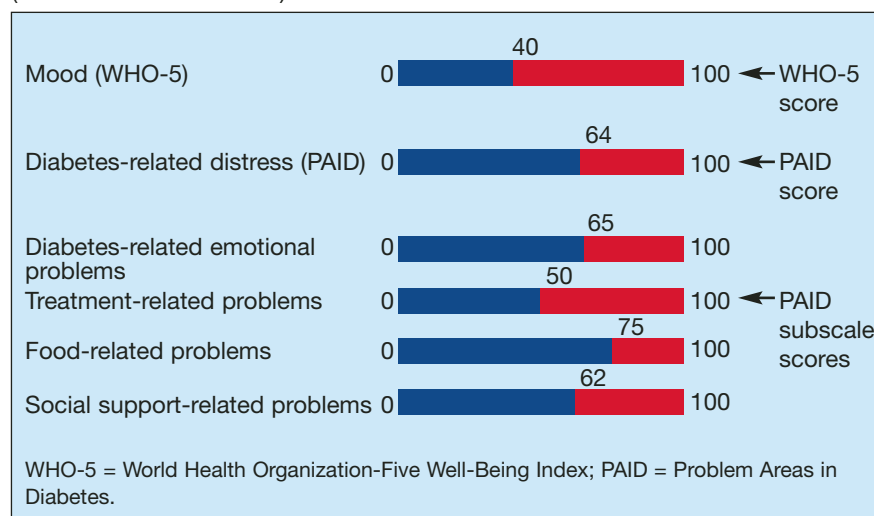
India: a low-cost approach

In implementing the DAWN philosophy, main obstacles which Sanjay Kalra encountered include HCPs who expect patients to behave as passive recipients of care, officials afraid of the financial burden, and patients unfamiliar with their rights and failing to learn basic self-management skills. Moreover, limited facilities and low availability of trained nurses and dietitians are challenging. Due to financial and logistic constraints the focus has been on a low-cost approach, with priority for raising public awareness and improving physicians' attitudes. Initiatives, like the Changing Diabetes Bus, mobile clinics, media activities and improving awareness of HbA_{1c} as a target, are bearing fruit. Physician training in patient-centred care (PCC) is expanding, as is the Multipurpose Diabetes Worker programme that trains young people in diabetes care under supervision.

Argentina: improving HCPs' knowledge, skills and attitudes

As described in the Summit workbook, Juan José Gagliardino (who was unable to attend) identified various factors contributing to non-optimal diabetes care in Latin America. To improve HCP-related deficiencies an online course for primary care physicians was set up at La Plata University. Participants' activities are monitored through written tests on content, clinical cases and attitudes. Successful completion of the didactic portion is followed by practical sessions in small groups, and successful candidates are granted academic certification. Data recorded from participants' patients one year before and after the course showed significant improvement in procedures, outcomes (including rate of hospitalisations) and attitudes, and attendees' satisfaction was high. The course will be implemented throughout Argentina, and a pilot course is being developed in five Caribbean countries. The Spanish-language

Figure 1. Example of an automatically generated report using the computer-led DAWN MIND tool as part of the patient's annual assessment. (F Snoek and L Dobson)



course is available on the internet (interested readers are advised to contact cdmfr@network.com.ar).

DAWN MIND (Monitoring of Individual Needs in Diabetes)

Psychosocial factors play a key role in diabetes management but are often neglected and psychological comorbidities are common but often go undetected, said Co-Chair Frank Snoek, Professor of Medical Psychology (*The Netherlands*). Although the evidence for monitoring of psychological well-being is strong, limited time and unfamiliarity with instruments and outcomes are barriers for implementation in daily practice.

Presenting the results of the multinational DAWN MIND project, Professor Snoek and Lene Dobson (*Denmark*) showed that these barriers can be overcome. Nurses in clinics from nine countries found the computer-led DAWN MIND tool quick and easy to use as part of the annual assessment. An automatically generated report (Figure 1) to be shared with the patient, drives discussion, and enables identification of problem areas and ways in which to address these.

Preliminary data from 1153 patients show that most are doing well, with 20–30% reporting poor well-being and/or high diabetes-related emotional distress. Involved nurses reported benefits in their relations with patients. Part of the

project is additional training in communicating about the report and dealing with the psychosocial endpoints.

DAWN Youth Improving psychosocial support for young people

Barbara Anderson (*USA*) stressed, as highlighted in *Diabetes Voice*, that psychosocial support for children and adolescents with diabetes and their families is a primary need. Children and adolescents are confronted with a responsibility not faced by those without a chronic condition, and childhood diabetes is a major burden for the family, leading to stress and anxiety. As HbA_{1c} in youth reflects family-related factors (as shown by the Hvidore studies) ISPAD's President, Thomas Danne (*Germany*), advocated for assessment of family functioning at the time of diagnosis.

The DAWN Youth initiative, launched in 2007, aims to examine the needs of young people with diabetes, raise awareness of the challenges and encourage global change to help young people and their families cope with, and manage, their diabetes.

A fact-finding study assessed policies, education, guidelines and care strategies in more than 25 countries. The insights from this study were complemented by the DAWN Youth WebTalk survey 2007–2008 which gathered feed-



Table 2. The five DAWN Youth key focus areas for globally-unified action. (B Anderson and T Danne)

- Improve support in school for children with diabetes and their families
- Provide more age-appropriate education and psychosocial diabetes care
- Better support for parents and families
- Facilitate peer support and networking for young people with diabetes
- Promote prevention of childhood obesity and type 2 diabetes in young people

back from around 2000 young adults with diabetes, 4000 parents and 800 HCPs.

Thirty percent of young adults felt that their diabetes was never under control, and 35% had poor psychological well-being or likely depression. Poor well-being/depression was also reported in more than 40% of parents. HCPs reported that only half of children and adolescents achieve adequate HbA_{1c} levels; 27% thought this was due to unresolved psychosocial issues and 45% cited lack of support from schools as a reason for poor adherence to insulin regimens. Parents and young people thought schools could provide additional support. The transition from paediatric to adult care and psychosocial support from HCPs were also identified as needing improvement.

Based on these results and the output of DAWN Youth leadership summits involving all stakeholders,

five priority areas have been defined (Table 2).

Awareness, training, and validated tools and strategies are needed to enable action in these fields. Encouraging initiatives have started in many countries, as highlighted at the Summit and in *Diabetes Voice*. The children's circle tool,¹ for instance, appears useful for facilitating discussion between children, family and their diabetes team on issues related to quality of life.

Young leadership initiatives

A key element is the involvement of DAWN Youth ambassadors, who contribute by sharing their experience in living with diabetes, identifying effective tools for change and engaging in advocacy. They were encouraged to suggest initiatives that improve quality of life and care for children and adolescents with diabetes all over the world.

The two winning propositions were presented.

Hirokazu Kono, representing a group of six, proposed four projects to target unmet needs in Japan: to develop a website for youth, to establish a camp for children with obesity and/or type 2 diabetes, to develop manuals for staff of existing camps for type 1 diabetes, and to re-establish a Diabetes Camp Summit.

Anja Østergren Nielsen, in the front line of diabetes advocacy in Denmark, proposed a number of projects focusing on empowering youth to get involved in PCC. These included producing supporting materials for time-of-diagnosis and when starting jobs, introducing 'diabetes holidays' without responsibil-

ity allowing young people to take control in a gradual fashion, and sports camps and healthy food projects at school.

**Putting people centre stage
Facilitating diabetes self-management**

As outlined by Mark Peyrot (USA), effective self-management is fundamental to obtaining good outcomes, but pessimistic health beliefs and lack of self-efficacy, support, resources and facilities are barriers. A key principle of PCC is the role of HCPs and relevant services in providing patients with the information, support and skills that allow them to make informed decisions, while at the same time respecting their choices. Providers may know best, but patients know what they are able and willing to do. Asking questions and listening, rather than instructing, are essential to understand the patient's needs and provide the support required. Even after appropriate education patients usually need help with problem solving and behaviour change. He described a stepwise approach, with sample questions for use during standard visits, as published recently.²

He emphasised that patients are as good as the team of which they are part. Individual change requires social change, enabling accessible and adequate support at all levels. HCPs are ideally placed to advocate for the necessary social action.

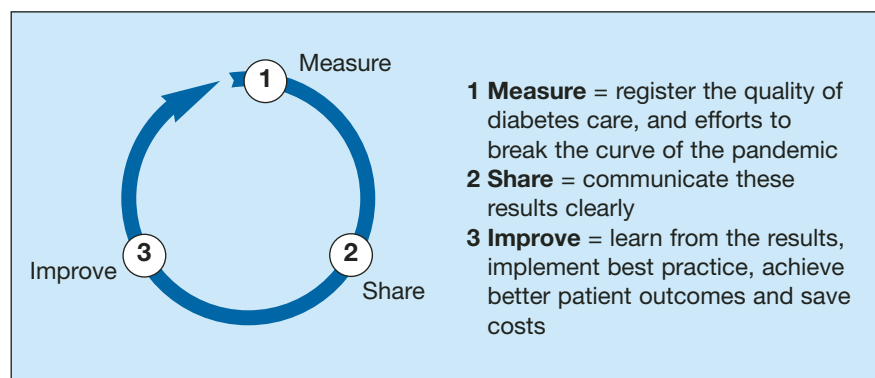
Different perspectives

From the **patient perspective**, Michael Weiss (USA) urged educa-

Table 3. Indicators for patient-centred care which need to be developed and implemented at three levels. (R Colagiuri)

The patient level	The health service level	The policy level
<p>Examples of patient-level indicators include:</p> <ul style="list-style-type: none"> • Availability of counselling and psychosocial support • Availability of timely and appropriate education and information • Opportunities for active involvement in treatment decisions and goal setting 	<p>Examples of service-level indicators include:</p> <ul style="list-style-type: none"> • Access to and continuity of care (acute and community) • Including patient perspectives in service design and delivery • Routine monitoring of quality of life and patient satisfaction alongside traditional quality of care indicators 	<p>Examples of policy-level indicators include:</p> <ul style="list-style-type: none"> • The inclusion of people with diabetes on national and local diabetes committees • The inclusion of recommendations for patient-centred care in national diabetes guidelines

Figure 2. The measure-share-improve concept promoted by the Changing Diabetes Barometer® initiative



tion to focus on the patient as primary caregiver, behaviour change strategies, the trial-and-error nature of self-management and the difficulty of the task, before addressing the clinical component.

For a **primary care practitioner**, Torsten Lauritzen (*Denmark*) said PCC is about creating a dialogue between doctor and patient, leading to common understanding and resulting in joint decisions or management. He evaluated the effect of PCC training on health care use and outcomes, and found improved communication, satisfaction and cardiovascular risk, without increasing demands on resources.³

Joanna Groves (*International Alliance of Patients' Organizations [IAPO], UK*) outlined the **perspective of patient's organisations** around five principles: respect for individuals' preferences and needs; choice and empowerment; patient involvement in health policy; access and support; and accurate information presented in an appropriate way. IAPO encourages patients' organisations in promoting PCC to improve outcomes. An interesting review is available online.⁴

The **policy-maker perspective** was illustrated by Paola Pisanti (*Ministry of Health, Italy*), highlighting the value of regulating and organising diabetes care by law, by a Ministry adopting the DAWN philosophy and participating in the Diabetes Education Awareness and Leadership (DEAL) programme, and involving patients in defining a national programme that responds to their needs.

Measuring progress Building on the past – determining the future

Ruth Colagiuri (*Australia*) compared the development of PCC to constructing. Starting with a design (vision, goals) the foundation is laid (research, consultation) and building one brick at a time (using a balanced mix of policy, practice, evaluation and feedback as mortar) the PCC-building is taking shape. From the recognition of empowerment, revitalised by DAWN, and now inspired by the Changing Diabetes Barometer® initiative, the spotlight concentrates on (putting) people centre stage.

The acknowledged interaction of glycaemic control and well-being requires looking beyond HbA_{1c} as sole measure of effective care and education. Indicators for PCC need to be developed and implemented at three levels (Table 3).

Preliminary data on current 'barometric pressure' showed, for instance, half of 96 replying countries to have a national diabetes programme. Final results will help to drive change.

At the health services level

Carol Brownson (*USA*) favours the measure-share-improve concept promoted by the Barometer initiative (Figure 2).

She described the Assessment of Primary Care Resources and Supports for Chronic Disease Self-management (PCRS) as a useful and user-friendly tool fitting in with this approach. Individual team members assess patient and organisational support by eight items each, and

resulting scores are discussed together. It can be used in different settings, and improved scores have already been reported.

Tool and instructions can be downloaded, and an online version is under way.⁵

At the individual patient level

Soffia Gudbjörnsdóttir reported on a project to extend the Swedish National Diabetes Register to include quality indicators from a patient perspective, using validated patient report measures that will be linked to the clinical indicators.

Commitment to change

Charlotte Ersbøll (*Novo Nordisk Corporate Vice-President*) and Martin Silink expressed the company's and their own commitment and urged participants to follow their example by writing a personal action plan.

Delegates, encouraged by the display of inspiring and useful models, strategies and tools to help improve patient-centred diabetes care, will agree that David Matthews closed a truly phenomenal DAWN Summit.

Annette HOD Ovink, MD, Editor-in-Chief of the Dutch Diabetes Interactive Education Programme, and Chair of the Executive Committee of the DIEP Foundation, Maastricht, The Netherlands

References

1. DAWN in young people. *Diabetes Voice* Oct 2008; **53**(special issue).
2. Peyrot M, Rubin RR. Behavioral and psychosocial interventions in diabetes. *Diabetes Care* 2007; **30**: 2433–2440.
3. Lauritzen T, Ager Jensen MS, Thomsen JL, *et al.* Health tests and health consultations reduced cardiovascular risk without psychological strain, increased healthcare utilization or increased costs: An overview of the results from a 5-year randomized trial in primary care. The Ebeltoft Health Promotion Project (EHPP). *Scand J Public Health* 2008; **36**: 650–661.
4. <http://www.patientorganizations.org/pchreview>
5. <http://diabetesinitiative.org/lessons/tools.html> (<http://www.improveselfmanagement.org> – coming soon).