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The diabetes marathon

A report from the 10th Annual Conference of the Federation of European Nurses in Diabetes (FEND) 9–10 September 2005, Athens, Greece

'For a person with diabetes, every day is like a marathon,' FEND Chairwoman, Anne-Marie Felton (UK) told a capacity audience of delegates. 'To be involved in a marathon requires training, commitment, endurance and the support of a professional team – and in this case, the professional team consists of dietitians, doctors, psychologists, scientists, laboratory people, and, of course, diabetes nurses.' Ms Felton stressed the need, in the context of diabetes, to maintain the pressure on European political leaders; and urged all delegates to sign FEND's *Athens*

Declaration – to be submitted to the EU (see Box).

The European dimension

The opening address was given by Sotirios Raptis, Chairman of the local Organising Committee. Professor Raptis explained the systems implemented by the Hellenic National Diabetes Centre for the Research, Prevention and Treatment of Diabetes Mellitus and its Complications (HNDC) Network to create a national diabetes database, which now connects the 13 regional diabetes centres. The HNDC also conducts ongoing

diabetes education programmes for healthcare professionals.

EU focus

John Bowis, MEP, FEND Advisory Board member and person with type 2 diabetes, pointed out that while communicable conditions, such as AIDS and tuberculosis quite rightly receive important media attention, non-communicable conditions such as diabetes have a lower global profile. He said that the task of the diabetes community is to alert the world to the potentially devastating threat of diabetes. Laying down a challenge to other politicians with



diabetes to speak openly about their condition, he urged them not to perceive their diabetes as a stigma. He focused on the need for strategies to address the burden of diabetes, including screening, more nurses, improved access to diabetes information, and increased funding for research. He stressed the need for improved diabetes education for the general population. He maintained that increased public awareness would lead to greater interest from governments, and ultimately more spending on diabetes care and prevention.

Diabetes nursing in Europe

Malgorzata Gaslorowska reported on the status of diabetes in Poland: around one and a half million people – 4% of the population – have the condition, about 800 000 of whom are currently undiagnosed. Despite these figures, no government initiatives have been implemented to support the education of nurses in diabetes care. Furthermore, only a small number of nurses have sufficient foreign-language competence to be able to benefit from courses abroad – or indeed most diabetes literature. The achievements of the recently established Polish Federation of Nurses in Diabetes (2004) were highlighted: with a membership of 130, this is the only organisation in Poland to offer diabetes education programmes; the Federation is currently engaged with the Ministry of Health in organising formal diabetes training courses for nurses – the first of these attracted 30 participants.

Stijn Deceukelier described to delegates the approach to healthcare in Belgium, a country with a federal structure in which diabetes comes under the responsibility of various governments. The Vlaamse Diabetes Vereniging (VDV, Flemish Diabetes Association) defends

FEND Athens Declaration

10 September 2005

The pandemic of diabetes mellitus presents a major health challenge for all European national healthcare systems. It is estimated that 30 million European citizens have diabetes today within the European Union with a prevalence of 7.5% in member states. In addition, a further 50% of EU citizens are estimated to have this incurable condition but are currently unaware. This indicates a pernicious low level of awareness and demonstrates a serious and unacceptable deficiency in diagnosis of high risk groups and a lack of national diabetes prevention policies within the EU.

Diabetes continues to be a leading cause of premature death, a 3–4 times higher risk of cardiovascular disease, a 20-fold higher risk of lower limb amputation, the commonest cause of renal failure and blindness. In recent years the emergence of type 2 diabetes in children and adolescents is a new and serious health challenge to the youth of Europe, their families and society. It is further estimated that pre-diabetes affects 100 million people of whom 50% will develop diabetes within the next five years.

The Federation of European Nurses in Diabetes is of the firm conviction that DG SANCO and the Commissioner have a unique responsibility to the citizens of Europe to establish, in partnership with national ministries of health within member states and the relevant pan European NGOs, an EU Framework for the prevention and management of diabetes.

Such is the magnitude of the problem that micro plans are deemed inadequate to meet the challenge of the European diabetes epidemic. A comprehensive European strategy is required to reduce the cost burden in terms of human suffering and economic loss.

The imperative to establish EU leadership, true connectiveness and relevance with its citizens is an opportunity that must be grasped urgently with generosity and sensitivity in partnership with key stakeholders.

We the undersigned urge the political leaders of the EU, members of the European parliament, national members of parliament and Ministries of Health to respond positively and in a timely fashion to this urgent request.

the interests of people with the condition in the region of Flanders. One of the principal objectives of the VDV is to achieve official recognition for professional diabetes nurses. In 1984, the VDV initiated a diabetes educator training course for nurses and dietitians. Ten years ago this was transferred to higher-education institutions. While the course itself is officially recognised, an officially endorsed professional qualification has yet to be approved.

According to Emanuela Orsi, the situation of diabetes nursing in Italy offers cause for optimism. The Operatori Sanitari di Diabetologici Italiani (OSDI), the association representing nurses in diabetes care, research and education, implements

successful training courses for its members. The OSDI plans to create a group of professionals with a self-regulating structure that will enable the management of OSDI training activities. The current design will carry the OSDI training programme, which endeavours to improve ongoing diabetes nurse training, through to 2009.

Masterclasses

In the empowerment masterclass, Gerrard Reach (France) and Montserrat Castellsagne-Perolini (Switzerland) used the case study of a woman who, at diagnosis of diabetes, had already developed ketoacidosis, and faced a range of personal and social problems. Delegates were invited to discuss



<ul style="list-style-type: none">• Type 1 diabetes UK cohort 23 751 <30 yrs. 1972–1993 FU 2000 369 IHD deaths
<ul style="list-style-type: none">• The SMR higher in women than men 20–29 yrs. SMR 44.8 30–39 yrs. SMR 41.6 Laing SP, <i>et al</i>, <i>Diabetologia</i> 2003; 46: 760–765
<ul style="list-style-type: none">• Coronary calcification 3-fold higher in 30–55yr women than men with Type 1 diabetes Colhoun HM, <i>et al</i>, <i>J Am Coll Cardiol</i> 2000; 36: 2160–2167

Table 1. Type 1 diabetes a stronger CVD risk in women than men

optimum approaches to address this situation. It was felt that while empowerment is suitable for most people, it is not necessarily appropriate for everyone; a flexible individualised line – neither fully, nor permanently paternalistic or informative – was seen as the key to reinforcing the patient's autonomy, and represented a sound objective in her care.

Molly Courtenay, June James and Deirdre Kyne-Grzebalski discussed training in extended nurse prescribing. Some of the factors underpinning the drive towards nurse prescribing in the UK were explained, including: the major task represented by chronic disease management in the 21st century, an increasingly aging population, and a lack of specialist knowledge among general practitioners. She outlined the results from published research on the benefits of nurse prescribing. Patients were reported to be generally positive about the initiative; their time was optimised, there were greater reported levels of convenience and continuity of care; and more detailed information on medicines was received. Doctors had improved professional relationships with nurses, faced

fewer interruptions to sign prescriptions and, overall, enjoyed a reduced work load. For nurses, improvements were reported in job satisfaction, status, autonomy and time-management. However, nurses reported anxieties relating to making diagnoses and writing prescriptions – through, for example, a lack of pharmacological knowledge.

Perspectives on diabetes

The autobiographical approach

In a particularly well-received presentation, Natalia Piana (Italy) used music and a voice-over by co-presenter Aldo Maldonato to explain the 'autobiographical approach' to diabetes management. Summer camps are organised to provide therapeutic education for young people with type 1 diabetes, during which they describe the impact of diabetes on their life and what they have learnt from the experience at the camp. Healthcare professionals applied the same methodology in their training: in order to take care of another person, and offer effective self-care education, the health professionals focused on self-knowledge – reflecting on their own educational philosophy, and the extent to which this influences their professional practice.

Diabetes and women

Anne Dornhorst (UK) explained the diabetes-related differences between women and men: neonatal diabetes can be X-linked recessive; the earliest peak of type 1 occurs in girls; Maturity-Onset Diabetes of the Young (MODY) is often diagnosed in pregnancy; mitochondrial diabetes is exclusively maternally inherited; there is an excess maternal transmission of type 2 diabetes; and gestational diabetes is, of course, exclusively a female condition. The impact of diabetes on a person's life and on the people who care for them is

influenced by gender; biological and physiological differences exist. For example, in the middle years, type 2 diabetes is a stronger risk for cardiovascular disease in women than in men (Table 1). However, Dr Dornhorst stressed that women and girls are also exposed to different social and cultural pressures relating to their role in the family and workplace; the psychological pressures are also very different. Concerns relating to body image might result in the development of eating disorders in young women with diabetes, while concerns relating to pregnancy can result in the decision not to have a family. According to Dr Dornhorst, defining and understanding these differences would help healthcare professionals provide improved clinical and psychological support for the people in their care.

Evidence-based practice

Seyda Ozcan (Turkey) explained that evidence-based practice was an approach to problem solving and continual professional learning which required the use of current best evidence from research and recommended that this be integrated into clinical policy and practice. In the first step of the evidence-based approach, questions are asked which focus on information needs. Answers and strong evidence to support them are then sought from research findings in the literature. Professor Ozcan described the pyramid of such evidence in terms of its quality (Figure 1). Systematic reviews of rigorous studies provided the best evidence of the effectiveness of different strategies for promoting behavioural change. However, in evidence-based diabetes practice, the literature often fails to provide convincing evidence for complex non-pharmacological behavioural interventions, such as education and diet. Professor Ozcan



offered some practical recommendations. For example, access to the Internet was necessary and healthcare professionals should master how to discern reputable web-based sources of information.

Stem cell research

Alison Murdoch (UK) from the Newcastle Fertility Centre gave delegates a fascinating update on the latest developments in stem-cell research, which, she said, some people have already hailed as a future cure for diabetes. However, she warned, 'we are still a long way from therapy and we must caution against creating false hopes.' The implications for people with diabetes relate to, in the short to medium term, understanding the pathology and, in the long term, providing new treatments. Professor Murdoch explained the practical and ethical problems that need to be overcome and the complications caused by the wide variations in regulation in different countries. However, the ultimate goal will be to create patient-specific functioning insulin-secreting cells, thus overcoming the problems of rejection.

The industry perspective

Athol Grieve is the President of LifeScan for Europe, Middle East and Africa and he started his presentation by paying a warm tribute to FEND and its leadership which, he said, was providing a powerful voice for diabetes nursing within Europe when the future of diabetes care was being debated. Helping people with diabetes live normal lives without fear and complications should be the goal of all involved in the condition, he said. The role of all healthcare professionals but particularly specialist nurses, would be critical in achieving this. However, emphasised Mr Grieve, there was also a very important role for industry because discovery and

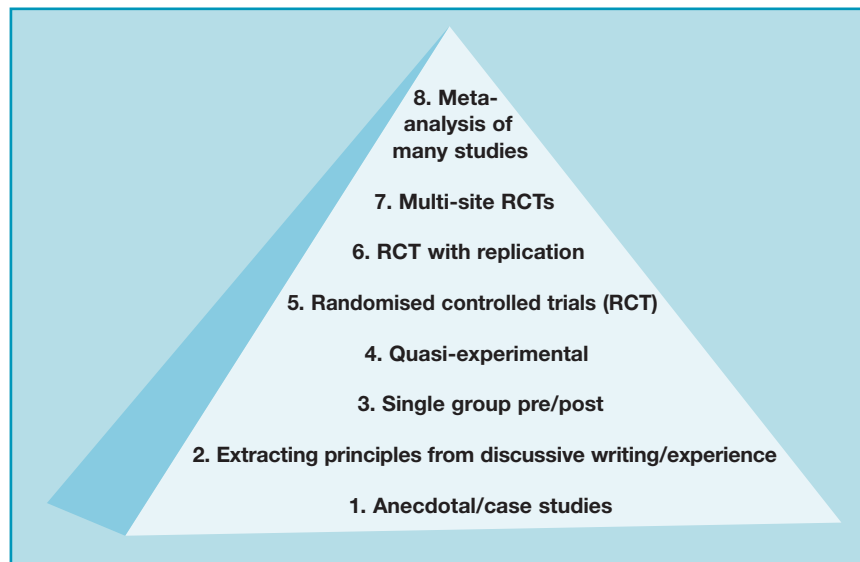


Figure 1. Pyramid of evidence-based approach

product innovation were essential to improve diabetes care. However, the industry could help in other ways, for example, by helping to ensure that patients were better informed and by ensuring that healthcare professionals were adequately armed. Mrs Felton noted that Lifescan had been a supporter of FEND right from the start and on behalf of the members she thanked them for their continued interest.

Posters

The FEND Poster Award went to Eileen Turner (UK) for her study on the socio-cultural implications of insulin. The study aimed to gain a greater understanding of the beliefs and assumptions surrounding insulin, explore the relationship between the perspectives of users and professionals, and identify factors that lead to a reluctance to use insulin.

The Diabetes Education Study Group (DESG) Award went to Gerlinde Feulner-Krakow (Germany) for her poster on an innovative diabetes self-management training programme, known as LINDA, for patients with types 1 and 2 diabetes. The modular structure allows continuing training, from nutrition and medication treatment through to all

kinds of insulin therapy, within a single programme.

Oral presentations

Oral presentations were given by Orvik *et al*, Osterbrink *et al*, Van El *et al*, Larsen *et al*, and Wils *et al*.

Closing the conference

Anne-Marie Felton said that FEND's executive committee could, from time to time, honour those who had contributed greatly to the success of the organisation. This year, the unanimous decision had been to honour a founder member of FEND, Sue Hamilton (UK). Ms Hamilton was a key player in the evolution of FEND since 1995, and served as Secretary between 1995 and 2005.

Ms Felton pointed to the many challenges that lie ahead but was confident in the membership's ability to surmount these. She applauded the many achievements of FEND during its first ten years, and predicted that the Federation will remain at the forefront of diabetes care within the nation states and at the EU level.

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