

**WorldWIDE**

Worldwide Initiative for Diabetes Education

WorldWIDE news

Quality of Life in Diabetes: the Importance of Patient and Physician Education

A message from the chairman

Welcome to the fifth issue of WorldWIDE News. In this issue we look at health-related quality of life (HRQoL) in people with diabetes with a focus on improving HRQoL, the impact of cognitive function, the effect of intensive management regimens on HRQoL, and the role of the diabetes educator in facilitating patient acceptance of insulin use. We look forward to your feedback!

Update on WorldWIDE activities and materials



The extremely popular video 'It's up to you', previewed at the WorldWIDE booth at the European Association for the Study of Diabetes (EASD) meeting last year, is now available to those on the mailing list. Using a combination of film and animation, this 8-minute sequence can be used by clinicians to help people with diabetes understand and avoid the complications associated with their condition. To order a copy, please visit www.worldwidediabetes.com, complete the enclosed form, or email your request to worldwide@adelphi.co.uk. Both VHS (PAL and SECAM) and DVD (any region) versions are available.

WorldWIDE satellite symposium at EASD 2002

I hope you will be able to visit us at the WorldWIDE booth at the EASD 2002, Budapest, Hungary, 1-5 September. As well, I am pleased to announce the first worldwide satellite symposium will be held at the EASD, entitled 'Insulin for People with Type 2 Diabetes — A WorldWIDE Symposium'. The symposium will consist of two sessions: 'Insulin good and bad' and 'Insulin simple or intensive?', and we hope to stimulate thought and debate through a

pros and cons discussion of the issues surrounding insulin use. Speakers include Rüdiger Landgraf (Munich, Germany), Jens Sandahl Christiansen (Aarhus, Denmark), Julio Rosenstock (Dallas, Texas, USA) and Robert Heine (Amsterdam, The Netherlands). The symposium will take place on Sunday, 1 September, from 9:00 am – 11:30 am in the Red Hall at the Budapest Fair Centre.

www.worldwidediabetes.com

The WorldWIDE website, www.worldwidediabetes.com, has proved popular since its launch at the EASD 2001, and the number of visitors is increasing every month. Development of the website will continue throughout 2002, with a number of new exciting features coming later this year, including:

- An online slide selector, allowing you to browse the extensive WorldWIDE slide resource, and create and download your own presentation.
- An interactive teaching tool based on the UKPDS results to help demonstrate the importance of glycaemic control in preventing the complications associated with diabetes.

In addition, we will continue to update and develop the existing content to ensure the site remains a source of high-quality, up-to-date information. If you would like us to notify you when the site has been updated, please visit www.worldwidediabetes.com and register for the update email service. This edition of WorldWIDE News, as well as previous newsletters, are also available on the website.

Philip Home
Chairman, WorldWIDE



Previous editions of WorldWIDE News are available at www.worldwidediabetes.com

Mission of WorldWIDE

To challenge and shape the future management of diabetes in order to provide optimal treatment for all patients and to enhance professional education for physicians and other diabetes professionals

Health-related quality of life: addressing the challenge

There has been much debate and discussion about health-related quality of life (HRQoL) in people with diabetes. A WorldWIDE Working Group met to discuss how clinicians can help people with diabetes in balancing short- and long-term HRQoL. Participants at the meeting were Philip Home, Massimo Massi-Benedetti, Frank Snoek, Tero Kangas and Tim Dornan.

What is meant by the term 'quality of life'?

What is meant by the term 'quality of life'? The more thought that is put into this question, the more difficult it seems to be to answer. To complicate matters, the terms 'quality of life', 'well-being', 'health status' and 'patient satisfaction' are often used interchangeably. HRQoL is a multi-functional construct, encompassing aspects of psychological, social and physical well-being and the Working Group agreed that it should reflect the person's subjective evaluation of well-being.



Dr Tim Dornan



Professor Massimo Massi-Benedetti

Dr Tim Dornan is a Senior Lecturer in Medical Education and a consultant physician at Hope Hospital in Salford, UK. One of his primary interests is professional education, and he is currently involved in teaching communication skills to healthcare professionals.

Professor Massimo Massi-Benedetti is based in the Department of Internal Medicine at the University of Perugia in Italy. He is also Chairman of the International Diabetes Federation (IDF) Europe, an aim of which is the empowerment of people with diabetes through diabetes associations.

Dr Tero Kangas works in private practice in Helsinki, Finland, having recently retired as Chief Physician and Consultant for Internal Medicine and Diabetes of the Eastern Health Centre, Helsinki. He has a vested interest in the study of diabetes and patient care as he himself has Type 1 diabetes.

The impact of diabetes on cognitive function

Dr Frank Snoek discussed the impact of diabetes on cognitive function. Find out more by reading the article by Frank Snoek on page 3 of this newsletter.

HRQoL from the perspectives of the physician and person with diabetes

The role of the clinician can be viewed either as an authority in diabetes healthcare or as an equal and co-operative partner with the necessary knowledge to identify and solve problems — people with diabetes expect to be treated as an equal partner with their healthcare team.

How to improve patient HRQoL

HRQoL can be enhanced by improvement in physician-patient communication and education that targets behaviour change. These issues are discussed further in the article 'Improving quality of life in people with diabetes' below.

Talking point — Improving quality of life in people with diabetes

Interventions suggest that improved patients' health status and perceived ability to control their diabetes (coping skills) result in improved health-related quality of life (HRQoL).



Improved patient-physician communication

Improved communication between the patient and physician has been shown to improve psychosocial outcomes, treatment adherence and biomedical outcomes. A consultation should be regarded as an exchange of information between two experts — the physician and the person with diabetes. Patients should be encouraged to seek information and express their priorities and fears. The physician can then help to provide relevant information and negotiate goals.

Education, knowledge and the application of knowledge

Knowledge, or specifically the ability to utilise knowledge appropriately, is considered to have a great impact on HRQoL. In recent years, educational techniques have shifted from didactic presentations to interventions involving patient 'empowerment'. However, disease insight does not necessarily improve HRQoL. Anxiety-provoking information can be perceived in different ways depending on the quality and intensity of the information. Education about complications should include positive information. Effective diabetes-coping skills can result in a positive cascade of enhanced well-being, active diabetes management, improved glycaemic control and fewer complications.

Behaviour change

The importance of behaviour change in patient-focused strategies to improve diabetes care and HRQoL has recently begun to receive attention. Two elements that are central in helping people with diabetes to achieve long-term behavioural changes are:

- Highlighting the importance of change
- Building confidence to encourage change.

A technique that focuses on assisting healthcare professionals to change patients' behaviour is motivational interviewing. This aims to increase motivation to change by encouraging patients to explore any ambivalence about altering their self-care behaviour.

An objective of WorldWIDE is to help bring about a change in behaviour through a number of initiatives. These initiatives include the video 'It's up to you', developed with the purpose of helping clinicians explain the complications associated with diabetes to patients. A number of teaching tools are available on the website, www.worldwidediabetes.com, such as interactive case studies, copies of WorldWIDE News, a slide resource kit, and patient communication tools.

The impact of diabetes on cognitive function

Dr Frank Snoek is Associate Professor in Medical Psychology at the Vrije Universiteit Medical Centre in Amsterdam, specialising in psychosocial aspects of diabetes. Dr Snoek has been involved as consulting psychologist in emotional and behavioural issues in diabetes care, and has studied the psychological barriers to optimal diabetes self-management and exploring quality of life issues. He is founder and chair of the Psychosocial Aspects of Diabetes (PSAD) Study Group of the EASD and a member of the Consultative Section Education of the International Diabetes Federation (IDF).

Cognitive function in people with diabetes has increasingly gained attention over the years; however, in the context of health-related quality of life (HRQoL) it is not yet well understood.

Hypoglycaemia and hyperglycaemia

When determining HRQoL, the extent of diabetes-related issues such as hypoglycaemia and hyperglycaemia comorbidity needs to be assessed, as both of these impact on the level of cognitive function. Evidence shows convincingly that acute hypoglycaemia results in temporary impairment of cognitive functioning. Acute hyperglycaemia is less well studied, but generally results in mental slowing. Severe hypoglycaemia, particularly in the early years of life with a maturing brain, has detrimental effects in the areas of attention, memory, processing speed and execution functions (Ryan et al, 1985). In addition to — and perhaps even more than — hypoglycaemia, chronic hyperglycaemia may impact adversely on brain function as a result of 'central neuropathy' characterised by mental and motor slowing, reflecting slowed neural transmission efficiency.

Cognitive function plays an important role in health status and should be included in the evaluation, but assessment of HRQoL questionnaires reveals that questions on cognitive performance are few or even absent. If we regard HRQoL as a multidimensional construct, cognitive functioning — particularly from a subjective perspective — should and can be included.

An interesting point regarding the assessment of cognitive function and health status is the extent to which people are actually capable of rating their own cognitive performance. People may report a subjective decline, for example, in memory or concentration, but objectively they do not perform badly, i.e. below the norm. This subjective experience is important, however, as it can cause anxiety and worry.

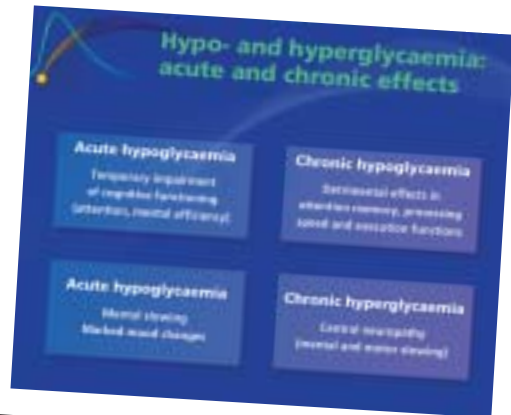
How does cognitive function impact on self-care?

Self-care is the cornerstone of diabetes management, but very little is known about the clinical relevance of cognitive function on self-care. In Type 1 diabetes, diabetes-related cognitive impairment — if it exists — will impact on school performance and psychosocial development. With regard to Type 2 diabetes, a better understanding of the threshold of cognitive dysfunction that impacts on both HRQoL and interferes with adequate self-management is required.

Some key questions still remain. How can cognitive dysfunction be prevented? In those people who have developed cognitive dysfunction, what are the opportunities for rehabilitation?

Reference

Ryan C, Vega A, Drash A. Cognitive defects in adolescents who developed diabetes early in life. *Pediatrics* 1985;75:921–927.



Talking point — Is intensive glycaemic control related to quality of life?

The relationship between glycaemic control and health-related quality of life (HRQoL) is a complex one. Some people with diabetes experience good glycaemic control in conjunction with good HRQoL, while in others, poor HRQoL exists despite good metabolic control; this may be related to the day-to-day burden of having to self-manage diabetes. Other people report satisfactory HRQoL despite poor glycaemic control — people in this group may 'deny' their diabetes, allowing them, at least in the short term, to enjoy life without having to worry about their diabetes. Poor glycaemic control and poor HRQoL can coincide in people, often affecting each negatively as both the cause and effect of poor diabetes control.

Good health does not guarantee happiness

An intriguing finding from HRQoL research is the relatively weak association between patients' objective health status and their subjective life quality. Studies assessing the relationship between glycaemic control (HbA_{1c}) and subjective well-being report a poor correlation (Dornan et al, 1992; Petterson et al, 1998); it appears that good health in itself does not guarantee happiness, and neither does good glycaemic control.

Intensive diabetes management and HRQoL

The benefits of improved glycaemic control may be outweighed by the burden of intensive self-management required to achieve strict glycaemic control.

In this scenario, it could be argued that perceived HRQoL may not necessarily agree with objective parameters of metabolic control. However, large prospective studies such as the Diabetes Control and Complications Trial (DCCT) and the UK Prospective Diabetes Study (UKPDS) have found no evidence for an adverse effect of strict glycaemic control on patients' well-being (DCCT, 1993; UKPDS, 1999).

Over the years, HRQoL has been recognised as an important outcome of medical treatment and has become a core issue in diabetes management. Evidence suggests that certain interventions, designed to facilitate the development of diabetes-specific coping skills, can improve both glycaemic control and HRQoL in people with diabetes.

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The role of the diabetes educator in facilitating patient acceptance of insulin use

Brigitte Osterbrink is a diabetes educator and member of the Committee for Education of the German Diabetes Association (DDG). She is currently involved in teaching diabetes educators for certification by the DDG.

Integrated programmes of treatment that include input from general practitioners (GPs), diabetes specialists, diabetes educators and people with diabetes themselves are increasingly being used by healthcare systems. As well as spreading the large load of diabetes care and reducing costs, such programmes promise to ensure more comprehensive provision of optimal management of diabetes and its complications. The importance of diabetes self-management education in this strategy is emphasised in current clinical practice recommendations (Mensing et al, 2002).

Diabetes nurse specialists (diabetes educators) can play a central role in this process. In addition to providing a vital link between primary and secondary healthcare, they can teach patients the appropriate behaviours and techniques required for effective self-management. Accordingly, several national bodies now provide formal certification for diabetes educators, including the National Certification Board for Diabetes Educators (NCBDE) in the USA, the Certified Diabetes Educator Certification Board (CDECB) in Canada and the German Diabetes Association (DDG).

A good example is provided by looking at the extensive role of the diabetes 'counsellors' certified by the DDG. These professionals generally work in hospitals or the practices of specialists or GPs. They are responsible for the education and counselling of people with diabetes as delegated by, and under the supervision of, medical specialists or GPs. They may also offer further education for hospital or community care staff, in addition to visiting and supporting patients in hospitals.

One of the main tasks of these diabetes counsellors is to conduct education and self-management programmes. These can address a range of issues such as comprehension of the disease and complications; self-monitoring and diet; injection and the effects of insulin; contraception/pregnancy; skin/foot care; sports/exercise and coping strategies. Aspects of the programmes also address issues specific to insulin use and increasing its acceptance. Group education can also be offered specifically for patients who inject insulin, including information on the importance of insulin use in relation to minimising late complications.

Whereas the role of the diabetes educator is well established in countries like Germany, there is a need for more diabetes counsellors globally. Other strategies may also help improve the integrated team approach. Examples include the development of new credentials (such as the 'advanced diabetes manager' in the USA [Daly et al, 2001]), or the concept of the GP diabetes specialist (within a large practice of other GP specialists) that is gaining acceptance in some countries, such as the UK.

References

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Do you have a case history or discussion topic that may be of interest to your colleagues? We would like to hear from you.

Although we cannot guarantee that your case history or topic will be discussed, we hope to be able to feature them in future issues of WorldWIDE News and on the www.worldwidediabetes.com website.

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Don't forget to include your contact details!

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