Patient self-management education and long-term follow-up

Highlights from the 2nd International Congress on Therapeutic Patient Education, 5–8 November 2008, Budapest, Hungary

As Congress Chairman Aldo Maldonato stated, the growing burden of chronic disease – often associated with unhealthy lifestyles – requires more efficient strategies that facilitate individuals' inner motivation and sustain permanent lifestyle changes, to improve outcomes and quality of life.

Self-management education

Martha Funnell (USA) described the evolution in diabetes self-management education (DSME) from didactic presentations that improve short-term outcomes and quality of life, to more evidence-based empowerment models that provide ongoing support. As patients in chronic care are involved in 95% of health-related decisions, they are the experts for their own lives, who are responsible for their futures. Patients are not interested in diabetes, but in living with their own diabetes, the speaker stated, and empowerment is the path to responsible self-care. Culturally and age-appropriate learning programmes and group education strategies are definitely effective. Behaviours can be symptomatic of problems, stressed Martha Funnell. Consequently, addressing psychosocial issues as an integral part of DSME has high priority and is associated with improved outcomes.

Empowerment approach

Martha Funnell and Robert Anderson (USA) defined empowerment as 'creating the conditions for patients to be responsible for the self-management of their diabetes'. Empowerment is a patient-centred approach that is designed to facilitate self-directed behaviour change, psychosocial adaptation and improved quality of life. Healthcare professionals (HCPs) should be responsible *to*, not *for*, their patients, serving them by helping them reflect on concerns, priorities, choices, resources and goals.

The speakers' experiences with group education in African Americans[1] resulted in a radical departure from traditional education strategies. Lectures were discarded and the content of their course is determined by participants' questions and concerns, and the findings of their self-management experiments.

After identifying a problem and formulating a goal (and action plan) related to self-management, solutions are presented during the next session, taking the form of learning experiments. The speakers described other key elements; namely, systematic problem-solving and integrating emotional, behavioural and clinical aspects into education programmes.

T Tang (USA) showed that this intervention resulted in significant improvements in HbA_{1c}, body mass index and low-density lipoprotein levels after 12 months.

To direct, or not?

Koula Asimakopoulou (UK) raised this question by analysing assumptions about what constitutes an equal partnership. Minimum standards are needed to establish the knowledge level sufficient for rational decision-making and communication skills in HCPs. Moreover, Koula Asimakopoulou warned delegates to be careful about abdicating responsibility to someone who is not interested in being, or able to be, equal. She felt that there was room for a clearer definition of empowerment, advocating motivational interviewing as a client-centred directive method. She also challenged the concept of patient-centred empowerment, commenting that HCPs should listen and choose a consultation style best fitting the HCP and patient in a given phase of the relationship.

TPE/DSME: organisation and evaluation

A Musilli (Italy) demonstrated the feasibility of a team-based model of care – which included well-trained care managers in general practices – to educate and empower patients with chronic conditions. Joan Everett (UK) reported the growth

The 2nd International Congress on Therapeutic Patient Education: Patient-centred self-management education and long-term follow-up strategies in diabetes and other chronic diseases provided a meeting place for around 600 participants from 53 countries.

Participants were mainly behavioural scientists and healthcare providers. The selected diabetes-related topics described in this report were presented in workshops, lectures, communications and poster sessions.

of structured education after the Type 1 Education Network was set up in 2003. This network supports diabetes teams that are implementing programmes such as DAFNE. A Clarke (Ireland) developed effective group education for type 2 diabetes patients in areas with limited access to diabetes services.

Helen Mosnier-Pudar presented a survey of diabetes patient education in France, and identified insufficient funds, resources and training as being the main barriers for implementing therapeutic patient education (TPE) in routine care. The speaker stressed the importance of structuring TPE and training HCPs.

AF Pauchet-Traversat reported on a very useful guide on structuring TPE (from the French National Authority for Health[2]), which includes a list of criteria to assess its quality. Quick reference guides were available in English at the congress; however, only the French version of the complete guide could be located by the author of this report, who is confronted with comparable implementation problems in The Netherlands (as demonstrated in a poster).

Knowledge and understanding, self-management, self-determination and psychological adjustment were identified by Ruth Colagiuri (Australia) as outcomes that are most directly affected by diabetes education. A critical appraisal of available tools led her to conclude that suitability, adequate psychometric testing for the intended purpose, burden and feasibility must be considered before adopting tools for measuring these outcomes.

The American Association of Diabetes Educators regards measurable behaviour change as the desired outcome of diabetes education, outlined Amparo Gonzalez (USA). The effectiveness of DSME can be determined by evaluating before (and at regular intervals after) education seven self-care behaviours: healthy eating; being active; self-monitoring; taking medication; reducing risks; problem-solving; and healthy coping. Amparo Gonzalez examined evidence relating to these behaviours and their underlying theories. Her findings provide increased evidence for the value of DSME and support the AADE7™ framework. That TPE is cost-effective was shown by Alain Golay (Switzerland), who calculated the number-needed-to-treat to be about nine.

Learning from the many varying TPE programmes across diseases, centres, countries and cultures can be helpful in setting up or improving programmes, especially when enabling a critical appraisal of the increasing evidence underlying them. Therefore, the Hamburg group (led by Ingrid Mühlhauser) proposes to establish an international internet-based scientific network based on the UK Medical Research Council framework. This would include a database for which authors are asked to provide publications and educational materials. The aim is to systematically identify components that appear indispensable for the development, evaluation and implementation of self-management programmes. For more information please contact the speaker, M Lenz (matthias-lenz@uni-hamburg.de).

Shared decision-making

Shared decision-making is based on effective communication of information that patients can trust. How difficult this can be was illustrated by Andrew Brooks (UK), who showed differences in how HCPs, medical students and patients interpret risk-related terminology, and by C Cates (UK), who described the challenges in translating evidence into practice when trying to stop treating acute otitis with antibiotics.

Ingrid Mühlhauser (Germany) deplored the lack of decision aids in diabetes, stating that the quality of diabetes trials is poor, because patient-important outcomes are missing. The fact that the German parliament recently accepted a petition by breast cancer patients who demanded accessible and understandable information about guidelines and evidence-based studies, thus honouring the right of patients for autonomy and informed decision-making, can be seen as a great leap forward.

Psychosocial support

The importance of family-centred psychosocial support was addressed by Barbara Anderson (USA). The assessment of psychosocial needs in the clinical encounter was outlined by Frank Snoek and Maartje de Wit (The Netherlands), and presented as part of the DAWN MIND (Monitoring of Individual Needs in Diabetes) project at the DAWN Summit. Psychosocial factors play a key role in diabetes management but are often neglected. Psychological comorbidities are common but often go undetected. Limited time and unfamiliarity with psychological instruments and outcomes among HCPs were barriers that can (and should) be overcome, to support patients to change behaviours and cope with the demands of chronic illness.

Peer support

As the emotional impact and daily lifestyle decisions also affect those around the patient, peer-led interventions are seen as promising strategies for sustained support.

WHO-representative GC Xuereb reported on a 2007 WHO consultation[3] about the evidence of its effectiveness. Peers are defined as those who have diabetes or those who are affected by it, such as the parent of a child with diabetes. Their role as not-compensated volunteers and their contributions to diabetes care are acknowledged and shaped by their communities. Peers do not replace HCPs, but their support can alleviate the resource constraints facing professional programmes. A patient-centred approach, including goal setting and problem-solving, should be a feature, as should appropriate training and evaluation.

M Heisler (USA) stressed that DSM strategies have far more impact than any other strategy on a population's health, and that peer support adds to time-restricted professional interventions by sharing experiences, exchanging knowledge and skills, and receiving as well as providing support.

Highly structured teaching protocols for peers, covering different chronic diseases, were designed by Kate Lorig (USA). She described a peer-led Spanish DSME-programme[4] that improved HbA_{1c} levels, health status and self-efficacy at 6 months, with benefits persisting at 18 months. The results of a study on an internet-based group workshop, comparable with group sessions and the same programme in the UK, are awaiting publication. Finally, G Hochberg (France) identified family support, onset of complications and start of insulin therapy to be crucial elements in modifying behaviour.

Children and adolescents

Barbara Anderson, who directs TPE-programmes for diabetic children in Houston (USA), stressed the urgent need for age-appropriate education and psychosocial support. With the growing incidence of type 1 diabetes in children and type 2 diabetes in obese adolescents, it must have equal first priority alongside medical treatment, she advised.

The positive psychosocial, behavioural and sometimes metabolic benefits of group sessions, internet exchanges and camps for youngsters were shown in several lectures and posters.

Benefits of self-expression in chronic disease

The Italians have great experience with the narrative autobiographical approach, as shown by Natalia Piana, an inspiring performance by cancer patients at the opening session, and by D Bloise. The approach helps to discover and understand an individual's own way of living, and – especially when confronted with illness – to reveal condition-related needs and feelings, thus serving as a tool for acceptance and coping.

This was further illustrated by personal accounts of self-expression, such as writing about life with anorexia, painting, engaging in advocacy for diabetes, and the Italian running project 'I move my life' for type 2 diabetes.

Educating the educators and 'educating science'

Educating educators was an important poster theme; educating science was addressed in a session chaired by FEND president Anne-Marie Felton (UK) and DESG president José-Manuel Boavida (Portugal). Many presentations stressed the importance of better training of HCPs in educational theories and skills.

MG Albano's (Italy) recent analysis showed that only a minority of the increasing number of TPE-related articles concern diabetes. These mainly cover type 2 adults, with group-education as the most widespread strategy. Such articles address the positive effects of TPE rather than the problems.

Congress Chairman Aldo Maldonato commented that the challenges for future research and action are in finding methods to overcome barriers, providing access to effective TPE and implementing the art of education.[5] Jean-Philippe Assal, the European nestor of TPE, brilliantly illustrated the art of education demonstrated by pedagogues like Pestalozzi, Bernard and Montessori, who already used structure, observation and play to bring about autonomy. European Foundation for the Study of Diabetes Chairman PA Halban paid tribute to Joslin for starting diabetes education in 1935 in close connection with researchers at his clinic. He suggested that education could bring scientists and patients together in a two-way dialogue, that would (to mutual benefit) close the loop between those involved in healthcare, services, industry and research.

I hope that those gathered in the welcoming city of Budapest will have returned to their posts sharing the infectious enthusiasm of Obama, elected as US President during this congress: 'Change has come' and 'Yes, we can!'

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