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The diabetes education study group and its activities to improve the education of people with diabetes in Europe

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Abstract

In this article the activities of the diabetes education study group (DESG) are presented. It is an important example of the coordination of the European patient education in the field of diabetes. Given the therapeutic role of patient education, doctors must be involved in the entire process, as members of the multi-professional team, who carry the responsibility for the planning and implementation of the educational process. Based on these assumptions, the DESG concentrated on the following activities: workshops, congresses, teaching letters, a 5-min education kit, a web-site, and a basic curriculum in therapeutisc patient education. The future of therapeutic patient education in the field of diabetes is discussed. © 2001 Elsevier Science Ireland Ltd. All rights reserved.

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1. Introduction

The diabetes education study group (DESG), a section of the European association for the study of diabetes, was founded in 1979 upon the initiative of Jean-Philippe Assal.

According to its constitution, the aim of the DESG is ‘‘to improve the quality of life of the diabetic patient through the development and evaluation of educational programmes designed to foster independence for the patient, to improve the quality of metabolic control, to emphasise the importance of prevention and early recognition of the disease and to encourage relevant research’’. In the pursuit of these goals, the DESG has organised many workshops and congresses, and has published more than 20 teaching letters to update health care providers on specific educational topics. It has also published two series of basic handouts for people with diabetes, the 5-min education kit and the patient education basics, to summarise selected topics in few minutes according to given guidelines.

These activities have been continued at the national level throughout Europe by organisations that have flourished in both western and eastern countries. These organisations, although not official sections of the DESG, refer in their name and/or in their constitution to the parent body as a source of continuing inspiration. Examples include the Italian

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Gruppo Italiano di Studio per l'Educazione sul Diabete (GISED) founded in 1980, and the French DESG de Langue Française founded in 1991. The written documents produced by the DESG have been translated into more than 20 languages and distributed all over the world. Most recently, the DESG has published a comprehensive web-site on the Internet, where all DESG publications can be found and freely downloaded.

2. DESG history and structure

The history of the DESG from its very beginning in 1977, its gestation, choice of name and logo, and the first few years' activities were described by Assal et al. in 1982 [1]. A more recent history of the DESG can be found in the chairman's annual reports, given at the annual meetings of the general committee, and which are published in the DESG web-site (chairman's reports in history section).

To lead the DESG, the president is assisted by a six member executive committee. Each executive committee member is elected by the general committee, and serves a term of 4 years. The general committee is composed of two representatives per European country, who serve for 3 years.

Membership of the DESG is limited to persons actively involved in the education of diabetic patients. Applicants must be endorsed by two active members. At the end of the year 2000, the updated list of DESG members includes 667 people from 67 countries. This list is available in the members' area of the DESG web-site, as is the list of the general committee members.

3. The DESG approach

Up to the 1970s, the education of diabetic patients had been practised by isolated pioneers and had just recently been accepted as a powerful therapeutic tool in the United States, thanks to the demonstration of its efficiency [2].

However, facing the widespread failure to translate optimal diabetes care into daily practice, the prevailing attitude of doctors and other health care providers was still to consider the diabetic patient, albeit not responsible for his care, guilty nevertheless for the failure.

From the beginning, the DESG approach has been based on a few assumptions that have guided its activity throughout the years [3]. People with diabetes do not necessarily cheat or lie more than anybody else. If they do not accept our advice, they either do not know why or how, they perceive the cost/benefit ratio as too high, or they have not yet come to terms with this particular life-long disease.

As a consequence, the responsibility of health care providers caring for people with diabetes extends far beyond the traditional tasks of diagnosis and medication. It includes informing patients, training them to acquire the required skills, and using all means to improve each one's motivation for treatment and monitoring (which is different for different kinds of individuals).

To be effective for the largest possible number of patients, health care providers need to acquire numerous skills that are not traditionally included in professional curricula, and that belong to the domain of the so-called human sciences: pedagogy, psychology, sociology, anthropology, and bioethics.

In addition, a profound change is required in the attitude of doctors, nurses and dieticians interacting with the majority of people with diabetes. A shift must be made from the traditional, authoritarian, paternalistic attitude, to an attitude of full acceptance, empathy, and encouragement to share the responsibility of treatment choice and day to day implementation.

Despite all the difficulties to be faced in acquiring new professional skills and in changing roles and attitudes, the effort is worth making, because it is the only way to improve our effectiveness in the treatment of chronic diseases. Given the therapeutic role of patient education, doctors must be involved in the entire process, as *the* members of the multi-professional team, who carry the responsibility for the planning and implementation of the educational process.

In accordance with these assumptions, the DESG has concentrated on:

- increasing the awareness of doctors, nurses, dieticians and other HCP caring for people with diabetes about the difficulties they encounter in educating people with diabetes;

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- encouraging health care providers to find ways to overcome these difficulties by improving their skills, their attitudes, and some aspects of the structure where they work;
- applying existing models, or developing new ones, to better understand what influences the motivation of different people with diabetes to learn and properly treat themselves;
- fostering research in the field of therapeutic patient education, and developing and evaluating educational programs for patients, based on current educational trends.

The activities which have been accomplished in accordance with the above are briefly summarised here.

4. Workshops

The DESG has developed a format of interactive workshop which through the years has become a sort of trademark of this. It typically consists of a full-time, 5-day meeting, with 30–60 participants. Several aspects of therapeutic patient education, kept logically together by the general title of the workshop which is almost always different, are analysed and worked upon. A comprehensive list of the workshops held so far is published on the DESG web-site (past workshops in history heading). Examples of workshop titles are: "to listen and to learn", "which objectives in diabetes education?", "which methodologies for patient education?", "improving long-term follow-up of people with chronic diseases", and "diabetes and management of long-term complications: amputations, neuropathies, blindness".

4.1. Formal lectures

Based on the principle of learning by doing, the DESG workshops have always given priority to group activities. The time devoted to formal lectures is limited to less than 25% of the total working time, e.g. one 20–30 min lecture in every 2 h. Many of these lectures are given by experts in disciplines other than diabetes, and who are often not even in the field of medicine. Examples are Elena Benaduce, psychopedagogue; Jack Bresnahan, editorialist and musician; Bernard Crettaz, ethnologist; Danilo Dolci, sociologist; Jean-Jacques Guilbert, medical pedagogue; Marcos Malavia, set designer and mime; Hassan Massoudy, Arab calligrapher; Ilario Rossi, anthropologist; Guido Ruffino, pedagogue; Caroline Simonds, clown; Sandro Spinsanti, bioethicist; and Alberto Zucconi, psychologist.

4.2. Interactive group sessions

Interactive group sessions take 75–80% of working time, e.g. 1.5 h, following each lecture. They consist most often of one of the following.

- 'Group discussions' on certain aspects of the topic introduced by the lecturer. These are held in small groups of 10–15 people, using the technique of Metaplan®, which facilitates interaction among group members and the production of a written document, ready to be reported in the plenary session. They are particularly useful to analyse difficulties, find solutions, plan actions, or establish priorities, both in the education of people with diabetes and in the training of HCP.
- 'Experiential learning': people with diabetes are faced with new tasks to accomplish and new skills to acquire. HCP can only sense how difficult it can be to learn something new, and which help is useful and which is not, if the new task they are confronted with is something not related to diabetes. Continually finding new tasks for the participants, and keeping them secret until the last minute, is a challenge for the organisers. Here, we may recall that the learning objectives have often been inspired by typical local or regional activities.
- 'Experimenting with handicaps': when the topic of the workshop includes helping people with diabetes face handicaps of late complications, participants are given simple tasks that have to be performed with one of the handicaps that may be induced by diabetes: loss of vision, loss of foot sensory capacity, amputation of a leg, etc. The aim is to increase the awareness of the burdens of diabetes complications and improve health care providers' empathic attitude.
- 'Role-playing': this well-known technique is used when dealing with the attitudes of both patients and health care providers. It helps to try and illustrate,

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often in a caricatural way, less effective or more effective attitudes in the HCP/patient relationship.

One particular characteristic of DESG workshops is the strict enforcement of the principle of 'learning by doing': therefore, every activity is both an occasion to focus on a specific aspect of TPE, and an opportunity to experiment a learning method that can also be adopted with patients. A second hallmark is 'creativity', which is known to be associated with more effective teaching: an effort has always been made to renew teaching methods, exercises, perspectives and metaphors, as an example of what health care providers are expected to do in their own practice to meet the different requirements of their patients. Another typical feature is 'the use of art' — mostly music, but sometimes painting as well — to 'tune' participants' minds to the topic of the day: this again is both a tool and a suggestion to search in art, the utmost expression of human intuitive understanding of reality, for a shortcut to help patients' acceptance of the disease and its treatment.

In its 20 years of activity, more than 2000 doctors, nurses, dieticians, and other health professionals have participated in DESG workshops, many of them more than once. A good deal of them have been able to reproduce similar activities in their respective countries all over Europe, thereby initiating the desired snowball effect, which is estimated to have significantly improved the way diabetic patients are cared for in many European diabetes centres.

5. Congresses

Two European symposia on patient education were organised, in 1979 and 1982, in Geneva. In 1994, a large congress was held in Geneva under the auspices of the WHO and Geneva University. Although not organised by the DESG, a significant proportion of DESG members actively attended. There were more than 600 participants. The title was ''patient education 2000: international congress on treatment of chronic diseases''. The topics covered nine chronic conditions: arterial hypertension, autonomous dialysis, back pain, bronchial asthma, colostomy, diabetes mellitus, epilepsy, laryngectomy, and Parkinson's disease [4].

6. Teaching letters

From 1983 to 1988, the DESG produced a series of 20 teaching letters during four 3-day workshops in Switzerland and Greece. They consisted of about four pages each, in the 'medical letter' format, and have been translated into 26 languages and distributed world-wide.

Updating was started in 1995, and publication of the revised teaching letters will soon be completed. In 1998, the DESG began the production of a new series, aimed at highlighting several aspects of therapeutic patient education, which either had not yet been considered specifically, or deserved consideration from another point of view. A first series of five new teaching letters was produced by a group of 28 doctors, nurses, dieticians and psycho-pedagogues from 13 different countries, all experts in therapeutic patient education, during a 5-day workshop in Italy.

The experience of this group of health professionals with the use of the first series of teaching letters allowed them to offer suggestions on the possible fruitful use of these documents.

- The previous teaching letters have been used as a reference of basic standards for therapeutic patient education to provide curricula for: (a) HCPs; (b) patients; (c) policy makers.
- In several instances they have been used as tools to educate the educators, to facilitate the use of a common language, to focus attention on specific topics and to change HCPs' attitudes. They have been used in several contexts, e.g. during interactive workshops for HCPs on therapeutic patient education or during conferences.
- They have proven to be especially useful in team work, helping to define the role of each member of the diabetes team, facilitating problem-solving discussions within the diabetes team and interactions between staff members, enabling all team members to stay on the same educational track.
- They have also been helpful in the evaluation of patient education, making it easier to define results.
- The teaching letters have proven most valuable in the multidisciplinary approach, the problem-solving approach, the interactive approach, and in

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their proximity to the patients' condition, when HCPs knew of their existence and had them readily available.
- Sound use of the teaching letters has been preceded by an analysis of the educational needs of HCPs and by an adaptation to individual local situations, making them part of a project for personal and team development.

An updated list of teaching letters is shown in Table 1. The documents can be read and downloaded, both as plain text and in the original editorial aspect, from the DESG web-site (our-materials in teaching letters section).

7. The 5-min education kit

This is a document for health professionals and patients, produced in 1994, during two 3-day workshops in Switzerland, by 57 health care providers from 24 countries.

Its 'raison d'être' is well explained by Assal in his introduction to the document. "Lack of time is, and always will be, a frequent excuse for not educating patients with diabetes. The executive committee of the DESG has decided to approach this problem in a very pragmatic way. After extensive enquiries, many physicians told us that they would be willing to spend 5 min to teach their patients but they did not, because of lack of specific guidelines. This is the reason why we have organised two seminars to deal with the problem of 5 min 'education for patients with diabetes'. Even 5 min can be part of life-long learning. Shortage of time makes it even more necessary to identify the most efficient strategies. This is why we have developed the concept of the survival kit for health care providers and patients, the concept being: do not teach, but at least give just the key information to your patient".

The document covers nine topics, with two pages each:

1. one is a guideline for health care providers;

Table 1
List of the teaching letters (updated and new)

Sl. No.	
1	Oral agents
2	Hypoglycaemia
3	Self-monitoring
4	Putting a patient on a diet
5	Counselling on late complications
6	Foot care
7	Patient education: a life-long process
8	Therapeutics and education (with poster)
9	Help your patients to improve self-management: building a therapeutic chain (poster)
10	Managing the patient with excess weight and diabetes
11	Checklist for diabetic patient education
12	How to improve follow-up in the long-term disease
13	Motivating the diabetic patient
14	My patient is poorly controlled, how do I approach this problem?
15	Right from the start: education at the time of diagnosis (new series)
16	Diabetic retinopathy and therapeutic education (new series)
17	Educational approach to the elderly diabetic patient
18	Group vs. individual therapeutic patient education
19	Therapeutic diabetes education in camp settings (new series)
20	The function of psycho-social support in diabetes education (new series)
21	Therapeutic education: what a diabetes centre should provide
22	Planning an educational program
23	Diabetes education and cost control: time to measure (new series)
24	Evaluating diabetes education

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Table 2
The 5-min survival kit

Sl. No.	
1	Prevention of hypoglycaemia: initiating an insulin treatment
2	Intercurrent illness, sick-day rules and acetone
3	Meal planning: type 1 diabetes
4	Meal planning: type 2 diabetes
5	Weight loss: type 2 diabetes
6	Prevention of foot lesions: for patients having no vascular or neuropathic problems
7	Loss of pain sensation: long-term complications and prevention of amputations
8	Follow-up of eye problems
9	Pregnancy and diabetes

2. one, repeated, is a summary in the form of a handout for patients.

The nine titles of the 5 min survival kit are listed in Table 2. The documents can be read and downloaded, as plain text, from the DESG web-site (our-materials in survival kit section).

8. Patient education basics

These documents are being produced by the DESG with the general practitioner in mind. Dealing in particular with type 2 diabetes, which is most commonly managed in general practice, they address two essential questions.

1. How can we deliver, in a few minutes, useful information to the patient regarding better management of his/her diabetes?
2. How can we be sure that the patient will follow advice once he/she returns home?

An updated list of patient education basics is shown in Table 3. The documents can be read and downloaded in the original editorial aspect, from the DESG website (our-materials in patient education basics section).

9. DESG web-site

As a result of a 3-day workshop, held in Italy in November 1998 with 11 members from eight European countries, all experts in therapeutic education and informatics, a comprehensive web-site of the DESG was planned, in order to improve communication between members and make all published material on diabetes education easily available.

Table 3
List of patient education basics for type 2 diabetes

Sl. No.	
1	How to prevent low blood sugar
2	Lose weight by eating better
3	Diabetic retinopathy and follow-up of eye problems
4	Prevention of foot problems
5	'You have type 2 diabetes': meaning and implications
6	Preventing late diabetic complications
7	Ageing and diabetes management
8	Improving follow-up in the long-term disease
9	Blood glucose monitoring: a must in diabetes management
10	Diabetes treatment and 'the others' (the role of the family and the social environment)
11	Prevention of heart problems
12	Physical exercise: a therapy for diabetes at all ages
13	Intercurrent diseases: a challenge for diabetes control
14	Preventing diabetes in your relatives

The DESG web-site was officially opened on 1st September 1999. Its registered domain name is DESG.ORG (http://www.desg.org). It is intended for health care professionals involved in therapeutic patient education in the field of diabetes, and the largest portion is freely accessible. An indication is given for people with diabetes, directing them to a page with links to several informative sites for patients and patient associations.

For reasons of privacy, both the general committee members' list and the complete list of members are in a restricted area of the site, accessible to members only. The members' area may eventually allow for internal exchanges and communication. As an example, a set of slides, "old and new attitudes in doctor/patient relationship", has been inserted in this area and can be downloaded as a PowerPoint file.

The general philosophy, however, is to leave the site as open as possible, offering as comprehensive as possible a source of information, publications, education tools, various materials, produced either by the DESG or by others, in the field of therapeutic patient

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education. A scheme of the site map is shown in the first figure.

The web-site has also been used to launch an inquiry on the educational needs of health care providers, planned during a 5-day workshop held in Italy in March 2000. A 26-item questionnaire has been published on the web-site to evaluate the need of training/updating in the topics relevant to therapeutic patient education, as perceived by the health care providers world-wide.

10. Basic curriculum in therapeutic patient education

An expert workshop was held in Italy in March 2000, with the aim of planning a basic curriculum in therapeutic patient education for health care providers, based on the indications of the WHO–Europe working group report [5].

The workshop was entitled ''diabetes therapeutic education at the primary care level: planning a basic curriculum for health professionals'' and was attended by 16 members of the DESG from 11 countries, each with a great deal of experience in therapeutic patient education in primary care and informatics. As a result of the workshop, eight 1-day modules were drafted for training HCPs at the primary care level in therapeutic patient education.

11. Future

Although much has changed regarding the treatment of people with diabetes in the last 20 years, much still remains to do in order to increase both the quality and the implementation of therapeutic patient education in the field of diabetes. Medical science is making astonishing progress, and the cure and prevention of diabetes appear closer and closer. This may have induced some scientists to forget the essential role of therapeutic patient education, as can be seen in recent 'comprehensive' books on diabetes in the new millennium, where patient education is totally omitted. This attitude parallels that of those who contend that diabetes can be fully explained on the basis of psycho-social disorder, and pretend to treat it accordingly. The DESG commitment has always been to bridge between these two attitudes, filling the gap between medical research and human sciences, and in the future it will continue to act on the same line.

The basic curriculum in therapeutic patient education at the primary care level will be the object of the next DESG/servier partnership workshop, which will take place in Italy in March 2001. On that occasion, the results of the inquiry on the educational needs of health care providers involved in diabetes care at the primary level will be reported. This will allow to implement locally, on a national or regional basis, training courses in therapeutic patient education, based on the format recommended by the DESG, and on the needs expressed by HCPs.

Sections of the DESG web-site to be implemented in the future include space dedicated to national study groups, the publication of the different translations of DESG documents, and a forum on therapeutic patient education. As in many other domains, the usefulness of the Internet is only partially exploited and understood. The DESG web-site can be considered a powerful tool that can facilitate future research and development in the field of therapeutic patient education.

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