Empowerment-inspired patient education in practice and theory

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Background

In trying to meet the challenges of the diabetes pandemic, healthcare systems face heavy burdens. The traditional didactic education offered to diabetes patients appears not to be very successful, because patients are often reluctant to take advice given by healthcare professionals.[1] As a result, desired goals for diabetes control are unmet, giving rise to serious medical complications later in life. The lack of success naturally brings about frustration among health professionals who, in turn, reflect on these old practices and begin exploring new avenues.

Facing these burdens, health care systems worldwide have a strong incentive and strong economic rationale to establish more effective forms of education. Furthermore, an increasing number of individuals with chronic disease have their quality of life challenged in the absence of effective education. A new approach is necessary to motivate diabetes patients to develop self-monitoring, and self-management of lifestyle changes.

This article describes the experiences gained in an empowerment-based type 2 diabetes group education programme, developed at the Diabetes School, Hillerød, Denmark. Group-based education is a very effective way to improve the control of blood glucose levels.[2] To date, however, few studies of empowerment (using group-based education) have been undertaken in type 2 diabetes patients.[3–5] The intervention taking place in the Hillerød Programme differs from that offered by other schools, not least with regard to the longer amount of time spent with patients on this programme.[2,6] The Hillerød Programme also differs from other schools in terms of the composition of the diabetes team that delivers the education, which comprises a dietitian, nurse, physiotherapist, and general practitioner (GP).

To ensure that all aspects of the programme are well integrated, the professional disciplines hold classes together and are actively engaged in each others' teaching processes. The diabetes team finds it very important that, in order to develop acting competence and bring about lifestyle changes over the course of the programme, the type 2 diabetes patients become actively engaged in the practical aspects of improving their daily life, such as cooking healthy food, exercising with a physiotherapist or measuring blood glucose levels regularly. Such engagement is a fundamental part of the programme.

Who are we?

Our diabetes team takes the patients through an integrated, structured-group programme, based on the empowerment philosophy.[7] Each professional team member has additional educational qualifications, which include diplomas and degrees in health prevention and promotion; some have studied at the Danish Institution for Supervision Employees Development, teaching and consultation, which has a specific psychological patient-educator approach.

Summary

The Hillerød Programme has held empowerment-inspired courses for type 2 diabetes patients, in group settings, since 2003. The courses take patients through a 1-year programme consisting of three modules (4 days, 2 days and 1 day). The programme aims to help individuals to discover and develop an inborn capacity to monitor and control type 2 diabetes, and to realise why lifestyle changes are necessary. This paper describes the methods employed in the Hillerød Programme.

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Key Words

Hillerød Programme; empowerment; inborn capacity; acting competence; type 2 diabetes; patients education

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The team's 'working toolbox' (Table 1) is actively employed in interactions with type 2 diabetes patients, whenever relevant situations occur during classes. This gives a good flow between educators and patients, helps patients to develop an understanding of the emotional side of living with diabetes, and moves them towards acting competence.

As empowerment of type 2 diabetes patients is the programme's goal, team members receive continuing education regarding empowerment theories (Table 1). Awareness of this theoretical basis has proven to be invaluable for enabling team members to understand the life situations that patients face. The implementation of empowerment theories through the programme is described further in this paper.

Empowerment is not a theory; it is a philosophy

The empowerment process is regarded as an individual's discovery (and development) of their inborn capacity to control and take responsibility for their lives.[7] Patients are empowered when they have:

- "Enough knowledge to make rational decisions"
- "Enough control"
- "Enough resources to implement their decisions"
- "Enough experience to evaluate the effectiveness of their decisions".[7]

The role of patients

Since September 2003, over 1100 patients with type 2 diabetes have attended 1-year programmes at the Diabetes School in Hillerød. These empowerment-based education programmes comprise of day-time or evening courses, held in group settings that spouses may also attend. Before each module begins, patients complete questionnaires which examine their knowledge of type 2 diabetes and how they rate their quality of life;[8] at the end of the study, results are fed into a Health Technology Assessment form, which provides data for further research purposes.

Recent blood-glucose, glycosylated haemoglobin and lipid levels, together with bodyweight and body mass index, are obtained from each patient's GP. Comparing data from different modules of the course facilitates a measurement of the programme's effectiveness.

People with type 2 diabetes have to make many choices every day, several of which have significant influence on blood glucose levels. Such choices may be related to food, physical exercise, or relations with friends and family. In the Hillerød Programme, it is fundamental that educators do not judge how patients should relate to their diabetes. It is, however, the educators' job to impart patients with knowledge about type 2 diabetes, so that they develop an understanding of their situation and therefore make individualised, qualified decisions regarding issues such as what to eat and how to exercise.

The team focuses on the individual. At the beginning of each course, patients share the difficulties and barriers they encounter in daily lives, such as choices related to food, medicine, physical activity and relations with family, friends, and colleagues. Emphasis is placed on both theoretical understanding (facts, behaviours), and on practical aspects, e.g. how to cook healthy food, as well as the emotional side of living with diabetes.

The self-management aspects are based on patients taking responsibility for themselves by self-monitoring blood glucose and acting on given facts, but also developing an understanding of their own emotional reactions to the process they go through. Antonovsky's theory of sense of coherence[9] and his flood metaphor can help explain to each of the patients how they may learn to live with type 2 diabetes. The theory also helps to explain how each individual is unique, and will have to find his or her own way of living with type 2 diabetes: what works for one group member may not work for another! Using the 'stages of change' concept[10] helps patients to understand how far they have come in changing their lifestyle. This concept also helps explain that it is common for some people to fall out of a good rhythm and then come back again, with better knowledge of their own behaviour and the process of change that they have undergone.

The role of educators

Educators have to define their own empowerment vision and their own role as healthcare professionals. To achieve this, and to help team members reflect on their daily practice, off-site supervision classes are held to guide educators through some of the more difficult situations that they face with patients. In addition, the team is supported by a psychologist, who assists the educators with professional supervision and helps the team to focus on the group dynamics in the diabetes education programme.

Unsurprisingly, this brings about both professional and personal development for the educators, but it also reduces the temptation for educators to solve the patients' problems. The educators must be careful listeners; they have to help patients to make informed choices about their self-management. They must, however, realise that they are not responsible for patients' lives. The educators' role is to give the patients experience, motivation and sufficient knowledge to allow them to make their own decisions and develop skills for self-care, which they do by asking questions rather

than giving answers. Their role is also to help develop the patients' capacity to feel socially and emotionally supported, enabling them to develop self-efficacy,[11] to believe in decisions about behavioural change, and to reflect on their choices and on the goals which they hope to achieve.

Anderson and Funnell – "Empowerment in diabetes education"[7]
Antonovsky –"Sense of coherence"[9]
Bandura – "Self-efficacy, how firmly do you believe in your lifestyle changes?"[11]
DiClemente and Prochaska – "Stages of changes" [10]
Dalum and Sonne – "Motivating education, resistance, barriers"[12]

Table 1. The diabetes team's toolbox: studies of empowerment theory

Programme modules

Module 1 (4 days; 28 hours)

Emphasis is placed on facts about type 2 diabetes, and understanding behavioural aspects of living with the condition. First, patients share their diabetes history, the onset of their disease, personal experiences with difficulties and barriers to living with diabetes. During this introduction, patients tell the team what expectations they may have for the programme, and life in general. They talk about the areas where they need more information, and look for greater understanding and for motivation to better manage how they live with diabetes. In this way, patients decide the contents of the module and the diabetes team tries to accommodate all expectations. Certain elements of the module are fixed, however, because some theoretical knowledge, in line with empowerment philosophy,[7] is required in order for patients to choose how to change their attitudes towards living with diabetes. Since type 2 diabetes has few symptoms and little pain for a long period, it is also very important to work with psychological aspects of the process towards acceptance of this condition.

In order for the patients to develop acting competence, it is as important for them to be motivated and change their lifestyles as it is to gain as much knowledge about diabetes as possible, so that they make qualified choices.

Learning to measure blood glucose, and to understand the symptoms of high or low blood glucose, are important elements in the programme. Also important is the encouragement of diabetes patients to relate to his or her blood glucose level and to take action with regard to physical exercise, food and medicine.

Structured parts of the programme begin with the nurse taking patients through subjects such as blood glucose metabolism, symptoms of high and low blood glucose and the genetics of type 2 diabetes. Late complications are addressed, as is the risk of developing heart failure due to the high lipid concentrations. Medications that lower blood glucose and blood pressure are also covered.

Healthy food preparation is also part of the programme, and patients are often enthusiastically engaged at working in the kitchen with a dietitian and nurse. Different recipes are tested and tastes are challenged. Patients often express surprise that healthy food, with all these vegetables, can be so tasty! Here the patients are also able to talk about the experiences that they gain from the course, while cooking the meals.

The dietitian also seeks to meet the type 2 diabetes patients' need for knowledge about carbohydrates and fibre, and how these influence blood glucose levels. First, the group discuss their experiences, then the dietitian teaches about low animal-fat meals, how to lose weight and how to maintain healthy weight. The group visits a nearby shop to discuss food shopping, learn how to read food labels, and be guided in the process of choosing food items.

Physical activities that are relevant for this group, e.g. Nordic walking (brisk walking with sticks), are tried out. Patients measure their blood glucose levels before and after physical activity, to help illustrate the positive effect of activity and ideally to build their motivation to be more active. Back pain (and other joint pain), which are frequently reported by patients, often act as barriers to become more physically active. The after-exercise blood glucose measurement, however, presents a good basis on which to discuss how to overcome such barriers.[12]

Part of this module also aims to empower patients for their GP consultations, so that they feel they are allowed to address any problems. The importance of coming to the clinic every 3 months is discussed, on the basis that this will enable timely adjustment of medicine doses and will allow early detection of possible late complications.

At the end of this module, each patient sets goals and defines what lifestyle improvements he or she wants to undertake, until the group meets again. The educators support the patients to develop strategies in order to meet their goals. The team finds that Bandura's theory[11] about self-efficacy is useful, helping type 2 diabetes patients to realise how determined they are with regard to each goal for lifestyle change and,

on a scale from 1 to 10, how firmly they believe in each specific change.

Module 2 (2 days; 14 hours)

The patients return 3 months later for the second module, which focuses on the individual's need for finding motivation and overcoming barriers; this module also provides further theoretical education. As in Module 1, the patients decide how the 2 days should be formed. If the team senses that a group of patients have specific difficulties with changing their approach towards lifestyle changes, they are asked to reflect on the problems in small groups. This setting is particularly conducive for discussions about the benefits of a changed lifestyle. Here the patients discuss what the advantages of changing lifestyle may be, compared with keeping the lifestyle they have, which often causes them to see their diabetes differently. Spouses work in another group, which gives them the opportunity to share their concerns regarding their husband's or wife's attitude towards his/her disease.

The team emphasises the importance of each patient's goals. Each patient shares how well he or she has managed to purse the goals of Module 1. What worked? What didn't? The Stages of Changes concept[11] is used to illustrate that changing lifestyle is not a linear process. It is not unusual for habits to improve for a little while, then the patient falls back into his previous habits. The patient gets to express at what stage of change[11] he finds himself, and how the experience gained over the previous 3 months will help him reach the next stage. Patients are asked to focus on what they would like to be able to do in another 10–15 years and define what is worth living for, using the images of these inspirations to help them stay on track.

Patient discussions cover how complicated it can be for them to handle work, family, medicine, physical activity and diet. With regard to the latter, it is not least the fact that it can be difficult to be socially accepted when in some situations it is necessary to say 'no' to food offered. These are stressful choices that patients have to make every day.

Module 2 also discusses how to travel with diabetes, focusing on handling medicine, accessibility of healthy food and staying physically active during a trip. The GP is involved in this discussion.

Healthy food preparation is also covered, and if the patients wish to continue enjoying their favourite dishes we help them to exchange unhealthy items in the recipes, so that they develop their acting competence in a way that gives them courage to change lifestyle.

Finally, again, patients set goals for their lifestyle changes, paying particular regard to building motivation to maintaining the changes brought about following Module 1.

Module 3 (1 day; 6 hours)

The final module takes place 9 months after Module 2 (12 months after Module 1) and is a follow-up on managed lifestyle changes.

Each patient shares how he or she has managed to remain motivated regarding their lifestyle changes, and expresses goals and hopes for the future. In this session, patients have the opportunity to seek personal guidance to help build motivation and resources for a life with type 2 diabetes.

Again, healthy food is prepared, but this time for a feast.

The patients and educators participate in a 1–3 km walk, and at the end of the module, the patients play a specially designed game that refreshes their knowledge about type 2 diabetes. This gives patients the possibility to express all their emotions about living with a chronic disease.

Over the course of the programme, patients' relationship building is observed: for instance, some may decide to meet for Nordic walking. Patients are encouraged to contact their local type 2 diabetes organisations and visit websites operated by the National Diabetes Foundation.

Experiences gained from the 5 years of study

Quantitative data obtained via the Health Technology Assessment form[8] will not be published before the end of 2008. However, anecdotal observations made by the diabetes team suggest that patients develop an understanding of their situation and build practical knowledge. Patients appear to share responsibility with their group, which helps them to accept the many psychosocial issues that are related to living with diabetes. Relationships within the group help maintain motivation, caring and focus.

Whereas discussions regarding the need for lifestyle changes are an important part of this intervention, experiences in the Hillerød Programme show that it is also very important to address the emotional side of living with a chronic disease, such as sorrow, anger and the need for acceptance that this disease is chronic and will never disappear. These can be frightening to discover.

Discussion

The Hillerød Programme is designed to help patients to develop their inherent capacity to manage living with diabetes, thereby causing their diabetes to become self-managed. The structure and content of the 1-year programme, as well as the diabetes team's close involvement, appear to help type 2 diabetes patients to achieve their goals.

At the end of the programme, patients often ask for further contact and follow-up, suggesting that they would like to come back, to refresh their motivation and diabetes knowledge. Patients say that they enjoy meeting other group members, as it gives them the opportunity to talk freely about their diabetes in a manner comfortable for them. This contrasts with the situation at home or at work, where they feel they need to restrain themselves.

Future

With the considerable experience that we have gained, it is time to consider programme modifications and improvements. The current team wishes to expand the programme with open-house events, where former participants are invited. Recently, a pilot study focusing on a particular ethnic Turkish minority has taken place, and we expect to increase this into other ethnic groups.

Similarly, a group of ethnic Danes (non-attenders) has been identified, who do not respond to invitations to attend the Hillerød programme. This group is generally comprised of younger people with poorer health than the reference group attending the programme. A pilot study involving a group of non-attenders was undertaken in spring 2008, primarily to understand why these people do not respond to invitations to participate. While it is premature to report on this study, interviews with the non-attenders give some clues. Specifically, one lady said that she was very engaged in the life of her children and grandchildren, whose social circumstances were such that her support to them was vital. All this took time away from her, so she felt she did not have time to focus on her own health (Sanne Kliim Petersen, unpublished data).

It is conceivable that healthcare professionals working in other chronic disease areas have similar issues with non-attenders. It is, however, striking that searches of all major databases did not identify a single study which looked into the issues facing non-attenders. Such a finding is somewhat surprising, since this group will develop into a heavy financial burden for the societies concerned.

Conflict of interest statement

None

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