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Policy Brief

Effectiveness of Diabetes Self-Management Education and Digital Self-Management Support

Diabetes Literacy Consortium

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Diabetes Literacy
Policy Brief

Effectiveness of Diabetes Self-Management Education and Digital Self-Management Support

This is the second of two policy briefs of the European Diabetes Literacy project. It focuses on the effectiveness of diabetes self-management education (DSME) and on the role of health literacy. Like the first policy brief, which gave an overview of the current practice and cost of DSME in Europe, this second policy brief combines the results of the Diabetes Literacy project with the outcomes of policy dialogues held during the 18th European Health Forum Gastein 2015 and the 23rd World Diabetes Congress 2015.

The results of the Diabetes Literacy project show that there is a window of opportunity to empower patients to take up diabetes self-management. Education for self-management is a crucial success factor. The project provides evidence that education during the initial stages of diabetes is effective in changing patients' self-management behaviour, also amongst people with low health literacy. It is possible to develop IT-based programmes that engage people with low health literacy while remaining acceptable for people with higher health literacy levels. Too many diabetes patients in Europe do not receive self-management education. Policymakers are called upon to invest in making DSME programmes available and accessible for all diabetes patients in Europe.

Diabetes Self-Management

The number of people with type 2 diabetes in European Union (EU) Member States and worldwide is increasing at an alarming rate, costing EU Member States between 5–15% of their total health expenditure. Worldwide, 1 in 11 adults have diabetes, and this will rise tobe 1 in 10 in 2040. Health systems need to consider cost-effective measures to fight the growing burden of diabetes and to improve the health and quality of life of people with or at risk for diabetes. As self-management depends on a diabetes patient's capacity to obtain, process and understand basic health information, the basis for improving self-management is education. The level of health literacy of a patient is a critical factor in successfully addressing diabetes and improving the outcome of treatment.

The initial focus of DSME was on enhancing knowledge and compliance to treatment. Recently, we have come to recognize that diabetes education should address knowledge, behaviour and psychosocial aspects, and provide ongoing support.

Diabetes Literacy

Diabetes Literacy (www.diabetesliteracy.eu) is a pan-European project aimed at strengthening patient self-management by exploring what programmes for diabetes self-management exist, what is their effectiveness and cost-effectiveness, and what is the potential for improvement. The Diabetes Literacy project (2012-2015) received funding from the EU's 7th Framework Programme for research, technological development and demonstration. The project was implemented by a Consortium of research organizations from six EU Members States (Austria, Belgium, Germany, Ireland, Netherlands, UK), three non-EU countries (Israel, Taiwan and US) and two collaborating partners (Denmark and South Africa).

Effectiveness of Self-Management Education and the Potential of Digital Communication

The Diabetes Literacy project assessed the effectiveness of selected diabetes self-management education (DSME) programmes that use different communication channels. In addition, it studied the role of health literacy in diabetes education, as well as factors in the organizational context and implementation of programmes that contribute to effectiveness, and investigated whether interactive digital communication for people with low health literacy can improve their self-management. This policy brief summarizes the results of the project with regard to the effectiveness of different diabetes programmes, factors that contribute to behavioural change, and the potential of delivering IT-based education to diabetic patients with lower levels of health literacy.

Effectiveness of Diabetes Self-Management Education Programmes

The Diabetes Literacy project assessed the effectiveness of selected diabetes self-management education programmes in a multi-centre and multinational pre-post study. The role of health literacy and factors related to the organizational context and implementation were investigated.

Information Basis

The analysis of the effectiveness of various DSME programmes was based on information collected from 600 diabetes patients in the early phases of diagnosis. Patients participated in a diabetes programme in one of the countries involved in the project. Questions about health literacy, key self-management behaviours, and health and well-being were asked before and three months after they started the programme.

As a theoretical basis, the study used a diabetes self-management outcome framework, developed in the first phase of the project. The effect of implementation fidelity (i.e., the degree to which programmes are delivered as intended) was measured via a newly developed instrument for programme providers. Organizational effectiveness was assessed through a survey reaching 66 diabetes programmes in ten countries and 12 case studies in nine countries.

That we find positive changes in different programmes in different countries adds to the evidence that diabetes self-management education is an essential element of good quality diabetes care.

Main Findings

Positive effects of involvement in a DSME programme were found for all key self-management behaviours, such as healthy eating, problem solving, reduced risk behaviour and healthy coping strategies. Positive changes were also found for the main outcome variables, such as health-related quality of life and well-being, measured three months after participation in the programme compared to the measurements taken before people entered the programme. Although differences in outcome were noted between programme types, these were not systematic. It can be concluded that in the initial stages of diabetes, DSME is effective in changing patients' attitudes and behaviour, regardless of the communication channels used.

With regard to health literacy, the Diabetes Literacy project found a significant overall effect of education on diabetes-specific health literacy. This means that the programmes were effective in raising awareness and knowledge. Importantly, diabetes education can be effective for people with different levels of health literacy.

Another finding worth noting is that outcomes improved after programme participation, regardless of the providers' strict adherence to the programme guidelines. So while fidelity with regard to the core components of the programme is important, adapting the programme to participants' needs upon the implementation can enhance effectiveness.

The scale of organizational effectiveness was divided into ten aspects, such as easy access to services, availability of cross-disciplinary teams, availability of information systems, and evaluation of services. The selected self-management programmes showed a mean score of 52% on this scale of 0-100%. At the current organizational level, there is still room for improvement in Europe.

Potential of Interactive Digital Communication for People with Low Health Literacy

The Diabetes Literacy project studied the potential of interactive digital communication in diabetes education. Digital communication for personalized education is valued by users and attractive to providers because of its scalability. The study assessed if digital communication increases the risk for health inequalities by excluding lower levels of health literacy.

Information Basis

To study the potential of interactive communication tools such as websites or apps, digital communication materials were developed to encourage patients to use physical activity to manage their diabetes. The content for these materials was developed through consultation with experts. A website was created in English, translated into German and Mandarin, and adapted for use in Ireland, Germany, Austria, Taiwan and the US. Features of the website included tailoring the material to users (e.g., attitudes and age), audiovisual presentation formats, and quizzes and tools to support self-management tasks. Qualitative feedback from interviews with 65 diabetic patients in five countries led to modifications. A trial of the digital material involving 1045 people from the UK, Ireland, Austria, Germany and Taiwan completing short questionnaire before and after viewing the website compared two versions of the website: static written material vs. interactive and audiovisual material.

Digital materials can be designed to improve health literacy and support diabetes self-management in people with all levels of health literacy, without increasing health inequalities.

Main Findings

Interactive digital communication tools were found to have a great potential to support self-management. The diabetes specific health literacy of users in all countries and of all health literacy levels improved after using both versions of the website. Positive effects were demonstrated for key variables such as knowledge on how physical activity can improve health for people with diabetes, the intention to undertake physical activity, the belief that physical activity has health benefits for people with diabetes, the sense of enablement, understanding of diabetes, and knowledge on how to self-manage it. It was shown that a good design of web-based programmes is more important than adding interactive and audiovisual elements to web-based materials, and that materials can be modified for use in different countries. As such, well-designed digital communication material can provide a cost-effective means to answer the currently unmet need for support in the self-management of health.

Policy recommendations

Effectiveness of DSME and the role of health literacy

Diabetes self-management education programmes in Europe are generally effective in changing behaviour and improving health-related psychological outcomes.

As no systematic differences were found regarding the effectiveness or cost-effectiveness of different types of programmes, DSME programmes can be considered as generally cost-effective.

Diabetes education programmes can be as effective for people with lower levels of health literacy as well as for people with higher levels.

There is evidence that cultural and status-related covariates, such as age, migration status, and social status, influence the effectiveness of DSME programmes, pointing to a need to tailor these programmes to the patients.

Adherence to the proven-effective core programme guidelines (implementation fidelity) is essential. However, changing other elements to adapt a programme to the needs of participants can enhance the effectivity of DSME programmes.

There is potential for improving the organizational effectiveness of DSME programmes, particularly with regard to the evaluation of services in view of quality improvement and the involvement of patients in the organization of programmes.

Effective digital communication for people with low health literacy

Digital materials can be developed to improve health literacy and support self-management among people with all levels of health literacy, without increasing health inequalities.

A good design of web-based programmes, with user input, may be sufficient to effectively support diabetes self-management. Investment in interactivity or audio-visual presentation is not always necessary.

Website materials for self-management support can easily be modified for use in different countries without losing programme effectiveness.

The findings of the Diabetes Literacy project on digital communication indicate that a reduction in the cost of developing material is realistic.

In the future, well-designed digital communication materials can provide a cost-effective means to answer the unmet need for self-management support for diabetes and other chronic diseases.

The Diabetes Literacy project shows that currently only 50% of people with diabetes in Europe take part in diabetes self-management education. Strong evidence was found that DSME is effective, although the quality of self-management education can be improved. The implementation of effective and cost-effective DSME programmes should be increased to make these programmes available and accessible to all patients in Europe.

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