



PATIENT EDUCATION

– a health technology assessment

Summary

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Summary

The boundaries between the tasks related to chronic disease for which the health care system traditionally has taken responsibility and the activities for which individual people are expected to take responsibility have shifted rapidly in Denmark and elsewhere in recent years. People with chronic diseases are increasingly being involved in the treatment for their illness.

In Denmark, changes in the composition of the population, life expectancy and lifestyles have led to changes in the patterns of disease. In 2005, 1.7 million of Denmark's 5.5 million residents had one or more chronic diseases, and people with chronic diseases account for an estimated 70-80 % of total health care expenditure. Projections of trends in the age distribution of the population show increasing numbers of people with chronic diseases in the coming years. Based on a health policy perspective, it is therefore appropriate to examine critically how to optimise resource use and how the treatment of people with chronic diseases can be optimally organised in the increased efforts to improve their health. In this context, health policy increasingly advocates that people with chronic diseases should increasingly participate in their treatment. Further, research indicates that people with chronic diseases have a stake in developing competencies for managing disease.

Patient education is one of several initiatives that aim to get people to participate in management of their own chronic disease. The purpose of patient education is to get patients to acquire competencies that enable them to manage their chronic disease better. Before the Danish Local Government Reform in 2007, hospitals carried out most patient education, and municipalities provided little patient education. According to the Health Act clinical prevention is now defined as a joint task of Denmark's 98 municipalities and 5 regions. Patient education is an important aspect of strengthening clinical prevention, which the regions and the municipalities implement through the Health Care Agreements, mandated by legislation, between each region and the municipalities within the region. Thus, the Danish Local Government Reform established the basis for municipalities potentially playing a greater role in patient education. Nevertheless, how patient education should be organised most appropriately has not been determined. The organisation of patient education is complicated further by the fact that the effects of patient education are largely undetermined.

Purpose

The purpose of this health technology assessment was to critically assess patient education with the aim of identifying opportunities and barriers for the future organisation of patient education in Denmark. This critical assessment included the following analyses:

The section on technology focuses on the effects of patient education. Further, it assesses the mechanisms of effect for patient education programmes in the form of the theoretical basis for patient education programmes, the existing descriptions of the educational methods used and the competencies of the teachers.

The section on the patients investigates who uses patient education, the benefits the participants obtain and which user-based needs are significant for the future organisation of patient education.

The section on critiquing methods discusses whether the methods used to assess the effects and benefits of patient education are appropriate and relevant.

The section on organisation investigates the current organisation of patient education in the municipalities and regions to identify the opportunities and barriers for the future organisation of patient education.

The section on economics assesses the costs and benefits of carrying out patient education.

This report provides scientific guidance for decision-makers by broadly describing the evidence on patient education in Denmark and thereby contributing to a solid basis for determining the future use of patient education in the efforts to prevent chronic diseases and to improve the health of the people who have them.

Target group

The main target group for this report is health policy-makers and administrative decision-makers. The report is also relevant for everyone involved in patient education in any way, such as health care professionals, people with chronic diseases and researchers.

Definition and scope

The report defines patient education as follows: *“Education of patients with a diagnosed disease in a structured education programme targeting individuals or groups of patients and perhaps family members. The education programme may be disease-specific and target patients with a specific disease or generally target patients with different diseases. Patient education is part of clinical prevention.”* Nevertheless, this report limits patient education to being a group-based technology that may include individual components. Patient education may involve both patients and their family members. Patient education may be carried out and organised in different ways. The report includes general patient education and disease-specific patient education. The Chronic Disease Self-Management Program (CDSMP) of the Stanford University School of Medicine is the most widely known model for general patient education. CDSMP is implemented in Denmark as ‘Learn to live with chronic disease’². The report limits the assessment of disease-specific patient education programmes to patient education for adults with chronic obstructive pulmonary disease (COPD) or type 2 diabetes. The report includes studies that focus on the perspective of family members or significant others of the people with chronic disease. The report limits the assessment of organisation and economics to patient education programmes carried out under the auspices of the regions and municipalities. Thus, the assessment does not include patient education carried out by such organisations as patient associations.

Methods

This assessment investigated the questions related to assessing health technology by conducting systematic literature searches for all the topics. The studies included as the basis for assessment were solely those that were found to be relevant and of sufficiently high quality based on critical assessment of the literature.

An overall assessment of the quality of literature was produced for each question in this health technology assessment (Annex 4.2.2, 4.3.5, 5.2.2, 5.5 and 6.5), and the quanti-

2 Lær at leve med kronisk sygdom

tative studies included are described using evidence tables (Annex 4.2.10, 4.3.6, 5.5.1 and 6.6). The evidence in the quantitative studies was graded based on the Levels of Evidence and Grades of Recommendation of the Centre for Evidence-Based Medicine in Oxford (Annex 2.1), which grades evidence according to the study design.

Annex 2 provides a general introduction to the assessment and grading of the quantitative and qualitative studies. Annexes 3–7 describe the specific search strategies, inclusion and exclusion criteria and provide an overall assessment of the quality of the literature for the specific questions related to assessing health technology.

The assessment of organisation is supplemented by a survey of current patient education programmes obtained by compiling documents in the five regions and five selected municipalities. Further, focus group interviews were conducted with actors in the regions and municipalities and among general practitioners to identify opportunities and barriers in organising patient education.

The model for economic assessment was prepared based on the international literature. The cost analysis was based on cost data from selected patient education programmes in Denmark.

Technology

The assessment of technology answers the following question:

- What effects can be identified in relation to patient education for persons with type 2 diabetes, COPD and for general patient education programmes?

For all three types of patient education programmes, the effects found resulted from one or more controlled studies, which is the highest grade of evidence. Nevertheless, several studies are small and have varying dropout rates among the participants. The observation period is limited to 2 years or less for all studies, such that the long-term results are not known. The overall evidence is therefore assessed to be moderate to weak.

Type 2 diabetes

Group-based patient education leads to increased knowledge, moderate but clinically important improvement of glycated haemoglobin (HbA1c) concentrations, increased empowerment (improvement in personal competencies) or self-efficacy (confidence in one's ability to manage disease) and greater satisfaction with diabetes treatment. The effects obtained generally tend to decline or disappear over time. Individual studies provide evidence of increased understanding of diabetes, improved ability to manage stress, reduced worry about the person's own health in the short term and improvement in symptoms of hyper- and hypoglycaemia. The evidence is moderate but is weak in certain areas.

COPD

Studies have found improvement in ability to carry out daily activities, psychosocial illness, self-efficacy, anxiety and subjective experience of symptoms in the short term. In the slightly longer term, group-based patient education contributes to fewer COPD-related deaths, fewer physician consultations, greater satisfaction with treatment by a physician and a higher degree of self-management in severe exacerbation of COPD. All these results are based on the findings of small studies. The studies further indicate that

group-based patient education for people with COPD should not be carried out as an isolated initiative but should be combined with rehabilitation. The evidence is weak.

General patient education

Group-based patient education based on the Chronic Disease Self-Management Program contributes to increasing self-efficacy, less worry about the person's own health and increasing use of cognitive strategies for managing symptoms in the short term. Other methods of group-based patient education with health care professionals as teachers are associated with reduced hospitalisation and acute physician consultations, improved quality of life and fewer sleep problems in the slightly longer term. Anxiety, stress and depression declined in the short term. The evidence is moderate to weak.

- What types of theoretical basis and educational methods do the various patient education programmes have?

Regarding the theoretical basis of patient education, moderate evidence indicates that patient education programmes for people with type 2 diabetes are effective if they are based on therapeutic patient education in accordance with participant- and empowerment-oriented principles and the principles for how adults learn. Further, effective patient education programmes tend to be based on the theories of self-efficacy and/or self-management. For educational methods in type 2 diabetes, weak evidence indicates that education that uses social learning techniques (group approaches) and behaviour-modifying exercises has greater effect than interventions that do not use these approaches in the education.

Few studies have examined the effects of the theoretical basis and the educational methods of patient education programmes for people with COPD. New research should be initiated to generate knowledge in this field.

CDSMP is the only general patient education programme with demonstrated effects that also has a well-described theoretical basis and well-described educational methods. CDSMP is based on the concept of self-efficacy as developed by Albert Bandura and uses educational tools and strategies associated with the theory: acquisition of skills (action plans and problem-solving), use of role models and reinterpretation of symptoms and group dynamics. Nevertheless, no studies have investigated the effects of the theoretical basis or the educational tools except for a study of the effect of the function of role models. The study provided weak evidence indicating that using patients (role models) as teachers is just as effective as using health care professionals.

- How well do the patient education programmes convert the theoretical basis into educational methods?

For type 2 diabetes, the theoretical basis and/or the educational methods of the patient education programmes are generally described in such a way that this question cannot be answered. Only the Diabetes Self-Management Program of the Stanford University School of Medicine is specifically described, and the Program has coherence between theory and educational methods, which bolsters its quality, since this is assumed to support the potential for participants to obtain the intended effects of the patient education.

The patient education programmes for people with COPD are generally described in such a way that this cannot be assessed.

For general patient education, only CDSMP describes the theory and practice specifically. This has coherence between theory and educational methods, which also bolsters its quality, since this is assumed to support the potential for participants obtaining the intended effects of the patient education.

- What competencies are required in practice?

Moderate to weak evidence indicates that teachers in patient education for people with type 2 diabetes do not need to have a specific health care profession for the education to be effective. Nevertheless, regardless of their background, teachers should be trained in teaching in the specific programme. Weak evidence also indicates that the effects of patient education increase if the teacher has both educational competencies and knowledge about diabetes and methods of treating it.

No studies on COPD show which competencies influence the effects of patient education programmes.

In relation to the competencies of teachers, CDSMP is the only general programme that describes well the competencies and educational background of the teachers. Patients typically teach the program or a health care professional and a patient teach jointly. Weak evidence indicates that whether the teachers are patients or professionals does not influence the effects of patient education.

The limited evidence, the tradition of exclusively using quantitative study designs and the often unclear explanations of concepts³ mean that more initiatives are generally needed to generate knowledge on which theories and educational tools are appropriate to use in the future in carrying out patient education.

Patients

The assessment of the patients answers the following questions:

- Who uses the patient education programmes?

Patient education is often considered the development of empowerment, meaning knowledge, competencies and self-confidence that enable people with chronic diseases to take responsibility for and manage their illness and life situation. Nevertheless, patient education programmes tend to especially appeal to people with more education, to women and generally to people who already have ample resources and are relatively independent. The people with chronic diseases who need the most support and empowerment more often do not enter programmes, drop out or report less satisfaction and benefits from the programmes. Wide recognition that the people with the greatest needs have the least access to patient education – especially ethnic minorities in high-income countries – has led to attempts to adapt patient education to people with diverse backgrounds. The teachers in such programmes thus try to use these people's special cultural prerequisites as advantages instead of considering them as barriers to achieving benefits, such as in teaching about dietary recommendations.

- What benefits do the participants experience in relation to patient education?

The users' subjective benefits from participating in patient education comprise mainly learning practical and bodily competencies for managing diseases and especially the

³ This does not apply to the Diabetes Self-Management Program and CDSMP.

exacerbation of disease more effectively and more independently in daily life, to understand better the severity and manageability of the disease and to obtain a higher degree of internalisation of disease management and self-control. Further, participants describe the development of social networks, positive social experiences and accumulating experience with disease in a social framework as important benefits. In addition, participants emphasise the experience of support in developing new meaningful life perspectives in connection with the life-changing event of acquiring a chronic disease.

The participants describe their physiological benefits in very different ways and contexts. Some participants consider it important whether they can walk up and down stairs; others assess physical capacity in relation to their ability to take care of their grandchildren. Qualitative studies thus provide a contextual perspective. They can also identify other dimensions and criteria for the benefits of patient education than those typically measured in effects studies.

- Which needs of people with chronic diseases are significant for the future organisation of patient education?

People with chronic diseases need disease-specific knowledge and skills, but the literature review did not provide any comprehensive overview of these needs. The literature reviewed supports the need to keep the intensive disease-specific instruction as part of patient education. The literature reviewed also identifies several general needs that need to be integrated into the future organisation of patient education. These needs can be divided into the following themes:

Communication between health care professionals and people with chronic diseases

The literature reviewed indicates that patient education needs to prepare people with chronic diseases for communicating with health care professionals. The unreflective assumptions and habits of health care professionals also need to be changed since they can hinder empowerment (the ability of participants to take responsibility). Further, empowerment strategies should be used critically, since empowerment may be less accessible to people with constrained resources and may create difficulty in meeting other needs.

Initiatives oriented towards user needs

Patient education must be adapted to the needs and preferences for educational topics and methods of learning of each participant. Various types of patient education are therefore needed instead of an overall system, and the focus should be on the potential participants instead of the teachers' assumptions about the needs and preferences of the participants. Initiatives oriented towards user needs may be promoted by involving participants in the design process and by screening potential participants for special needs, such as by posing questions on patterns of problem-solving. The literature reviewed further shows that the framework of group-based patient education cannot meet all needs, and individual patient education is therefore also necessary.

Timing of patient education and the provision of information

Providing information on disease and how to manage it at the appropriate times is decisive in determining whether individual people obtain benefits from patient education. The timing is determined individually and depends on the stage of the process of each individual's recognition of consequences of their disease. Patient education must thus be made available at different stages of the course of illness for the various people with chronic diseases. More information at earlier stages is generally needed that is

adapted to each person's situation and emotional reactions. Further, follow-up education is needed to sustain the benefits obtained and to support development through the various phases of people's disease awareness and disease management through which people with chronic diseases pass at different stages.

Involving social settings

The organisation of patient education needs to consider the family and workplace as settings for recognising and managing chronic diseases. Family relationships can especially promote or hinder participants obtaining benefits from patient education.

Mental health factors

Living with chronic disease may change a person's perspective on life and may cause several types of mental health reactions such as stress, anxiety, insecurity and depression. The organisation of patient education should consider this. One way is by screening participants for factors that may influence the benefits obtained such as depression, motivation, sense of coherence and self-experienced control and by using psychotherapeutic and mental health methods such as coaching, goal-setting, stress reduction, meditation and mindfulness and developing self-efficacy during the patient education programme.

The needs of special groups

Reaching special population groups with patient education requires considering cultural and religious traditions, since they may be important factors in understanding and managing health and disease. Similarly, socioeconomic factors may influence the understanding and management of disease, and patients' ability to comprehend complex written and verbal material is especially decisive in disseminating information and carrying out education. Further, men and women seem to have different needs related to managing chronic disease.

Critique of methods

The critique of methods answers the following question:

- How can the effects of patient education be measured, and which methods can and should be used in future research on patient education?

Quantitative studies of effects need to be combined with qualitative methods. Besides, high-quality studies that have a longer duration than 1- 2 years are demanded.

Qualitative methods supplement the relevant measures of effect, such as in developing disease-specific measuring tools. Further, qualitative studies provide insight into the conditions underlying changes in lifestyle and such interventions as patient education, which closely interact with the participants' resources and daily lives. In addition, the theories, the specific educational tools and the practical educational methods need to be used and described more systematically. This can be used in comparing patient education programmes and provide greater insight into the instruments that provide the greatest benefits for participants.

Organisation

The assessment of organisation answers the following questions:

- What experiences in organising patient education outside Denmark can be reviewed?

Experience from the United Kingdom shows that the following factors pose challenges in implementing and organising general patient education: recruiting participants and teachers; managing the programmes; integrating patient education into the organisation of the rest of the health care system; communicating the availability of a patient education programme; carrying out the patient education; and the organisational location and acceptance of patient education programmes in the health care system.

- How are disease-specific and general patient education programmes organised in Denmark?

No form of organisation for the disease-specific patient education programmes has become very widespread across regions or seems more appropriate than any other form. In all five regions, the patient education programmes assessed are part of an overall strategy related to people with chronic diseases, but the strategies vary in how detailed they are. All regions specify the division of tasks related to people with chronic diseases through the Health Care Agreements with the municipalities within the region and through Disease Management Programmes. The regions and municipalities differ, however, in the progress they have made in developing Disease Management Programmes. The disease-specific patient education programmes that have existed for years within hospitals vary substantially in content, form and length even for the same patient groups. Most of the administrative regions plan to standardise the patient education programmes offered at hospitals. All five municipalities assessed have made considerable progress in implementing disease-specific patient education programmes, but the extent to which these programmes are described in relation to the overall initiatives of the municipalities towards people with chronic diseases varies greatly. For disease-specific patient education programmes, the municipalities have generally made more progress on patient education programmes for people with COPD than for people with type 2 diabetes. According to the formal descriptions of the programmes, only two of the five municipalities selected for the assessment are explicitly aware of the special challenges associated with patient education for people from ethnic minority groups. Nothing in the overall data material describes reflections, strategies or the like related to special challenges in recruiting and educating socially marginalised people. In contrast to the disease-specific patient education programmes, one model has become very widespread within the general patient education programmes. All five municipalities assessed use CDSMP for organising their general patient education programmes. The Municipality of Holstebro further offers a different type of patient education that is organised based on 'learning and mastery course for people with chronic diseases'⁴.

- What barriers and opportunities can be identified related to organising the disease-specific and general patient education programmes in Denmark's regions and municipalities?

The barriers to organising patient education identified by the assessment are associated with cultural differences. Traditions in hospitals, which are administered by the regions, are mostly based on evidence obtained using the natural sciences whereas the approach of the municipalities is more oriented towards health education and social learning, emphasising patients' subjective experiences. Further, the fact that the municipal disease-specific patient education programmes are so diverse poses difficulty for the regions and hospitals in developing uniform programmes in hospitals, and the formal

4 Lærings- og mestringsforløb for kronisk syge.

framework does not ensure that all municipalities have disease-specific programmes now or in the future. The system of Health Care Agreements between each region and the municipalities within the region supplemented by the concomitant Disease Management Programmes have resulted in systematic dialogue that has promoted the development of new programmes in both the regions and the municipalities. The municipalities that have made the most progress have political and administrative support for efforts to prevent disease and promote health, previous experience with similar work and very engaged staff members who have promoted progress. The two types of patient education programmes draw on three types of competencies: systematised patient experiences, health education competencies and health professional competencies at various levels within several groups of health care professionals.

- What competencies are required for teachers of disease-specific patient education programmes and for teachers of general patient education programmes?

The assessment of organisation does not provide the basis for concluding about which combinations of competencies are optimal but indicates a need to develop health education as a discipline.

- What are the perspectives for the future organisation of patient education based on the analysis of the challenges mentioned?

A more uniform set of patient education programmes in the municipalities would provide a different basis for developing the dialogue between the municipalities and the regions within the system of Health Care Agreements between each region and the municipalities within the region, enable the regions to standardise the programmes offered under their auspices and create a more uniform division of labour between the regions and the municipalities. The assessment does not provide any basis for concluding about which organisational models are most appropriate for the two types of patient education, but systematic and more uniform evaluation and systematic exchange and dissemination of knowledge are needed with the aim of gradually developing the organisation of patient education programmes in Denmark.

Economics

The results from the economic assessment of patient education programmes show the following.

- What are the overall costs to society per participant in patient education programmes?

The total costs of patient education programmes to society (including such costs as patients' loss of productive work time) are calculated as being DKK 5,900-8,600 per participant in diabetes-specific programmes and DKK 4,500-11,350 per participant in COPD-specific programmes. If a subsequent exercise training programme is included, the overall costs to society increase by DKK 5,000-13,000 per participant. These estimates are based on four specific examples of patient education programmes in Denmark. The total costs to society of the general patient education programmes are DKK 3,000-5,450 per participant.

- What potential economic benefits can the effects of the patient education programmes have in reducing the utilisation of health care?

It is not yet possible to determine whether patient education can provide economic benefits by influencing the health of participants. The reason is that no scientific evidence indicates the effects on participants' health or utilisation of health care, such as the number of days the participants are hospitalised. Nevertheless, patient education has been shown to affect the glycosylated haemoglobin (HbA1c) concentrations of people with type 2 diabetes, and this effect must influence the frequency of sequelae. The magnitude of these effects and how they influence the use of health care resources are not yet known and should be investigated further.

- What is the cost-effectiveness of patient education?

Since the effects of patient education programmes on participants' health have not generally been determined, the cost-effectiveness of individual programmes cannot be determined yet.

- How does offering patient education programmes affect the fiscal situation of the municipalities and regions (hospitals), respectively?

The fiscal analysis of expenditure and income for the municipalities and regions in offering patient education programmes shows that the public expenditure per participant is DKK 2,400-5,100 in a diabetes-specific programme, DKK 3,200-4,100 per participant in a COPD-specific programme and DKK 1,100 per participant in a general programme. For the municipalities, fiscal benefits in the form of income or reduced expenditure resulting from offering patient education cannot be calculated directly, but improving the health status of people with diabetes would provide an opportunity to reduce expenditure. For hospitals, the size of the positive economic incentives can be directly assessed, since the activity-based reimbursement system ensures that the hospitals at least cover their expenditure on patient education through increased reimbursement from the regions for increased health care activity.

- Which uncertainties are related to the estimated costs?

Uncertainties are related to the estimated costs even though a joint cost model based on existing literature is utilised. For instance a number of costs are based on estimations (e.g. time used for transportation and quality assurance) and it is difficult to price the value of the participants' time. Those problems are attempted solved by calculating intervals for average costs to indicate the extent of uncertainty. However, there is a need for more research including prospective cost studies to further clarify the uncertainties.

Overall assessment

Numerous opportunities and barriers related to the future organisation of patient education in Denmark have been identified based on this critical assessment. The most important challenge is that patient education has uncertain effects. The evidence is assessed overall to be moderate to weak for the patient education programmes analysed, but the evidence for COPD programmes is considered weak overall. Many studies show that patient education has moderate to weak effects, and when studies do demonstrate effects, these are usually short term or were only measured for a brief peri-

od after the intervention ended. Further, the studies have been small and not always of high quality. Although the evidence on the effects of patient education seems to be limited, this is not necessarily because patient education has no effects but could result from the necessary research not being optimal and comprehensive.⁵ The effects that the studies found include increased knowledge, empowerment, improved clinical status (glycated haemoglobin (HbA1c) concentrations) and management of the disease and reduced use of health care.

The assessment systematically investigated which types of theoretical basis and educational methods influence whether patient education programmes achieve the intended effects. The results show that patient education for people with type 2 diabetes has effects if it is based on therapeutic patient education, is oriented towards the participants and towards empowerment and is based on the principles of how adults learn. Further, weak evidence indicates that programmes that use social learning techniques (group approaches) and behaviour-modifying exercises have effects. This was exclusively investigated for type 2 diabetes.

Further, the assessment showed that general patient education programmes and programmes for people with type 2 diabetes have effects when they are based on theories of self-efficacy or self-management. The assessment also showed an association between general programmes that have effects and the use of educational tools. Little evidence indicates the effects of the theoretical basis and educational methods of the programmes, and the assessment thus indicates that investigating educational methods further is key in developing future patient education programmes.

Overall, the assessment shows that few studies have investigated the effects of the teachers' competencies. Nevertheless, studies on type 2 diabetes show that teachers should know about disease and treatment and have educational competencies that are weighted as highly as their technical competencies. The educational competencies should correspond to the educational principles used in the specific patient education programme. This means that the teachers should be taught how to teach the specific programme. The assessment of organisation supports the supposition that health education competencies are a field of development that should be in focus within both the regions and the municipalities. The assessment of patient aspects shows that teachers may have a dilemma in teaching participants to take responsibility for managing their disease if the teachers exclusively teach using very traditional, hierarchical, treatment-oriented methods of teaching.

Qualitative studies show that people obtain benefits from patient education in such ways as developing networks and positive social experiences. Nevertheless, the benefits the participants obtain do not show any consistent pattern. The assessment instead indicates that a broad social-science approach should be taken that can qualify the knowledge about the settings and life situations, such as home, leisure and family, in which people with chronic diseases participate. Concepts used in this field, such as empowerment, self-management and self-efficacy, express dynamic processes aiming to improve how people manage disease. Qualitative and quantitative methods should complement each other in describing these factors.

The assessment indicates that patient education programmes should optimally be timed individually and support independent management of the challenges posed by living with chronic disease. The assessment therefore finds that people with chronic diseases may need to participate in patient education several times during a course of

5 This conclusion applies exclusively to general patient education and to patient education for people with COPD and people with type 2 diabetes.

disease. Similarly, the variation in individual needs shows that the group-based patient education cannot always meet these needs. Studies therefore show that individual patient education is still important. Disease-specific programmes are needed, but the assessment of patients further indicates general needs that should be included in the future organisation of patient education. These include people's daily lives, acquisition of practical competencies and management of individual mental health needs, such as worry, stress and depression.

The people using patient education seem to mainly be women, people from the middle or higher social classes and ethnic Danes. Getting patient education to contribute to reducing social inequality in the future requires critically considering the initiation of other types of efforts that better meet the needs of people in socially marginalised groups and ethnic minorities.

The assessment of organisation shows that organising patient education poses several challenges. According to the Health Act, the regions and the municipalities share responsibility for clinical prevention, and the regions and the municipalities are responsible for specifying the division of labour. Since the regions and the municipalities may locally determine the extent to which they will offer patient education, ensuring coherent and uniform programmes for people with chronic diseases is a challenge. The regions and the municipalities currently agree on the division of responsibilities and tasks and describe this in the Health Care Agreements between each administrative region and the municipalities within the region and in the Disease Management Programmes. Nevertheless, the programmes offered are very diverse across the municipalities and regions at an overall level. This means in practice that the regions have difficulty in organising their patient education in relation to that offered by the municipalities, and patients may find that their municipality does not offer any relevant patient education programmes. Finally, the present organisation is vulnerable, since a few very active staff members take responsibility for patient education without this necessarily being incorporated into a structured and coherent organisation.

The assessment discusses the overall problem of the extent to which patient education should be standardised or whether greater flexibility in the programmes is desirable. The advantage of standardisation, which is a feature of such programmes as CDSMP, is that the education programme is relatively easy to implement since the structure, content, educational background of the teachers and other factors are defined in advance. This means that a municipality can use the standardised model to initiate patient education without great start-up costs. Further, standardisation may contribute to making it easier to evaluate the effects of the programmes, since the programmes become more homogeneous and comparable. Nevertheless, the assessment shows that any standardisation must be implemented without any solid evidence, and it is therefore probably not appropriate to move too rapidly in using standardised patient education programmes before the effects and mechanisms of effect have been better documented.

Although the average cost of a patient education programme is not high, relatively many resources are used in this field at the societal level, since almost half the adult population in Denmark might use the programmes. The cost varies from DKK 3,000-11,350 per participant per programme. Given the future demographic trends and the fact that every patient probably will need to participate in several programmes during his or her life, the cost of patient education will increase sharply and be a huge social investment.

Demographic projections for Denmark for 2040 indicate a huge increase in the number of older people, and the prevalence of chronic diseases increases with the prevalence of older people.

In conclusion, greater insight into patient education programmes is generally lacking for content, health education methods, mechanisms of effect, target groups, organisation, how to measure the effects and the need for monitoring. This requires structured, interdisciplinary efforts in research and the development of quality, with the state, regions and municipalities sharing knowledge. The required research efforts should be interdisciplinary and involve both quantitative and qualitative research, and large, high-quality studies that have a longer time perspective than 1–2 years are desirable.

Guidance

This health technology assessment leads to the following guidance for key actors in the municipalities, regions and the state.

- Patient education programmes should be further developed in the coming years with the aim of creating an evidence base for the effects, documentation, mechanism of effect, health education methods, teachers' competencies, target groups, organisation and content of the programmes
- Interdisciplinary research on patient education should be ensured in the fields mentioned above
- This development and sharing of knowledge should be coordinated and structured across the municipalities, regions and the state.

The content of the knowledge development and research should include the following:

- The programmes should focus on the needs of the participants and thereby ensure differentiated efforts such that having criteria for success oriented towards the patients is one factor determining the content of the programmes
- The programmes should include educational strategies that do not solely focus on transferring knowledge to participants. For example, they should focus on getting the participants to actively train to change their behaviour
- The target groups for the patient education should be considered carefully, and the programme should be adapted to the specific target group, such as people who have just been diagnosed with a chronic disease, ethnic minorities and socially marginalised groups
- The programmes should actively involve important settings for life changes such as workplaces, family life and leisure activities
- The scope of the programmes should be considered, including determining how often the programmes should be offered to people with chronic diseases, such as people who have just been diagnosed with a chronic disease and people with exacerbation in disease
- The programmes should be designed actively so that the theoretical basis and educational methods are harmonised
- The municipalities and regions should strive to achieve a clear division of tasks and responsibilities with the aim of creating a coherent and coordinated supply of patient education programmes and achieving a high degree of recruiting
- Comprehensive efforts should be made across municipalities in carrying out specific tasks that are difficult for individual municipalities to carry out alone

- The opportunities to recruit participants from socially marginalised groups and/or ethnic minorities should be investigated
- Teachers with relevant competencies should be recruited, and the competencies of teachers should be developed
- The organisation of patient education in the regions and municipalities should become less vulnerable, since very few people (highly engaged staff members) currently organise patient education.

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