



# HEALTH EDUCATION PRINCIPLES IN PATIENT EDUCATION

A literature review of selected health  
education principles used in patient education



Region Syddanmark



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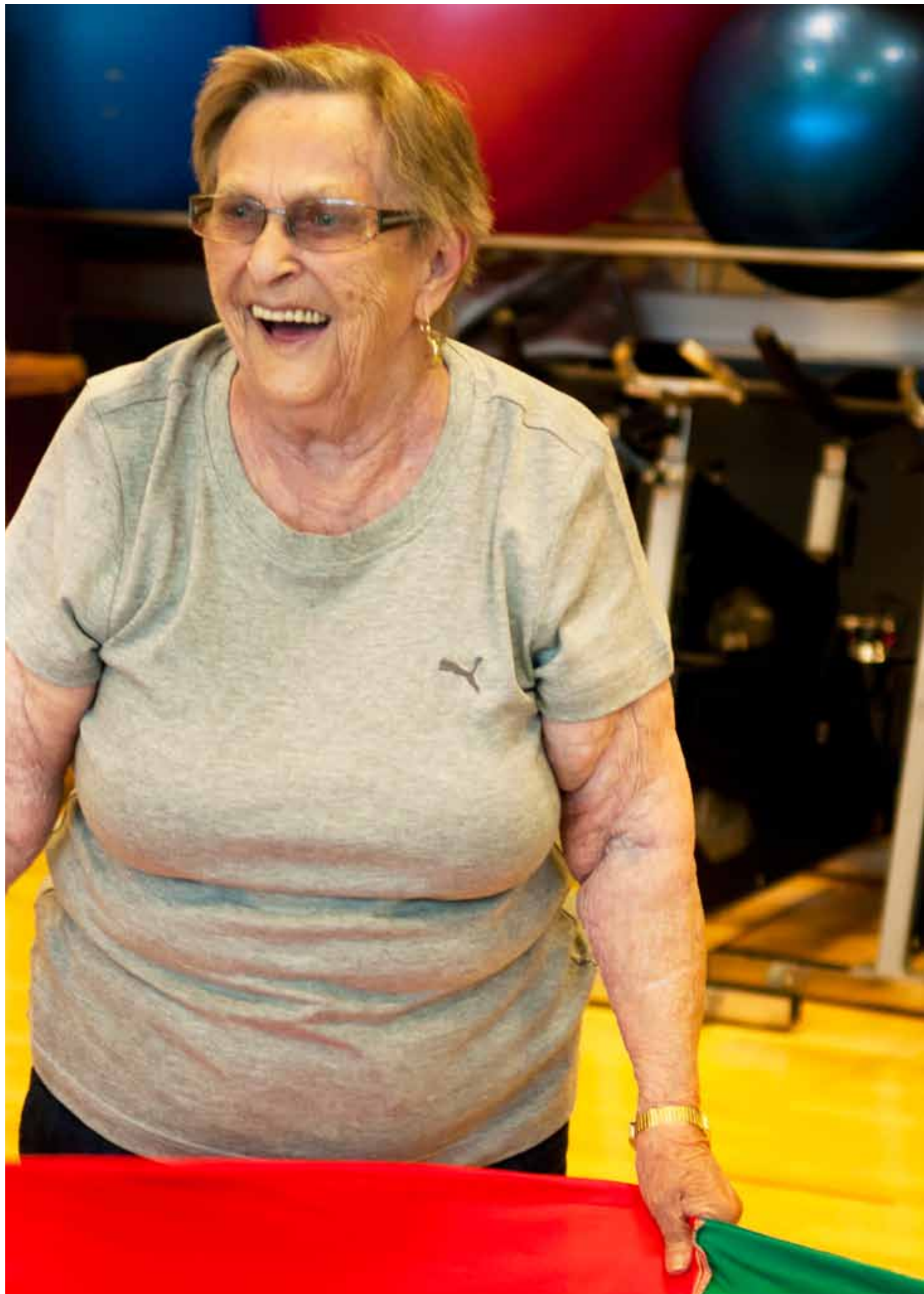
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# Foreword

One of the major challenges in the field of healthcare is to ensure coherent interdisciplinary patient treatment pathways and especially to ensure coherence and quality in the care of an increasing number of individuals with chronic illness. An important part of treatment of the chronically ill is to provide training to strengthen patient skills and the ability to handle their own condition.

Patient health education is a field that is not currently especially well described from a research point of view or as the basis for most existing patient education programs.

One of health education's major strengths is that it provides a hub for addressing various medical approaches and views. Accordingly it enables medical, humanistic, therapeutic and psychological regimens to be linked together, thus linking different interpretations of concepts such as self-care and quality of life that are significant elements in most existing patient education programs.

Therefore there is the need for further research and development to study and test which methods and approaches are effective and how health education principles

can increasingly help develop the field. At the same time, a conscious health education approach and methodology in the work done on strengthening patients and citizens ability to cope with their own illness could optimize this effort and provide better, measurable efficacy for those with chronic illness.

In 2009, the National Board of Health issued a health technology assessment of patient education that among other things indicated the necessity for using health education strategically to create a bridge between the theory and practice of health education. This is the task we are now tackling, starting with this publication.

The target group for this publication is managers, planners and health professionals engaged in patient education. The publication also forms the basis for an ambitious collaborative project on developing a concept for municipal patient education regardless of diagnosis also in conjunction with Steno Health Promotion Center, the Danish Committee for Health Education and the Region of Southern Denmark.

Enjoy the read!

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&

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# Patient health education principles

This publication is an edited and abridged version of the original report "Health education principles in patient learning" (Grabowski et al., 2010), which can be downloaded at [www.dialog-net.dk](http://www.dialog-net.dk).

The objective of this publication is to specify the options for applying health education principles in patient learning. This is done on the basis of selected international literature on patient education with respect to chronic diabetes, chronic obstructive pulmonary disease and cardiovascular disease.

The patient health education principles in the selected literature are elucidated using example such as how health education methods are used in patient education. This is done on the basis of five selected, recognised core concepts. On this basis, the publication defines and analyses five

core health education thematic challenges in patient education. The analysis here focuses on how the involvement of health education methods is expected to make a significant contribution to the future development and improvement of patient education.

Chapter 1 presents the background for the publication, its objectives and various core concepts. It is followed by five chapters that use selected themes to elucidate the use of health education principles in existing international literature on patient education. Various citations from the international literature have been included in the narrative. Each chapter ends with a conclusion and a short description of upcoming challenges. Finally there is a summary of the tasks and perspectives facing patient health education in future.

## 1.1 The latest Danish publications on patient education

In the course of the past five years, the National Board of Health has published several Danish publications relevant to patient education. Most recently, much of the

literature has been systematically reviewed in the report on "Patient integration - a health technology assessment" (HTA) issued by the National Board of Health in

2009 (National Board of Health, 2009).

All reports indicate a lack of knowledge on effective, sustainable patient education, and point to the considerable potential for developing patient education, including the theories and methodology and the research on which education should be based.

The most important parts of patient education are addressed below on the basis of the HTA from 2009.

### **1.1.1 Educators' (health professionals') competencies**

The HTA takes a more detailed look at the conditions required to undertake effective, targeted patient education for patients with chronic illness. The necessity for educators to develop teaching skills is described here. The conclusion is also that health professionals should be trained with a view to changing the practice and assumptions amongst health professionals.

Further to the above, there is the need for more detail and specification of teaching skills, of the knowledge required and how the interaction between competencies and knowledge should work in practical training situations. What should educators /health professionals be able to do and what is the best way to employ their abilities so that they can be actively used by patients? Finally, a pressing issue arises on the best (fastest) way professionals can develop their skills.

### **1.1.2 Patient skill sets**

There is only very limited documentation on the development of patient competencies as the objective for patient education.

Various aims of patient education are addressed, including goals for changes to patient behaviour, treatment objectives (often physiological), psychosocial goals (e.g. quality of life), and utilisation of healthcare services.

It is also important to identify and measure the skills that patients with chronic illness need to be able to cope with living with chronic illness. In this respect, it may be a good thing to differentiate between different types of settings, for example with respect to family and working life and leisure time. The literature thus reveals a range of needs in patients that are not catered for in more illness-specific goals, for example being able to communicate with health professionals and education that involves patients' social arenas. The question is how, and on what conditions, such competencies can best be developed in patients?

### **1.1.3 Health education research**

In general, a limited amount of documentation has been found for the efficacy of using targeted health education methods and the HTA report gives no clear, specific guidelines for choice of method for patient health education. Instead, the emphasis is on the fact that at the more general level, much greater effort should be made to correlate the theoretical basis with patient education practice.

The HTA concludes that there will be a need in future for patient education research that helps identify the inter-relationship between relevant theories, concepts and the associated methods and their practical applications. Further to this, the conclusion is also that scientific tradition, in which quantitative studies are regarded as the highest level of evidence,

<sup>1</sup>Settings are taken to mean patients' surroundings, environment, framework and backgrounds.

forms a barrier to the existence of applicable research-based literature on patient education. According to the report, one possible reason for the lack of evidence in this area could be that the methods applied do not make it possible to generate comprehensive, applicable knowledge on appropriate methods and the efficacy of patient education.

Health education is a matter of organizing conditions to enable a target group (patients with chronic illness here) to develop ideas, take decisions and act on a well-founded/qualified basis. Health education research should thus indicate what this so-called qualified basis might be. Health education research focuses on goals, content and process and their consistency and interrelationship between these.



## 1.2 Developing new patient education models

New models for patient education should be based on patient health education theory and methods, with inspiration from multiple scientific disciplines, for example anthropology, sociology, psychology and communication.

The aim is to combine theoretical thinking from several scientific disciplines that may all be relevant into a coherent patient education program where the overall goal is to develop patients' action competence. Many scientific disciplines have the potential to make significant theoretical contributions to patient education. We feel

that in its methods and structure, patient health education can bring together such content, methods and objectives.

In conjunction with Region of Southern Denmark, the Danish Committee for Health Education and various local authorities, Steno Health Promotion Center has taken up the challenge with collaboration between research and practice on the development of patient education with an explicit health education approach. The work done on this publication constitutes the first phase.

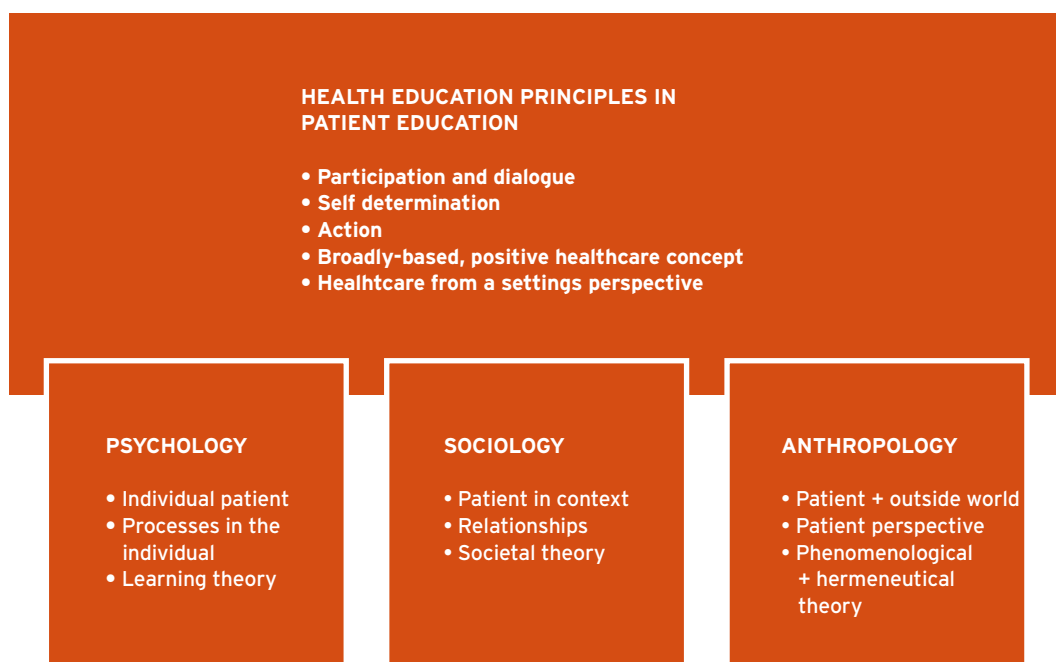


FIGURE 1.1: MODEL FOR THE INTERRELATIONSHIP BETWEEN SELECTED HEALTH EDUCATIONAL PRINCIPLES AND SIGNIFICANT SCIENTIFIC DISCIPLINES

## 1.3 Method

The analysis of the literature in this publication includes international literature on patient education, and includes studies of individual interventions, oversight articles and reviews. Special emphasis has been given to selecting articles involving one or more of the five selected core concepts for patient health education (Jensen, 2009):

1. Participation and dialogue
2. Action competence
3. Action
4. A broadly-based, positive health concept
5. Health from a settings perspective

An initial review of the literature for these five concepts resulted in formulating five core themes (for a more detailed description of a review of the literature and analysis, please see Grabowski (2010)):

1. Multifaceted patient education - What advantages, disadvantages, opportunities and limitations are there for different degrees of multifaceting?
2. Individual and context in patient educa-

tion - What health education outcomes are there for differing types of individual and contextual focus in patient education?

3. Participation and motivation - How to ensure and influence patients' motivation and active participation?
4. Identity as a theme in patient education - How can knowledge of changes in identity be involved in patient education for chronic illness?
5. Professionals' competencies - What are the most efficacious ways for health education skills to facilitate the development of patients' action competence?

Using the five themes in analyzing the literature influences the discussion of the application and significance of the core concepts of health education and thus does not provide a systematic overview of the efficacy of specific types of intervention, objectives or methods in patient education. Please see instead National Board of Health (2009).

## 1.4 Core concepts in patient education

Many concepts may be seen in the literature relating to patient education, such as self-management, self-efficacy, life skills, etc. Analysis shows that in most instances, the many concepts relate to involvement of patients in managing chronic illness but there is a clear need for a more systematic approach in the way these concepts are applied.

The following four concepts appear most frequently in the literature:

- Self-management
- Self-efficacy
- Empowerment
- Quality of life

These concepts are reviewed below. Since different elements of health education appear occasionally in the literature on the other concepts, there is by way of introduction a brief presentation of a patient health education approach on the basis of the five core health education concepts.



### 1.4.1 Patient health education

Patient health education is about achieving health promotional change by way of patients' actions. These actions are implemented on the basis of patients' action competence that is developed and refined in dialogue with a professional. The following acknowledged core concepts from research and development in patient health education jointly define a health education approach (Jensen 2009):

1. Participation and dialogue: Participant involvement means working to ensure that participants can influence the patient education process. Patients with chronic illness must achieve ownership of the process. That is a precondition for enduring change.
2. Action competence: The ability of patients to manage their own lives and change the conditions and framework within which they live so that the framework supports day-to-day living with chronic illness. Action competence can only be achieved when patients themselves influence how their own health can be promoted.
3. Action: What knowledge contributes to patients being able to take action with respect to managing their own lives and creating an environment that promotes health? This question is closely related to development of action competence in patients but goes further: What barriers are there to specific actions taken by patients and how can these be overcome or broken down? What potential is there for individual action and for action taken jointly for example with other patients or relatives? In other words, action competence must be given sufficient scope to lead to specific actions.

4. A broadly-based, positive health concept: The health concept should be interpreted more widely than as just a counterpoint to sickness and death. The health concept also embraces a dimension of the good life and the significance of social relationships. Health is also about the positive aspects of day-to-day living and of the language used in healthcare. "Diet and nutrition" are for example remote, scientific concepts compared to "food and meals". "Dancing, play and movement" approximate much more closely to day-to-day living than the expression "physical activity".
5. Health in a settings perspective: What is the patient's social environment with respect to work, home and leisure? What frameworks cause change? And how can frameworks support patients in achieving health-promoting change for example in the workplace or at home with the family? As with all other activities, patient education is an activity that is expressed in certain specific physical, cultural and social frameworks.

### 1.4.2 Self-management

Self-management is the most commonly used term in the reviewed literature and covers a large proportion of the various approaches to patient education. There is currently no unique, universally acceptable definition of the term but differing definitions and differing supplementary terms are used depending on the context and focus of the area under discussion. For example, self-management is often juxtaposed with such terms as empowerment and self-care.

What many of the definitions have in common is that they relate to the development of self determinant skills, shared

decision-making and goal-setting between patient and health professional, and that self-management education/support is regarded as a supplement to traditional patient education, with training being given in illness-specific information and technical skills such as self-monitoring.

There is a differentiation here between self-management with respect to patients maintaining their health by looking after themselves and self-management with respect to illness, which can mean active participation in therapy, knowledge acquisition, drug administration, measuring blood sugar and collaborating with health professionals, etc. (National Board of Health 2006b).

One of the most commonly used tools for measuring changes in self-management is the "Patient Activation Measure" (PAM), developed to measure degrees of patient activation on the basis of four phases. Measuring tools have also been developed for determining self-management in individuals with specific types of illness, such as cardiac failure.

### 1.4.3 Self-efficacy

The term self-efficacy was originally developed by Bandura in 1977 (Bandura 1977; 2004). Bodenheimer et al. (2002) describe how self-efficacy is a core concept in self-management, since self-management programs often endeavour to stimulate patients' belief in their own abilities so as to achieve desired treatment outcomes.

When these skills have been successfully gained in various situations, individuals develop a sense of self-efficacy, characterised in the belief of an individual in specific actions and his /her ability to successfully perform them.

Self-efficacy is closely associated with the concept of action competence. Someone with well-developed, active action competence will be more able than others to build up their belief in their ability to manage their illness satisfactorily. Self-efficacy is also closely associated with a patient's sense of "self". If patients have a meaningful image of themselves and their own identity and role, it makes it easier to believe that they are able to meet expectations arising from a specific context.

The level of self-efficacy may be measured by applying a validated scale of 33 questions. In this, participants are asked to assess their belief in their ability to perform various self-management tasks relating to their chronic illness (Long et al. 1996).

### 1.4.4 Empowerment

The concept of empowerment was not developed in the health service but originally derived from work done by Paulo Freire on repressed groups' fight for equal rights (Freire, 1970). Since then, the term has gradually become a core concept in the work done on health promotion (Wallerstein 1992). Empowerment has been defined in several ways. For example, Funnel et al. (2007) define empowerment as a therapeutic philosophy that emphasises a collaborative reproach to promoting self-determinant changes in patient behaviours. Empowerment is regarded as a core issue in supporting self-determination for individuals with chronic illness. Similarly, Meyer et al. (2008), state that empowerment is important for helping patients gain control of their own lives.

In many cases, an interrelationship is described between empowerment and self-efficacy by measuring the effect of empowerment. Anderson et al. found that

the Diabetes Empowerment Scale is a valid, reliable tool for measuring diabetes-related psychosocial self-efficacy (Anderson et al. 2000). However, it is important for the interrelationship between self-efficacy and empowerment to be made apparent as part of patient education and that the two concepts are not regarded as independent of each other.

The concept of empowerment is generally used in many different ways and with very different degrees of insight into patient health education. Basically, empowerment is closely associated with action competence and it paves the way for working on a broadly-based, positive health concept.

Settings are integrated to varying extents in approaches to empowerment, depending on whether the focus is on empowerment of an individual or given structures. The concept also includes the fact that it is possible to achieve empowerment in individuals by way of interaction with those around them who have been empowered.

### 1.4.5 Quality of life

Since 1947, indicators for quality of life have been used as a way of investigating more subjective goals for clinical therapies. These indicators consist of a wide range of scales, for example scales to measure emotional, physical and social functionalities.

As for the other concepts discussed, there is no universally accepted definition of the concept. Quality of life means different things to different people and can have a different significance depending on the circumstances in which the concept is used. The concepts of health-related and illness-specific quality of life are also employed, requiring special measuring tools which

have been validated and scientifically recognised to a greater or lesser extent. If we wish to use quality of life to measure the efficacy of a patient education program directed at patients from a specific illness group, we need to use a validated goal for illness-specific quality of life.

Measuring quality of life may be complex since as a goal, quality of life can be mediated by numerous interdependent variables. For example, quality of life can be affected by expectations for life, level of optimism and pessimism, individuals' social and cultural values, etc. Another challenge in measuring efficacy using a goal such as quality of life is also that it is most often measured immediately after a patient education intervention, irrespective of its length which can be highly variable. With a short follow-up period, it is highly improbable that an effect on quality of life can be determined.



# Theme 1: Multifaceted patient education

## 2.1 Identifying the problem

Patient education is often made up of a range of different approaches and methods such as teaching, telephone counselling, access to exercise facilities, support group meetings and help in developing and follow-up on patients' own action plan, etc.

One problem with multifaceted interventions is however that the various elements may appear not to be clearly interconnected and not to have a common basis of values. Coordination and coherence in the overall patient education process thus requires a consensus on the overarching goals amongst educators and also on

the methods and principles to be used in teaching and goal setting. If for example patients' own participation and influence are to be taken seriously as a principle in education, it is essential that this should apply to all parts of patient education.

Another problem attaches to assessment and documentation. In patient education which includes many different elements that build on different principles and educational concepts, it can be very difficult to assess which parts of education can have led to the outcomes achieved.

## 2.2 Trends in the literature

The problems arising in the literature are discussed below. It is apparent from the literature that there is agreement that chronic illnesses lead to highly complex problems for patients and that there is therefore the need for interventions in many different areas. Generally the literature points to the fact that such multifaceted interventions have better efficacy than more narrowly based or individual interventions. For example, Bourbeau et al. write that successful programs for COPD require

a multifaceted strategy and that this not only involves education in the illness but also effective methods to be implemented aimed at promoting behavioural changes (Bourbeau et al. 2004; 276).

It is logical that there is a correlation between the complex nature of chronic illnesses and the complex challenges in organizing and undertaking patient education. This does not however mean that there is agreement in the literature on the

best way to put together such as a multifaceted intervention. The subcomponents for inclusion in a multifaceted approach often lack systematisation and categorisation and descriptions are often limited to pointing to the insufficiency of just focusing on disseminating knowledge (Steed et al. 2005; 263).

Insofar as a multifaceted approach to patient education is defined and delineated in the literature, the differing definitions reflect different starting points. A multifaceted approach may for example consist of different groups of health professionals, different scientific disciplines, different philosophies, different methods and different practice.

In an article on DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed), Ockleford et al. define multifaceting thus:

*“Development of DESMOND involved a multidisciplinary, multicentre collaborative team which agreed upon a core set of philosophical principles that cohered about the use of ‘informed choice’ as the key to ‘empowerment’, and drew on three theoretical approaches: the commonsense model of illness, social learning theory and use of a discovery learning process” (Ockleford et al. 2008; 29).*

One of the most widespread models, the “Chronic Care Model” (CCM), however takes another view of the multifaceted approach. In this, the emphasis is on support for patients being organized and multifaceted and the model contains considerations with respect to how treatment, support for self-determination and clinical decision-making,

organisation of healthcare services and clinical information systems, and resources and local community policies are organized (Barr et al. 2003).

CCM is thus a multifaceted approach in the sense that it involves interventions and considerations at different structural levels, aimed at optimizing the interaction between different levels in the health service. In contrast, the DESMOND project endeavours to create an interrelationship between an underlying set of principles and specific activities.

Another challenge in multifaceted interventions relates to documentation on the efficacy and definition of effect measurement. The direct and indirect efficacy measurements of subelements may often be difficult to define and keep apart from each other. Having many efficacy measurements automatically creates complexity in evaluation which is difficult to handle. There is the risk of the purpose of patient education “drowning,” as it were, in multifaceting if efficacy cannot be made measurable and related to specific types of intervention.

This versatility in topical areas thus involves a series of pitfalls and challenges. Overall, the literature points to the fact that it can be difficult to integrate and create an interrelationship between different elements so that education becomes an entity for patients and educators in multifaceted patient education.



## 2.3 Conclusion and challenges

It may be concluded that multifaceted patient education generally increases the probability of an effect but there is also the risk of losing coherence and the effects of synergy as subelements accumulate. Accordingly, preventing the many different issues from becoming isolated is a challenge and also that the learning resident in one element is not subsequently included in the others.

Multifaceting often makes it difficult to stick to the theory and philosophy underlying the intervention and taken together, the articles give a picture of different philosophies, theories, methods, processes, strategies and efficacy measurements not being used stringently or coherently. In many instances, there is an absence of overview and educational coherence and patient education appears as a collection of integrated subelements that patients and professionals find it difficult to work with.

Developing skills in an interdisciplinary group of educators is also a challenge which taken all in all can cover the content of a multifaceted patient education course. The common denominator may be a selected range of health educational

core concepts. This means that all parts of education must be organized on the basis of these concepts for methods, implementation and goal setting and that the professionals must be trained and qualified to use these concepts so as to be able to work together to complete their task.

The challenges in this area are thus:

1. To create coherence and integration in a multifaceted intervention so that individual parts interact.
2. To establish an overall educational approach and uniformity in all parts of patient education, also by way of participation and dialogue as core concepts for relations between patients and professionals.
3. To ensure that the various elements are directed at a common goal, namely the development of patients' action competence in a series of further specified areas.
4. To ensure interaction between instructional and social, cultural and physical frameworks in patient education and that the training of professionals reflects such interrelationships.



# Theme 2: Individuals and context in patient education

## 3.1 Identifying the problem

This chapter deals with how individuals - patients - are perceived and participate in patient education. In principle, this covers two different themes.

The first deals with how patients' illnesses can be verbalised. If the emphasis is solely on the patient's own behaviours without this being made part of the context, this is characterised as an individualised approach. This view is often characterized in the international literature as 'Blaming the victim' ideology, that is, patients should get the blame for their illness. It is clear that such feelings of guilt do not provide the most fruitful starting point for their engagement with patient education.

The second theme addresses the perspective of action and hence how patients

act to manage their own illness. An individualised approach means that the focus is solely on how to motivate individual patients to directly change their own lifestyles. Such thinking means that changes in social networks, in the workplace for example, are not included in possible action strategies. Below, there is an illustration of various types of action associated with patient education.

The starting point is for patients to act solely and jointly and that they can act directly or indirectly to improve their own health. The model thus provides for different types of action which in principle should fundamentally be discussed when a group of patients is working on possible solutions in patient education.

	Direct actions	Indirect actions
Individual	1	2
Joint	3	4

FIGURE 3.1: FOUR DIFFERENT CATEGORIES OF ACTION THAT PATIENTS CAN UNDERTAKE (ACCORDING TO JENSEN 2009)

The first field in the model illustrates the fact that individuals can decide to try to change their behaviour or lifestyle, for example by changing their eating habits. Field 2 illustrates the fact that individuals can try to change the frameworks for their health, that is an attempt to affect health indirectly. This might for example consist of creating better opportunities for taking exercise and keeping fit at the workplace or trying to change the provision of (healthy) food in the canteen.

The third field illustrates a group of patients making a joint attempt to try and change their behaviour. The aim is still to change their own behaviour but here the emphasis is on for example support from other patients at weekly meetings which provide reciprocal sparring and feedback and where they share ideas for sticking to a given behaviour. The fourth field characterises a form of action in which patients jointly try to affect the general framework for their lives, for example by making it possible to take exercise in the workplace.

Given the above, an individual approach may be defined as belonging in field No. 1. If patient education solely deals with getting individual patients to change their own behaviour, the model will help in understanding that this precludes many other possible types of potential change.

One central and important point is that alternatives to an individualised approach do not exempt patients from taking responsibility for their own health and illness management. Instead, the model paves the way for considering that such responsibility can be administered and stimulated in many ways. And similarly, there are different ways it can be integrated in patient education.

Below, we take a look at the literature on the basis of these considerations and investigate closer the role intentionally or unintentionally played by patients provided by different types of patient education.

## 3.2 Trends in the literature

Generally speaking, for some years there has been pronounced criticism of individualisation in the health sector (Crawford, 1977; Jensen, 2009; Tesh, 1990). The same trend has become apparent in the field of patient education and the treatment of chronic illness.

For example, Barr et al. (2003) identify the same tendencies in addressing the problem of an individualised approach:

*"The approach was criticised for assigning blame to individuals for their own health problems. If ill health was "caused" by poor judgement and decision-making around*

*smoking, nutrition and physical activity patterns, then it is easy to see how individuals could feel judged by campaigns and programming that focused entirely on individual responsibility for behaviour change" (Barr et al. 2003; 75).*

For the same reason, they propose (Barr et al. 2003) supplementing the widespread Chronic Care Model with a perspective from "Population Health Promotion", which includes healthcare determinants, supportive environments, etc. This "Extended Chronic Care Model" operates with the local community as an important contributor, also in patient education and treatment

and thus endeavours to get over the individualistic perspective.

Wilson et al. (2007) discuss the British Expert Patient Programme (which corresponds to the US "Chronic Disease Self-Management Programme", in which experienced patients serve as coaches). They emphasise that the content and structure of the entire program is dominated by a biomedical paradigm and on the basis of their own studies, question whether empowerment goes further than the purely individual level.

There is a tendency in the literature for patient education to be mainly regarded from a psychological viewpoint which can reinforce an individualising approach. This is apparent from the use of concepts and approaches that are traditionally applied in various psychological situations. By way of example, various coaching models are integrated to supplement or replace the more traditional approaches to interaction between patient and health professional.

### 3.2.1 "Self concepts"

Many different concepts of self are involved in patient education. For example, in an article titled "Development, content, and process evaluation of a short self-management intervention in patients with chronic illnesses requiring self-care behaviours," Schreurs et al. (2003) employ such terms as "self-management", "self-regulation", "self-monitoring" and "self-efficacy" for describing the same method.

These many 'self' mechanisms result in a marked focus on the individual and cannot avoid having consequences for patient education. The concept of self-management appears in many instances to serve as a common designation for patient

education. The concept then gets to cover many different meanings, thus risking the loss of its meaning and usability.

In their article on "From DSME to DSMS: Developing Empowerment-based Diabetes Self-Management Support," Funnell et al. (2007) describe how there has been a shift in diabetes education towards more long-term interventions, containing parts of classic education but also with the emphasis on helping to provide support functionality with respect to development of the patient. This proposition represents an approach to self-management that aims at developing robust, enduring life skills.

The individual's relational environment and social context must be involved in patient education. Methods must be developed to support patients in making use of their environments and networks insofar as at all possible. There are examples in the literature of including a focus on settings in patient education.

Bourbeau et al., for example emphasised that it is often advantageous to include a spouse and family to support patients' self-monitoring and does provide positive reinforcement (Bourbeau et al. 2004; 274). This involves an example of including the patient's family setting in patient education. In the same way, the workplace or school can be involved in managing chronic illness.

Schreurs et al give another example of endeavours to overcome the individualistic perspective in which participants in group-based patient education were asked to write their own individual action plan for achieving a target, for subsequent discussion in the group so as to get good advice and feedback (Schreurs et al. 2003; 135). In the process, there is an illustration that the social setting provided by patient education

can be exploited to overcome individualistic perspectives. The assessment further indicated that least well-educated, unemployed patients had the most to gain from this process.

Despite these examples, there is however clear prevalence of an individualised perspective in patient education.

### **3.2.2 Group and individually-based patient education**

The literature gives examples of many different variants of group and individually-based patient education. It is apparent that outcomes and satisfaction vary depending on the needs and characteristics of individual patients and groups of patients. Different patients and different groups of patients can benefit from group and individually based interventions since both include potentially good, constructive health educational elements.

In their article on "Education and self-management for people newly diagnosed with type 2 diabetes: a qualitative study of patients' views," Ockleford et al. specifically describe diverging perceptions of, and limited evidence for, the type of intervention that is best. There is a special discussion on whether group-based education has special benefits compared to individually-based education with some studies indicating that group-based education is just as effective as individually-based education, whilst also providing the opportunity for a more efficient and cost-effective service (Ockleford et al. 2008; 29).

Group-based education has been shown to have different efficacy at the individual level. A core principle of group education is that patients are expected to share their

experience with respect for example to being diagnosed with diabetes. Patients often have very different expectations and different assumptions which may therefore lead to very different levels of outcome and satisfaction amongst participants. Successful group education thus requires very careful preliminary work on recruiting and motivating patients.

It is naturally easier to adjust individual interventions to the individual patient. For example, integrating different forms of coaching in patient education. This represents a highly individually-oriented format which tries to varying extents to involve patients' environments (Whittemore et al. 2002).

Since individual interventions are typically more demanding on resources than group interventions, there have been various efforts to utilise the positive parts of individual orientation without this necessarily being structured as face-to-face-sessions between patient and health professional. This typically involves interventions using computer-based communication that enable individual patients to modify the learning process according to their own needs and tempo (Jenny & Fai, 2001).

There are advantages and disadvantages for both approaches from a patient health education perspective. There is much to indicate that a balance between the two types would be ideal in efforts to reach out to as many patients as possible, and thus prevent patient education helping to create (additional) inequalities in healthcare. It therefore requires an individual assessment of patients' circumstances, expectations and life situation so as to assess the educational offerings there would be most effective for them.

## 3.3 Conclusion and challenges

A tendency has been noted for patient education to involve almost exclusively individualised approaches. There are however examples of methods that endeavour to involve relatives, just as there are examples of processes in which patients make reciprocal use of each other.

The individualised approach is evidenced among other things by the use of “self-” as part of the terminology, for example “self-determination”, “self-management” and “self-efficacy” are examples of this. Despite the use of these concepts not necessarily needing to lead to an individualised approach, this is often the case.

As a result of the above, involvement of patients’ multifaceted settings is downgraded and they therefore do not get involved and utilised sufficiently. Three challenges to the future of patient education arise in the light of the above:

1. Methods must be developed to emphasise the importance of patients being able to be dealt with as individuals and as group patients and that they can develop and support each other in testing out common actions for example directed at changes in lifestyle. Further, other communities such as the family or coworkers could potentially provide support in initiating actions.
2. Methods must be developed to support patients in focusing on managing their own lives and making changes or getting support from those around them so as to promote their health.
3. Before making a start on patient education, there should be an assessment or screening in which the needs and resources of individual patients are assessed before assignment to group or individually based education.





# Theme 3: Participation and motivation

## 4.1 Defining the problem

This chapter addresses the interrelationship between motivation and participation by patients in patient education. In brief, patients' active participation is a precondition for developing ownership which again is a precondition for long-term change and the efficacy of patient education. Patient participation is therefore a key parameter in patient education if we are to create change and better health.

Participation as a health education concept is however not the same thing as patient management and the use of the "bottom-up" principle in which the professional is often sidelined and is solely ascribed the role of process consultant. Instead, the emphasis should be on interaction or dialogue between patient and professional and the knowledge, skills and medical competencies of the professional therefore have a decisive, core significance. This accordingly indicates a third way between the "top down" and "bottom up" principles.

Participation is a complex concept which is also reflected in the profusion of terms used for the phenomenon: involvement, participation, activation, interventional, target group management, co-determination, influence, decisionsharing, bottom-up, empowerment processes, etc.

There is accordingly the need to specify the concept of participation without this weakening its content and core. The figure below crosses four different categories of co-determination with five typical phases in a patient education process (modified from Jensen 2000).

Categories/ Phrases	Included in Project?	Examination/ Elucidation	Vision/ Goals	Strategy/ Action	Assessment/ Follow-up
Patient initiative Joint decision					
Patient initiative Patient decision					
Professional initiative Joint decision					
Professional informs Patient acceptance/ rejection					

FIGURE 4.1: MODEL FOR PARTICIPATION. DIFFERING CATEGORIES OF PARTICIPATION AND DIFFERENT QUESTIONS THAT PARTICIPATION CAN ADDRESS

The lowest of the four categories reflects a situation in which patients get the opportunity to join a predesigned project which in effect limits self-determination; in other words it is limited to a “take-it-or-leave it” concept. The three other categories differ from each other by their combination of 1) who takes the initiative and make suggestions and 2) who takes the final decision. In the top category, it is for example patients who make proposals and suggest ideas and it is then the professional who provides feedback. Finally, a decision is made jointly.

Horizontally speaking, the model has a range of phases, or questions, that a specific patient education process often needs to take into consideration. According to the first question, patients may play different parts in reaching a decision as to whether they will take part in a process or not. The next question is about patients investigating their own illness and its pathway. What routine day-to-day issues for example make it worse and which do the opposite? The third question is about developing a series

of realistic changes (goals/visions) whereas the fourth question focuses on developing specific action strategies for the necessary changes.

In other words, this model can be used to give a nuanced picture of when and how work should be done on patient participation in a specific patient education process. The idea is not to formulate an ideal model for a health education process in which participation is to be interpreted and used in absolutely specific ways and where the crosses are to be placed in the “right places” in the matrix. What is important is rather to insist on professionals, possibly in conjunction with patients, taking the time to discuss how handle what issues and decisions they wish to work on the aspect of participation.

In the light of the above, we take a closer look below at how the literature contributes in addressing the theme of patient involvement.

## 4.2 Trends in the literature

The main tendency relating to participation in the literature on patient education is clear and unambiguous, in any event at the theoretical and rhetorical level. Active participation by patients has been a dominant "buzzword" in the literature over the past 10-15 years. And attempts are made in several ways for compliance by various groups of professionals.

Steed et al. (2005) showed that five weekly 2½ hour sessions with patients with type 2 diabetes, in which the emphasis was on involving participants and their views on education, lead to very significant improvements compared to a control group. Participants also saw a significant improvement in their knowledge and they also increased their confidence in the efficacy of their treatment and their feeling of being in control of their diabetes (Steed et al. 2005; 272).

Cooper et al. (2001) emphasised on the basis of a comparison of twelve meta-analyses that the general tendency is for the top-down approach to be least efficacious and that the greatest impacts in patient education are seen in approaches based on social learning techniques. And Bodenheimer et al. report how the inclusion of patient participation is involved in a more general paradigm shift in which patients are regarded as their own carers whereas professionals appear rather as consultants who support them in this role (Bodenheimer et al. 2002; 2470).

The trend according also to Bodenheimer et al. (2002), is towards patients being seen as experts who, like the professionals, use their expertise in identifying and raising the profile of their own problems. The general idea of the patient as an expert is repli-

cated in various other approaches, including the British Expert Patient Programme, which was inspired by the US Chronic Illness Self-management Programme, which include experienced patients as key educators.

In their article on "The Expert Patients Programme: a paradox of patient empowerment and medical dominance", Wilson et al. (2007) review the positive aspects of the program (including the fact that participating patients develop action competence since the empowerment strategy in fact worked) but they also emphasise a series of criticisms also noted in UK. They conclude among other things that the patient education program reinforces a biomedical approach and that its effect is to exclude weak and vulnerable groups.

Finally, Guided Self-Determination (GSD) is mentioned as a structured process that uses so-called reflection sheets to support professionals and patients in joint dialogue and decision-making (Zoffmann & Lauritzen 2006). The sheets are completed by patients before and between sessions with professionals and/or are intended to raise the visibility of and maintain the patients' situation as a basis for dialogue. The method has been shown to be effective in providing patients with type 1 diabetes better control of their condition and fewer diabetes-related problems. The method is further described in Chapter 12.

In an article titled "Assessing Inpatient Pulmonary Rehabilitation Using the Patient's view of Outcome," Van Stel et al. (2002) describe how in a patient-centric approach to patient education, the emphasis is on routine involvement of the patient in assessment and this helps to ensure

enhanced motivation in the longer term.

*“The new method implies a shift to a patient-centered approach, in which the patient is actively involved in setting, prioritizing, and assessing his or her own treatment goals, all in consultation with the treatment team” (van Stel et al. 2002; 202).*

#### 4.2.1 Barriers to participation

The selection of articles noted above illustrates that there is great potential in participant-centric perspectives in patient education. However, various barriers have been identified to the application of such a perspective in practice.

Paterson (2001) showed for example that professionals (here GPs), despite their stated ambition of making use of patient participation and empowerment, in practice worked against this. This happened in two different ways, partly by not taking patients' own perceptions and experiences seriously and partly by not making the necessary resources (such as information and time) available to the patient.

This then placed the challenge of working on participant-centric treatment of patients in this study on the professionals. Paterson concludes that professionals often have a naive impression of how to achieve participation and employment.

*“The underlying assumption of many practitioners is that an invitation to people with chronic illness to participate as equal partners is sufficient to guarantee their empowerment” (Paterson 2001; 574).*

The research generally shows that professionals' intentions to involve patients in managing their own chronic disease are more pronounced than their documented ability to put their ideas into practice. Qualitative research in diabetes has for example shown that in interacting with patients, the approach of professionals, who had explicitly adopted the philosophy of empowerment and hence the wish to use a participant-centric approach, was seen as paternalistic (Andersen & Funnell 2009; Hernandez 1996; Paterson 2001).

There thus appears to be a tendency for health professionals to take it for granted that patients become involved in their condition and that the professionals can therefore make do by just telling patients to participate and get involved. Several authors stress that in many ways, a more traditional top-down approach is in many ways deeply anchored in the medical culture, making it rigid and difficult to change. In this light, it is challenging to create real awareness amongst health professional that such involvement does not come about all by itself.

Finally it should be added that there will be patients who need the security provided by competent people taking over and removing the pressure by taking important decisions for the patient. This provides the foundation for the model presented in Figure 4.1 since it indicates that participation can occur at several levels with varying levels of professional involvement.

#### 4.2.2 Patient education - motivation for all?

One of the core issues for patient education is who participates. The British Expert Patient Programme has been criticized for excluding those whose resources are weak (see e.g. Wilson et al. 2007). In several

cases there have been descriptions to how the patients in education are those with relatively strong resources with the surplus energy and who can easily identify with the content and format of the education. The risk then arises of these programs contributing to cementing and perhaps even increasing inequalities amongst patients with chronic conditions.

Echoing the criticism amongst other things of the British "Expert Patient Programme" (Wilson et al. 2007), Anderson (1996) argues that greater emphasis on participation leads to the risk of excluding the vulnerable and weak, thus increasing inequalities in healthcare. According to Anderson, this often occurs if individualised approaches are being taken. Schreurs et al. (2003) however further show that their participant-centric patient education program actually motivates the least educated and unemployed patients. They ascribe the success of the program for vulnerable patients to the structured approach taken by professionals in the program.

On the basis of the above, it is appropriate to focus on programs that first break away from the individualised perspective and secondly, use structured ways of working that are more able to capture the interest and motivate more vulnerable patients.

### 4.2.3 Compliance

Last, we address the concept of compliance which occurs with great frequency in the literature on patient education, also with respect to patients' active participation. In many ways, compliance is the opposite of participation, namely a kind of acquiescence and surrender on the part of the patient, in any case if sticking with the traditional understanding of compliance. Even so, participation is often linked to

compliance, as illustrated by the quotations below:

*"Meta-analyses of studies assessing compliance with cardiovascular prevention reveal that interventions become more effective with active participation of patients" (Sol et al. 2005; 22).*

*"The results of this study suggest that cognitive and behavioural strategies as part of self-management programs would be useful for motivating and maintaining compliance to a regular walking program among moderate to severe COPD patients" (Bourbeau et al. 2004; 273).*

However, there are various examples of researchers who are sceptical about the concept of compliance in the light of the growing patient-centric paradigm.

Anderson & Funnell also address this problem and they emphasise the fact that a new paradigm characterised by collaboration between professional and patient favours the way to new interpretations of compliance.

*"For some patients, the treatment (diet, swallowing pills, going to the physicians), rather than the disease, is the main problem. "Noncompliance", appearing irrational to the professional, may be a rational choice from the patient's viewpoint" (Andersen & Funnell, 2000).*

Finally, Bodenheimer et al. emphasise in a description of Collaborative Care that the



concept of compliance has no relevance in a modern approach to patient education.

*“In traditional care, medical professionals may blame patients for their shortcomings. They may say things about patients like: “He’s noncompliant with his pills” or “She refuses to check her blood sugars.” In collaborative care, when physicians accept the validity of patient-defined problems, the concepts of compliance and adherence—based on physician identification of problems and patients failing to solve physician-defined problems—no longer apply” (Bodenheimer et al. 2002: 2470).*

If the concept of compliance is developed to include openness and cooperativeness, it cannot however be excluded that it can serve as a part of patient education oriented towards such concepts as participation, involvement and motivation. But this means that patients themselves must be involved in determining the final content of compliance with respect to their specific situation and condition. This changes the significance of the concept with respect to its original point of departure and the concept then loses much of the aura of power implicit in the classic roles of patient and clinician. In the light of current changes in patient education, this is perhaps a necessary development.

Here too the model in Figure 1 can be used to nuance the discussion. For example, there will be lots of scope for patients to participate in developing ideas and action plans which relate to compliance with a goal proposed for example by a professional.

## 4.3 Conclusion and challenges

On the one hand, there is a general, unambiguous tendency for current patient education to have ambitions in some way or other for involving patients as active participants. On the other hand, it is also clear that such involvement arises in many different ways, stretching from symbolic to genuine participation and that what is needed therefore is a more precise and nuanced conceptual apparatus to be developed to embody this diversity.

There are various examples of patients, despite the declared ambitions of professionals, not experiencing proper participation in practice. This may be due to insufficient professional skills, and it may also reflect the fact that a traditional medical authoritarian culture is highly ingrown and difficult to change.

Various studies have further shown that several patient education programs tend to exclude vulnerable patients with few resources. Yet again, other studies show that structured participant-centric programs that are not only based on an individualistic approach also appealed to those patients with the fewest resources.

The following four challenges for patient education would seem to pertain in the light of the above:

1. It is important to develop a coherent set of concepts for participation, based on the one hand on common, fundamental ideas about participation as a precondition for motivation and change and on the other hand, with the cultural sensitivity to allow them to be used in practice in various therapeutic areas and differing groups of patients. The model in Figure 4.1 may again serve as the springboard for this process.
2. With respect to the phenomenon of “inequalities in healthcare”, it is key that the methods developed also take into account those groups of patients with the fewest resources and below average motivation. What should therefore be done to develop a structured program that does not compromise with the principle of active participation and which reflects the social dimension.
3. It is important to identify and develop the professional skills that make it possible to work on medically important and well-founded knowledge in an involving way.
4. Despite the criticism of the compliance as a core concept, consideration should be given to whether it can be “opened up” by the professionals so as to provide the scope for participation and influence, and hence development of ownership by the patients involved.



# Theme 4: Identity as a theme in patient education

## 5.1 Identification and problems

Where patients are concerned, the concept of 'self' involves their relationships and those around them and the way in which the individual patient/person builds up, develops and maintains their identity. An individual's identity closely correlates with the values they find in themselves and their social environment.

Social psychologist Thomas Ziehe's authorship has addressed identity-related problems, and he emphasises that identity can no longer be regarded as something we merely acquire but that identity must now be tested, changed, stylized and actively taken possession of (Ziehe & Stubenrauch, 1983; 30).

Jenkins (2004) describes how identity is formed and developed (and modified). A given identity will always differ from person to person and from context of context which should have a major impact on the design of patient education.

An individual creates a meaningful correlation between identity and the outside world through an ongoing process in which the image of the external environment and of the self is constantly matched with respect to each other. It is this matching process that is breached or displaced when individual become patients with a chronic

disease, thus finding themselves in a completely new context.

In many instances, a chronic condition will lead to a perception of loss of identity. Some patients focus completely on the restrictions a chronic condition can mean whereas others will focus on the opportunities they still have. Patients need to be able to regard themselves as meaningful in a new situation (chronic illness) and in a new context (health service, patient education). Further, previous contexts such as the workplace may also change character as a result of a chronic condition arising, for example as a result of certain duties that can no longer be performed. Health professionals can help patients to develop this ability to be able to see and recognize themselves in unusual situations and environments.

Loss of identity and changing roles and concepts of self in patients with newly diagnosed chronic disease are accordingly problems and need to be addressed in patient education. Otherwise, identity problems can constitute a significant barrier to patients' ability to develop in an educational process.

## 5.2 Trends in the literature

There is a displacement between identity and the outside world when someone is diagnosed with a chronic illness. This has consequences for patients' perception of their own identity. There are several different ways of reacting.

In their article on *"Education and self-management for people newly diagnosed with type 2 diabetes: a qualitative study of patients' views"* Ockleford et al. investigate the acknowledgments, understanding, viewpoints and experience of diabetes and diabetes education in patients newly diagnosed with diabetes: They identify four different categories of patients (Ockleford et al., 2008; 28):

1. "Accepters" who have both accepted their condition and the changes required to their lives.
2. "Identity accepters - consequence resisters", who have accepted their condition but resist making changes to their lives.
3. "Identity resisters - consequence accepters", who find it difficult to acknowledge that they have contracted a chronic disease even though they have changed their lives.
4. "Resisters" - who both refuse to acknowledge the disease and to make changes to their lives.

The four categories reflect the different ways that patients react when they contract a chronic disease. It is important for professionals to know about these four typologies which also constitute knowledge about patients' very different reactions to identity changes. Such knowledge can make it easier to support individual patients in a process.

For patients, being able to maintain a "nor-

mal" existence means a lot for their ability and will to be receptive to patient education. Various elements of daily routines can be key to the identity and 'self' concept of different patients.

*"Our findings suggest that the social demands of everyday lives and the need to maintain a coherent identity and a 'normal life' are key challenges for people attempting to manage diabetes. As in other chronic illnesses, the diagnosis of diabetes may involve grief for a former self and a struggle to reconcile that with the 'new' self" (Ockleford et al., 2008; 35-36).*

### 5.2.1 Roles

Roles are not the same as identities. Identity may be defined as the overarching concept of self whereas roles more or less consciously serve as the functions we perform in our day-to-day lives to adapt to the various environments of which we are part.

A chronic illness means that patients are faced with a range of new but unknown roles in their daily routines. The ability or lack of it, to fill these roles can have consequences for identity. In their article *Vascular risk management through nurse-led self-management programs*, Sol et al. also emphasise the following on roles:

*"Living with a chronic illness implies that one has to adopt different roles. The role of the "sick" is often the role of a patient with acute illness and is merely a passive one. This role*



*fits in a medical model, and patients do not feel responsible for their own temporary state. The focus is on a quick cure. In contrast, the roles one has to play when "at risk" are less obvious. This requires such attitudes as active control over disease-related symptoms in a way that functioning can become as normal as possible" (Sol et al. 2005: 21).*

Zoffmann & Kirkevold also reveal that patients may have different roles in different "lives", for example one role in "a good life" and another in an "illness life" in which in some phases of the patient's life, the "good life" gets greater priority than their illness-oriented life. In this connection, it is key for the health professional to be aware of whether the identity of an individual patient at a given time derives from the good or the illness life.

Patient education needs to work to make any new roles comprehensible for the patient on the basis of awareness of individual patients' prior understanding and prioritisation of such new roles.

The increased focus on the need for patient education to be patient-centric creates new roles for both patients and professionals. It is not possible to automatically assume that all those involved know how these new roles should be filled. If patients are used to feeling confident in a passive role as patient, they may feel that it is a major change of role to have to assume a role as an active, participating patient. So in this way too, there is the need for attention to be paid to the change of role as an issue in patient education.

## **5.2.2 Broken identities and self-images**

In an article "Changes in self-concept during pulmonary rehabilitation" Laurel Kersten gives a specific example of the evaluation of patients' self-concept as part of a lung rehabilitation program in which patients were asked to assess their previous, current and future selves at the beginning and end of the program and 2-6 months after the end of the program.

*"If personal or environmental changes are great, an elderly person, such as an individual newly admitted to a pulmonary rehabilitation program, cannot integrate the change without a fundamental reorganization of his or her theory of the self. In this case, an identity crisis may occur. Whether it actually occurs depends on how central the change is to the individual as well as the extent of anticipated change. In essence, it is a person's interpretation of events, not the events themselves, that determines whether crisis results" (Kersten, 1990; 457).*

Patients' ability to understand illness (and the content of patient education) with respect to themselves is crucial for whether a decided identity crisis arises. When someone starts on something new, there will always be expectations of possible changes and impacts and in this connection, it is important that health professionals are able to assist in harmonizing these expectations in a meaningful way so as to achieve a realistic relationship between the present and future image of self.

The literature shows that it is possible to influence patients' positive self-concept and positive expectations for the future by way of a focused education process in which there is a targeted attempt to make

their illness, and tasks relating to self-determination, relevant for the patient. Imagining a future without a normal life is thus an absolutely key part of experiencing a breach of identity. Patients are on unknown ground, as it were, when they try visualizing their future. The future scenario no longer has any meaning for them - they become uncertain and insecure and seek for recognition and security in their life.

*"Since COPD is a deteriorating long-term illness, patients may also need some readjustment; as the patient passes on to another phase of his illness,*

*he has to readapt" (Bourbeau et al. 2004: 274).*

Depending on the nature of their illness, these changes do not only happen as part of diagnosis but also as part of the progress of the disease. Patients must have the time and opportunity to understand and acknowledge the significance of these changes to their identity. If health professionals force this process, it can be difficult for patients to play an active role in other parts of patient education. Patients need to "find themselves" (and hence their identity) in their new roles.

## 5.3 Conclusion and challenges

The overarching conclusion is that the diagnosis of chronic illness often has major consequences for how patients perceive their own identity. It is possible to outline various types of roles that will be included in patients' identity during transitional phases.

A breach of identity experienced by a patient in the format of a discrepancy between the identity and the outside world, can lead to limitations in the development of action competence for individual patients.

Finally, a switch in identity as a chronic patient may be involved. If used to a passive role in which the health professional leads and informs, the patient is now expected to adopt a role as a participating and proactive patient. Here, too, there are grounds for being aware of the need to support patients in a changed process.

Three challenges to the future of patient education arise in the light of the above:

1. Patient education must be organised so as to engage with and support patients in processing identity experiences and identity breaches. Professional support and guidance can lead to greater understanding and acknowledgement of a changed identity and there can be the need for support for processing negative developments with a limiting perception of identity.
2. Action-oriented tools and methods must be developed to support professionals in reacting to a range of predictable/possible reactions from patients and on the basis of these reactions, to endeavour to implement a forward-facing process in patients.
3. Patient education should use participant and action-oriented health education principles in such a way that also patients who are used to a more passive patient role, benefit from these processes. Flexible health education models and methods need to be developed for use in working with various types of patient.



# Theme 5: Professional skill sets

## 6.1 Defining the problem

The final analytical theme deals with the skill sets required by health professionals and the grounds and conditions required to provide effective patient education. Patient education using health education methods also challenges the professional environment. Accordingly, there is the need to specify the professional task, including the necessary professional skill sets.

Three main problems stand out in this respect:

- The first focuses on how to facilitate the development of interactions and relations between patient and health professional so as to create the opportunity to exploit the potential in both parties.
- The second deals with how health professionals can be enabled to plan and provide health education-based multifaceted patient education. What professional skills are required and suf-

ficient to ensure coherence and equality in patient education that involves, and is built on, several types of intervention?

- The third is about patient education with patients acting as educators. What opportunities, limitations and possible risks does this method involve?

In the process of developing patients' skills, health professionals' own relational and personal competencies play a key role. Only a limited number of health professionals regard themselves as experts in health education methodology. Increasing use of patient health education will mean that many health professionals need to develop skills in this.

## 6.2 Trends in the literature

By way of introduction, it should be stated that there are few articles that investigate

professional competencies from a health educational perspective.

## 6.2.1 Necessary skills

Various articles do emphasise the fact that the health service generally faces a changing role with respect to relations with patients, as do individual health professionals, too. In one description of the "Expanded Chronic Care Model," Barr emphasises (Barr et al., 2003; 78):

*"If healthcare professionals can be reoriented to become advocates for health, rather than simply part of the repair service, they can become powerful allies for those seeking to promote health".*

The fact that the health professional now has more of a health education role, meaning that the necessity for patient participation, involvement and ownership appears and becomes the starting point for developing patients' action competence. The question is how to make this transition when the previously clearly defined roles of the health professional have to change.

Several people maintain that relational skills lie at the core of professional skills. Collaboration between patient and health professional and joint decision-making is not possible if relations are too distorted.

*"As we consider the notion of empowerment for patients, generally, the asymmetry in the relations of power between patients and health care professionals becomes apparent, along with the need for more equitable distribution of power" (Anderson 1996; 703).*

The literature generally states that in order to achieve the greatest possible effect, professionals should be aware of social

and group cohesion, they should be willing to surrender power and make room for patients to participate themselves and they should be aware of personal relationships between patient and therapist.

## 6.2.2 Barriers

In the section on participation and motivation, we touched on the fact that there are various barriers to patients having the opportunity for participation and involvement. Some of these barriers reflect the whole medical culture that still dominates the health service. Many more are a function of the skill sets of professionals.

In their article on "Evaluation of the UCL Diabetes Self-management Programme (UCL-DSMP): A Randomized Controlled Trial" Steed et al. address the problem of health professionals' lack of training in health educational methods.

*"The role of the facilitator often requires the learning of new skills therefore the details of the training that has been provided should be stated. This is particularly important as typically health care professionals are not trained in behaviour change skills such as problem solving and goal setting. For example, commonly health care professionals offer patient solutions to problems rather than facilitating the patient to identify their own strategies to overcome problems" (Steed et al. 2005: 262).*

Lemmens et al., stress that in many instances, ideas on patient education develop no further than being good intentions. They emphasise that there is a gulf

between what health professionals do for patients with chronic illness (e.g. COPD), and what should be done. This raises the question of medical commitment to change the treatment of chronic illness (Lemmens et al. 2009; 232).

Finally, many writers emphasise that the medical culture that is characterised by expert knowledge, top-down approaches and a disease-oriented healthcare concept is very long-standing and is therefore difficult to change. Professionals trained to regard clinician-patient relations in a certain way have developed professional identities that cannot just be switched to a totally different professional identity. This provides one of the explanations for the fact that a participant-oriented paradigm meets many barriers in the present health service.

However, it is not possible to generalise on the group of professionals who come from several different medical groups. Indeed, several articles claim that nurses constitute the group that is best trained to undertake patient education for patients with chronic illness on the basis of participation and dialogue. They stress among other things that nurses (unlike doctors) are used to providing instructions in healthcare and that as a profession, nursing is more oriented towards the individual living with chronic illness whilst the medical profession is primarily oriented towards diagnosis and healing the symptoms in the acute phase of the illness, rather than focusing on risk profiles and behavioural counselling (Sol et al. 2005; 20).

### 6.2.3 Patients as educators

The British "Expert Patient Programme" is an example of patient education using patients as educators and is an adaptation of the so-called Stanford model developed

at the Stanford Patient Education Centre. In an article titled "*The Expert Patients Programme: a paradox of patient empowerment and medical dominance*," Wilson et al. identify a core problem with this program:

*"Despite its potential as a lay-led empowering initiative, the Expert Patients Programme has been criticised as perpetuating the medical model and failing to reach those in most need" (Wilson et al. 2007; 426).*

Articles about patients as educators agree that such programs have considerable potential, for example role model thinking and the direct identification that comes from meeting kindred souls. The literature does however identify a problem in that the classical subdivision between the treatment culture and patient culture is not broken down but rather enhanced in these programs. When patients coach other patients, they risk confirming each other in the role of patient. This therefore does not only mean increased patient focus but that there may be the risk of patient marginalization, with patients' ability to participate and get involved in treatment actually being limited (Wilson et al. 2007, Jerant et al. 2008, Lorig et al. 2005).

There is also, according to Wilson et al. (2007) the risk that patient educators serve to reinforce the biomedical approach to illness and treatment.

The advantage in patient-patient contact can be utilised by extracting the best of programmes with patients as educators whilst combining this with the involvement of health professionals who have expert knowledge and experience in illness pathways, treatment and tertiary prevention.

## 6.2.4 What knowledge?

In conclusion, the discussion of knowledge needs to be briefly addressed. Several articles indicate that the best efficacy in patient education can be ensured if professionals possess illness-specific knowledge and teaching skills (Barr et al. 2003; Lemmens et al. 2009). But what knowledge does the professional need to bring to discussions with patients and what knowledge should professionals themselves possess as part of their skillset?

An overarching objective in patient education is for patients to develop the skills required to handle and create improvements in health and this has implications for the choice of knowledge and insight amongst professionals. In other words, medical knowledge should essentially be action-oriented. Four dimensions may be used to illustrate such action-oriented knowledge.

The first dimension on the effect of risk behaviours addresses the factors that

exacerbate the illness (for example the fact that type 2 diabetes is exacerbated by lack of exercise and being overweight).

The second dimension of the fundamental reasons relates to the basic social, cultural and financial aspects impinging on the chronic illness. For example, someone with type 2 diabetes and few resources may find it difficult to get advice about buying lots of vegetables and may therefore find it difficult to eat healthy food.

The third dimension covers the actual aspect of change. How can patients themselves tackle things as they try in various ways to change aspects of their behaviour, of their workplace, family or the local community because they can then reduce the risk of complications associated with chronic illness?

The fourth dimension includes knowledge of how others cope with chronic illness - that is knowledge of specific scenarios for different ways in which people live out a high quality life with chronic illness.

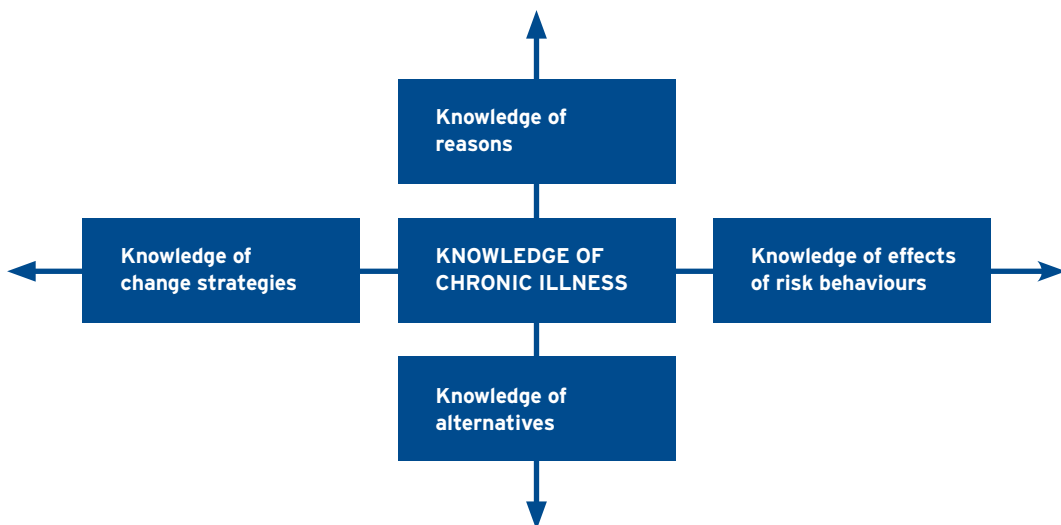


FIGURE 6.1: MODEL - KNOWLEDGE DIMENSIONS (MODIFIED FROM JENSEN 2009)



With respect to this model, it is essential for professionals to decide on the knowledge required to provide the best support for individual patients. Traditional outreach in healthcare emphasises primarily the first dimension: knowledge of the effects of risk factors (the consequences of not eating in a certain way and not taking at least 30 minutes of exercise a day, etc.). Such knowledge does not necessarily promote action, especially if taken by itself. If it is not followed up by information about the reasons and change strategies and alternative scenarios and visions, it might have a directly destructive impact on patients' commitment and thus contribute to paralysis of action. This applies regardless of whether it relates to type 2 diabetes, changes in eating habits or attempts to provide opportunities for more exercise in daily lives.

A participation and action-oriented approach therefore imposes very considerable demands on the medical overview of the health professional involved. Only the possession of highly qualified professional skills will release enough energy for the professional to tackle the difficult but necessary problems arising when electing to work with patients in a dialogue on health education.

The claim is therefore that the best efficacy in patient education is obtainable by professionals having both professional and educational skills and that medical requirements would not simply be covered by traditional biomedical competencies. In other words, health education methods aimed at action competence not only impose demands on how knowledge should be communicated but also what is communicated.

## 6.3 Conclusion and perspectives

The review of the literature leads to three main conclusions:

The patient health education perspectives deriving from the new streams in patient education impose very great demands on professionals. The emphasis is especially on the skills in handling dialogue in which patient groups are involved in decision-making processes without this precluding medical knowledge.

In the literature, there is a major focus on the fact that professionals need to acquire educational skills and that the greatest effects of patient education are achieved when methods include medical and educational skills. Meanwhile, consideration of the knowledge and medical skills needed by patients with chronic illness is almost totally absent from the literature.

The widespread programs in which experienced patients act as coaches provide potential and challenges. The challenges raised in the literature also include the fact that programs appear exclusive and that they primarily communicate a bio-medical paradigm.

The following three challenges in patient education arise as a result of the above:

1. As the starting point for identifying the skills of professionals, the skills required by patients with chronic illness need to be identified and specified.
2. On the basis of the first point and a series of action research projects with professionals and patients in which various participant-oriented methods are tested, a schedule of the competencies needed by professionals should be

drawn up together with a strategy for how these skills can be acquired.

3. New studies will need to investigate how the greatest synergy can be obtained in collaborations between teams of different types of professional, also including collaborations in which expert patients are involved in close interaction with professionals.





# Conclusion and future perspectives

This publication identifies and analyses five core problems in the literature on patient education in which a patient health educational approach is expected to make a significant contribution to developing and improving patient education.

1. It is apparent from the literature that programs employing a range of different methods and approaches can have a greater effect than more limited programs but these programs are often characterised by the lack of interrelationship between the elements involved. This makes for poorer outcomes and less satisfaction amongst patients as well as health professionals. Different elements in a multifaceted approach should therefore be based on the same educational principles and values.
2. The review points to the fact that existing patient education programs often take an individualised approach. The starting point for education is typically that individual patients are solely responsible for making lifestyle changes whilst the social contexts of which patients are part are only involved to a very limited extent as the focus for intervention. Future developments will have to focus on involving patients' contexts so as to support the options for action and how they handle a life of chronic illness. Using a combination of individual and group-based patient education can be crucial for patient education outcomes, not least for patients with few social and educational resources.
3. Programs make very limited use of patients as active participants and this is often only symbolic. This also applies with respect to drawing up therapeutic goals. A participant-oriented approach has also been demonstrated as appealing to individuals with few resources and can thus be expected to help cut inequalities in healthcare and at the very least would not increase inequality.
4. The analysis further shows that diagnosing a chronic illness can have a negative impact on how patients view their own identity. Disparities between one's own perception and that of the outside world can reduce individual patients' life skills considerably and in the worst case, lead to a sense of powerlessness. Patient education programs can be organized to provide positive support for patients in working on the perception of their identity and hence also their development and performance. This could for example be done by using support groups and providing support and guidance by

professionals specially trained in initiating such appraisal processes.

5. Patient education must be based on the fact the professional educators are trained and supported to cope with dialogical processes in which patients are involved in decision-making processes without this taking over from medical professionalism. Such medical professionalism must reflect action and change-oriented perspectives.

In summary, it may be concluded that there is still a major requirement for developing and documenting health education programs based on patients with chronic illness. And that the best place for this development to occur is to be associated with health education research and development in close collaboration with educational researchers and reflecting professionals and patients.

Finally, it should be emphasised that many analytical and interpretational opportunities remain unaddressed in the selected literature.





Notater

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# Examples of models for patient education taking a patient health education approach

The five health education concepts are to be utilised, specified and tested in educating patients with chronic illness. Some of the concepts have already been partially addressed in existing methods, models and programs for patient education. Five patient education models are briefly described in this section which build to varying degrees on selected parts of the core concepts of patient health education. It is felt however that the quality of all the models presented here could be improved

by more systematic use of the principles of health education.

In this review we have elected to use the term "model" rather than "method." There is a lack of consistency in both the Danish and the international literature in the use of these terms and differentiation would require more detailed consideration of the theoretical complexities and with respect to practice.

## Guided Self-Determination

Guided Self-Determination (GSD) is a model for patient education. The model can be used by patients and professionals in clinical decision-making and healthcare guidance when one or both parties find that it is important for the patient to implement and maintain changes in living with chronic illness.

GSD is a research-based model designed on the basis of grounded theory studies in the field of diabetes. GSD is further based on theories of change, motivation and dynamic problem-solving with life skills as a goal. GSD has been developed so as to overcome barriers to the involvement of patients by health professionals in managing their illness. The GSD model guides the patient and professional through a mutual

recognition and decision-making process in which patients' acknowledgement and decisions are treated as goals whereas those of the professionals are given the status of means - the role of the healthcare professional is as a facilitator. GSD endeavours to see patients making decisions that can be characterised as their 'own', with such decisions reflecting the goals set by patients and the actions they implement (Prochaska et al. 1994; Zoffmann et al. 2007; Zoffmann et al. 2008; Zoffmann et al. 2009; Ryan et al. 2000; Bos 2001; Nutbeam 1986).

GSD can be used by professionals that are aware of the theoretical basis of the model and who have been trained in its use. The approach of health professionals must be their readiness to support patients in

identifying and mobilizing their potential to achieve and maintain desired changes in the way they cope with illness in their daily routines. GSD can be used individually or in groups and the acknowledgement and change processes can be supported by various medical professionals, by fellow patients in a group process and by family who can participate as supporters or as part of joint problemsolving, for example with young people and their parents.

GSD paves the way for a very different framework for collaboration than the one patients and professionals have been used to. For example, endeavours are made to make reciprocity and disagreement legitimate.

GSD makes use of semistructured Swedish-style reflection sheets. Reflection sheets are filled in by the patient before and during sessions with professionals; they help the parties gain common insights into the patient's situation. Reflection sheets guide patients in expressing their thoughts and feelings in narrative and figures. This employs both rational and creative thought processes, enabling people to become more independent and aware in assessing their situation. Discussion of the reflection sheets requires the professional to have been trained in communicating using mirroring, active listening and valueclarifying response. The patient's situation is elucidated by way of a systematic mapping process of the ways patients have solved their problems to date; the patient provides verification and the knowledge obtained is challenged by both parties during the process (Arborelius et al. 1988; Gordon 1979; Steinberg 1986).

GSD has been adapted to other chronic illnesses such as COPD and cardiac illness. A randomized trial has demonstrated that GSD has been effective in helping adults with type 1 diabetes and persistent poor glycaemic control to improve their own

management of diabetes, including their glycaemic control for 3-12 months after having received 16 hours of nurse-led group training. A qualitative assessment demonstrated that using the model led to change by the patient with respect to the professionals, the team and interaction with family, friends and colleagues in daily lives (Zoffmann et al. 2006).

## **Patient health education perspectives**

GSD is an example of a model for patient education with chronic illness in which a range of health education methods may potentially be involved. Participation, dialogue and developing life skills serve as the fulcrum whilst another possibility is involvement of the patient's network via a settings perspective. GSD has been developed to solve complex, persistent problems in patients with long-term, poorly regulated type 1 diabetes. The complete version of the method is therefore comprehensive and requires a process of change over time for both patients and professionals. At the same time, GSD is ambitious with respect to the extensive changes that can be achieved and maintained. This imposes requirements for training and skills from the educators who train health professionals in GSD. The efficacy of the method therefore depends crucially on the health professional motivating and supporting patients in making decisions themselves rather than controlling decision-making. GSD requires relatively extensive training for the health professionals who will be using the method.

GSD primarily focuses on how individuals can do something to improve their situation. There could therefore be the risk of GSD working in such an individually-centred way that the overriding emphasis is on patients themselves and alone having to manage their situation. This thus precludes the option of including support for patients

in various contexts such as working life and family life. The use of reflection sheets in GSD - which covers reading, writing and discussion, must be expected to have different appeal to different patient groups and individuals.

## Stanford model

The Stanford model, also known as the Chronic Disease Self-Management Program, was developed by Professor Kate Lorig of Stanford University and has subsequently been implemented in healthcare systems worldwide - including the Danish health service.

In its original version, the program was run over six weeks with participants meeting in group session once a week for 2½ hours. Groups included individuals with different chronic illness healthcare problems and had two trained educators, one or both of whom suffered chronic illness. Educators have attended educator courses and are called certificated instructors.

The program is structured around modules with predefined content. Issues covered during the process are:

- 1) techniques for coping with problems such as frustration, fatigue, pain and isolation;
- 2) exercise to retain and enhance strength, flexibility and stamina;
- 3) appropriate use of medication;
- 4) effective communication with family, friends and health professionals;
- 5) nutrition and
- 6) assessment of new treatments.

The emphasis is on the fact that the process under which the program is learned /undertaken makes the model effective. Group sessions emphasised the importance of participation, with mutual support and success being the cornerstones of participant confidence in their own ability to manage their health and maintain active, full lives.

GSD may be regarded as a significant contribution to patient education for some type 1 diabetes patients and probably also for patients with other chronic illnesses.

The Stanford model is designed to enhance the usual treatments and illness-specific education, for example for pulmonary and cardiac disease or diabetes. Many individuals have more than one chronic condition and the idea of the model is for patients to acquire skills in coordinating the personal input required to retain and improve their health and level of functionality.

The studies that have evaluated the Stanford model have demonstrated that it has a short-term effect on such issues as physical activity, enhanced self-efficacy, self-assessed health, reduction of pain, fatigue and loss of functionality (National Board of Health, 2009). The studies also show that participants are typically middle class women from the dominant ethnic grouping and that supplementary offerings are required for patient groups who do not access the program, especially minority groups and the socially vulnerable (Kennedy et al. 2007; Osborne et al. 2008). The model has further being criticized for only having limited engagement with how social relations and the surrounding community can support individuals with chronic illness (Geenhalgh 2009). Doubts have also been raised about the long-term efficacy of the results achieved (Wilson et al. 2007; Lorig et al. 2005; Jerant et al. 2008).

### Patient health education perspectives

The Stanford model makes extensive use of participation and can thus help provide ownership and life skills in specific areas. It

employs a healthcare concept of a certain breadth and it is possible to introduce different settings. Sticking to a predefined program limits the options for involving other issues that are important for participants and there is no integrated obligatory dialogue with health professionals, which

can prove a limitation when discussing illness-specific problems.

The model should be regarded as a good supplement to illness-specific patient education.

## "It's your decision"

Arborelius developed "It's your decision" in the mid 1980s, primarily as a pupil-centric model in health counselling for teenagers at school.

The model is based on three groups of theories: Coping and behavioural theories, self-efficacy and social modelling theory. Using the model in small group sessions boosts the effect which has been studied amongst the young. The model had a positive effect on how young people cope with their own situation with respect to health, wellbeing, self-esteem and their ability to cope with problems to do with school.

Groups of five young people used the model for two months with six sessions lasting one hour, with three sessions being individual and three in groups. Sessions were guided by an adult health counsellor who had taken a two day induction course to the model followed by six x 2-hour supervised sessions while working as health counsellors for students (Arborelius et al. 1988; Arborelius 1992).

In the 1990s, Arborelius introduced the model to general practitioners and home-visiting nurses for use in for providing patients with health counselling on health behaviours.

Instead of instructing on appropriate lifestyle in general, the model goes directly to patients' own health behaviours and addresses the considerations they have in

their habitual attitudes to their health. Why does she keep on living the way she does? What advantages and disadvantages does she see in her health behaviour? What does she want to change and what restrictive and promotional factors does she see for achieving her own goals for behavioural change?

The model is intended as a nonprejudicial or evaluational approach that can meet individual needs. The method builds on voluntariness and gives patients the opportunity to define for themselves the healthcare issues they wish to work with.

The model makes use of a series of working papers of which three especially are known. These working papers are available in a Danish book about the model: one addresses the advantages and disadvantages of self-selected healthcare issues and the two others can be used for phased targets in a process of change. Connections are made in the process to the factors that patients feel tend to restrict or boost the change process (Arborelius 1992).

### **Patient health education perspectives**

"It's your decision" is an example of a model for patient education, with participation and dialogue especially being a core theme. Developing action competence and a broad, positive healthcare concept may

be involved to a certain extent whereas the settings perspective may not necessarily be involved. Whether the patient's network and other outsiders are included in the process depends on the patient's approach and guidance from the health professional.

As a model for individual guidance, there may be the risk of too much emphasis being placed on patients' ability to cope with their situation - an individualised approach. The model was actually originally intended as a change from individual and group processes. If this model is employed, there

is the opportunity for a dynamic exchange of experience and building up a supportive network which can be appropriate for patients with chronic illness. No studies that test the model in chronic illness have been found.

The model should be regarded as a potentially appropriate supplement or as one to be supplemented by other patient education models. Use of the model in new respects and new target groups needs to be tested and appraised.

## Motivational interviewing

Motivational interviewing was developed by Miller and Rollnick (1983).

- Motivational interviewing endeavours to identify and mobilize patients' innate values and goals for encouraging behavioural change.
- The motivation for change comes from the patient and is not transposed from outside.
- Motivational interviewing is designed to identify, clarify and solve ambivalence and to acknowledge the advantages and disadvantages of change.
- Readiness to change is not only associated with the patient but is a changeable product of human interaction.
- Resistance and denial often indicate that motivational strategies need to be changed.
- It is essential to clarify and support patients in their belief that they can strive for and achieve a specific goal.
- Therapeutic relationships involve partnership with respect for the autonomy of patients.
- Motivational interviewing comprises a set of techniques as well as a guidance style.
- Motivational interviewing provides

targeted, patient-centric guidance for understanding and implementing behavioural change.

The efficacy of motivational interviews has been studied in relation to weight loss, lipid reduction, increasing physical activity, diabetes, asthma and quitting smoking. A Danish study of randomized trials concludes that motivational interviews appeared to have been effective in 75% of the studies (Rubak et al. 2005). There is a lack of studies of specific models for holding motivational interviews in practice and there is a lack of evidence that motivational interviewing can be implemented in practice and used by health professionals for the benefit of patients. One randomized study showed that patients with type 2 diabetes gained greater understanding of that illness after an intervention in which GPs used motivational interviewing during consultations (Rubak et al. 2009).

### Patient health education perspectives

In its optimal form, the motivational interview integrates several health education methods by way of participation, dialogue,

life skills and opportunities and conditions for real action. It is however a precondition that the health professionals have been trained in the method and comply with the intention and do not manipulate or force on patients motivation that may not be there.

A settings perspective may be added that that is not explicitly included in the model. There may be the risk of an individualistic approach in which patients are made responsible for development and change.

The fact that the focus is on behavioural change is implicit in the model and this can involve the risk of a narrow healthcare concept that can make it more difficult for patients to set their own priorities in a change process.

Motivational interviewing should be regarded as an important part of any kind of patient education and it can be a good thing to integrate it in communication with patients.

## Active assessment

Active assessments, also termed values clarification, were developed in the field of humanistic psychology (Grendstad 1977) and have been used in various contexts from children at school (Steinberg 1986) to adults with various complaints (Berger et al. 1975).

Values clarification can either be done orally and by certain special responses, also known as value clarification responses, that are specially designed to get recipients to make an active assessment. If the pupil or patient is “exposed” to such responses from the teacher or health professional, they can become clearer about the issues that are important for them, enabling them to be better at prioritising and striving for their goals.

Value clarification responses can also be obtained in writing, with the patient or pupil working alone to prepare for an interview with the teacher or the health professional. This format makes it easier to undertake the value clarification process which is a highly advanced form of communication in practice. It also enables patients to consider or reflect on important issues at home.

In the ‘It’s your decision’ method and in GSD for diabetes, COPD and cardiac disease, reflection sheets are used for

values clarification (Zoffmann et al. 2009). An especially effective sheet designed as incomplete sentences is reproduced here from Steinberg (1986). It is highly suited for initiating a discovery or acknowledgement process prior to an important session with a health professional.

### Patient health education perspectives

This model is very much designed for participation and to a certain extent dialogue but one pitfall could be the risk of individualization, with patients taking sole responsibility for the outcome of the process and their own health. There is no explicit intention either to include a settings perspective or to actually develop action competence. A broadly-based, positive healthcare concept may be used in this respect but it will be highly dependent on the health professional’s approach to the process - overall the application of this method in health education depends strongly on the conduct, standards and intentions of the health professional.

As in motivational interviews, values clarification can be an important part of patient education, since it proposes alternative forms of communication that can serve as openings for difficult situations.

