

## **Educating adults to live with a chronic disease in their everyday life - a state of the art**

Paper to the Fourth Nordic Conference on Adult Learning, 11-13 April, Trondheim, Norway

### **Abstract**

In this paper I present the results of a state of the art in progress concerned how adults learn to live with a chronic disease in their everyday life, and in particular adults with affective disorder. The search strategy is divided into two parts: 1) a review in the newest reports there pull together research-based evidence and 2) a review of the reference lists in the reports. The findings showed factors that influenced on the topic of this state of the art, but a lack of knowledge who directly concern the topic. The findings may lead to the future research question: How does patient-education influence the patients' development of competences used in their everyday life?

Key-words: Patient-education, affective disorder, non-formal education, chronic disease and everyday life.

### **Background**

The topic of this state of the art is how adults learn to live with a chronic disease in their everyday life, and in particular adults with affective disorder. Adults are understood as being 18 or older.

'Intended learning' is planned and has a purpose and non formal learning is systematic and takes place in a learning environment, but does not afford formal qualifications (Wahlgren, 2010).

Patient education can be seen as an intended non-formal learning form which can be defined as:

*"Education of patients with a diagnosed disease in a structured education programme targeting individuals or groups of patients and perhaps family members. The education programme may be disease-specific and target patients with a specific disease or generally target patients with different diseases. Patient education is part of clinical prevention."*  
(National board of Health, 2009)

Patient education is assumed to optimize self-care and build up competence to disease-management amongst adults with diseases who require chronic treatment. This is expected to reduce the resources used in the health-care system, and to enhance the well being and quality of life for the individual (Jørgensen, 2005). The political and the health-care system wish to depart from an approach where decision-making about patients' health-care is in the hands of the health-care professional, and to adopt an approach where they make health-related decisions together. Patient education is seen as a way to make the patient a competent partner in the decision-making (Willaing, 2005). Even though the advantages and disadvantages of the self-care approach

has been discussed (Dørfler, 2005), the health-care system is considered responsible for providing the individual the knowledge and skills to practice self-care, and the patient is expected to be active, competent and responsible for their own health-care (Sundhedsstyrelsen, 2011). As indicated in the definition of patient education, it is assumed that certain basic factors in health education are not specific for a diagnosis. This is also assumed to be valid in relation to psychiatric disorders (Grabowski, 2010; National board of Health, 2006, 2009; Jørgensen, 2005).

A chronic disease is defined as having one or more of the following characteristics: "*persistent, sustained accompanying conditions, irreversible changes, require prolonged treatment and care or a special rehabilitation effort*" (Jørgensen, 2005). Bipolar affective disorder is a severe episodic condition and carries a high risk of recurrence, reduced psychosocial functioning and suicide (Parnas, Kragh-Sørensen, & Mors, 2009). Adults with bipolar affective disorder has on average symptoms half the time after outbreak (Kessing, 2006) and depression is, measured in the number of healthy life years, the most burdensome disease in Denmark (Kjøller, 2007) and has the highest score of "healthy life" lost to the disease in Europe (SfR, 2007). After one depressive episode the risk of recurrence is 60%, and after two depressive episodes the risk of recurrence is 80%. 70% of patients who are hospitalised in a psychiatric ward due to a depression will develop recurrent episodes, and 60% will suffer more than two recurrent episodes. It seems that the severity and the frequency of depression is increased with the number of episodes. Furthermore, depression causes chronic disabilities such as sustained depressive symptoms, problems with memory and concentration (SfR, 2007). Between the episodes of illness 30-60% of adults with affective disorder have reduced psychosocial capacity in relation to leisure activities, satisfaction, income and relationships with friends and family (Kessing, 2006). Affective disorder, even it is an episodic disease, require prolonged treatment/care and a special rehabilitation effort which meets the criteria as a chronic disease. Furthermore it may develop to be a chronic course. It is obviously important to prevent recurrence. To this end, three approaches are traditionally applied; pharmacological, electro-convulsive therapy and psychological. Psychological treatment includes educating patients through cognitive therapy and psycho-education.

In this paper I will state the art of transfer between what is learned in patient education and the patients' outcome in relation to live everyday life with a chronic disease particular for adults with affective disorder.

## Methods and materials

This state of the art in progress is based on two combined search strategies. The first strategy involves a view in the newest reports there pull together research-based evidence. Eight reports written by experts with aim to assess current research-evidence or clarify concepts within a topic where identified. Seven of the reports are published by the Danish National Board of Health. One is published by a centre with expertise in health education for patients. The reports focusing on health education primarily had a generic or somatic approach (Grabowski, 2010; National board of Health, 2006, 2009; Jørgensen, 2005; Willaing, 2005). Two reports has focus on treatment of patients with affective disorder (Kessing, 2006; Sfr, 2007). One report is a concept analysis of the concept "self-care", which is central because self-care is a goal for patient education (Dørfler, 2005).

Each report was read with the following five questions in mind:

What is known about;

1. didactics in patient education?
2. learning to live with a chronic disease?
3. transfer of patient education to everyday life?
4. the everyday life with a chronic disease?
5. relevant recommendations for future research?

The second search strategy involved a review of the reference lists in the eight reports. 120 references that seemed to contain additional knowledge were marked. A list of abstracts were selected based on the following criteria; written in English, published from 2000-2010 and treated empirical research studies. Articles were excluded if they; concerned economy, were not based on empirical research, compared pharmacological treatments, pilot projects, concerned relapse/treatment without any educational approach and articles about educating health professionals. This lead to 25 articles. Furthermore, 8 articles were included either from the reference list in the first 25 articles or from searching on the name of a particularly prominent researcher. Those articles also follow the rules for inclusion and exclusion as described above. The articles were read with the above five questions in mind. The 33 articles can be divided, according to their research design. Eleven randomized controlled trials, nine meta-analyses of randomized controlled trials, one cohort study and twelve qualitative studies. Fourteen studies concerned patients with depression (Badamgarav et al., 2003; Casacalenda, Perry, & Looper, 2002; de Mello, de Jesus Mari, Bacaltchuk, Verdelli, & Neugebauer, 2005; de Maat, Dekker, Schoevers, & de

Jonghe, 2007; DeRubeis et al., 2005; Dimidjian, 2006; Hegerl, Plattner, & Möller, 2004; Helen, 2004; Katon et al., 2002; Lin et al., 2003; Neumeyer-Gromen, Lampert, Stark, & Kallischnigg, 2004; Pampallona, Bollini, Tibaldi, Kupelnick, & Munizza, 2004; Simpson, Corney, Fitzgerald, & Beecham, 2003; Teasdale, 2000), one patients with bipolar affective disorder (Lam et al., 2003), one chronic disease including patients with depression (A. Jerant, Moore, Lorig, & Franks, 2008). One was designed to investigate the effect of "Life skills programs" for persons with chronic psychiatric diseases, but only managed to include investigations of schizophrenia (Tungpunkom P., 2008). Three studies concern somatic chronic diseases (Lorig, 2001; Rubak, 2005; Schreurs, Colland, Kuijer, de Ridder, & van Elderen, 2003). One article does not define the patients through diagnosis, but included patients who defined themselves as having a chronic illness (Kennedy et al., 2007). All 21 studies concerned the effect of educational/therapeutic interventions. The Most frequent methods of measuring effect in the articles were adherence to treatment, reduction in symptoms/relapse/ recurrence and quantity of hospitalised days.

The twelve qualitative studies can be divided in relation to which diagnosis-groups they concerned. Six concerned patients with somatic diseases (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008; Koch, Jenkin, & Kralik, 2004; Kralik, Koch, Price, & Howard, 2004; Paterson, 2001; Riegel & Carlson, 2002; Thorne, Paterson, & Russell, 2003), two concerned patients with chronic diseases including depression (A. F. Jerant, Friederichs-Fitzwater, & Moore, 2005; Wilson, Kendall, & Brooks, 2007), and four concerned patients with bipolar affective disorder (Pollack & Aponte, 2001; Proudfoot et al., 2009; Russell & Browne, 2005; Suto, Murray, Hale, Amari, & Michalak, 2010). Only one study concerned patient education (Wilson et al., 2007), the researcher in another study assumed that the patients have received formal disease-specific education when hospitalised (Riegel & Carlson, 2002), and one study collected data through an online psycho-educational program (Proudfoot et al., 2009). The other nine studies do not concern patient education. The studies are aimed to provide a better understanding of experiences of living with a disease, decision-making, strategies or competence from the patients' point of view. They are also aimed to generate knowledge about the opportunities for supporting/educating/helping patients live their everyday lives with a chronic disease.

There is a third building block search strategy in progress.

## Results

In the following section, the findings are presented in relation to the five questions.

### *Knowledge in relation to didactics in patient education*

When interventions in patients' schools and in group-based patient education are investigated, the focus is in general on efficacy rather than on method and content. This implies a very limited description of the didactic approach. Educational- or behavioural theory is rarely used in the development of the intervention or measurements of the outcome (Jørgensen, 2005; Willaing, 2005). This is also seen in the included randomised controlled trial studies. The endpoints focused on medical issues as pharmacological adherence, relapse and reduction of symptoms. The content of the intervention is not clear, especially in the meta-analysis where different kinds of interventions are pooled, related to reluctance to describe the learning theoretical and the didactic approach. Willaing (2005) considered this to be a result of the use of a biomedical approach rather than a pedagogical approach.

Patient education usual content: pathology, treatment, prevention, management of pharmacological treatment and side-effects, change in lifestyle, preparation of action plans, physical exercise and training in competence, coping skills and social skills (National board of Health, 2006; Jørgensen, 2005). A research group in the U.S developed The Chronic Care Model 'The Stanford Model' there is a well-described generic educational program. The model is perceived as holistic and involves the community, the health-care system and the patient's active efforts. Patients teach solely in the program, based on a teaching certification and a highly structured manual. The program comprises six weekly 2,5 hour -modules with the following content 1) technical skills in coping with fatigue, frustration, pain and isolation, 2) physical exercise, 3) appropriate use of medication, 4) effective communication with relatives, friends and health-care professionals, 5) nutrition and 6) evaluation of new treatments (National board of Health, 2006; Jørgensen, 2005).

It seems uncertain whether educational interventions have an effect. The studies show:

- 1) a significant effect (Badamgarav et al., 2003; Helen, 2004; Lorig, 2001; Teasdale, 2000)
- 2) an effect depended on the severity of the disease (Katon et al., 2002; Teasdale, 2000)
- 3) that therapy in relation to certain severities of depression works just as well as medicine (Casacalenda et al., 2002; DeRubeis et al., 2005; Dimidjian, 2006)

- 4) that patient education may influence treatment adherence positively (Lin et al., 2003; Neumeyer-Gromen et al., 2004; Pampallona et al., 2004)
- 5) no significant effect (de Mello et al., 2005; Simpson et al., 2003; Tungpunkom P., 2008)
- 6) an effect in 64% studies based on a meta-analysis of "motivating interview" (Rubak, 2005)
- 7) a moderate evidence for better outcome by combining pharmacological treatment with initiatives where patients learn about pathology, the importance of pharmacological treatment and its side effects, problem-solving and early warning signals inclusive actions opportunities (de Maat et al., 2007; Hegerl et al., 2004; A. Jerant et al., 2008; Kennedy et al., 2007; Lam et al., 2003).

Kessing et al. (2006) recommend three treatment methods designed to teach for persons with affective disorder to manage their everyday lives in combination with pharmacological treatment

- 1) Psycho-education in groups or individual,
- 2) Psychotherapy and
- 3) psychosocial support.

The educational treatment methods differ and the educational and didactic approaches are not clearly described.

It seems there is a lack of insight in the didactic and theoretical background of existing patient education and therefore about why and how patient education has impact. From the reports written by experts it is assumed education has a positive impact and educational interventions are recommended in combination with pharmacological treatment. But it is not known what, why and how the educational interventions have effect.

#### *Learning to live with a chronic disease*

Individual conditions seem important for the ability to learn to live with a chronic disease. A study of a group-based educational program showed that young age, high level of education and an active worklife was associated with less satisfaction with the education. Those participants were especial annoyed with the high degree of structure in the education (Schreurs et al., 2003). It also seems that the severity of the disorder is important for the educational benefit (Hegerl et al., 2004; Katon et al., 2002; Teasdale, 2000). For adults with depression the efficacy of psychotherapy depends on the patient's age, cultural and socioeconomic background, psychological insight, childhood conditions and social and relational problems (SfR, 2007). Gender appears important, because men often have less confidence in and expectations to their own disease management and also to the public support, than women. Furthermore women more likely attended patient education (National board of Health, 2009). Schreurs (2003) find that denial of the disease increased the dropout rate from patient education. While a high insight into disease is enhancing the self-care ability (National board of Health, 2006; Kessing, 2006). Adults with depression can

have cognitive impairment in relation to memory, concentration, attention, problem solving etc. which reduces their ability to manage the disease (SfR, 2007). Even in periods without other symptoms adults with affective disorder may have problems with learning capacity and memory (Kessing, 2006) .

In addition to the adults' individual conditions Dørfler (Dørfler, 2005) and the Danish National Board of Health (Jørgensen, 2005) state that the approach in the health-care system is important for the possibility to learn to live with a chronic disease. Development of self-care is believed to require a health-care system that involves patients as participators in decision-making.

Three studies concerned the experience of becoming ill: 1) newly diagnosed patients with bipolar disorder who participated in a online psycho-educational program (Proudfoot et al., 2009), 2) hospitalised patients with bipolar disorder (Pollack & Aponte, 2001), and 3) patients with different somatic diseases with a wide range (1< - >10 years) of illness experience (Aujoulat et al., 2008). The experience of becoming ill is revealed as a dichotomy: 'Holding on' and 'Letting go' i.e. holding on to the person you are and to develop a new and valuable sense of oneself. This can be done by to differentiate one's self from the disease and to integrate the restrictions caused by the disease as part of a unified self (Aujoulat et al., 2008). This is also described as coming to terms with the diagnose (Pollack & Aponte, 2001). Proudfoot (2009) examined newly diagnosed and concluded that one issue for them in the process was the question 'who am I?'. It seems that different aspects has a positive impact on learning to live with a disease; e.g. to be able to form a conception of the disease as something separate from oneself – to be a 'person with a disease' instead of a 'sick person' (Aujoulat et al., 2008), knowledge about the disease (Aujoulat et al., 2008; Pollack & Aponte, 2001; Proudfoot et al., 2009) and to have achieved acceptance (Pollack & Aponte, 2001). It was a big challenge to find personal limitations, but the patients were unable to pretend the disease did not set limits on their usual social life (Aujoulat et al., 2008). Knowledge about the disease and treatment makes it possible to keep the disease at a distance from one's self, but the patients also need to give a personal meaning to their experience of illness to discover that their lives are meaningful and worth living (Aujoulat et al., 2008; Pollack & Aponte, 2001). Knowledge is not only know that/know how, but is also achieved through recognition and interpretation of bodily sensations and emotional states (Aujoulat et al., 2008; Pollack & Aponte, 2001), which is a challenge for newly diagnosed (Proudfoot et al., 2009).

To live with a chronic disease is also examined through experience from expert-patients who are people living well with their disease. The issue is examined within specific diagnoses; bipolar disorder (Russell & Browne, 2005; Suto et al., 2010) and diabetes (Paterson, 2001) and within a variety of chronic somatic diseases (Thorne et al., 2003) inclusive patients with depression (Wilson et al., 2007). Despite the variety of the diagnoses, the findings have many similarities.

An expert patient has **knowledge about the disease** (Paterson, 2001; Russell & Browne, 2005; Suto et al., 2010; Thorne et al., 2003; Wilson et al., 2007). The knowledge about pathology is often obtained from health-care professionals and from self-education through the Internet or textbooks. If the health-care professionals did not involve the patients' real life with the disease, the advice was seen as impractical textbook lore. The expert patient has developed a personal knowledge from experience and experimenting in everyday life e.g. the ability to monitor themselves were describes as 'body listening', 'sensitive self awareness' and as observation of very small changes in personal warning signs (Russell & Browne, 2005; Suto et al., 2010), which cannot be learned from a textbook (Thorne et al., 2003). Some expert patients found that warning signs that health professionals considered early signs were actually late ones (Paterson, 2001; Russell & Browne, 2005). Monitoring could be practiced by keeping a diary (Wilson et al., 2007). Monitoring also involved family and close friends as helpers in assessing the health condition (Russell & Browne, 2005; Suto et al., 2010). To stay well the patient had learned to make choices and take control over the disease. This could imply taking both small and major decisions; changing workplace, remember to sleep, cancelling appointments if necessary or consulting a health-care professional (Paterson, 2001; Russell & Browne, 2005; Suto et al., 2010; Thorne et al., 2003; Wilson et al., 2007). To be able to take control demanded a accept of the disease as a part of life, but separated from one's self (Russell & Browne, 2005). To stay well was also connected with living an organized, planned healthy life including healthy nutrition, regular sleep, minimized stress, to take medicine, exercise, to spend time with love ones and to have unscheduled time. The patients had the goal to live as normal as possible and the attitude to the future was positive (Russell & Browne, 2005; Thorne et al., 2003; Wilson et al., 2007). For the expert patients to live normal was also to decide to go against the health advises in occasions when that choice made life more meaningful (Thorne et al., 2003). The relationship between patient and healthcare professionals is important for the patients. Patients may choose to change health-care professionals if they not live up to the patients' expectations. It is important that the



communication is experienced as clear and apt. Expert patient find out what they can and cannot use the health-care professionals to. It is important for the patients to experience a mutual respect between the parties (Paterson, 2001; Thorne et al., 2003; Wilson et al., 2007). Some patients experienced doctors who took the role of control, which the patients experienced as the doctors distrust to their capability to take decisions. The patients thought it was a problem when the doctor presented a care-plan, where the patients everyday life is not taken into account (Paterson, 2001). Patients experienced that doctors would not support nor even listen to patients experiments with the treatment (Paterson, 2001).

One study that compared two educational programs concluded that the development of the “expert patient characteristic” was not depending on participating in a patient education, but that it was possible to strengthen the characteristic through patient education (Wilson et al., 2007).

#### *Transfer of patient education to everyday life*

Health education can be understood to be all about transfer to everyday life, because it is in the daily life knowledge, actions and attitude learned in health education should be applied.

Grabowski (Grabowski, 2010) argue that patient education programs tend to exclude the social contexts in which patients live their lives and he advised to involve patients’ everyday contexts in relation to their action- and support opportunities when managing life with a chronic disease in the education.

With reference to Paulo Friere an educational process is understood as - not a transfer of learning but - a process of communication and dialogue and therefore an understanding of treatment as a continuation within the patient's illness narrative, rather than something a health-care professional can create from outside (Aujoulat et al., 2008). This is underpinned by patients wishing the health-care professionals to incorporate their strengths, identity and their tendency to make their own explanations about the cause of the disease, in the treatment (Pollack & Aponte, 2001)

Findings show weak to moderate evidence that group-based patient education can provide patients with diabetes increased knowledge about their disease, but findings did not reveal effect on change in health behaviour. It is demonstrated that many patients has difficulties to transform

abstract principles from health education into their everyday live. Short school education is connected with reduced capacity within; acquirer knowledge, follow treatment and transform knowledge into practical problem-solving (Jørgensen, 2005). In contrast qualitative studies of group-based education demonstrated an experience of acquiring competencies there enhances their ability to handle both the disease and outbreak of disease more independently in their everyday live. In addition the social aspect of group-based education is experienced by the patients as an aid in changing behaviour. However, these qualitative studies are assessed to be methodologically and analytically weak because there is primarily included participants who have found the education meaningful and it has not been studied what actually happened when the patients returned to their everyday live (National board of Health, 2009).

In relation to adults with affective disorders there are identified some barrier to follow the pharmacological treatment e.g. the time distance between antidepressant pharmacological treatments is initiated and the experience of symptom relief. This means that patients do not associate intake of medicine with relief of symptoms. Additional patients may experience side effects before effect. This means one have to take medication daily without experiencing symptoms and without being able to sense any effect (Kessing, 2006). Neither adults with somatic chronic diseases nor adults with psychiatric disorders follow the recommended pharmacologic and non-pharmacological treatment (National board of Health, 2006; Jørgensen, 2005; Kessing, 2006; SfR, 2007). 30-50% of adults with depression do not adhere to the prescribed pharmacological treatment (SfR, 2007). This show that the aim of getting the patients to take their pharmacological treatment as prescribed is not transferred to everyday life. Adults, who are able to recognize and manage early symptoms of a new disease episode, usually have a better course of illness than others (Kessing, 2006).

For adults with depression there are four factors there affect adherence to treatment. 1) Disease-related factors such as depressive symptoms, impaired cognitive functioning, psychotic symptoms, abuse or personality disorder. 2) Patient-related factors such as lack of knowledge about the disease/treatment, lack of familial and social support, lack in acceptance of disease, fear of side effects, economics and negative attitude to medical intake. 3) Treatment-related factors such as experienced side effects, cost of medication, complicated treatment regimen, lack of continuity of

care. 4) Factors related to the treatment provider such as inadequate knowledge about treatment and disease and poor ability to establish contact and alliance with the patient (SfR, 2007).

#### *Everyday life with a chronic disease*

Studies has showed that adults with affective disorders, even after symptoms disappear, can have a persistent negative effect on their mental and physical function in relation to spouses, children, other family members, friends, leisure activities and satisfaction (Kessing, 2006). Everyday life events (divorce, illness, unemployment, death) and how humans understand and interpret the events is related to the incidence of affective disorders. A depression can be maintained or exacerbated by inadequate support from the network and by social isolation, furthermore, it appears that unhealthy lifestyle may trigger, maintain or exacerbate a depression. It is more difficult for adults with depression to maintain a healthy lifestyle in relation to diet, smoking, sleep, stress and exercise than adults without a depression . The social environment, including perceptions of illness, strategies and habits in the family is affecting how a chronic condition is handled (National board of Health, 2009; SfR, 2007).

Self-care or self-management in everyday life are explored in relation to patients with different chronic diseases inclusive depression (A. F. Jerant et al., 2005), chronic heart failure (Riegel & Carlson, 2002), arthritis (Kralik et al., 2004) and asthma (Koch et al., 2004). One study examines barriers experienced by patients as preventing them to practise active self-care. The barriers are: depression, problems with weight control, hard to exercise regularly, fatigue, poor communication with doctors, lack of family support, pain and economic problems [43]. It can be discussed if all the eight mentioned barriers actually are barriers or if some of them are the visible signs of a barrier. Anyway the “barriers” are supported from another study who confirm that personal struggles with e.g. family, friends, work and financials have influence on the self-care ability (Riegel & Carlson, 2002) and difficulties to recognise and interpret symptoms was common and lead to delayed action (Riegel & Carlson, 2002). Furthermore it seems as to take care of oneself, also is to cheat with the health-care advice, when it is important for quality of life (Riegel & Carlson, 2002). Self-care competence is related to a shift in self-identity, an altered perception of self where the disease becomes a part of life. Self-care is more than doing, it is being and becoming which involved reconstructing a self-identity through exploring personal limits and boundaries (Kralik et al., 2004). To practice self-care it is important to identify personal limits, take and maintain control

over life, plan daily routines and to some extent follow health-care advice as a part of self-care (A. F. Jerant et al., 2005; Koch et al., 2004; Kralik et al., 2004; Riegel & Carlson, 2002).

Patient education was not associated with developing self-care competence, because self-care was learned through daily life experiences (Kralik et al., 2004). Some patients had an experience of 'being on your own' because the health professionals cannot tell exactly what to do and not to do (Riegel & Carlson, 2002). The patients' experienced they had to learn to adapt and doing things, in their everyday life (Kralik et al., 2004; Riegel & Carlson, 2002). This is in contrast to a study where three models of self-care are identified; medical, collaborative and self-agency. The medical model, where the doctor manages the disease for the objectified patient, who follows the prescriptions, is concluded to be the dominant one (Koch et al., 2004). One difference related to diagnoses was the pain that persons with arthritis struggle with. This indicates a chronic disease that cause pain may have some different significant factors relevant for self-care competences, than those diseases that do not cause pain.

#### *Relevant recommendations for future research*

Danish National Board of Health recommend research that increase understanding of the conflict between the health advices and the everyday life. They point there is a dilemma when persons have to changes lifestyle and behaviour, because the wish and obligation to live healthy, can conflict with the norms in and routines of everyday life (National board of Health, 2009).

Grabowski (2010) argue that there is a lack of knowledge about how and under what conditions adults with chronic diseases develop competence e.g. how they develop the competence to make decisions about their illness and their health in everyday life. There is also identified a need to complement the knowledge about effect of patient-education with knowledge about processes about how and why the effect is achieved (National board of Health, 2009). In relation to health education, Grabowski (2010) concluded there is a need to identify necessary skills for adults with chronic disease in Denmark and a need to develop ways of involving patients both as individuals and as a person in a community that focuses on patients' management of their own lives and focus on the patient's ability to change and get support in the community in relation to promoting Health. Dørfler (2005) pointed at the need to explore, how to strengthen patients' self-care as an individual and in society. In this task the diverse meanings and definitions of the self-care concept must be clarified in relation to work with adults with chronic diseases.

### *Summing up*

The findings showed that patient education/therapeutic interventions with educational aim seem to have an effect on outcomes as e.g. symptom reduction, readmission and pharmacological adherence. This means we can assume that patient education does make a difference, but we do not know how and why.

It is also shown that it is difficult to live with a chronic disease because the disease in different ways reduces the person's functioning and because it involves both a personal transformation and a need of change in lifestyle and social life. Important factors that either facilitate or obstruct to learn to live with a chronic disease are age, gender, level of education, an active work-life, cognitive impairments and severity of the disease. Those factors are also influential in relation to being able to transform abstract principles learned in patient-education into action in everyday life. It seems as the social environment, family and friends have great influence. They can be a help in relation to monitor the patient's condition, but inadequate support and personal struggles with friend and family influence the self-care capability negatively. Patients experience the relation to the health-care professionals as important. From the patients' experiences it can be assumed that it is positive when the patients experience that 1) the health-care professional involves the patients' everyday life as a basis for the treatment and patient-education, 2) there is a mutual respect and 3) the communication is clear and precise.

It also seems as the patients' need to accept the disease to be able to learn to live with it. This is a personal transformation where the disease has to be seen as separated from one self but as a part of life. The findings showed that factual knowledge about pathology and treatment are fundamental for learning to live with a chronic disease. It seems as the patients have learned about pathology and treatment either through intended non-formal learning from health-care professionals or through informal learning from the Internet and textbooks. But the findings indicate that competences to live everyday life are developed incidentally through the personal experience happening randomly in everyday actions and to some extent also through informal trial and error experiments in everyday life. Further it seems as following competences are important for being able to live with a chronic disease: self-monitoring, personal limits, decision-making, to have control over the disease, problem-solving, to live a planned and organized life and collaboration with friends, family and health-care professionals.

There is identified a lack of knowledge in relation to understand the gap between health-care advises and action in everyday life. How do persons develop competence to handle their everyday life? And what, how and why do patient-education has an effect?

### **Discussion**

The findings reveal a lack of knowledge that directly concern the main topic in this state of the art; 'research based knowledge about transfer between patient education and the patients' outcome in relation to live everyday life with a disease'. This can be blamed an incorrect search strategy and may be strengthen with the performance of the third search strategy in progress. The reason may also be that there isn't research-bases knowledge precisely about this topic. This could be underpinned by the lack of didactic and learning theoretical awareness in studies about patient education in the findings, because many studies have a biomedical approach where insight in transfer between education and daily life is not a concern.

It is common to understand "competence" as consisting of three elements; knowledge, skills and attitudes (Wahlgren, 2010). In relation to the findings this could lead to the hypothesis that knowledge understood as knowhow/know that can be learned in the intended non-formal patient education programs, while the competence to live everyday life with a chronic disease are learned, based on the knowhow, as a combination between incidental and informal learning in everyday life. From the National Board of Health it is assumed that patient-education can teach adults to live with their chronic disease, but the above findings may point at some limits within the learning potential of patient-education. It is known that patient-education has an effect and it is known that specific factors are important for competence to live everyday life. But it seems as there is a lack of research-based knowledge about the learning-processes between knowledge learned in patient-education and action in everyday life. This could lead to this preliminary research question: How does patient-education influence the patients' development of competences used in their everyday life?

## References

- Aujoulat, Isabelle, Marcolongo, Renzo, Bonadiman, Leopoldo, & Deccache, Alain. (2008). Reconsidering patient empowerment in chronic illness: A critique of models of self-efficacy and bodily control. *Social Science & Medicine*, 66(5), 1228-1239.
- Badamgarav, Enkhe, Weingarten, Scott R., Henning, James M., Knight, Kevin, Hasselblad, Vic, Gano, Anacleto, Jr. et al. (2003). Effectiveness of Disease Management Programs in Depression: A Systematic Review. *Am J Psychiatry*, 160(12), 2080-2090.
- Casacalenda, Nicola, Perry, J. Christopher, & Looper, Karl. (2002). Remission in Major Depressive Disorder: A Comparison of Pharmacotherapy, Psychotherapy, and Control Conditions. *Am J Psychiatry*, 159(8), 1354-1360.
- de Mello, M. Feijo, de Jesus Mari, J., Bacaltchuk, J., Verdeli, H., & Neugebauer, R. (Writer). (2005). A systematic review of research findings on the efficacy of interpersonal therapy for depressive disorders, *European Archives of Psychiatry and Clinical Neuroscience*: Springer Berlin / Heidelberg.
- de Maat, Saskia M., Dekker, Jack, Schoevers, Robert A., & de Jonghe, Frans. (2007). Relative efficacy of psychotherapy and combined therapy in the treatment of depression: A meta-analysis. *European Psychiatry*, 22(1), 1-8.
- DeRubeis, Robert J., Hollon, Steven D., Amsterdam, Jay D., Shelton, Richard C., Young, Paula R., Salomon, Ronald M. et al. (2005). Cognitive Therapy vs Medications in the Treatment of Moderate to Severe Depression. *Arch Gen Psychiatry*, 62(4), 409-416.
- Dimidjian, S.; Hollon, S.D.; Dobson, K.S.; Schmaling, K.B.; Kohlenberg, R.J.; Addis, M.E.; Gallop, R.; McGlinchey, J.B.; Markley, D.K.; Gollan, J.K.; Atkins, D.C.; Dunner, D.L.; Jacobson, N.S. (2006). Randomized trial of behavioral activation, cognitive therapy, and antidepressant medication in the acute treatment of adults with major depression. *Journal of consulting and clinical psychology*, 74(4), 658-670.
- Dørfler, L; Hansen, HP. (2005). *Egenomsorg - en litteraturbaseret udredning af begrebet*. Copenhagen: Viden- og dokumentationsenheden.
- Grabowski, D., Jensen, B.B., Willaing, I., Zoffmann, V., Schiøtz, M.L. (2010). *Sundhedspædagogik i patientuddannelse*. Gentofte: Region Syddanmark.
- National Board of Health (2006). *Patienten med kronisk sygdom. Selvmonitorering, egenbehandling og patientuddannelse. Et idékatalog*. Copenhagen.
- National Board of Health (2009). *Patientuddannelse – en medicinsk teknologivurdering* (No. 1399-2481). København.
- Hegerl, Ulrich, Plattner, Anita, & Möller, Hans-Jürgen. (2004). Should combined pharmaco- and psychotherapy be offered to depressed patients? *European Archives of Psychiatry and Clinical Neuroscience*, 254(2), 99-107.
- Helen, S.; Teasdale, J.D. (2004). Mindfulness-Based Cognitive Therapy for Depression: Replication and Exploration of Differential Relapse Prevention Effects. *Journal of Consulting and Clinical Psychology*, 72(1), 31-40.
- Jerant, Anthony F., Friederichs-Fitzwater, Marlene M. von, & Moore, Monique. (2005). Patients' perceived barriers to active self-management of chronic conditions. *Patient Education and Counseling*, 57(3), 300-307.
- Jerant, Anthony, Moore, Monique, Lorig, Kate, & Franks, Peter. (2008). Perceived control moderated the self-efficacy-enhancing effects of a chronic illness self-management intervention. *Chronic Illness*, 4(3), 173-182.

- Jørgensen, S.J. (red). (2005). *Kronisk sygdom. Patient, sundhedsvæsen og samfund*. Copenhagen: National Board of Health. Enhed for Planlægning.
- Katon, Wayne, Russo, Joan, Von Korff, Michael, Lin, Elizabeth, Simon, Greg, Bush, Terry et al. (2002). Long-term Effects of a Collaborative Care Intervention in Persistently Depressed Primary Care Patients. *Journal of General Internal Medicine*, 17(10), 741-748.
- Kennedy, Anne, Reeves, David, Bower, Peter, Lee, Victoria, Middleton, Elizabeth, Richardson, Gerry et al. (2007). The effectiveness and cost effectiveness of a national lay-led self care support programme for patients with long-term conditions: a pragmatic randomised controlled trial. *Journal of Epidemiology and Community Health*, 61(3), 254-261.
- Kessing, Hansen HV, Hougaard E, Hvenegaard A, Albæk J. (2006). *Preventive outpatient treatment in affective disorders. Results from a Health Technology Assessment (HTA)*. Copenhagen.
- Kjøller, M.; Juel, K.; Kamper-Jørgensen, F. (Ed.). (2007). *Folkesundhedsrapporten, Danmark 2007*. København: Statens Institut for Folkesundhed og Syddansk Universitet.
- Koch, Tina, Jenkin, Peter, & Kralik, Debbie. (2004). Chronic illness self-management: locating the 'self'. *Journal of Advanced Nursing*, 48(5), 484-492.
- Kralik, Debbie, Koch, Tina, Price, Kay, & Howard, Natalie. (2004). Chronic illness self-management: taking action to create order. *Journal of Clinical Nursing*, 13(2), 259-267.
- Lam, Dominic H., Watkins, Edward R., Hayward, Peter, Bright, Jenifer, Wright, Kim, Kerr, Natalie et al. (2003). A Randomized Controlled Study of Cognitive Therapy for Relapse Prevention for Bipolar Affective Disorder: Outcome of the First Year. *Archives of General Psychiatry*, 60(2), 145-152.
- Lin, Elizabeth H. B., Von Korff, Michael, Ludman, Evette J., Rutter, Carolyn, Bush, Terry M., Simon, Gregory E. et al. (2003). Enhancing adherence to prevent depression relapse in primary care. *General Hospital Psychiatry*, 25(5), 303-310.
- Lorig, K. Sobel, D, Ritter, P, Laurent, D, Hobbs, M. (2001). Effect of a self-management program on patients with chronic disease. *Effective Clinical Practice*, 4(6).
- Neumeyer-Gromen, Angela M. D. M. P. H., Lampert, Thomas Dipl-Soz, Stark, Klaus M. D. PhD, & Kallischnigg, Gerd Dipl-Math. (2004). Disease Management Programs for Depression: A Systematic Review and Meta-Analysis of Randomized Controlled Trials. *Medical Care*, 42(12), 1211-1221.
- Pampallona, Sandro, Bollini, Paola, Tibaldi, Giuseppe, Kupelnick, Bruce, & Munizza, Carmine. (2004). Combined Pharmacotherapy and Psychological Treatment for Depression: A Systematic Review. *Arch Gen Psychiatry*, 61(7), 714-719.
- Parnas, Josef, Kragh-Sørensen, Per, & Mors, Ole. (2009). *Klinisk psykiatri* (3. udgave ed.). Kbh.: Munksgaard Danmark.
- Paterson, Barbara. (2001). Myth of empowerment in chronic illness. *Journal of Advanced Nursing*, 34(5), 574-581.
- Pollack, Linda E., & Aponte, Miriam. (2001). Patients' Perceptions of Their Bipolar Illness in a Public Hospital Setting. *Psychiatric Quarterly*, 72(2), 167-179.
- Proudfoot, J. G., Parker, G. B., Benoit, M., Manicavasagar, V., Smith, M., & Gayed, A. (2009). What happens after diagnosis? Understanding the experiences of patients with newly-diagnosed bipolar disorder. *Health Expectations*, 12(2), 120-129.
- Riegel, Barbara, & Carlson, Beverly. (2002). Facilitators and barriers to heart failure self-care. *Patient Education and Counseling*, 46(4), 287-295.
- Rubak, S. et.al. (2005). Motivational interviewing: a systematic review and meta-analysis. *British Journal of General Practice*, 55, 305-312.



- Russell, S. J., & Browne, J. L. (2005). Staying well with bipolar disorder. *Australian & New Zealand Journal of Psychiatry*, 39(3), 187-193.
- Schreurs, Karlein M. G., Colland, Vivian T., Kuijer, Roeline G., de Ridder, Denise T. D., & van Elderen, Thérèse. (2003). Development, content, and process evaluation of a short self-management intervention in patients with chronic diseases requiring self-care behaviours. *Patient Education and Counseling*, 51(2), 133-141.
- SfR. (Sekretariatet for Referenceprogrammer) (2007). *Referenceprogram for unipolar depression hos voksne* ( : 1.0 ed.). Kbh.: Sundhedsstyrelsen.
- Simpson, S., Corney, R., Fitzgerald, P., & Beecham, J. (2003). A randomized controlled trial to evaluate the effectiveness and cost-effectiveness of psychodynamic counselling for general practice patients with chronic depression. *Psychological Medicine*, 33(02), 229-239.
- Sundhedsstyrelsen. (2011). Patientrettet forebyggelse Retrieved 9. marts, 2011
- Suto, Melinda, Murray, Greg, Hale, Sandra, Amari, Erica, & Michalak, Erin E. (2010). What works for people with bipolar disorder? Tips from the experts. *Journal of Affective Disorders*, 124(1-2), 76-84.
- Teasdale, J.D.; Segal, Z.V.; Williams, J.M.G.; Ridgeway, V.A.; Soulsby, J.M.; Lau, M.A. (2000). Prevention of relapse/recurrence in major depression by mindfulness-based cognitive therapy. *journal of consulting and clinical psychology*, 68(4), 615-623.
- Thorne, Sally, Paterson, Barbara, & Russell, Cynthia. (2003). The Structure of Everyday Self-Care Decision Making in Chronic Illness. *Qualitative Health Research*, 13(10), 1337-1352.
- Tungpunkom P., Nicol M. (2008). Life skills programmes for chronic mental illnesses. *Cochrane Database of Systematic Reviews*.
- Wahlgren, Bjarne. (2010). *Voksnes læreprocesser* (1. udgave ed.). Kbh.: Akademisk.
- Willaing, I., Folmann, N.B., Gisselbæk, A.B. (2005). *Patientskoler og gruppebaseret patientundervisning – en litteraturgennemgang med fokus på metoder og effekter*. København.
- Wilson, Patricia M., Kendall, Sally, & Brooks, Fiona (Writer). (2007). *The Expert Patients Programme: a paradox of patient empowerment and medical dominance*: Blackwell Publishing Ltd.