

Family perspectives in treatment of schizophrenia

1. Changes in the role of relatives in different perspectives of schizophrenia
– From causes to resources
2. Impact of a psychoeducative intervention on caregiver burden

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Background information

It is by now widely accepted that the relatives of a person with schizophrenia should be included in the patients' mental health treatment (1-3). It has not always been like this in mental health services. On the contrary, the relatives of a mentally ill person have been both accused of being the cause of the illness and to have a negative impact on the course of the rehabilitation and been kept out of contact with their hospitalized family member (4-6) .

Today guidelines for treatment of schizophrenia do recommend family intervention both for the benefit of the patients' rehabilitation, and for the family members' own health and quality of life. (1-3). Still, there is a challenge in fulfilling the guidelines in parts of the mental health system (7-9).

A specialized rehabilitation inpatient unit for persons with schizophrenia at Østmarka, St. Olav Hospital, Norway provides psychoeducational courses aiming to reduce stress and enhance coping for family members and caregivers based upon the stress-coping model of Lazarus and Folkman. For the last five years, this program has been evaluated for a research study.

This thesis is twofold, first in paper 1 I will attempt to summarize the historical and scientific perspectives of mental health treatment and the changes in the relatives roles, and second in paper 2 I attempt to evaluate the impact if a six session psychoeducative intervention for relatives on their appraisal of experiences of caregiving and evaluation of own health and functioning.

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ABSTRACT

Purpose: The current paper aims to describe the last century changes in the relatives' role in treatment of individuals with schizophrenia in medical, psychological, social, and research perspective.

Methods: A literature review was obtained by searches on Bibsys, Helsebiblioteket, ISI web of Science, and PubMed. Key words were schizophrenia, psychosis, psychiatric history, caregiver burden, family intervention. Evidence based literature was obtained via searches of ISI Web of Science, EBCON, Pubmed, and Google Scholar computerized databases from 1960 through November 2008. Reports of earlier reviews of literature and original research were included.

Conclusions: From being assumed as a cause of mental illness, to influence course and relapse, and now to be an important resource of the treatment and recovery of the patient, the relatives now are also recognized as caregivers with their own needs for help and support. There are still challenges to include evidence-based treatment in the clinical settings.

INTRODUCTION

Schizophrenia is a serious condition with symptoms as hallucinations, delusions (often by bizarre nature), psychomotor disturbances and incoherent speech. Individuals with such disturbances may be associated with persons that are dangerous, lazy, incompetent at work, and unable to be a family member that fulfil his or hers social obligations. The illness lasts long and may lead to different disabilities. Rehabilitation is often considered as difficult and especially if it has to take place in a hostile environment characterized by ignorance and prejudice (10).

Several theoretical (e.g. medical, psychological, and sociological paradigms), has affected the way severe psychiatric disorders are understood (11-15). The different perspectives has emotional and practical consequences, both for the ill individuals and for their family (6, 13). Today, the family members of people with severe mental illness, now also named *caregivers*, are considered important and helpful resources in the treatment and rehabilitation for the patient. This is a relatively new perspective. Only a few decades ago, relatives were considered as causes of the illness (4-6).

The first part of this paper gives an overview of the perspectives and treatments of psychosis and schizophrenia during the last century, and the consequences for the relatives of the patients. In the next chapter there will be a brief examination of schizophrenia research, research on family and social relationship, stigma, recovery, family members as caregivers, and family intervention. I will summarise and discuss information from the psychiatric history and other events that have influenced the altered perspectives of mental illness and the consequences that changed perspectives have had for the role of family members of the mentally ill, and discuss the challenges for the future.

Research questions

- 1) Description of changes in the treatment perspectives and the role of the family members of individuals with severe mental illness during the last century in mental health treatment settings.
- 2) Review of the research for the role of the family in treatment of schizophrenia.
- 3) What challenges are there in the treatment of individuals with psychosis and their family members in the future?

Literature search and selection

The computer generated search was limited to text books and empirical studies published in scientific journals written in English or Norwegian, and textbooks with approved conceptualizations of themes in this thesis were accepted. All literature chosen describes situations in the western part of the world. The search was conducted using the following keywords: schizophrenia, family, caregiver, caregiver burden, caregiver experience, expressed emotion, family intervention, and psychoeducation.

Search strategy for history information. Literature research was accomplished on PubMed, ISI Web of Science, Helsebiblioteket, Bibsys Ask, Cinahl, and Google Scholar, and in the NTNU university library.

Search strategy for empirical studies. Relevant trials from 1960 to November 2008 were identified by electronic literature searches at: ISI web of Science, PubMed, EBSCO Psychology and Behavioural Sciences Collection, Scirus, Google scholar, Cochrane Library, and the reference lists of identified studies and other reviews were examined.

TRADITIONALLY TREATMENT PERSPECTIVES OF SEVERE MENTAL ILLNESS AND THE ROLES OF THE FAMILIES

This chapter aims to describe and understand the history of, and the situations for the family members of individuals with schizophrenia in mental health treatment. The roles of family members of patients with schizophrenia have changed as the theoretical and clinical perspectives have changed during the last century.

Biomedical perspective

The sign of a modern society is the development of science for various areas and that the religious perspective of the world is replaced by the scientific view. Humans are no longer under the influence of any heavenly body but seen as a machine administrated by physical and chemical processes. As a result of this modern explanation mental illness became psychiatry, a medical discipline (13). *Schizophrenia* (Greek: schizein=split, and phren=mind) is the name the Swiss psychiatrist Eugen Bleuler in 1908 gave the state that the German psychiatrist, Emil Kraepelin, a few years earlier had called Dementia Praecox. During the last century when psychiatry has strived to unveil the cause and aetiology of schizophrenia and other psychotic conditions it has been conceptualised predominantly as a medical illness as other medical illnesses. One looked for a clear cause like a bacterium, a brain damage, a diseased gene, or pathological developmental condition (14, 16, 17).

From late 19th century through the first decades of the 20th century mentally ill people were taken care of in asylums segregated from the community according to a *moral treatment* model. Moral treatment implied physical custody, food, clothing and work but there was lack of specific treatment methods. The caring function period was succeeded by new experimental physical treatment methods at mental hospitals and was assumed curative. Early in the 20th century when the bacterium causing the syphilitic's brain damage was discovered, and the experience of syphilis successfully cured by penicillin, it gave even more reason to believe that schizophrenia was an organically deterrent disorder that could be cured. (1, 4, 5, 13, 14). In the 1950s, the modern pharmacological neuroleptica, antidepressiva and anxiolytica were documented as very effective to calm the symptoms of psychosis, to cure deep depression faster, and to reduce anxiety and insomnia. Medical treatment replaced lobotomies and reduced compulsory methods. There was new optimism for the future for a large group of hospitalized patients (14, 16, 17).

In the moral treatment perspective and asylum period the patients were separated from their family, and there is no discussion found from the time period describing the relatives' situation but there were assumption to hereditary which must have influenced many families' lives. In the first part of the 20th century mentally ill people, among others with defined aberrations e.g. blindness, Huntington's Chorea, feeble-mindedness, alcoholism, nomadism, and prostitution, considered to be a hereditary defect and sufferers were in many countries subject to *eugenics*. Thousands were sterilized as the result of the assumed genetically unfit, and thousands incarcerated. Even though the scientific reputation of eugenics started to decline in the 1930s, a time when eugenics was used as a justification for the racial policies of Nazi Germany, some western countries continued this treatment until the 1970s (18). In the 1970s and the 1980s, when mentally ill patients were discharged from the hospitals, little effort was made to provide facilities in the communities because the guiding principle was that the chronic disorders were caused and maintained by institutional subcultures. Most patients therefore moved in to live with their families which got a custodial role without getting information or supervision about the illness and how to manage. Despite the assumptions, the ex-patients' "institutionalized behaviour" remained incongruous, independent upon their living environment, and became a disruption to family life (19-21).

Psychoanalysis and psychodynamics

The medical model does not have preferences only to the biomedical approach. During the first half of the 20th century the treatment was mainly based on psychoanalytic methods and even if antipsychotic drugs were developed and available from the 1950s, psychiatric treatment continued to be influenced by psychological approaches (22). Contemporaneous Kraepelin's scientific descriptions of symptoms and prognosis of mental illness, Austrian neurologist and psychiatrist Sigmund Freud attributed neurosis and other mental disturbances to the patient's childhood development and experiences in his former life and that the more severe mental illnesses such as psychosis, paranoia, and manic depressive conditions were expressions of deep emotional disturbances causing emotional attachment to other people problematic. Schizophrenia, he claimed, was a result of unresolved feelings and repressed libido. There were polarizing fronts among psychiatrists to the psychoanalytic approach, from full dedication to skepticism and even hostility. Still, psychoanalytic and psychodynamic explanations became the foundation for both treatment methods and academic theory about the child's development and the driving forces in the human mind. The *psychoanalysis* introduced by Freud, was proposed to interpret the individual's present mental

state with the elucidation that his former life and experiences has importance to the meaning of his or hers thoughts and feelings. This anchored in theories of the unconscious mind and defence mechanisms as repression. Treatment by psychoanalytic methods intended to cure psychopathology through the patient's free associations or in dialogue between the patient and a psychoanalyst. Following Freud there were several schools with psychodynamic perspective built on the psychoanalysis. There was Mahler with self- and object differentiation, Fairbairn and Kernberg with object relation theory, and there was Kohut who was most concerned about self-representations (13, 22-24).

Both the psychoanalytic and the psychodynamic perspective see psychological problems in adulthood as anchored in the early childhoods. This would be described as disturbances in development, faulty understanding of the environment, early lack of security and fulfilling of needs, or inadequate quality in attachment to others, especially the mother (12, 13, 25). Prior to the 1970s, individual and group psychotherapies for schizophrenia were generally based on psychodynamic theories, or theories that conceived of schizophrenia as being caused by pathological behaviour or communication patterns of the patient's family. These treatment methods stigmatized the patients' families, often their main or only support system (26).

Social perspective – a debate about illness and normality

Psychiatry became a product of the welfare state and the Enlightenment. Even if doctors in the early 1900s defined mentally illness as an inheritable brain disease, there was strong faith in humans as rational beings, and if surrounded by common sense could heal the madness, the so called moral treatment. The positive results of the segregation of mentally ill in the huge asylums failed to come, the patients did not get well, and the asylums became overcrowded. Simultaneously society called for stronger demands for normality and efficacy, and the most important intention from society to psychiatry became to keep deviants in control and away from their families and the community (16, 27). After dramatic events like both World War I and World War II the psychoanalysis and offspring's like the psychodynamic theories thrives and the interest of the individuals social and emotional factors increased, mostly because of all the physically and mentally harmed veteran soldiers and the perspective of humans health as a public matter. In the 1920s the behaviorist perspective grew both theoretically and clinically. Perspectives on humans as physical objects: one by objective observations of behavior could reveal the psychological problems scientifically, and the treatment approaches were reinforcement, forming and learning by role modeling. Post WW

II, adherents of humanistic and systemic perspectives were critical to what was seen as insufficient in the psychodynamic perspective. *Humanistic perspective*, in brief, claims each human is a free individual, capable of response, and able to make his and her own choices to fulfill his potential. The *systemic perspective* based on cybernetic and homeostasis in biological systems was transferred to the interaction between individuals and between the individual and the environment or the context (13).

Ronald Laing and colleagues, a group of psychiatrists based in London, led a movement to treat psychiatric illness politically rather than technically, the *antipsychiatry* arose. They regarded the psychotic person not as ill, but as an individual in an alienated society, the one that could unmask the madness of society in large and the family in particular. With the advent of the antipsychiatry in the following decades, the idea of saving the person with schizophrenia from the family became stronger. The family was considered as a repressive institution, and there was no reason to repair a dysfunctional family because a functional family was considered even worse. The psychotic person literally had to be saved from his family and the psychiatrists attempt to normalize him (14). In 1956, Palo Alto, California, anthropologist Gregory Bateson and colleagues with a perspective based on interaction and linear systemic theory articulated that schizophrenia was a disease stemming from *double bind* situations. Double bind is explained by that the communication from the parents to the children are incongruent or formed as abstract conflicting messages. The perceived symptoms of schizophrenia was therefore an expression of distress by the communication style where the child grew up “guessing” about which messages were relevant or worthy of attention (4, 24). In Italy, at about the same time, the perspective also was that schizophrenia was connected to family interaction, but the Milano group substituted the linear view of the schizophrenia caused by family with a circular systemic perspective as a kind of co-evolution between the person with schizophrenia and the patterns within the family. The psychotic person does not see any existential sense in the family, and his behaviour does not make sense for the other family members (26). In Europe these principles arouse the discussion of whether the disturbances came from inherited or environmental problems, or a combination. Several psychiatrists, among them German Frida Fromm-Reichmann and American Theodore Lidz founded the foundation for schizophrenia in the environment of the families where children grew up, and the terms “skewed” family and “schizophrenogenic” mothers became common concepts. Lidz noted that schizophrenogenic mothers managed to be impervious to the needs and wishes of other family members, and that there was a malfunction of the parents that caused the child’s mental disturbance. He described the

mothers' psychotic or very strange concepts to remain unchallenged by the husband; creating a reality within the family. In his book "Schizophrenia and the Family" (28), Lidz calls this phenomenon *folie à deux*, a shared delusion between the two parents. If the delusional ideas of the dominant parent are shared by all family members, the result is a *folie à famille*. Still, Lidz criticised a culture of blame against schizophrenogenic mothers, writing:

"I also find it very distressing that because the parents' attitudes and interactions are important determinants of schizophrenic disorders, some therapists and family caseworkers treat parents as villains who have ruined the lives of their patients" (28 p. 26).

In wake of the psychodynamic perspective, there were both implicit and explicit views that the atmosphere in the family, and so called dysfunctional communication pattern, could influence the course of severe mental illness. British psychologist George W. Brown and colleagues, who search for links between peoples' vulnerability for mental illness and their social conditions, realized that despite new treatment methods and care, discharged schizophrenia patients still had a tendency to relapse with a recurrence of symptoms. This was even more frequent for those who moved back into the family home than those who lived elsewhere. The hypothesis was that a high degree of expressed emotion (EE) in the family environment was an index of characteristics of relatives which were likely to cause a relapse of symptoms, independently of other factors such as length of illness, type of symptomatology or severity of previous behaviour disturbance (6, 29).

With the accusation of being cause of a family members' mental illness or representing a risk for the patients relapse, the family would be exposed for stigmatization. Stigmatisation is a dimension of suffering added to illness or diversity experience, and has been found to lead to social isolation, limited life chances and delayed help-seeking behaviour. Persons with schizophrenia - and their family, friends, and social group - may be shunned, denied protection under the law, and treated as humans of less worth (27, 30, 31).

Consumers' movement

The consumer movement established in 1948 in New York, was a self help group for discharged mental hospital patients with very strong ethics for empowerment (32). At about the same time in UK, The Mental Health Research Fund was set up by a group of people who were dismayed by the lack of funding for research into mental health problems. The self help groups set up funds to provide grants for research and development projects and they adopted an integrative approach bringing together professionals from a range of disciplines which recognised that mental health was influenced by a combination of both

social and biological factors. By the 1960s, as a key founder for research, consumer movements had the power to influence government policy on mental health. By the 1990s they realized the huge potential for spreading information by the World Wide Web, and the consumer movements became large online mental health informants and sources for campaigns. Similar organisations by former patients, their families, and health professionals all around the western world arose. They had testimonies from individuals that had experienced recovery from severe mental illness. There were longitudinal studies on former patients documenting that the course of the illness is more variable both within and across individuals and that many individuals with strict diagnosis have a very good outcome (33, 34).

Current perspective of schizophrenia and recovery

The American psychiatrist Joseph Zubin, in the mid 1970s, searched for a wider perspective to describe and understand why some young people developed psychosis. He unified the biomedical and psychosocial knowledge about the course of schizophrenia in a *stress-vulnerability model* (12, 35). The model conceives the symptoms and course of schizophrenia as the results of combined effects of environmental stress and biological vulnerability in individuals, an integrative perspective. The stress-vulnerability model describes that the individual has his or her own level or degree of vulnerability which can be described both by a biological and psychological nature, and has by these a strength or weakness for physical or psychic frustration, generally called stress. Thus, the rehabilitation program to prevent onsets of new psychosis is highly dependent on the interactions with the environment and social circumstances. Environmental stressors may include substance abuse, stressful disruptive life events, or a hostile or critical family (35). Still, within the integrative perspective for serious mental illness, we are allowed to see the person in process to get out of a patient role situation. One should not only focus on getting free of symptoms of an illness, but for the individual to have the same main goal for life as any other adult person; to get an education, a job, living space, friends and family, and good physical and mental health. *The Recovery Model* for severe mental illness is conceptualized by professionals, politicians, as well as consumers, families, and former consumers of mental health services. Although there are different definitions, angles of perspective, meanings, graduations and even contrasting understandings of the terms *Recovery*, *Psychosocial Rehabilitation*, and *Psychiatric Rehabilitation*, they all describe a collaboration between the patient, the community, health services, family members, and peers. There is no longer top-down, clinician-driven treatment,

meaning there is an emphasis on empowerment: helping the consumer develops a sense of control in his or her life (12, 20, 22, 36-41).

Family members and caregivers

The family members of a person with psychosis are currently respected as some of the most important resources for the patients' way to recovery, and are respected as caregivers with lots of responsibility and burden, and as individuals with their own needs. The family members' knowledge of the patient through their relationship: their knowledge of his history, his personality, and his resources, are important information for the health care system, and for the treatment and recovery (42). Still, the relatives have a history of their own. Relatives of a person with difficult or strange behaviour will wonder what is going on. After months, or even years with worry and wonder they have to admit that professional help is unavoidable. Meanwhile they may have worried so much that their own health is poor, their income reduced, their social and leisure activities being restricted and their domestic routine upset (21). Relatives own needs will be secondary and they may feel that they always have to 'be there' for the sick family member what is described as *caregiver burden*: Family members of persons with schizophrenia often provide emotional support, financial assistance, and housing to their mentally ill ones. They have to be their advocacy and case manager as well, and they worry about their child's future, and his or her rejection to treatment (specified as an *objective* burden), the cumulative impact of the self-blaming, the grief, the confusion, the anger, the frustration, the guilt, and the consequences of social stigma (specified as *subjective* burden). The strain the family of a psychotic person must face and the stressors which they must contend with on a daily basis is a threat to their own quality of life and health. The family members will have to learn how to cope with the illness and the situation by gaining new comprehension and knowledge as tools to new ways for appraisal of their stressful situation. To achieve better circumstances of life, the health service professionals have to realize the family's real situation and be aware of their real needs which often are of a practical kind like financial or residential (21, 42-46). While families earlier were held responsible for both care and cause for their ill relative, they were excluded from the treatment. There is now increasing agreement that a collaboration between the patient, the family, and the service system are the ultimate base for recovery (47).

Family intervention

In the USA, at the beginning of the twentieth century, there was an understanding that mental disorders could be prevented by working therapeutically with the families of potential psychiatric subjects. This was a starting point for *family therapy*: an approach mostly

used for families of children with conduct disorders (26). The professional interest in family interventions for schizophrenia increased out of observations that about one third of schizophrenia patients discharged to live with families characterized by high levels of EE had three times higher risk of psychotic relapse than those who were discharged elsewhere, even if adherence to prescribed medication was adequate. The families had to learn how to behave to prevent relapse (6, 48). The family approach later shifted away from family therapy attempting to get families to change their 'disturbed' communication patterns, a perspective and kind of therapy which not only was ineffective, but perhaps even damaging for the patient and the family (47). In the "social learning", psychoeducation, the family as a whole should help the considered biologically mentally ill family member in a careful manner to get a better understanding and a better treatment for the patient (49). The psychoeducative models had common assumptions and were based on biological aspects of the illness. The assumptions were that the families were 'normal', that they have been hit by an illness, just as any other illnesses that are severe and chronic. The treatment included drugs and rehabilitation; the therapist should have an alliance with the sane recourses in the family and give the information needed to the family. The proper psychoeducative method was didactic, explicit, standardized, and empirically validated so there was no need for special trained or educated personnel (47, 49).

Psychoeducation today is an umbrella concept. There are countless versions of modern interventions for families. Since the mid 1980's they were grouped under this term which includes behavioural family interventions, eclectic psychosocial family treatment and the various kinds of multi-family and relatives' groups (49).

RESEARCH ON SCHIZOPHRENIA AND THE ROLE OF THE FAMILY IN TREATMENT AND REHABILITATION

As the earlier parts of this paper presented the interest for the family members of the schizophrenia patient has increased in the mental health system the last years. Table 1 shows the number of hits at PubMed, the world's largest database in medicine, of *schizophrenia* in general, and to *schizophrenia and family, family or caregiver burden and experience* during the last fifty years compared to EBSCO Psychology and Behavioral Sciences Collection with the same search words as in the medical base. This table shows that there currently are about 2 per thousand of the articles that include schizophrenia that also includes the families/caregivers experience or burden in Pubmed, where in EBSCO as much

as 63% of all schizophrenia articles included the family or caregiver. 20% of the articles about schizophrenia in EBSCO also included the family or caregivers *experience*.

Table 1

Search years 01.01-12.31	1960-1969		1970-1979		1980-1989		1990-1999		2000- nov 2008	
Database Search phrases	PubMed	EBSCO	PubMed	EBSCO	PubMed	EBSCO	PubMed	EBSCO	PubMed	EBSCO
Schizophrenia	2282	91	3747	135	6394	223	13152	1238	24658	4745
Schizophrenia And family	42	5	143	4	479	29	1097	124	1945	526
Schizophrenia And family Or caregiver		7		23	1	142	32	873	78	2988
Schizophrenia And family Or caregiver and burden		5		4		35	16	207	46	808
Schizophrenia And family Or caregiver And experience		5		6		50	10	227	21	956

There is still not found any single or definite cause of schizophrenia, and no curative medication. The research at the biomedical topics are wide and diverse, but not a subject in this thesis. As table 1 show, there is increasing interest in research of the family perspective in schizophrenia from several subject areas. There is research pro and con the assumed relational causes of the illness, there is research on the illnesses consequences for the family, and there is research in schizophrenia treatment perspective and methods involving and taking care of the family.

Double bind research

In the early 1940 the idea of eradicating mental illness through family prevention was well established in the USA. To work with this aspect one needed social conditions as well as scientific. The practical consequences of the great deinstitutionalization gave the social conditions, and the emergence of contemporary cybernetics, fostered by among others Gregory Bateson and his colleges in the Palo Alto group, gave the scientific conditions. The latter focused on the communicational and the interactional aspects of the relationships between any kinds of beings i.e. machinery, animals, and people. Bateson's group studied the settings by which they intended to prove in individuals got mentally ill – within the family,

and the product of the study was the concept *double bind*. Double bind is a communicative situation where a person receives different or contradictory messages from the environment (33).

Expressed emotion research

Based on their own former studies from the 1950s about the relationship between the schizophrenic patients course of symptoms and emotional environment, George W. Brown and his colleagues in 1972, surprisingly found that there were more relapses and rehospitalisation among patients discharged from the hospital to the family's home than among those who were discharged to live alone or elsewhere (6). Patients and their families were seen on several occasions and *The Camberwell Family Interview* (CFI) was developed as a device measuring "*Expressed Emotion*" (EE) (6, 29). The original concept of EE includes a set of positive and negative emotional relationships, among which three major negative components; criticism, hostility and emotional over-involvement, and became the focus of research (6, 48). The finding that EE was associated with the course of psychiatric disorder generated a great deal of clinical and research interest in EE as an important risk factor. Hundreds of family studies have been done based on CFI to discover and analyse the effect of EE. Most studies assume that the attitudes of family members with high EE are too strong to handle for the vulnerable patient, in addition to the mental illness. High family EE were shown as the best predictor of symptomatic relapse, and the "treatment" was to reduce contact between patient and family (48). The hypothesis that the dysfunctional family pattern caused relapse was never proved, but it was recognised that some families had high EE that correlated with the patients relapse rate. It was later acknowledged that the family appraisal of the circumstances of having a mentally ill family member living in the house was associated with high EE, and that high EE was found in about half of all families studied, with or without mentally ill family member (33, 53-55). Simultaneously as the criticism to the interpretation of EE, there was accumulating scientific evidence of a neurobiological basis of psychiatric disorders. A combination of biological and environmental factors emerged as explanations for the mental illness, and that the families dysfunction may be seen as a result of the illness, rather than a cause which resulted in a theoretical paradigm shift from blaming and pathologizing the family to the recognition and acceptance of family as an invaluable resource, both for the patient and the professionals.(46, 50).

Stigma research

Considerable research has documented the stigmatization of people with mental illness and its negative consequences also may have serious affect on families of psychiatric

patients. Phelan and colleagues made a study of 156 parents and spouses of a population-based sample of first-admission psychiatric patients. They found that while most family members did not perceive themselves as being avoided by others because of their relative's hospitalization, half of the informants reported concealing the hospitalization at least to some degree. Both the characteristics of the mental illness, and the social characteristics of the family were significantly related to levels of family stigma (51). Family members in other studies also report lowered self-esteem and strained relationships with other family members because of stigma and that they may be the victims of a "courtesy-stigma" (i.e. being stigmatized because of their association with someone with a severe mental illness) (52, 53). To study stigma of schizophrenia patients and their families, Corrigan & Penn recommend looking at studies of other stigmatized groups and taking lessons from social psychology on discrediting psychiatric stigma. Approaches as protests, education, and promoting contact between the general public and persons with these disorders should not be accepted by faith. These methods may give better life to some, but they may also result in a rebound effect or resistance to change. They also conclude that having the focus on changing public attitudes should not exclude the fact that persons with mental illness must learn some strategies to cope with the impact of stigma (54). A meta-analysis of 49 empirical studies of whether stigma has reduced during the last decades, showed no clear evidence for that, but the authors could see what they call some meaningful pattern (55),

Schizophrenia recovery research

As a natural consequence of the medical perspective, that severe mental illness could not be cured, treatment had emphasized on maintenance and stabilisation of the patient's functional level and the research had emphasized on the psychopathology of the illness. Still, some professionals had wider perspectives and claimed that a fundamental basic need for a person with schizophrenia who is trying to recover is that the community is well prepared to assist and give recommended service. In 1980 Stein & Test gave publicity to their invented and proved successful conceptual model for the development of community-based treatment for psychiatric patients as alternative to hospitalization. Their goal was to avoid the revolving-door hospitalization many patients experienced. The model, called Assertive Community Treatment (ACT), was based on years of studying patients' need for support and helped to develop skills to cope if they should live in and become included in the community. The conceptual model is based on a multidisciplinary team that serves the individual. The service is available all day year round to get help with basic needs and motivation. In addition they are offered education, help with problem solving, financial management, health care,

medication, and family involvement to be part of the society (56). The program got a Golden Award of Hospital and Community Psychiatry in 1974, and has since spread gradually, being used community by community, and state by state until it became in use nationwide (US). ACT has been subject of numerous randomized controlled trials and research has shown that this type of program is effective to maintain the contact with the severely mentally ill persons. It reduces hospitalization, and is considered more satisfactory to the patients and their family than standard care (57, 58). Some critics to the evidence of the success of ACT are addressed to the methods of studies done and that the compared standard care called 'home services' is not defined clearly enough to be distinguished from the ACT. There have also been discussions to see if the model is too paternalistic; the ethics of 'forcing' treatment on people that are of no danger to themselves or others, and that there are problems with early health-seeking care (59, 60). Courtenay Harding presented in 1987 the findings on two 32 years longitudinal studies of schizophrenia outcome. It showed that about two thirds of 269 ex-patients from Vermont State Hospital did well in a cohort following a 10 year bio-psycho-social rehabilitation program after deinstitutionalization. The former patients had, besides being treated with antipsychotic drugs, been followed up by a special team of professional caregivers and provided with housing, jobs, education and social support. Harding's study may represent a centrepiece of the recovery movement (61). Research on recovery is wide. As described elsewhere, there is diversity and disagreement of the definitions of the terms used in the recovery/rehabilitation, and about how to measure possible results. Some claim 5 years without hospitalization, some two. Some ask if periods without symptoms is valid as recovered, and if, for how long periods? Some say totally lack of symptoms and some say coping with symptoms are fine, some say no need for medication while others mean that a well medicated person with good adherence is great, some measure function compared to people without mental illness, some say subjective experience of recovery and some say objective (33, 62-64). Resnick and colleagues describes the confusion about the conceptualization of recovery and demand clear operational definitions a necessity for the research agenda within the recovery vision to advance (65). The original Schizophrenia Patient Outcomes Research Team (PORT) from 1998, with recommendations for the treatment of schizophrenia based on existing scientific evidence (66), was updated as recent as in 2003 since new knowledge already had occurred to help people with schizophrenia: This evidence points to the value of treatment approaches combining medications with psychosocial treatments, including psychological interventions, family interventions, supported employment, assertive community treatment, and training skills (67, 68).

Research on family members as caregivers

In the last few decades with a new approach to schizophrenia, there is a new approach on the family members' roles. Caregiving is referred to as the relationship between two adult individuals who are related. The caregiver undertakes an unpaid and unidirectional responsibility for the other who's mental health problems are disabling and long-term in nature (45, 69). In 1978, the first article found on PubMed' list of the subject *schizophrenia and caregiver*, Hatfield was studying how the parents of adult schizophrenia patient living at home searched for help and support. He found that families of the mentally ill risk reduction of their psychological and physical resources to the point that their personal efficiency may be reduced and that the organization and stability of their family life is threatened (19). Gubman & Tessler searched for consequences of the families after the deinstitutionalization of the mentally ill in a sociological perspective. There was much concern about the former patients. Were they going to be neglected by society? What burden of care and support would there be for the family of the patients who came from institutions with care and support 24 hours a day? They defined the term *family burden* as to characterize the load, carrying capacity, and strain experienced by family members as individuals and as members of a social system. They saw the historical perspective of studies of families involved in their ill relative in three different phases. The first consisted of mental illness in the perspective of family interaction and communication as the causal agent, followed by the double bind theory. The second perspective, or social scene, view families as agents of rehabilitation, in focus to prevent relapse. Both of these perspectives are characterized by Gubman & Tessler as only limited and useful in explaining the impact of mental disorder on other family members. The third perspective is to study the family burden literature where the family problems are explained relative to the patients' illness. Though they acknowledged that the use of the term *burden*, could tend to blame and stigmatize the ill person, which was not intended. The term is in wide use and easily understood (45). Brady and McCain found in a review of 63 studies of family perspectives that many experiences of living with someone with schizophrenia were adverse with respect to; the uncertainty about the cause of the disease, disturbing behaviour, lack of support, lack of reciprocity as it relates to the patient, and the family members reaction to the schizophrenia symptoms and the way they interpreted the symptoms. The patient's negative symptoms such as lack of energy, lack of purposeful activity, and general responsiveness, were often attributed to the patient's personality. The relatives often thought this kind of behaviour was purposely designed to aggravate, annoy, or provoke other family members (70). Veltman interviewed 20 caregivers and got all the information about frustration, fear,

concern, confusion, hope, sympathy, sadness, grief, anger and guilt. The theme most resonant were: stigma of mental illness and the caregiving role, system issues, love and caring for the ill relative and the life lesson learned. Some of the interviewed spoke about the stigma they sometimes felt unappreciated, blamed, and misunderstood by the general public and sometimes by health professionals as well. Stigma was also a challenge for their social life, the isolation they felt, and that there was no quality of life for a caregiver. The stigma, some told, was not only theirs as caregivers, but also very significant for the ill relative. Several families and the ill relatives kept the mental diagnosis as a secret from extended family and friends. Some were frustrated by the lack of service and help caregivers of family members with other disabilities like cancer or dementia were given compared to themselves. The caregivers were very eager to talk about the struggles with “the systems”: the health services, treatment, hospitalization, and the financial strains and oversight. The caregivers were also concerned about issues *not* taken care of by the system for their ill relative such as support to get a fit place to work and adequate housing (71). The experience and consequences of providing care to relatives with chronic mental illness are mainly focused in the adverse perspective. Veltman’s study also proved that there are many family members that emphasise the positive aspects; it seems to depend on the relatives’ appraisal of their circumstances. The caregivers were a bit surprised at first when questions about positive sides of caregiving came up, but the majority felt that the caregiving had made them stronger, more patient, and more appreciative about time spending with the family (71). The latest review confirms the caregivers’ burden experienced by family members of declined freedom to live their own life on own terms; conflicting perspectives and expectations between patient and family members. Cost of time, emotional and psychological impacts, and economy; and cost of general health quality for the family members. Three concerns matter to the experience of burden: the patient and the disorder itself with symptoms and long-term course; the caregivers’ ability to cope; and the community and the context where the caregiving takes place. Even if the role of the family is recognized useful, and even if the community-based services are gradually better organized, services for families are described as fragmented and inadequate (72).

Family Interventions by professionals

Spaniol and colleges wrote in 1992 that numerous studies have shown the dramatic difference between the professionals’ understanding of what families need and the families own perception of their needs. The professionals’ beliefs and attitudes, and their lack of appropriate help skills and knowledge often lay an extra burden of guilt on the newly traumatized families. Few families are prepared to deal with such a trauma as realizing that a

family member is seriously mentally ill. The family goes through the normal crises reaction: shock, denial, depression, anger, acceptance, coping, and affirmation as any person confronted with a traumatic illness. When families begin to accept the limitations of what can be done, they focus more on how to manage the symptoms and improve the function of their mentally ill family member. Professionals that are familiar with the families' process of crisis and loss may be a resource and can work more closely with the family at a time when they have less self blame and more assertiveness. Professionals can help families to see their experience as a natural result of a traumatic crisis, one which requires new coping and adaptation skills (73). Most studies on family intervention some decades ago used the relapse or rehospitalizing of the patient as measurement for efficacy. There were few studies that examine whether the relatives who attended the family interventions gain benefit in terms of reduction of stress or burden of care, and if, it was as a secondary aim. The study of Fallon and Pederson was the only one, out of 23 research groups, that systematically investigated the effect of family intervention on relatives' distress. They found that those relatives included in family intervention had less global burden and greater levels of coping (74). A significant consensus about critical elements of family intervention in treatment emerged in 1999 under the encouragement of the leaders of the World Schizophrenia Fellowship. A group of scientists: McFarlane and colleagues, developed the original consensus, which was then refined and ratified by clinicians, consumers, advocacies, family members, and by clinical researchers working in this field (75). In 2000 Dixon reviewed 15 studies of family interventions and concluded that the new recovery paradigm for consumers and families has underlined the importance of looking beyond relapse when assessing program efficacy. She finds the efficacy compelling, and that family education programs should be differentiated to fit parents or siblings, and that it should be implemented in the best practice guidelines as it is in PORT, although, she reveals that it is hardly used in a clinic environment (76). Families need and want education and information about coping and communication skills. They need emotional support, and to be treated as collaborators. In some cases it may even be necessary for the professionals to entice families into collaboration by acknowledging the difficulties they have experienced and apologize for the way they have been treated by the mental health services (36). It was later recognized what crucial role family had on the outcome after an acute episode of schizophrenia had occurred. The new paradigm with collaboration between the family and the mental health service have changed the perspective and the focus (47). The goals for working with families are considered twofold as McFarlane and colleagues describe:

1. "To achieve the best possible outcome for the individual with mental illness through treatment and management that involves collaboration among professionals, family, and patient.
2. To alleviate suffering among the members of the family by supporting them in their efforts to foster their loved one's recovery" (47 p 225).

A few years later, 2006, Pharoah and colleagues who's review is measuring EE, frequency of relapse, hospital admission, and compliance with medication, found that family interventions may reduce the risk of relapse and improve compliance with medication, but because of inadequate data in several of the studies they concluded that further studies are needed to give confidence to the effect of such intervention (77). There are now numerous programs and guidelines for recovery of schizophrenia involving the family. They might appear different and have diverse approach, but the main goals and principle of all family interventions are twofold: the fact that family is a valuable resource for the patient and the recovery process; and the knowledge that family members also need attention for their own needs (20, 38, 78-80).

DISCUSSION

The main purpose of this paper was, based on literature, to investigate the last century's history of the roles of the relatives of persons with psychosis or schizophrenia. This was done in the context of the current situation where relatives are considered as important resources in the treatment and recovery of the patient and that they need to be taken care of as caregivers. This is a relatively new perspective, now we know the severity of the illness and how it also engraves the surroundings. Knowledge of mental disorder has been situated, bounded to the historical, cultural, and social context. The concepts used are socially constructed categories that reflect and are connected to the conceptualization at the time (13, 14, 16). We have seen that the explanatory models for schizophrenia are not only deterrent for the treatment of the patient, but that it has a ripple effect on how the society reacts on diversity, and that it also has a great consequence for family members of the considered mentally ill person. I will first briefly describe the known roles of the relatives' through the historical view from the medical, the psychological, and the sociological perspectives of schizophrenia and treatment. Second, I will discuss how the current perspective on relatives as valuable sources for treatment and individuals in need of their own have arose through sociological perspectives, consumers movement and research, then I will finish with a few perspective of the future.

The medical, psychological and social perspectives on mental illness described in this thesis have shown the societies and the mental health professionals' different views. These perspectives are not necessarily bounded to time periods and shifting paradigms, but could rather be seen as different angles to view the phenomena of schizophrenia. The different perspectives, or angles, have through the last century in some periods run parallel at different professional sites or schools and in some periods one perspective has been predominant to the other. Even with these different perspectives the treatment or the societies' caretaking of the mentally ill patients has in superior view been fairly linear and uniformed based on the conceptualization at the time period, and based on societies need of structure and control: ill in contradictory to not ill, segregated from society inn asylums with the issue of moral treatment, and hospitalization with experimental treatment; psychopharmacological treatment as curative and deinstitutionalization in the view that "old treatment" in asylums and hospital had maintained the mental illness.

In the family burden perspective: when the patients were taken care of in the asylums and hospitals kept away from family and society, either to be raised in moral treatment or treated with physical methods, without any literature describing their situation we only can assume that the families was burdened by worry and maybe ashamed. Little information of mentally illness was exchanged except for the psychiatrists contacted the relatives at an early stage of the hospitalization to secure information (81). Later, when psychological and social perspectives of mental illness disseminated in the western world, the discussions about heritage or environment as cause of the illness arose, which again led to unintended blame of the family. First, by the psychoanalytic and psychodynamic perspectives, it was assumed that lack of fulfilling of needs in early childhood, and especially unsatisfactory quality in the relationship from the mother to the child. Then by the antipsychiatry, were the politically aspect of the patient as a sane victim of a mad family in a mad world. And further by the social aspects of normality discussion of families' dysfunctional communication style, double bind, schizophrenogenic mothers, or expressed emotion was the cause of the illness or to have negative influence on the course of the rehabilitation (82). These perspectives seemed to be interdisciplinary shared and was basis for interventions for the family. The families needed to be learned how to get out of their dysfunctional patterns and behave normal (26). Though the history of the treatment of individuals with schizophrenia and their families seems to be of an adverse character, there is to admit and to be underlined that all approaches for treatment was done with the best intentions to help the patients.

The recovery model on schizophrenia as we see today, are based on the theoretical and clinical fact that all humans have the same value and right to fulfil his life and potential in the community and research proving that former patients has recovered with the right interventions (36, 56). Still, we have the same perspectives with us. Researchers are still hunting for the brain deficit, or inherited genes to explain the illness. The genes may be a part of the vulnerability in the stress-vulnerability model as well as the environment or amount of external stressors that has impact on the psychological strength (35). The recovery model, although it is an idiom with many explanations, see the patient as a person who are carrying the illness or the vulnerability, but still be allowed to live a decent life like anyone else. It is described as the integrative model. The family members are currently also respected and treated as important actors in the recovery and as individuals with their own needs (2, 33, 62, 63). How did it change to be this way? There is probably many and complex explanations and answers to the question. A lot has happened in the world, perspectives on individuals are changed, and politics and economics have changed. Some of the elements are shown in table 2a. The biggest event or change was probably the deinstitutionalization of mentally ill which is described reasoned in the effective psychopharmacology, social economy, or idealism. Anyway, during the 1970s and 1980s the mentally ill patients moved back to the community and they often lived with their family (15, 45, 83).

The whole perspective of health and illness in general has changed: Decrease in infectious disease is mostly matched by an increase in disease caused by social and behavioural factors. This has again increased the achievement of prevention of illness and encourages and instructs people to be responsible of their own health. A lot of the medical treatment are moved from the hospitals to the community settings, the doctor-patient relation are in some degree changed to treatment by interdisciplinary expert groups, on-line and other information channels gives people more knowledge of health and illness, and there is a new consumer perspective on those in needs for support. These factors must be seen as political and sociological approaches in addition to the medical, and also explain some of the changed approaches in the mental health care system (84). After the deinstitutionalization, when it was demonstrated that the communities did not have the needed facilities for the mentally ill, many families had to take care of their ill relatives, which later was concluded as disturbance to the family life (19, 43, 45).

Enterprising mental patient advocacies grounded consumers' movements and foundations to fulfil their rights as humans as anyone else's. A main goal was to found economical possibilities to research on mental health and possibility for rehabilitation. Early

in the 1980s, especially in the US and UK, there was a rapid growth of a non-professional family self-help. Family advocacy movements were mainly initialized because of the experienced burden imposed upon them by the prevailing professional and society practice. This often led to unsupported family care-taking of impaired patients. Growing consumer movements among people with schizophrenia that had experienced recovery challenged both the traditional perspective of the course of the illness and the associated assumptions about the possibilities of people with the illness living a productive and satisfying life. Their will to fight was supported by long term studies that suggest that as much as 50% of people with schizophrenia have good outcomes. It was earlier assumed that it was unlikely that afflicted individuals could make a complete return to full functioning, or the assertion that about 20% of people with psychosis had a benign form of the illness, or were misdiagnosed in the first place, and therefore would be able to come back to the functional level they had before the episode of psychosis (33, 40, 85). The self-help groups started out with relatives of individuals with severe mental illness but were soon supported by prominent psychiatrists and other mental health professionals. These groups became very strong in encouraging brain research. In addition, being a major part in reversing any beliefs about the family being to blame for the mental illness. It should be recognized that self-help groups, not only give education, but also network support. Reduction of stigma and social alienation are other benefits of this approach. Though, families are different and this kind of program does not release pure enthusiasm, it does not fit all families in all situations (42, 86). However, the consumers' and their families' contribution and achievement may have catalysed the process to where we stand today. Not only did they fight for their human rights, respect, and a decent life, they also organized for economical constraints for research, which again opened a wider scientific perspective at mental diseases and recovery.

The cause of schizophrenia is still not discovered, and the research on this issue is vast. Optimal drug therapy remains the cornerstone of clinical management of psychotic disorders and is a psychiatrist issue. The intention of people with mental illness remain in their homes whenever possible require the community to be prepared to oblige the pragmatic needs of the individual is not seen as a psychiatrist issue. In addition to the biomedical and natural science on the illness itself, researchers from social sciences have been studying the phenomenon of schizophrenia in interaction with the environment for a few decades. That means that the hegemony of the psychiatrists to study psychiatry is repealed. Especially after the deinstitutionalisation sociologists, social workers, and mental health care professionals, other than psychiatrists, have in theory and clinical work gradually built their own

perspectives of persons with mental illness included their families' needs at home and in the community. Gubman & Tessler described in 1987 three analytic themes in studies of social sciences on families and mental illness: 1) – in a view of family interaction as a causal agent, 2) – family as agents of rehabilitation as help preventing relaps, and 3) – the family as bearers of burden (45). These total different approaches were all relevant at about the same time period, in the 1970s and 1980s. In the first two themes studies were describing the dysfunctional or skew family, and a strong assumption that families with high EE caused or at least were factors for adverse course on the schizophrenia patient i.e. (5, 6, 48). These conclusions were considered as facts for a long time and may in retrospect be seen as the strongest elements to a blaming attitude to parents and in particular the mothers. The psychodynamic explanations of mental illness were popular, but the theories lost their credibility by the lack of supporting evidence. Family therapies based on systemic dysfunction as a cause of the mental disability, did not demonstrate the clinical efficacy that was hypothesized (87, 88). Later reviews of EE studies show the controversy and criticism about the concept as i. e.: that there are a number of other relevant issues that should be considered, that there is not proven any continued linkage of the EE components in one single global variable, that even if high EE could predict relapse there still is no evidence that it causes relapse, and that it is not advisable that treatment strategies should be based on those who tend to blame relatives for the patient's continuing difficulties. Even if Brown et al could give evidence to the emotional and interactional problems in the family might precipitate relapse for the patient, they have failed to show that family factors are necessary and sufficient causes to schizophrenia (50, 89, 90). However, this research on family members' influence on the individuals with schizophrenia must be considered as a base for the reversed perspectives. New explorative phenomenological research based on the family members own descriptions of their experiences having a mentally ill relative living at home reversed the perspective: that families with a person with schizophrenia had reasons to express emotions and that EE was found in half of all families, with or without a mentally ill family member (50, 52). In the wake of the consumers' movement and the failure to prove the psychosocial perspectives by research, the biomedical perspective of schizophrenia again became the principal perspective. Studies of schizophrenia as a brain disorder or neurocognitive deficits resulted in new understanding of the family (82).

For family members to be the important collaborators and involved in the treatment of the ill relative, or as a supporters to him living his own life as described in the recovery terminology, they need knowledge and information. As the understanding of family

burden actually was explored by the expanded research of expressed emotions, the current family intervention may also be described as a refined result upon the interventions given to improve family behaviour. The systemic theory admits that the patients as a family member, like the other family members, are in interaction to each other and have a mutual influence on each others' life. This perspective is later described by the term of a new relevance of the symbolic interactional approach, where the roles of the lay people improve the quality of the treatment programmes (83). Family members in need for help and support after the deinstitutionalization is first described by Hoenig & Hamilton in 1966 (43) and is considered the main source for this perspective followed by Hatfield in 1978 (19) and further by Gubman & Tessler in 1987 as caregivers with objective and subjective burden (45). Although, during the last few years more studies are done to reveal personal costs of having a family member with schizophrenia that is most burdensome for the relatives. The relatives describe illness related issues as positive and negative symptoms, they describe lack of knowledge and information, they describe severe impact on their own life, and they describe problems with the mental health system (70-72). Even if most of the research on schizophrenia including relatives is continually focused on the benefit for the patient and measurements are relapse rate, rehospitalisation, and compliance with medication (77), there is an amount of studies on family intervention programs with intentions to help the relatives to cope with the situation available today and the research is confirming this as evidence-based treatment both for the patients' recovery and the relatives well being (2, 47, 76, 91, 92).

Along this way the relatives of persons with schizophrenia and other psychoses have moved from not be mentioned, to be viewed as cause of the illness in different ways, to be agents for bad course of the rehabilitation, and now to be considered as a main resource in the recovery process. The radical change of perspective of the relatives of individuals with schizophrenia may be a discussion of linearity in development of knowledge or paradigm shifts. The examination of the historical treatment perspectives and research in this thesis may give an impression of many perspectives or disciplines that has developed themselves and each others to find a kind of consensus for the best treatment for schizophrenia which also is described (93). In retrospect it is neither easy to overlook an explanation of paradigm shifts. According to Spaulding and colleagues, *paradigms* are sociological phenomena, in the way that they represent the collective beliefs and conventions of a community. In scientific communities, paradigms are associated with philosopher and historian Thomas Kuhn who claimed that communities generally tend to adhere to a single, dominant paradigm even while new, alternative paradigms evolve. Spaulding and colleges pursue Kuhn's argument with their

conclusion: “The new paradigms evolve in response to limitations in the explanatory or practical power of the dominant paradigm. Eventually, the value of the dominant paradigm becomes outweighed by an alternative, and the community undergoes a *paradigm shift*. New paradigms bring fundamental changes in key premises and usually an expansion of explanatory and practical power” (22 p. vi).

Table 2b continues the perspective from table 2a in today’s perspective and with open questions for the future. This can be the story of improvement on a scientific and a macro level, but there are still a lot of challenges for the individuals in the clinical setting. The paradigm shift may still not be completed. The knowledge that is available today both for the mental illness and the influence it has on the relatives must be transferred so that all stakeholders are attended to for their own individual needs, not the least of which is to prevent distress and illness for already heavy loaded relatives, an approach which also is good social economics. In combination with medication, skill training, education, and assertive community treatment, family interventions are established with evidence to reduced relapse rates, improved compliance with medication, and reduced cost of care for schizophrenia patients and their family members. Still, there is a gap between this knowledge and approaches applied in routine mental health service settings. This is described as the biggest challenge to give the best services for all involved in the illness to have their needs taken into account (2, 7-9, 94). There are described obstacles in the systems, systems which are clearly most concerned for the patient. Even if the patients have the right to the best known treatment, the majority of routine mental health programs do not include evidence-based treatment where family intervention is an essential part, and even indicating the best way to utilize limited health resources (2, 8, 94). Researchers look forward to positive changes in the clinical world which includes: investing more in research for curative treatment; research must be available to all stakeholders in the system, maybe in plain language; the need for developing a training program for the professionals letting the patient, the family, and frontline staff solve problems according to the consumers goals; and, more cooperation between grass root organizations and the health system i.e. (7-9, 93, 95-97).

Limitations of this study

The described situations in this thesis are focused on the western world. The time periods described must be and are approximate because the modifications and corrections have happened gradually and at some different timeperiods in different continents and countries. As a master thesis of health sciences, this paper has only shown the main subjects naturally

belonging to this subject area and is not complete regarding to all changes in perspectives during the time period. The system of beliefs and scientific knowledge have changed dramatically in most areas in society during the last decades, e.g. economy, politics, technology, and knowledge management, which also are great mediators for the change in the perspectives of humans, and health both physical and mental.

Table 2a. Progress on the treatment perspectives and other aspects that influenced people with schizophrenia and their families-from about 1900

Roughly Time periods	1900 -	1930 -	1950 -	1965 -	- 1980s	1990s -	2000
Schizophrenia in-							
Medical perspective	No treatment but caretaking	Experimental physical treatments			Neuroleptica	Antipsychotica and therapeutic support	
Psychological & social perspectives	Psychoanalysis			Psychodynamic	Expressed Emotions Behavioural	Cognitive approaches	Biopsychosocial treatm. Symptom-based
Sociological Science theories	Pragmatism	Functionalism	Structurism	Fenomenology	Social constructivism	Humanism	Symbolic interactionism
Evidence-based treatment	No evidence-based treatment. Treatment performed by the individual psychiatrist			Disease runs in the family? Twin-studies	Brain research... Stress-vulnerability-coping...continues	Genetic research... Evidence-based family interventions	continues...
Aim of family intervention - models	Family therapy based on treatment for parents with children with problematic behaviour				Correction of dysfunctional family patterns.		Prevent relapse, Problem-solving compliance to medication,
Society aspects	Hospitalization				Dehospitalization		Community health care Client participation..cont.
World events	WW1	WW2.	UN: Human Rights Convention				
Consumers effort		US consumers' organisation	UK consumers' organisation		New Presidents Commission...		Mental health associations around the world
Perspectiv of the family		Cause of the mental illness	Dysfunctional system		Patient stressor-Cause of patients relapse		Source of information

Table 2b. Current perspective and future possibilities

Time	2000 - 2008		Future – goals, hope, dreams or reality?
Schizophrenia in:			
Medical perspective	An integrated perspective		Better medicine
Psychological & social perspective	Still antipsychotic drugs, new versions coordinated with psychosocial interventions.		Better options to live a dignified life with
Sociological science	See the individual's needs, respect the individual's own will and motivation. Phenomenology and symbolic interactionism		surroundings that reflect self-respect
Evidence-based treatment	On bio-medical aspects as well as psychosocial interventions, research and models for social skill training or help to improve the reduced functions. Governmental guidelines		Practical Health Service uses what the scientists evidence proves as effective methods
Aim of family intervention, model	Increase information and support for family members own needs. Alleviate the caregivers negative experiences Strengthen the function of interaction in the family. Collaboration to medication		Continued psychoeducative perspective anchored in the community health service as a regular activity?
Society aspects	Empowerment Network-/Buddy-/Peer-support		Comprised as a regular citizen with regular needs and wishes fulfilled?
World wide events	Internet, More common knowledge and acceptance about mental health		De-stigmatizing?
Consumers activity	Consumers and relatives associations, and client participation	Knowledge of rights. Coping and respect in society on own terms: getting education, job, house, family and friends	
Perspective on the family	Source of information Resources for the family member Caregiver		Just like another supporting family member?

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ABSTRACT

Objective: The aims of this study was to interpret the impact of a brief psychoeducational intervention on negative appraisal of caregiving experience, positive appraisal of caregiving experience, and health and functioning in relatives of patients with psychotic disorders compared to a waiting list control.

Methods: Family members (N=68) of patients with psychosis received a six-session (a total of 15 hours), multi-family format psychoeducative intervention, - and completed an Experience of Caregiving Inventory (ECI) and COOP/WONCA (CW), which is a self reporting measure of the general state of health and functioning at the beginning, and at the end of the intervention. Those who went directly to the intervention (N=36) was used as intervention group and those who had to be on a waiting list (N=32) was used as a control group.

Results: The study revealed significant differences between the psychoeducative intervention group on the ECI subcategory “problems with services” after the intervention period compared to the change in the control group (reduction mean -0.10 v. 2.36; P= 0.043, effect size 0.062). There were no significant differences at the ECI total negative, the ECI positive subcategories, or on the C/W.

Conclusion: The findings in this study suggest that psychoeducational intervention have reduced the relatives’ negative appraisal of the mental health services, but not increased the positive appraisals of experiences or the health and functional level.

INTRODUCTION

Schizophrenia is a severe mental illness recognized as having resistant psychotic symptoms, with a lifetime prevalence of approximately 1%. The condition is disabling and causes the patient and his or her family great personal suffering and loss, and significant costs for society in terms of frequent hospitalizations and the need for long-term economic support. The onset of symptoms typically occurs in adolescence or early adulthood. Evidence-based treatment includes medical and psychosocial intervention (1-3). The restructuring of mental health services from hospitals to the community has led family members of individuals with schizophrenia to play a major role in the care of their ill relative, with a majority of the patients living in the family home (2, 4).

Studies have shown that having a family member with severe mental illness has consequences for the relatives on both a pragmatic and emotional level, which has often been described as *caregiver burden*. The definition of *objective* burden is to handle an individual's behavior due to the illness and symptoms, as well as providing emotional support, financial assistance, housing, advocacy in addition to being the case manager in cooperation with health and social services; the cumulative impact of self-blame, grief, confusion, anger, frustration, guilt and the consequences of social stigma are recognized as *subjective* burden (4-11). The strain and stress faced by the family of a psychotic person on a daily basis may be a threat to the family members own health, and a lack of knowledge or information about the illness may also lead to frustration and strain for the family (5, 16, 17). Researchers have found that family members' or caregivers' experiences are closely associated with the amount of knowledge about the illness (12), and that their appraisal of the situation may enhance their coping skills and help to moderate the level of distress and burden experienced (13, 14).

There are several recovery and rehabilitation programs with family interventions for patients and relatives of persons with schizophrenia (23-25). Research on the impact or effect of family intervention, both clinically and scientifically, has traditionally been measured with patient outcomes such as a reduction of psychotic episodes, fewer hospitalizations and an improved adherence to medication. Family intervention is now considered to be evidence-based treatment for the benefit of the recovery process for the patient and is recommended in the best treatment guidelines (1-3). On a global basis, it has often been shown as a secondary outcome that family members included in family programs have less burden and greater levels of coping (15-17). Despite these recommendations, researchers have concluded that too little has been done by mental health services to reduce

the family's burden as an equal concern in the total approach for the recovery of persons with schizophrenia, asking them to look beyond relapse when assessing program efficacy and urging professionals to learn to see the family members' own perceptions in relation to the need for intervention (18-22).

It has been highlighted that we need scientific evidence of the effect or impact for more of the treatments that are offered and we need to implement evidence-based practice in ordinary treatment (23). It is within this context that this program has been evaluated for a structured research study. To investigate if there was any impact on a brief psychoeducation intervention in a clinical setting on caregivers it was necessary to find an inventory that measured the whole with of the family members' experience. By using the cope-appraisal theory, the inventors of the Experience of Caregiving Inventory intended to overcome the limitations of measuring *burden* which has no "gold standard" for research, but does have both objective and subjective aspects as concerns. The experiencing of distress may be described as a result of the appraisal and coping strategies used, in addition to being a process that is very much dependent on the level of stress or threat and the carer's capacity for coping and social situations (20, 24, 25).

The main aim of this study was to assess the impact of psychoeducative intervention in a group format consisting of six weekly sessions in appraisal of caring for relatives of individuals with psychotic disorder. The primary measure outcome was if there were any differences measured in the relatives reported negative appraisal of experience of caregiving before and after the intervention comparing with a waiting list condition. The second aim was to examine any different change on the positive appraisal of experience of caring, and the third aim if there were any difference in the participating relatives reported health and functioning before and after the intervention.

MATERIAL AND METHODS

Design - The study was carried out as a not randomized between groups comparative pre-post design. The participants were measured pre-intervention and post-intervention (six weeks). The relatives who could not go directly in to the intervention served as waiting list controls. They were measured pre- and post a six week period before their commencement of the psychoeducative intervention.

Subjects - The subjects were participating in a six-session psychoeducative family intervention and research program during five separate periods between March 2005

and April 2009. The subjects were 68 relatives of family members of patients receiving treatment at a specialized rehabilitation unit for persons with early stage psychosis. The subjects were family members of 34 inpatients and four outpatients of this unit. The catchments area of the hospital covers a population of approximately 280,000 inhabitants. The program aims to reduce stress and enhance coping for family members. The inclusion criteria were: 1) relative to a patient who have more than eight week examination and an established psychotic condition according to ICD 10 (F20 - F29) assessed by experienced psychiatrists and psychologists, 2) age between 18 and 70 years, 3) ability to speak and understand the Norwegian language, and 4) consents to participate from both the patient and a family member. For this study, family member was defined as being those nearest as stated by the patient him/herself. The patient orally consented for the participation of each of the family members invited, with a limit of three persons per patient. Although family intervention is presented to all patients and families as a routine part of treatment, the formal introduction and invitation to the study were distributed together with the invitation and program for the psychoeducative intervention.

Procedure and Intervention - After introducing the study to the relatives, written informed consent was obtained (Appendix 2). The relatives filled in two form packages. The baseline form package were completed by the participants at the start of the intervention, contained demographic data such as gender, age, educational level, marital status, type of relationship with the patient, amount of time spent with the patient, and capacity for work/studying. The Experience of Caregiving Inventory (ECI) (24) and the COOP-WONCA Functional Assessment Charts were also given out and completed (26). The post intervention form package, containing ECI and C/W, was filled out during the first week after the last session. The relatives on the waiting list for intervention completed the baseline form package in the pre-treatment period six weeks before their participating of the psychoeducative intervention and the post form package at the start of the intervention. The subjects participated in six weekly sessions, each lasting for 2.5 hours, which were conducted by three mental health professionals with special education in the performance of family programs. Sessions 1 through 4 were mainly educational and included a 30-minute informal pause for socializing with coffee and snacks, while sessions 5 and 6 were based on a shorter educational part followed by smaller discussion groups (Table 1).

Table 1 - Content of psychoeducative intervention.

Session 1 Lectures by an experienced psychologist	Introduction to the course and presentation of the course supervisors and the participants; Lessons 1 & 2: What are psychoses? A biopsychosociological approach. Description, symptoms, attitudes, diagnosis and prognosis
Session 2 Lectures by the course supervisors and/or other mental health professionals	Lesson 3: Psychosocial approach Lesson 4: Therapeutic milieu
Session 3 Lectures by a mental health professional and a social worker	Lesson 5: Substance abuse and psychoses Lesson 6: Social and economical rights
Session 4 Lectures by a psychiatrist	Lesson 7: Medical treatment Lesson 8: Mental health legislation
Session 5 Interactional session led by two experienced psychologists and the course supervisors	Lesson 9: Family members' experiences; Participants are organized into smaller groups for sharing experiences and discussion.
Session 6 Interactional session led by two experienced psychologists and the course supervisors	Lesson 10: Coping with a relative with severe mental illness; Participants are organized into smaller groups, focusing on stress appraisal and coping.

Description of the Instruments Used for Outcome Measures - *The Experience of Caregiving Inventory (ECI)* (24) is a measure of appraisal developed within a stress-coping paradigm, which was designed as a self-report inventory in relation to the experience of caregiving for a relative with severe mental illness. The ECI consists of 52 items measuring negative experiences and 14 items measuring the positive experience of being a relative. It has 10 rationally derived subscales with good internal consistency, eight of which are negative (difficult behaviors, negative symptoms, stigma, problems with services, effects on the family, the need to provide back-up, dependency, loss) and two that are positive (rewarding personal experiences, and good aspects of the relationship). Items are rated on a five-point

Likert scale (i.e. 1= never, 2= rarely, 3= sometimes, 4= often, 5= nearly always). Higher scores on the negative sub-categories are reflecting greater severity, and higher scores on the positive sub-categories are reflecting a more positive appraisal. A total negative ECI score was calculated by adding up the negative factors. The ECI was designed to be an outcome measure for interventions aimed at promoting caregiver well-being, and the scale has valid construct, a high internal consistency and is reliable (25, 27). For the present study, a Norwegian version translated by N. A. Smedby and revised by G. E. Folden was used (Appendix 1).

COOP-WONCA Functional Assessment Charts (Dartmouth Primary Care Cooperative Information Project-World Organization of National Colleges, Academies and Academic Association of General Practitioners/Family Physicians) (28) is a self-report measure of one's general state of health and functioning over the past two weeks that is comprised of six charts. Five of the charts present different domains: Physical fitness, feelings (emotional problems), difficulty in doing daily activities, limited social activity and overall health. The sixth chart measures the experience of a change in health status. Each chart is rated on a five-point scale ranging from 1 (good functional status) to 5 (poor functional status). The scale has demonstrated acceptable levels of construct validity, reliability and sensitivity to change (42, 43), and an official Norwegian version is used in the present study (28) (Appendix 1).

Statistical Analysis - All data and analysis were conducted using the Statistical Package for the Social Sciences (SPSS), version 16 (29). To compare the intervention group and waiting list controls, a parametric test (independent t-test) was used on the continuous variables: the relative's age and scores on the Experience of Caregiving Inventory and COOP/WONCA. A non-parametric test (chi-square test) was used to compare frequencies of the following nominal variables: gender, kinship to the patient, education level, marital or cohabitant status and the amount of time spent with patient. The scores on ECI factor "stigma" were not really normally distributed, but still acceptable according to generally accepted criteria (30). A one-way between-groups analysis of covariance, ANCOVA, was conducted to compare if there were any impact in appraisal of caring or health and functioning at post- psychoeducation compared with the post waiting-list period. The independent variable was the type of group (intervention or not), and the dependent variable was ECI and C/W scores respectively post intervention and post waiting list period. Participants' ECI and C/W score pre-intervention and corresponding pre-waiting-list period were used as the covariate in this analysis.

Exclusion and Missing - Seven participants of the psychoeducative course did not provide both pre- and post-questionnaires and were excluded from the study after two reminders. The variable, “How long have you considered yourself as a relative to a person with mental illness?” had 12 (18%) missing and 5 (7%) answers with a number corresponding to the patients’ ages and were not used. Two respondents had failed to answer the questions on one page of the paper questionnaire, although different pages. Except for one variable with three missing, there was one or two randomly missing, which was filled in with the mean for the variable as was done for the variables on the two pages that had not been answered.

Ethical Issues - Ethics approval was obtained from The Regional Medical Research Ethics Committee, Central Norway, and the Norwegian Social Science Data service (NSD) in order to do the research (Appendices 3 and 4). The subjects were informed about the purpose of the study and about the fact that the register and analysis would not imply any consequences for them. The data for the study was treated both anonymously and confidentially. The present study is practice-close research and the researcher has a close relationship to the family intervention program and to the current ward. It was therefore important to bear in mind that neither the patients nor the relatives were forced to participate, and were assured that they would have the same quality of treatment if they refused.

RESULTS

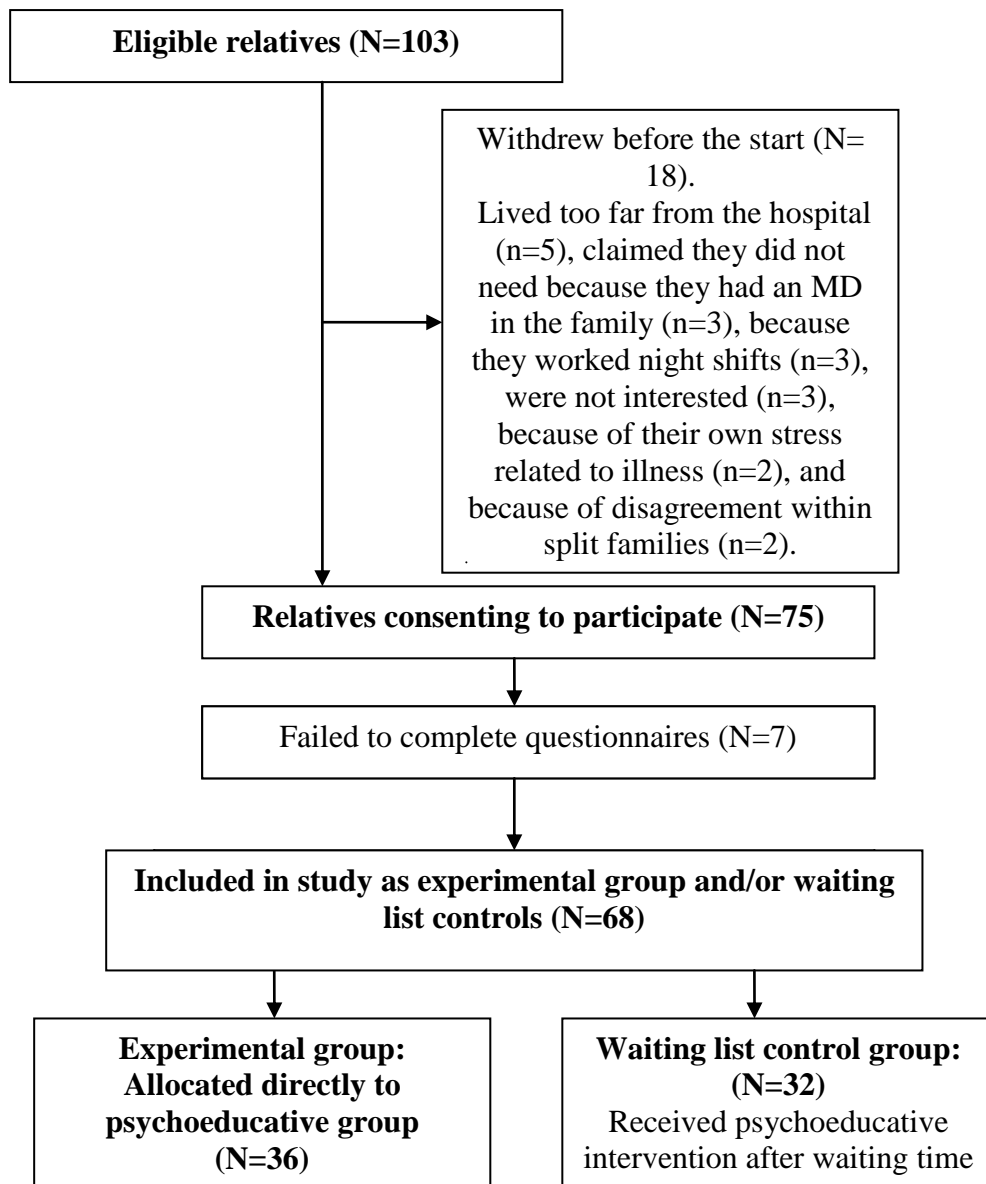


Figure 1. Flowchart of the participants

One hundred and three family members of patients were eligible and 68 were included. 36 went directly to intervention. The relatives were allocated to intervention group or waiting list depending on hospitalization time according to time of year the next psychoeducative intervention was to be arranged. Thirty-two relatives had to be on a waiting list before their commencement to the next groups coming up and were included to the study as waiting list controls. During waiting list period the patients and relatives received treatment

as usual. Treatment as usual for the relatives includes that the patient is encouraged to invite the family members to get involved in treatment with their knowledge and personal support. They are invited to visit the ward, to participate in meetings and treatment planning, and they are invited to personal conversations with the mental health professionals about their own experiences. The patient's leave for weekends are always discussed with the family: in forehand to create and agree for content of the leave and strategies for retreat to the ward, and afterwards to discuss the experiences. A total of 68 relatives of 38 patients, with a mean age of 23 years (SD±4), were included in the study according to the inclusion criteria (Figure 1) and were represented by 29 (42.6%) mothers, 14 (20.6%) fathers, 14 (20.6%) siblings, four (5.9%) spouses and seven (10.3%) others, including three grandparents, three stepparents and one aunt. At baseline the groups did not differ in the demographic issues or the baseline scores on ECI nor C/W. Other characteristics of the participants in the intervention group and the waiting control group are shown in Table 2.

Table 2. Demographic data of participants and baseline/ -pre treatment scores

Characteristics	Waiting list control baseline N=32	Intervention group baseline N=36	Total N=68	P-values
Age, mean (SD)	45.88 (±12.94)	45.36(±12.78)	45.6 (±12.8)	.870
Gender, no^a (%)				
Female	23 (71.9)	22 (61.1)	45 (66.2)	.349
Relationship, no (%)^a				
Parents	21 (65.7)	22 (61.1)	43 (63.2)	.700
Education level, no (%)^a				
College or university degree	15 (46.9)	16 (44.4)	31 (45.6)	.841
Marital status, no (%)^a				
Married or cohabiting	24 (75.0)	26 (72.2)	50 (73.5)	.796
Time with patient, no (%)^a				
Together once or more per week	14 (43.8)	16 (44.4)	30 (44.1)	.954
ECI total negative, mean (SD)	149.72 (±25.83)	141.47 (±33.92)	145.35 (±30.45)	.268
Coop/Wonca total, mean (SD)	14.13 (±3.94)	13.06 (±3.66)	13.55 (±3.80)	.250

^a Pearson Chi-square

After adjusting for pre- intervention/pre-waiting list scores, there was a significant difference between the two groups on post-intervention scores on the Experience of Caregiving Inventory (ECI) subcategory “problems with services”, (mean change -.10 v. 2.36; P= 0.043, effect size 0.062). This factor included eight items: how mental health professionals do not take you seriously, dealing with psychiatrists, how to deal with the mental health

professionals, how health professionals do not understand your situation, how to make complaints about his care, finding out how hospitals or mental health services work, doctors knowledge of service available, and difficulty getting information about his illness. There were no significant differences on any other ECI negative subcategory, in the total negative ECI scores, in the positive ECI subcategories, or the COOP/WONCA as shown in Table 3.

Table 3. ANCOVA results with mean and standard deviation of the groups

Instruments/ Factors (possible score range)	Waiting list				Psychoeducative intervention			
	Pre		Post		Pre		Post	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
ECI-total negative (66-330)	149.72	(25.84)	144.84	(28.64)	141.47	(33.92)	134.42	(28.93)
Difficult behaviour (8-40)	24.31	(4.86)	22.28	(5.75)	21.03	(6.81)	19.39	(6.12)
Negative symptoms (6-30)	18.63	(5.14)	19.22	(5.60)	18.19	(5.54)	17.97	(4.68)
Stigma (5-25)	11.84	(3.72)	11.09	(3.85)	10.50	(4.55)	10.56	(3.51)
Problems with services (8-40)	19.53	(6.24)	19.63	(5.88)	20.39	(6.88)	18.03	(5.88)*
Effects on family (7-35)	18.91	(5.00)	18.06	(4.82)	16.69	(5.82)	17.00	(4.93)
Need to back up (6-30)	18.88	(4.79)	18.44	(4.10)	17.00	(4.99)	16.08	(4.49)
Dependency (5-25)	16.28	(4.20)	15.78	(3.80)	15.72	(3.60)	14.58	(3.51)
Loss (7-35)	21.34	(4.24)	20.81	(4.94)	21.94	(4.99)	20.81	(4.96)
Positive experiences (8-40)	27.25	(6.03)	27.40	(5.68)	27.31	(5.82)	26.44	(5.43)
Good aspects (6-30)	20.25	(3.76)	20.31	(4.11)	19.67	(3.46)	19.83	(3.58)
CW-total (6-30)	14.13	(3.94)	13.69	(3.86)	13.06	(3.66)	13.33	(4.18)

*P < .05

DISCUSSION

The present study was conducted to evaluate the impact of a six-session family education program for relatives' appraisals of the experience of caring for a family member with psychosis compared to a waiting list control group. Of the eligible relatives 75 % consented to participate in the psychoeducative intervention and 70 % completed the survey. Significant positive change was demonstrated in the psychoeducative intervention group compared to the waiting list control group on Experience of Caregiving Inventory (ECI) subcategory "problems with services". There were no significant change for the psychoeducative intervention group compared with the control group on the total negative ECI, other negative or positive ECI subcategories, or the self-reported health and functioning on the COOP/WONCA.

The participation rate in this study was high as also was experienced by other researchers studying relatives of first episode psychosis patients (14, 31). This is in contrast to what is reported elsewhere in studies including relatives to patients with schizophrenia (32-34). This may be explained by the findings that relatives are more burdened at first episode psychosis, if the patient is young, or have short illness duration (4, 14, 20, 35). No other

studies are found that explicit describes and discuss that psychoeducational intervention for relatives by professionals decreases the relatives' negative appraisal of experiences of "problems with the services" as I have found in this study. Although Addington and colleagues discuss the overall reduction in levels of distress in a three year study, their results shows that ECI subcategory "problems with services" have significant improvement over time (14). Two studies of family-to-family 12 week programs confirm possibility to influence the relatives' knowledge about the illness and of the mental health services (36, 37). Magliano found significant increase in relatives' perception of professional support in an intervention group compared to a control group in a controlled trial (38). The amount of burden for the relatives in this study was in line with, or higher compared with the findings of Addington and colleagues (14). There is presumable room for improvement in the relatives' experience of the mental health system. Previous studies of caregivers adverse appraisals of experience have shown the burden caused directly by the illness: the patients symptomatology and frightening behaviour (4); and by the impact on the patient himself: lack of employment, lost ability to perform expected roles, or want of social life (4, 39). It is also experienced that relatives appraisal not necessarily are predicted by the patients symptomatology but by the impact of the illness on their own life which sometimes may be experienced of bigger strain than the illness itself: Stigma and problems with services or "the system" in general are reported, and there are described more specific experiences as lack of information, lack of understanding from the professionals, lack of respect and not being taken seriously, or lack of willingness from the professionals to include the family in treatment as collaborators (8, 14, 40-42). Patients have also reported low satisfaction with the services cooperation with their relatives (43). Research has confirmed that relatives are in need for information and support. There is consensus about family interventions as evidence-based treatment should be integrated in all treatment for psychosis or schizophrenia both as the best treatment for the patient and for the relatives well being. There are studies of effect or impact of family interventions that have outcome results showing how families have less distress, better quality of life or better general well being after participated in such (2, 12, 44). The improvement in the appraisal of the relation to the services could be interpreted in the light of Lazarus & Folkmans' stress-coping theory. This theory postulates that stress is a relationship between the person and the environment, and that it is how people handle demanding situations through two levels of appraisal that ensues stress or not. The stress-coping theory through appraisal includes a cognitive and emotional perspective on efforts to manage external or internal conflicts as a dynamic process. The goal of the stress-coping theory is: by strengthen

the mediating factors, the secondary appraisal process or state, and cognitive adaptation will decrease the experience of difficult situations or stressors. (45). In the opposite it is shown that relatives' with passive coping including: avoidance, resignation, and self blame is associated with increased burden (46). It is both pragmatic and inter-human more comfortable to cope with something and someone one are familiar to than to something or somebody one know nothing about. It is understandable to experience fewer problems with someone that invites you, respects you as a collaborator, gives you knowledge, and tries to understand and help out with your needs than with someone that ignores you and even excludes you from your relative's treatment. If the relatives' sense acceptance, are taken seriously, get knowledge of the illness and the mental health service systems, and meet others in similar situations, this can function as mediators for the distress (47). Lack of control and mastery are according to Noh & Turner powerful predictors of distress among family members. Perception of control and mastery are not fixed but develops as the individual attempts to master the surroundings (48). It is also confirmed in general caregiving literature that to get proper information, to be involved in decisions, to feel that there are someone to contact when its needed, and be assured they are doing the right thing improves coping strategies (49, 50). The improvement after psychoeducation demonstrated in this study on the ECI subscale, "problems with services," could also be explained as a benefit of new knowledge, by the content of the education served on pragmatic topics. The affirmation given during the psychoeducation that independent of the family as caregivers the patient will always have a broad spectrum of professional follow-up if needed, and that he or she has legal rights from both the health services according to treatment, care, and follow-up, and from the social services according to housing, economic support, adapted education or employment.

There may be several explanations for the failure to show significant improvements for the other aspects of a negative appraisal of the experience. From a time perspective, one reason could be that the distress and problems in the family have probably been in this state for a long time, maybe years, and that it should not be expected that a brief education program could change such a state of negative experiences and worries. Addington and colleagues have results from a longitudinal study which say that the more severe the distress, the longer it takes to improve the level of distress (14). Cuijpers claims to be fairly safe to conclude that interventions with less than ten sessions have no important effect on relatives burden (51). That some appraisal may change in a brief intervention Merinder and Pekkala have shown, they saw a good trend in the results of an eight-week family educational program for patients with schizophrenia and their relatives when focused and measured

relatives' knowledge and satisfaction with their involvement (52, 53), which is not as personal and emotionally loaded as the more predominant issues in this study. From a methodological perspective, Szmukler and colleagues are raising a question about what could be the most appropriate measures for an evaluation of carers' intervention, though we must bear in mind that carers are not patients and that the psychological morbidity may not be appropriate (24). Even if ECI measures the carers' appraisal, and given the chronicity of caring difficulties, it may be quite unrealistic to expect much change in caregivers' distress even if the interventions intention is to meet the carers' needs (32). Another reason could be that an inventory used were not sensitive enough to measure change as claimed by Leal and colleagues (54). A different perspective of why the appraisal of the negative experience is not modified could be in a the theoretical philosophical perspective, such as in the stress-coping theory of Lazarus & Folkman in a contrary way: If the relatives realized during the intervention what a serious impact the psychosis or schizophrenia has on the patient and on their entire family's life: the new information has brought in new and different reasons for distress. Coping seen as a complex process may have turned from problem-focused strategies of avoiding threats (the fear of serious illness in their child), to emotional strategies for achieving mastery of the new situation (45, 55, 56). The lack of effect on the reported health and function in the C/W scale could also be attributed to a scale insensitive to change. Kinnersly and colleagues tested consulting patients to primary care compared with a comparable non-consulting control group on the C/W. They found no change in reported health and functioning over two weeks in the non-consulting group (57). We must again bear in mind that our participants are not patients and there is no comparable data about an equivalent samples' reported health and functioning without having a relative with mental illness. A last and plausible reason for no significant overall effect being found on either an ECI or C/W in the intervention group compared to the control is that this psychoeducative intervention is only one of several approaches to the relatives included in ordinary treatment at this particular hospital ward. This could also be a methodological confounder in the study. Conclusions made in reviews of studies with similar topics are that this field struggles with a lot of methodological problems and that the lack of an existing framework for such research yields an implicit inconsistency (21, 58, 59).

However, it is stated through consensus that family interventions is considered evidence-based treatment to reduce relapse and rehospitalisation for the patient, that compliance of medication are increased when family members are involved, and it is also stated that relatives have reduced negative appraisal in the experience of caring when they are

involved in the treatment through family interventions (2, 14, 17, 18, 60, 61). Still, there is a gap between this knowledge and approaches applied in routine mental health services where there is and under utilization of family interventions (23, 61-63). To be able to collaborate in the treatment and recovery process it is important for mental health consumers and their relatives' to get knowledge of mental illness, the mental health services, the legislation, and their rights. "The services" should be considered as services, and not sources for distress and burden. Although this is a small study, the result that showed relatives' decreased problems with services after participating in brief inexpensive psychoeducative interventions should be replicated in larger randomized studies or qualitative examinations of the caregivers' general experiences.

Limitations of This Study

Accurate assessment of experience of caring for an individual with severe mental illness may be problematic. In the current study it was important to have reliable quantitative self-report measures of both negative and positive experience of caring (24). The use of self-reporting inventories to measure peoples experiences are discussed in the context of subjectivity. A study in a clinical setting creates several challenges: in this study it was difficult to isolate the impact of one approach among a wide spectrum of attention and approaches that is offered to the relatives in the same time period, especially when the control group received the same ordinary approaches in the waiting period; only one psychoeducative family intervention group was carried out per year, meaning that some patients were newly hospitalized while others were discharged and that the family members were therefore in a different state according to the crisis level (47); there was no way to randomize the relatives to allocate as participants or control group; the relatives' were familiar to the researcher's close relationship to both clinical work in the same ward and the psychoeducational program and could bring in a bias. There was no distinction between family members if they had more or less responsibility for the patient or could be called key carer. The small sample in this study did not allow examination of subgroups. Caregivers are homogenous in terms of what they report with regard to different appraisals and different needs in their situation. In a review of research on caregiver burden, Baronet addresses future researchers about the importance of giving attention to the diversity among subgroups of caregivers when analyzing their different needs (58). Although we have not been able to show any significant impact on the relatives' overall negative appraisals, positive appraisals, or health and functioning after the intervention in this study, it would be a risk of type two errors to conclude that

psychoeducative intervention for relatives has no significant impact on the aspects of caregiving without randomized studies with larger samples.

Implications for practice

Most of the participants in this study were relatives with a first time experience with the mental health services. For relatives to experience active support from the professionals early in the treatment process may increase the capability to collaborate in the further process which is for the better for the patient's recovery process and for their own well being. The difference between the intervention group and the waiting list controls may indicate that a brief intervention must be offered as soon as possible after the hospitalization. To have the knowledge that the professionals are taking care of their ill family member may also give the relatives an appraisal of being seen, heard and paid attention to as persons with their own needs which are aspects that may strengthen the coping strategy and give a sense of mastery and control. Additionally, we must bear in mind during the hospitalization and intervention that the relatives may be in a state of negative appraisal in regard to their severe situation, and we should include this as a topic while we are cooperating with them during the treatment. It would probably be a benefit to both the patient and the family members if a brief intervention at the first hospitalization could be offered in a combination with long term intervention such as Multifamily Group Treatment in a rehabilitation period if necessary.

CONCLUSION

This study has shown significant difference between the intervention group and the control group in decreased negative appraisal of experiences of the services. No significant results are found on other negative or positive appraisals of experiences or the health and functioning. Because of the described limitations, we cannot draw definite conclusions about the effectiveness of this intervention.

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SPØRRESKJEMA OM DIN ERFARING MED OMSORG

.....

De følgende sider inneholder en rekke påstander som ofte passer for mennesker som har omsorg for et familiemedlem eller venn som har en alvorlig psykisk lidelse.

Vi vil at du skal lese hver påstand og bestemme deg for hvor ofte dette har angått/ passet for deg siste måned.

Det er viktig å merke seg at det ikke er noe riktig eller galt svar. Det er også en erfaring at det ikke lønner seg å bruke for lang tid på en påstand. Ofte er det din første reaksjon som gir det beste svaret.

Selv om det er mange påstander, vil du se at det ikke tar så lang tid å svare på hvert enkelt spørsmål.

Experience of Caregiving Inventory (ECI) 1994
G. Smuckler, P. Burgess, H. Herman, A. Benson, S. Coulsa and S. Bloch
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Pårørendes erfaring med omsorg

I LØPET AV SISTE MÅNED, HVOR OFTE HAR DU TENKT:						
		Aldri	Sjelden	Av og til	Ofte	Nesten hele tiden
1. 3	at du skulle dekke over at han/hun er syk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. 3	at du har følt det umulig å fortelle andre om sykdommen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. 6	at han/hun har vanskeligheter med å holde orden på egen økonomi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. 6	at du må støtte ham/henne	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. 8	på hva slags liv han/hun kunne hatt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. 8	på faren for at han/hun skal ta livet sitt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. 9	at du har lært mer om deg selv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. 9	at du har bidratt til andres forståelse av sykdommen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. 7	at du har vært ute av stand til å gjøre de ting du kunne ha lyst til	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. 4	på hvordan helsepersonell forstår deg og din situasjon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. 7	på hans/hennes avhengighet av deg	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. 7	at du hjelper ham/henne å fylle dagen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. 10	at du har bidratt til hans/hennes velvære	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. 10	at han/hun yter et verdifullt bidrag til husholdningen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I LØPET AV SISTE MÅNED, HVOR OFTE HAR DU TENKT:						
		Aldri	Sjelden	Av og til	ofte	Nesten Hele tiden
15. 6	på effekten det vil ha på din økonomi hvis han/hun blir dårligere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. 4	på at du må forholde deg til psykiater	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. 7	at han/hun alltid er bak i tankene dine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. 8	at du kanskje gjorde noe som gjorde ham/henne syk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. 10	at han/hun har vist styrke i hvordan han/hun takler sykdommen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. 9	at du har blitt mer trygg på å forholde deg til andre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. 5	på hvordan andre familiemedlemmer ikke forstar din situasjon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. 10	at han/hun er godt selskap	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. 9	at du har blitt mer forståelsesfull til andres problemer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. 8	på hvordan han/hun tenker mye på døden	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. 8	på hans/hennes tapte muligheter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. 4	på hvordan forholde seg til psykiatrisk helsepersonell	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. 3	at du føler deg ikke i stand til å ha besøk hjemme	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. 5	på hvordan han/hun kommer overens med andre familiemedlemmer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. 6	at du bakker ham/henne opp når han/hun går tom for penger	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. 5	på hvordan andre familiemedlemmer ikke forstår hans/hennes sykdom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. 8	på hvordan han/hun med vilje prøver å skade seg selv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I LØPET AV SISTE MÅNED, HVOR OFTE HAR DU TENKT:						
		Aldri	Sjelden	Av og til	ofte	Nesten Hele tiden
9	32. at du har kommet nærmere noen i familien	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	33. at du har kommet nærmere vennene dine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	34. at du deler noen av hans/hennes interesser	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	35. at du føler deg nyttig i ditt forhold til ham/henne	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	36. på hvordan helsepersonalet ikke forstår din situasjon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	37. på om han/hun noen gang kommer til å bli bra	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	38. på det skamfulle ved å ha en i familien med psykisk lidelse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	39. på hvordan få forklart hans/hennes sykdom til andre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	40. at andre forlater hjemmet pga. virkningen av sykdommen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	41. på å hjelpe ham/henne til å få et sted å bo	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	42. på hvordan få klaget over behandlingen og omsorgen han/hun får	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	43. at du har møtt hjelpsomme personer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	44. at du har oppdaget styrke ved deg selv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	45. har du følt at du ikke har kunnet la ham/henne være alene hjemme	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	46. på effekten av sykdommen på barna i familien	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	47. at sykdommen resulterer i at familien har blitt splittet opp	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	I LØPET AV SISTE MÅNED, HVOR OFTE HAR DU TENKT:					
		Aldri	Sjelden	Av og til	ofte	Nesten Hele tiden
2	48. at han/hun har kommet i dårlig selskap	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	49. på hvordan hans/hennes sykdom virker inn på spesielle familiebegivenheter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	50. på å finne ut hvordan sykehus og det psykiatriske hjelpeapparat fungerer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	51. på legers kunnskap om de tjenestene som er tilgjengelige for familier	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	52. på at det er vanskelig å få informasjon om hans/hennes sykdom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	53. på ham/henne som svingende i humøret	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	54. på ham/henne som uforutsigbar og upredikerbar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	55. på ham/henne som tilbaketrukket	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	56. på ham/henne som taus og ikke interessert i å snakke med andre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	57. på ham/henne som ikke interessert	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	58. på ham/henne som langsom i å gjøre ting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	59. på at han/henne ikke er til å stole på når noe skal gjøres	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	60. på ham/henne som ubesluttsom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	61. på ham/henne som irritabel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	62. på ham/henne som lite hensynsfull	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	63. på ham/henne som en med uansvarlig oppførsel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I LØPET AV SISTE MÅNED, HVOR OFTE HAR DU TENKT:						
		Aldri	Sjelden	Av og til	ofte	Nesten Hele tiden
64.	på ham/henne som mistenksom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
65.	på ham/henne som en med skjemmende utseende	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
66.	på ham/henne som en som oppfører seg på en underlig måte	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
67.	på ham/henne som en som misbruker alkohol/medikamenter/stoff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
68.	på ham/henne som en med truende/voldelig atferd	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
69.	på at han/hun er plaget av merkelige/uvanlige tanker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Pårørendes løpenr: _____ Kjønn:----- kvinne
 ----- mann
 Type pårørende: _____

PÅRØRENDESKJEMA

Funksjonsmåling (COOP/WONCA)






Norsk bearbeidelse: Prof. B.G. Bentsen
 Institutt for allmennmedisin og samfunnsmedisinske fag, Universitetet i Oslo

I forbindelse med evaluering av våre kurs for pårørende, ønsker vi også å se på hvordan du vurderer egen helsetilstand. Vi ber deg derfor om å svare på de seks spørsmålene fra A til F nedenfor.

Du ser seks skjema som har som mål å angi din fysiske, psykiske og sosiale tilstand. Skjemaene besvares ved på hvert skjema å slå en ring rundt det tallet som best beskriver din nåværende situasjon.






A. FYSISK FORM

De siste 2 uker...
 Hva var den tyngste fysiske belastningen du greide/kunne greid i minst to minutter?

MEGET TUNGT (f.eks.) Løpe fort		1
TUNGT (f.eks.) jogge i rolig tempo		2
MODERAT (f.eks.) Gå i raskt tempo		3
LETT (f.eks.) Gå i vanlig tempo		4
MEGET LETT (f.eks.) Gå sakte - eller kan ikke gå		5






B. FØLESEMESSIG PROBLEM

De siste 2 uker...
 Hvor mye har du vært plaget av psykiske problemer som indre uro, angst, nedforhet eller irritabilitet?

Ikke i det hele tatt		1
Bare litt		2
Til en viss grad		3
En god del		4
Svært mye		5






C. DAGLIGE AKTIVITETER

De siste 2 uker...
Har du hatt vansker med å utføre vanlige gjøremål eller oppgaver enten innendørs eller utendørs, p.g.a. din fysiske eller psykiske helse?

Ikke vansker i det hele tatt		1
Bare lette vansker		2
Til en viss grad		3
En god del vansker		4
Har ikke greid noe		5






D. SOSIALE AKTIVITETER

De siste 2 uker...
Har din fysiske eller psykiske helse begrenset dine sosiale aktiviteter og kontakt med familie, venner, naboer eller andre?

Ikke i det hele tatt		1
Bare litt		2
Til en viss grad		3
Ganske mye		4
I svært stor grad		5






E. BEDRE ELLER DÅRLIGERE HELSE

Hvorledes vil du bedømme helsen din idag, fysisk og psykisk, sammenlignet med for 2 uker siden?

Mye bedre		1
Litt bedre		2
Omtrent uforandret		3
Litt værre		4
Mye værre		5

F. SAMLET HELSETILSTAND

De siste 2 uker...
Hvorledes vil du vurdere din egen helse, fysisk og psykisk i allminnlighet?

Svært god		1
God		2
Verken god eller dårlig		3
Dårlig		4
Meget dårlig		5

Dartmouth COOP Functional Assessment Charts/WONCA Copyright. Dartmouth COOP Project 1995.
Flere skjema kan fås ved henvendelse til Glaxo Wellcome AS, PB 4312 Torshov, 0402 OSLO, tlf. 22 58 20 00

Kjønn: _____ Alder: _____

GENERELL INFORMASJON:

Sett ring rundt det som passer (kun en ring):

1. Sivilstatus (kun en ring)

1. Gift, varighet: _____ (antall år)
 2. Samboer > 1 år: _____ (antall år)
 3. Enslig _____ (antall år)
 4. Skilt _____ (antall år)
 5. Separert
 6. Enke/ enkemann _____ (antall år)
- Barn:
7. Hvor mange egne barn har du? _____
 8. Hvor mange barn under 18 år bor sammen med deg? _____

2. Trygdeforhold (kun en ring)

1. I arbeid
2. Attføring
3. Ufør
4. Alderspensjonist
5. Selvstendig næringsdrivende
6. Skoleelev
7. Militæret
8. Annet (vennligst spesifiser): _____

3. Nåværende bosituasjon (kun en ring)

1. Bor sammen med ektefelle/ samboer
2. Bor som aleneforelder med barn
3. Bor alene eller i bofellesskap (eks. studenthjem, hybler i leilighetskompleks)
4. Bor hjemme hos foreldre eller andre slektninger
5. Uten fast bopel
6. Annet (vennligst spesifiser): _____

4. Høyeste fullførte utdanning (kun en ring)

1. Folkeskole/ ungdomsskole
2. Noe videregående
3. Videregående eller annen utdanning ut over videregående
4. Yrkesmessig utdanning
5. Høyskole, universitet eller teknisk skole tilsvarende 2 års utdanning
6. Høyskole eller universitet tilsvarende 4 års utdanning
7. Annet (vennligst spesifiser): _____

Fortsetter neste side

Sett ring rundt det som passer:

5. Nåværende yrkesmessig fungering (kun en ring)

1. Fulltidsarbeid
2. Fulltidsarbeid som hjemmeværende
3. Deltidsarbeidende
4. Skole/ studier i heltid
5. Skole/ studier i deltid
6. Arbeidsløs, men har arbeidsevne
7. Attføring eller rehabilitering
8. Vernet arbeid
9. Ute av stand til å arbeide
10. Pensjonert/ førtidspensjonert
11. Annet (vennligst spesifiser): _____

6. I hvilken grad begrenses din nåværende arbeidsevne av rollen som pårørende? (kun en ring)

0. Ingen begrensning
1. Lett
2. Moderat
3. Uttalt
4. I svært høy grad

7. Hvor ofte er du sammen med den du er pårørende til? (kun en ring)

1. Vi bor sammen og treffes flere timer hver dag
2. Vi bor ikke sammen, men treffes hver dag
3. Flere ganger og flere timer hver uke
4. En gang hver uke
5. Sjeldnere enn en gang hver uke
6. Nesten aldri
7. Annet (vennligst spesifiser): _____

8. Hvilken type pårørende er du? (kun en ring)

1. Mor
2. Far
3. Ektefelle/ samboer
4. Søsken
5. Voksnet barn (over 18 år)
6. Annen (vennligst spesifiser): _____

9. Hvordan har du tilegnet deg kunnskap om den psykiske lidelsen? (sett flere ringer ved behov)

1. Jeg har deltatt på kurs på for pårørende
2. Jeg har fått informasjon/ brosjyrer fra avdelingen
3. Jeg har lest på egen hånd
4. Jeg har snakket med venner/ familie
5. Jeg har snakket med andre pårørende
6. Jeg har lite kunnskap om den psykiske lidelsen
7. Jeg har ingen kunnskaper om den psykiske lidelsen

10. Hvor lenge vil du beskrive deg som pårørende til et menneske med psykisk lidelse?

Antall år: _____

Appendix 2 Consent Form

"Evaluering av pårørendekurs"

Forespørsel om deltakelse i vitenskapelig undersøkelse

Bakgrunnen for prosjektet er et ønske om å øke kvaliteten på kurset og å bedre vår kunnskap om pårørendes egne erfaringer og behov. Vi ønsker å undersøke dette med vitenskapelige anerkjente metoder. Ved å ha fokus på pårørenderollen håper vi å **bedre samarbeidet** mellom pårørende til alvorlig psykisk syke og helsepersonell i psykiatrien. Det er derfor viktig at du deltar i undersøkelsen.

Innsamling av opplysninger vil foregå ved at du svarer på spørsmålene i vedlagte spørreskjema (før kursstart) og i et spørreskjema etter kurslutt. Det handler om generelle spørsmål om hver enkelt deltaker, vurdering av egen helsetilstand og erfaringer med pårørenderollen. Etter kurslutt vil det i tillegg bli spørsmål knyttet til innholdet og omfanget av de ulike kurstemaene. Undersøkelsen inkluderer pårørende til pasienter ved post 3 og Spesialpoliklinikkens Team for nysyke med psykoseproblematikk.

Svarene behandles konfidensielt og oppbevares i godkjente arkiv. Prosjektslutt er satt til utgangen av 2009, hvoretter alle personopplysninger vil bli slettet. Det er frivillig å delta og du kan trekke deg fra undersøkelsen når du måtte ønske det. Det vil ikke få noen negative konsekvenser å ikke delta i undersøkelsen. Erfaringene fra arbeidet vårt vil bli forsøkt utgitt i internasjonale tidsskrifter. Opplysninger som kommer fram vil ikke kunne føres tilbake til enkeltpersoner.

Prosjektet blir ledet av Olav Linaker; Professor, Dr.med. Medarbeidere i prosjektet er: Berit Walla; prosjektkoordinator, spesialergoterapeut, Ingvill Gjelvold; prosjektmedarbeider, miljøterapeut med videreutdanning og Magny Sjøset; prosjektmedarbeider og psykiatrisk sykepleier.

Kontaktpersoner for eventuelle spørsmål:
Berit Walla eller Magny Sjøset - Post 3, Tlf: 73 86 46 90

Prosjektet er godkjent av Regional komité for medisinsk forskningsetikk (REK), Region Midt-Norge og Personverneombudet for forskning ved Norsk Samfunnsvitenskapelig datatjeneste (NSD). Helse Midt-Norge RHF har gitt økonomisk støtte til gjennomføring av prosjektet.

TAKK FOR HJELPA!

Med vennlig hilsen



Olav Linaker
Professor, Dr. med.
Det medisinske fakultet,
Institutt for nevromedisin

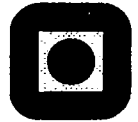
Samtykke-erklæring

Jeg har lest det som står ovenfor og har hatt mulighet til å stille spørsmål. Jeg er villig til å delta i denne undersøkelsen.

Sted/dato:

Underskrift:

Appendix 3 Approval from the Regional Committee for Medical Research



Professor Olav Morten Linaker

AFFU STPS Psykiatrisk institutt NTNU	
- 7 MARS 2005	
Jnr. _____	_____
Kopi _____	_____

Saksbehandler
Rådgiver Arild Hals
Telefon 73 86 7152
Fax 73 86 72 89
Epost: arild.hals@ntnu.no
rek-4@ntnu.no
Postadresse: St.OlavsHospital
Universitetssykehuset Trondheim
Kreftbygget 5. etg.
7006 Trondheim

Vår dato: 01.03.05 Vår ref.: 4.2005.389 Deres dato: Deres ref.:

Evaluering av psykoedukativt kurs for pårørende til personer med alvorlig psykisk lidelse.

Komiteen vurderte prosjektet i sitt møte 18. februar 2005 med følgende merknader og tilråding:

Hensikten med studien er å se om nære familiemedlemmer av personer med alvorlig psykisk lidelse vil ha nytte og utbytte av å delta i et slikt kurs. Det vil bli gjennomført 4 kurs, to for pårørende til nysyke og to for pårørende som har familiemedlemmer som allerede har blitt diagnostisert og behandlet. Som kontrollgruppe blir brukt pårørende til pasienter som står på venteliste. Det vil bli tatt inn 15 personer i hvert kurs til sammen 60 i de fire kursene.

Komiteen har følgende merknader til prosjektet:

- Komiteen viser til prosjektprotokoll og har ingen særlige merknader til målsetting eller plan for gjennomføring.
- Komiteen viser til informasjonsskrivene. De er identiske så langt komiteen kan se, og en ber om at prosjektleder gjennomgår disse og evt korrigerer skrivene slik at de gir korrekt informasjon til de aktuelle gruppene.
- ✓ Det korrekte navnet på komiteen er Regional komite for medisinsk forskningsetikk, Region Midt-Norge.
- ✓ Informasjonsskrivene må underskrives av prosjektleder, alle andre som deltar i prosjektet skal presenters i selve skrivet.

Komiteen ber om å få tilsendt artikkel/rapport når studien er fullført.

Tilråding:

"Komiteen godkjenner at prosjektet gjennomføres med de merknader som er gitt."

Vi viser til dette og ønsker lykke til med prosjektet.

Med hilsen



Arne Sandvik

Professor

Leder i komiteen



Arild Hals

Rådgiver

Sekretær i komiteen



Ingvill Gjelvold
Avd. Østmarka
Divisjon psykisk helsevern
St. Olavs Hospital HF
Østmarkvein 15
7040 TRONDHEIM

Vår dato: 09.03.2005

Vår ref: 200500302 PB /RH

Deres dato:

Deres ref:

KVITTERING FRA PERSONVERNOMBUDET

Vi viser til melding om behandling av personopplysninger, mottatt 10.02.2005. Meldingen gjelder prosjektet:

12287	<i>Evaluering av psykoedukative kurs for pårørende til personer med alvorlig psykisk lidelse</i>
<i>Behandlingsansvarlig</i>	<i>St. Olavs Hospital HF, ved institusjonens øverste leder</i>
<i>Daglig ansvarlig</i>	<i>Ingvill Gjelvold</i>

Norsk samfunnsvitenskapelig datatjeneste AS er utpekt som personvernombud av St. Olavs Hospital HF, jf. personopplysningsforskriften § 7-12. Ordningen innebærer at meldeplikten til Datatilsynet er erstattet av meldeplikt til personvernombudet.

Personvernombudets vurdering

Etter gjennomgang av meldeskjema og dokumentasjon finner personvernombudet at behandlingen av personopplysningene vil være regulert av § 7-27 i personopplysningsforskriften. Dette betyr at behandlingen av personopplysningene vil være unntatt fra konsesjonsplikt etter personopplysningsloven § 33 første ledd, men underlagt meldeplikt etter personopplysningsloven § 31 første ledd, jf. personopplysningsforskriften § 7-20.

Unntak fra konsesjonsplikten etter § 7-27 gjelder bare dersom vilkårene i punktene a) – e) alle er oppfylt:

- førstegangskontakt opprettes på grunnlag av offentlig tilgjengelige registre eller gjennom en faglig ansvarlig person ved virksomheten der respondenten er registrert,
- respondenten, eller dennes verge dersom vedkommende er umyndig, har samtykket i alle deler av undersøkelsen,
- prosjektet skal avsluttes på et tidspunkt som er fastsatt før prosjektet settes i gang,
- det innsamlede materialet anonymiseres eller slettes ved prosjektavslutning,
- prosjektet ikke gjør bruk av elektronisk sammenstilling av personregistre.

Personvernombudets vurdering forutsetter at prosjektet gjennomføres slik det er beskrevet i vedlegget.

Behandlingen av personopplysninger kan settes i gang.

Ny melding

Det skal gis ny melding dersom behandlingen endres i forhold til de punktene som ligger til grunn for personvernombudets vurdering.

[Redacted text]

Ny melding skal skje skriftlig til personvernombudet.

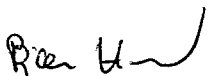
Offentlig register


Personvernombudet har lagt ut meldingen i et offentlig register, www.nsd.uib.no/personvern/register/

Ny kontakt

Personvernombudet vil ved prosjektets avslutning, 31.12.2009, rette en henvendelse angående arkivering av data benyttet i prosjektet.

Vennlig hilsen


Bjørn Henrichsen


Pernilla Bollman

Kontaktperson: Pernilla Bollman tlf: 55583348

Vedlegg: Prosjektbeskrivelse