



EIJA STENGÅRD

Journey of Hope and Despair

The Short-term Outcome in Schizophrenia
and the Experiences of Caregivers of People
with Severe Mental Disorder



ACADEMIC DISSERTATION

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Tel. +358 3 215 6055
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LIST OF ORIGINAL PUBLICATIONS

The dissertation is based on the following original publications, which are referred to in the text by Roman numerals I–V.

- I Salokangas, R.K.R., & Stengård, E. (1990). Gender and short-term outcome in schizophrenia. *Schizophrenia Research*, 3, 333–345.
- II Stengård, E., & Salokangas, R.K.R. (1997). Well-being of the caregivers of the mentally ill. *Nordic Journal of Psychiatry*, 51, 159–164.
- III Stengård, E., Honkonen, T., Koivisto, A.-M., & Salokangas, R.K.R. (2000). Satisfaction of caregivers of patients with schizophrenia in Finland. *Psychiatric Services*, 51, 1034–1039.
- IV Stengård, E. (2002). Caregiving types and psychosocial well-being of caregivers of people with mental illness in Finland. *Psychiatric Rehabilitation Journal*, 26, 154–164.
- V Stengård, E. (2003). Educational intervention for the relatives of schizophrenia patients in Finland. *Nordic Journal of Psychiatry*, 57, 271–277.

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1. INTRODUCTION

Over the past two decades, the deinstitutionalization movement has shifted the primary locus of care from psychiatric hospitals to community care, in Finland as well as in most other Western countries. Since the 1970s, several governmental reports (Lääkintöhallitus, 1977; Mielenterveystyön komitean mietintö, 1984; Lääkintöhallitus, 1988) have strongly emphasized the need to reduce mental hospital beds and to allocate additional resources for community care. The main arguments for the deinstitutionalization were the harmful effects of long hospital stays, the patients' right to live in the community, and the high costs of hospital care (Salokangas & Saarinen, 1998). Although this development started later in Finland than in many other countries (Salokangas, Der, & Wing, 1985), Finland has experienced one of the most rapid deinstitutionalization processes in the whole world (Salokangas & Saarinen, 1998). The number of psychiatric beds decreased in less than fifteen years from about 4 to slightly over 1 per 1000 inhabitants (Honkonen, Saarinen, & Salokangas, 1999; Salokangas, 1994). During this process the decrease in the number of psychiatric hospital beds was over 14 000 (Nenonen, Tuori, Pelanteri, & Kautiainen, 2001). Since the mid 1990s the decrease has leveled out. However, the funds for professional community resources have been limited and there are great regional differences in the resources for psychiatric care (Tuori, Kiikkala, & Lehtinen, 2000). Further, the role of primary health care services in the prevention, identification and treatment of mental health problems has increased in importance (Hyvönen, Nikkonen, & Tuori, 2002).

For the patients this movement has meant shorter stays in psychiatric hospitals and more opportunities to live their lives independently in the community. However, many patients need a lot of practical help and emotional support in order to manage their everyday lives. Given the limited resources of community care, this support is often provided by family members of people with mental illness. Thus the increased emphasis on community management has increased the responsibilities of patients and their families. Estimates of the number of relatives involved in the care of mentally ill adults have ranged from 30% to 70%, depending on the number of admissions (MacMillan, Gold,

Crow, Johnson, & Johnstone, 1986; Gibbons, Horn, Powell, & Gibbons, 1984; Creer, Sturt, & Wykes, 1982; Fisher, Benson, & Tessler, 1990; Schene & van Wijngaarden, 1995). In Finland, the number of schizophrenic patients returning to their families after hospitalization decreased in the 1990's, but the figure was still 33 % in 1994 (Salokangas, Stengård, Honkonen, Koivisto, & Saarinen, 2000). However, the family members of people with severe mental illness have often been uninformed and ill-equipped to manage the caregiving task. As a result of the caregiving consequences, family members have experienced burden and distress and expressed a need for informational and emotional support (Baronet, 1999).

In order to share their experiences, gain support and advocate for better psychiatric services for their mentally ill relatives, family members have founded voluntary family organizations in most Western countries (Katschnig & Konieczna, 1987). In Finland the first family organizations were founded at the end of 1980s and today there are over 20 regional family organizations in different parts of the country. These organizations have worked actively on behalf of family members by providing educational interventions, support groups and respite services.

The purpose of the present study was to examine the short-term outcome in schizophrenia and to contribute to the understanding of the situation and needs of family members of people with severe mental illness. The main aims of this study are 1) to examine the gender differences of new schizophrenia patients during the early stage of treatment, 2) to describe the well-being and need for information and support of the caregivers, 3) to determine whether the caregivers are satisfied with their situation and with the psychiatric services, 4) to identify the different types of caregivers to examine the differences between these types and 5) to examine the efficacy of a family education intervention.

2. REVIEW OF THE LITERATURE

2.1. The role of families in the history of psychiatry and mutual help

Although individual doctors have occupied themselves with the care of the insane since the time of the ancient Greeks, psychiatry did not exist as a discipline before the end of the 18th century. At that time Europeans living in rural districts had a horror of those who were different and they were intolerant of behavior that did not confirm to the norms. Great importance was attached to inherited social roles, to customs and traditions. Family was the basis of community life and disruptive behaviors were its responsibility. Those family members who were different were dealt with in the most brutal and unfeeling manner. It was common that mentally ill family members were beaten, chained or kept in cages (Shorter, 1997, 1–2; Riesser & Schorske, 1994, 4).

However, in the urban world the situation was somewhat different. Asylums had been in existence since the Middle Ages and cities had organized institutions to accommodate homeless psychotic or demented individuals. In Finland the first asylum was founded in 1619 on the island of Seili, although at first mainly patients with leprosy were confined there (Turunen & Achté, 1983, 94). These institutions had solely custodial functions and had no notion of delivering psychotherapy to patients. Thus, the history of psychiatry began as the history of the custodial asylum aiming to confine individuals who were dangerous to themselves and a nuisance to others. On the continent of Europe offering care had always been the responsibility of the public sector, but in England there were also private asylums in addition to the public ones (Shorter, 1997, 4–7).

The family's need to understand their relative's suffering was hampered by an inability to identify the problem. Symptoms of mental illness were frequently indistinguishable from other impairments. Primary professional guidance came from the community's clergy, who advocated a harsh theology based on controlling individual impulses. At the time, there were few practicing physicians and no mental health professionals. These few individu-

als who claimed to have skills in medical arts applied identical treatments to all diseases. There is no evidence that the medical treatments were any more beneficial than careful observation and management within the family. Behavioral control, through restraint and punishment, was most frequently the only option (Riesser & Schorske, 1994, 4–5).

It was not the notion that madness was curable that changed at the end of the 18th century, but the idea that institutions themselves could be made curative and confinement in them could make the patient better. Mental illness was differentiated from other illnesses and mere poverty and viewed as having distinct somatic origins. The victims were seen as human beings, needing humane and dignified environments. The founders of moral therapy envisaged two aspects of life in an asylum as therapeutic – the setting itself with its orderly routines and communal spirit, and the doctor-patient relationship. A calming setting was indicated, because madness was seen to come from excessive irritation of the nerves. Strengthening the patients' self-control was emphasized, since it was seen itself as therapeutic. The founders also believed in the salutary effect of isolation from the outside world serving to protect the patient from the confusion and pressure of the wider society. Removal of the patient from family and friends would contribute greatly to diverting them from the previously unhealthy passions that had ruled their lives. While an intimate bond between a patient and psychiatrist was seen as crucial to successful treatment, there was little recognition that the family had a supportive role. The idea that a visit might actually promote recovery was beyond thinking and the thought that loss of contact was having any impact on relatives would have seemed altogether irrelevant to the mission of the asylum (Shorter, 1997, 8–19; Riesser & Schorske, 1994, 5–6; Terkelsen, 1990, 5–8).

Asylums were founded everywhere at approximately the same time, in countries vastly disparate in social structure and level of economic development. By the 1840s, therapeutic asylums had burgeoned all over Europe as well as the United States. In Finland, in the first decades of the nineteenth century the responsibilities of the state in taking care of the poor and the sick started to become clearer. At the same time the institutions for the relief of the poor, health care and public order were differentiated. A new statutory regulation about the treatment of the mentally ill was issued in 1840 aiming to provide treatment and separate curable and incurable patients. The first asylum, Lapinlahti, was founded in 1841 (Jaakkola, Pulma, Satka, & Urponen, 1994, 63–64; Ach  , 1974, 15–32). The therapeutic asylum bore within it the seed of success, for people with major psychiatric illnesses are indeed

helped by sheltering in places they believe to be safe, by efforts to help them organize their time and lives, and by medication. The early asylum attempted all of these, and families must have perceived great benefits from moral treatment for their relatives with mental illness. Although this approach aimed at resocializing the patient in the ethos of paternalism, the new optimism and improved treatment environment were distinct advances in patient care. Moral treatment was also a first step toward substituting the authority of mental health professionals for that of clergy, kin and communities (Shorter, 1997, 33–35, 46–49; Riesser & Schorske, 1994, 6; Walton, 1985, 135).

Despite the good intentions, the dreams of the early psychiatrists did not come true. By World War I, asylums had become vast holding pens for the chronically insane and demented as the rate of confinement multiplied. Some of the increase in asylum admissions was a result of redistributing the ill. This redistribution had nothing to do with the overall rate of mental illness, but simply involved rearrangements in care. During the nineteenth century, individuals with major psychiatric illnesses were increasingly shifted from families, workhouses, prisons and poorhouses to the asylum. Another major component in the rising numbers in confinement was a genuine increase in the rate of mental illness. Between 1800 and 1900, the risk grew appreciably that the average person in his or her lifetime would be visited by a major psychiatric disorder. The psychiatric illnesses that most demonstrably increased in frequency during that time were neurosyphilis and insanity related to alcohol. There is also some evidence that the incidence of schizophrenia rose significantly during the nineteenth century (Shorter, 1997, 52–61).

Looking after the mentally ill was the responsibility of the family who decided to keep an afflicted individual at home or to seek care. The researchers describing the process of admitting ill family members have shown that the reasons of working-class families for seeking care were violence, delusions, suicidal or bizarre behavior of the ill family member. Thus the asylum was not resorted to lightly but brought many families relief from impossible circumstances. It was the last option when all else had failed (Walton, 1985, 140–141). However, before the nineteenth century, the wealthy families showed no interest in private asylums on the continent of Europe. The changed willingness of the wealthy families to send their relatives away was related to changing patterns of sentiment in family life. As the family started to consider itself increasingly an emotional unit, disruptive relatives at home began to seem more and more intolerable. Before the eighteenth century, the family was based more on property than sentiment and had little intimacy to disrupt. Late in the eighteenth

century a new style of family life emerged, in which mental illness in a dear member was no longer possible to behold (Shorter, 1997, 49–51).

Nevertheless, there is ample evidence from Victorian letters, diaries and autobiographies that upper and middle-class families also regarded the asylum as a place of last resort. Despite the impact of moral treatment and non-restraint on the ethos of asylums, the public image of even private asylums remained poor and there was a lack of confidence in the curative capabilities of the medical profession. The shame and embarrassment in families when one of their members became mentally disturbed could be very intense. The decision to confine a relative, even when it was believed that this was in the individual's best interest, could also lead to strong feelings of guilt (MacKenzie, 1985, 153–158).

The idea that social conditions could give rise to insanity was a radical departure from the beliefs of the earlier times. Viewed as an act of God, insanity required no other explanations and was not regarded as amenable to human intervention. By contrast, the medical community in the early nineteenth century thought of insanity not only in its social but also its biological aspect. The prevailing belief was that careful investigation of the brains of deceased insane persons would yield evidence of damage to the tissue of the brain, except that the damage might be too subtle to detect with contemporary medical methods. However, those physical changes were thought of as the end result of societal stress and chaos on the human organism. The prevailing theory was the notion of degeneration, stating that inherited mental illness worsened steadily over the generations. This was bad for the family, but also hurtful to society. It was difficult to elicit a family history of mental illness from relatives who were all terrified of finding degeneration in the family tree and used all means to conceal knowledge of such family taint (Terkelsen, 1990, 5–6; Shorter, 1997, 69, 94, 97).

At the same time psychiatric diagnostics was also developing. By 1899, Kraepelin had distinguished the two non organic psychoses – manic-depressive illness and schizophrenia. The diagnosis was made on the basis of the patient's history and current symptoms. The concept of prognosis was the basis of the diagnosis: patients with manic-depressive illness had a circular disorder that would naturally improve; patients with dementia praecox would deteriorate into what Kraepelin considered to be dementia. Rather than reassuring patients and their families, Kraepelin's classification terrified them (Shorter, 1997, 107).

By the first half of the twentieth century, mental hospitals had grown in size and fallen in therapeutic power. There was little scientific understand-

ing of mental illness. However, these 1930-style asylums were considerably cleaner than half a century previously. Discharge rates for younger patients were actually quite high. In Finland the development was similar to that of other countries. However, psychiatry was caught in a dilemma. On the other hand, psychiatrists could warehouse their patients in large institutions in the hopes that they might recover spontaneously. On the other, there was psychoanalysis, a therapy suitable for the needs of people desiring self-insight, but not able to cure real psychiatric illness. In order to find new ways to help patients, psychiatrists sought alternatives to confinement and psychoanalysis. Among these new treatments were fever cure for neurosyphilis, new drugs, prolonged sleep, shock and coma, electroshock, and lobotomy. Some of these alternatives proved dead ends and were discarded; others became the basis of a new vision of psychotherapy; still others laid the foundations for the revolution in drug therapy that would take place after World War II (Shorter, 1997, 190–228; Ojanen, 1995, 61–62; Turunen & Achte, 1983, 93–99).

In addition to the physical therapies there was one further alternative. It concerned the milieu of therapy rather than a physical approach to the body. Social and community psychiatry insisted that it was not the patients' genes nor early childhood that made them ill but the surrounding community. Psychiatric illness could thus best be addressed with therapies placing patients in a healing community environment. One of the components of the developing social and community psychiatry was open asylum, where voluntary patients could admit and discharge themselves at will. Another component was discharging patients to some kind of family-based community care, not necessarily to their own families. By the turn of the century, family care had become common in Continental Europe in both public and private sectors. Probably the most famous center of family care was at Gheel in Belgium. Further, outpatient clinics based in the asylum also increased the openness of mental hospitals towards the surrounding community. All these pieces were put together by Maxwell Jones in London, who developed the principles of therapeutic community emphasizing the empowerment of patients and the normalizing of their lives (Shorter, 1997, 229–235).

With the early psychoanalytic theories, the medical opinion had shifted and families, especially mothers, were now seen as the first cause of insanity. The combination of new neuropathological investigations and theoretical developments in psychiatry combined to produce the first strand of a novel orientation toward the family. Many patients had improved only to become ill again on return to open society. Instead of having to look into all aspects of society, the new theory suggested that instead one could look simply at family

life. The professionals became interested in the nuances of interaction between patient and relative. The reversal in perspective also gave rise to a new form of treatment aiming to alter the course of family interaction. This was the beginning of what came to be known as family therapy (Terkelsen, 1990, 9–11).

The developments in psychoanalytic and family interaction theory were emerging at the same time as neuroleptic drugs were becoming available. Patients long since consigned to a life of mental hospital were now seen as candidates for early discharge. Over decades of asylum treatment, it had become apparent that removal from society did not regularly achieve the desired result, and that the institutions had their own ill effects on the mentally ill. By the 1950s' experienced observers were noting that asylum life had profoundly disruptive effects on the social skills of the mentally ill and on their ties to family and to the wider community. Thus when the mental health pioneers of the 1950s' reversed their course, it was largely to shield their patients from the effects of institutional life (Terkelsen, 1990, 11–12).

Other important developments for the families in the history of psychiatry in Finland were the development of family therapy in Turku (Alanen, 1983, 267–269) and the development of psychiatric rehabilitation in Tampere since the beginning of 1960s. The Sopimusvuori Association especially developed psychiatric rehabilitation in therapeutic communities since 1970 (Elosuo, 1983, 281–283; Haataja, Karjalainen, Kauppila, Kulju, & Laakso, 2000, 1–3). These developments were carried further in the national program for the study, treatment and rehabilitation of schizophrenic patients conducted 1981–1987. The goal of this program was to reduce the number of new and institutionalized long-stay patients. Special support was given to the development of therapies engaging family and neighborhood, as well as to building up a stepwise rehabilitation system for long-stay patients discharged for outpatient care (Lääkintöhallitus, 1988, 20).

Since the 1950's the family's role in the treatment and rehabilitation of the ill family member has been seen in various ways in different frameworks. The psychoanalytic and family interaction theories see the family as a locus of problems (Wynne, 1994, 128). In the early theories schizophrenia was linked to excessive attachment in early childhood to the father, overinvolvement on the part of the mother, and parental rejection. During the 1950s and 1960s, psychoanalytic views were supplemented by theories emphasizing pathological family interaction patterns and dysfunctional hierarchies within the family as etiological agents in the development of mental illness. The critics of early family theories acknowledged that research documented a number of abnormal interaction patterns in the families of schizophrenics. However, the critics

argued that these findings might result from parent and offspring sharing a common genetic background, or arise as a form of adaptation in the parent to the disabilities often found in the prodromal stages of schizophrenia. It was also noted that high levels of communication deviance were not specific to families of schizophrenics, but were also found in the families of neurotic patients. As a result of these criticisms, research examining the interactional role of family in the onset of schizophrenia declined, but the ideas have continued to be widely held among practitioners (Fisher et al., 1990, 205–206). Especially in many family therapy programs the primary problem has been reformulated, not as individual patient illness but as family dysfunction. The primary goal is to break the dysfunctional family patterns. The family change is seen as the family's primary goal and that such change will provide optimal benefit for family relationships and for all of the family members (Wynne, 1994, 128). Families often respond to such professionals encounters with increased frustration, powerlessness, guilt and confusion (Holden & Lewine, 1982, 627–629).

The biomedical approach sees the family as a source of diagnostic information about the patient. This approach focuses on the diagnostic, symptomatic assessment of the patient and treatment with psychotropic medications, based upon a neurobiological interpretation of brain functioning. From this perspective, the primary purpose in meeting with family members is to obtain new or confirmatory information about the history of the patient's symptoms and past compliance with medications. This basic information, together with a genetically oriented family history of mental illness, is widely accepted as facilitating diagnosis and treatment for the patient (Wynne 1994, 127). Recently, the neuropsychological functioning of healthy relatives of people with mental illness has also been a focus of growing interest in studies searching for precursors of psychosis (Salokangas, 2001, 113). However, if the family has no opportunity to discuss their concerns, they might perceive that they are not needed or wanted and they should entrust the patient's care to the professionals (Wynne, 1994, 127).

In the third approach the families are seen as the caretakers of the patient. Families are viewed as a resource in community-based, psychosocial treatment programs. These programs aim to establish a therapeutic alliance between family and clinician, provide information and support, and to modify the environment to minimize unpredictability and stress (Fisher et al., 1990, 221). The family members are expected to help the patient to maintain a regular day and night rhythm, to encourage the patient to take his or her medication and engage in meaningful activities (Lähteenlahti, 2001, 181). Some families

accept this task willingly, but other families object due to inadequate economic and emotional resources. Therefore the decision to involve the family should be reached in a collaborative process between the patient and other family members and the professional staff (Wynne, 1994, 127).

The fourth framework sees the family as a stressor for the patient. Probably the most widely accepted conceptual framework for schizophrenia is the diathesis-stress, or vulnerability-stressor model. In this model, a significant genetic and biological predisposition is hypothesized, with biological or psychosocial factors precipitating or exacerbating clinical symptoms and impairment. Counteractive strengths and protective factors are emphasized as also contributing to the course and outcome. The family is regarded as the agent for the maintenance of therapeutic gains of the patient (Wynne, 1994, 127–128; Lähteenlahti, 2001, 174). Of the many stressors and protective factors that have been examined, especially prominent attention has been paid to expressed emotion (EE), a concept reflecting several key aspects of close interpersonal relationships. It reflects critical, hostile, or emotionally overinvolved attitudes on the part of a family member toward a relative with a disorder. Criticism is defined as comments about the behavior or characteristics of the mentally ill relative that the family member clearly resents or finds annoying. Hostility is rated on the basis of whether or not the respondent makes generalized criticism or expresses attitudes that are rejecting of the patient. The emotional overinvolvement is a composite measure of factors such as an exaggerated emotional response, overintrusive or self-sacrificing behavior, and overidentification with the patient (Barrowclough & Hooley, 2003, 850–851; Leff & Vaughn, 1985, 37–63, 118). High family levels of EE have been shown to be associated with higher rates of relapse in patients with schizophrenia even when potentially important patient variables are controlled statistically (Hooley & Gotlib, 2000, 136–137). However, EE research has been criticized for blaming families, overlooking the family's supportive and rehabilitative influence on the patient, and ignoring the family's need for support and advice in caring for the mentally ill family member (Hatfield, Spaniol, & Zippel, 1987, 222–224).

The four frameworks described above are characterized by an emphasis on the treatment of the patients, whereas the feelings, experiences and needs of family members themselves are ignored. However, a new paradigm emphasizing the strengths, resources, and competencies of families is gradually emerging. In contrast to the disease-based medical model paradigm, a competence paradigm is a health-based developmental model. Families are viewed as at least potentially competent and their positive characteristics are emphasized.

The role of professionals is seen as that of enabling agents and that of families as collaborators. The goal of intervention in the competence model is the enablement and empowerment of families. The perspective is on the ecological systems rather than on the family systems and it employs an educational services model. The competence paradigm has some common elements with the pathology paradigm in recognizing the possible presence of competence deficits, as well as the value of professional intervention designed to help families correct the competence deficits they might have (Marsh, 1994, 39–41).

Side by side with the history of family members' role within psychiatry exists another development in which families have had an important role: the history of mutual aid and self-help. Mutual aid seems to have an ancient history in practically every known society. The first forms of mutual aid date back to the hunting and gathering period, elaborating and becoming widespread in the agricultural villages and reaching their zenith in the modern urban-industrial period (Borman, 1979, 17–19). In order to cope with the stresses of industrialism the Friendly Societies were founded in England in the late 17th and early 18th centuries. These societies served to deal with the immediate needs of their members and also to politicize them. In the United States early American colonists initially followed the pattern of mutual aid through the spontaneous neighborliness of small communities. They banded together to produce necessities and for protection against nature. Different immigrant groups also organized extensive networks for mutual aid. The ideas of mutual aid came to Finland through Germany, Sweden and Great Britain. The Finnish Association for Mental Health was founded already in 1897 and is the oldest non-governmental, voluntary mental health organization in the world (Kivinen & Kivinen, 1999, 38). The development of different organizations for mutual aid was similar in Finland and in other countries in Europe and by World War I these organizations had established their position as a part of the Finnish social security system. Newer manifestations of self-help organizations arose in the decades following World War II. Organizations of parents of children ill or handicapped by a particular physical or mental problem were the first to surface after World War II; they were quickly followed by a multiplicity of special-purpose groups (Katz & Bender, 1976a, 266–277, 1976b, 15–22; Jaakkola et al., 1994, 149–150, 158).

During the 1970s self-help activities emerged in many areas concerned with psychosocial and medical problems such as cardiovascular diseases, cancer, multiple sclerosis and psychiatric disorders. The movement was encouraged by the considerable success such self-help activities were able to claim, a prime example being Alcoholics Anonymous, founded as early as 1935. An

important task of the self-help movement was also to reveal gaps in the health care and welfare system and demand that these gaps be filled in by establishing adequate services (Katschnig & Konieczna, 1987, 193; Johnson, 2002, 209).

The relatives' self-help movement in psychiatry also developed during the 1970s. The introduction of neuroleptics and newly developed psychosocial methods of therapy made it possible for the psychiatric hospitals in many countries to discharge chronic patients and to shorten the duration of inpatient treatment of new cases. This has been documented all over the world by the dramatic decrease in the number of psychiatric hospitals (Katschnig & Konieczna, 1987, 191–192). Since the locus of treatment shifted from psychiatric hospitals to community care, family members have become much more involved with their mentally ill relatives and have taken considerably more of responsibility in the community for their ill relatives (Fisher et al., 1990, 204).

The first association of friends and relatives of the mentally ill, *Unité Nationale des Amis et des Familles des Malades Mentaux* (UNAFAM) was founded in 1963 in France. In 1972, the National Schizophrenia Fellowship was founded in the United Kingdom; this organization essentially prompted the creation of similar associations in many other countries. Thus in Austria, a self-help organization (HPE, *Hilfe für Psychisch Erkrankte*) was established in 1977; The National Alliance for the Mentally Ill (NAMI) in the USA in 1978, and the World Schizophrenia Fellowship in 1985 (Katschnig & Konieczna, 1987, 191). In Finland the first family organizations were founded at the beginning of 1980s and the national organization *Omaiset mielenterveys-työn tukena keskusliitto ry* (National Family Association Promoting Mental Health in Finland) in 1991. In 2004 there were altogether 21 local family organizations in Finland (<http://www.omaisten.org>). The European Federation of Associations of Families of Mentally Ill People (EUFAMI) was founded in 1990, bringing together people from 43 associations across 26 countries (Ariño, 2002, 7; <http://www.eufami.org>).

One of the most important reasons for founding these organizations was probably a profound need within relatives to brave the stigma of mental illness, to advocate for better psychiatric services for the mentally ill family members, to share their burden and by coming together to share experiences and gain support and understanding (Davison, Pennebaker, & Dickerson, 2000, 214; Atkinson & Coia, 1995, 128–129; Johnson, 2002, 210). Many of these associations base their work on the biological theories of the etiology of mental illness, exonerating the family members for the onset of mental illness. These

associations advocate on behalf of their relatives and seek to influence both treatment practices and research priorities. This initiative on the part of families has created new issues for treatment professionals, as they must now renegotiate the caretaking role and responsibilities with the family. New models of cooperation and collaboration between families and professionals are being developed to meet this need (Fisher et al., 1990, 204; Böker, 1992). One of these new models is called *trialogue*, which stands for the encounter of people with severe mental illness, family members and mental health professionals. The aim of triologue is to facilitate communication about the personal experiences of dealing with mental illness and its consequences. The participant groups try to understand and share their subjective experiences and thus seek to establish a common language which is seen as the basis of working together effectively (Amering, Hofer, & Rath, 2002, 105). Redefining the relationship between family and treatment professionals has become a major trend of research in this area.

2.2. Family burden and caregiving

2.2.1. *History of caregiving research*

The beginning of the caregiving research lies in the era of deinstitutionalization. Since the 1950s, the reduction in mental hospital beds with concurrent increase in community care, has been a general trend in the United States as well as many European countries. For the families of people with mental illness this change has meant that many of the caregiving responsibilities reverted to family members. At the same time, perspectives in research have also changed from family dysfunction to the meaning of mental illness for family members.

The history of caregiving research has been divided into three periods by Schene and his co-workers (1996, 298–299). During the first period, 1940–1960, the first caregiving studies were conducted. Treudley (1946) was the first to investigate family reactions to mental illness, especially the effects on children. In the mid-fifties Clausen and Yarrow (1955) conducted their classic sociological study of the impact of mental illness on the family. During the fifties, interest in attitudes towards the mentally ill steadily increased in conjunction with the emerging influences of the social sciences and community psychiatry. It became essential to ascertain under which conditions people with

mental illness could live their lives in society (Schene, Tessler, & Gamache, 1996, 298–299).

In the second period, 1960–1975, more data on attitudes, burden, labeling, stigma and specific effects of different kinds of psychiatric treatments became available. During this period improvements in the measures for assessing burden were made by a number of investigators. The focus of attention also became broader so as to include not only the negative impact of the patient on the family (burden), but also the negative influence of family members on patients (expressed emotion) (Schene et al., 1996, 299–300).

In the third period, from the mid-seventies onwards, different scientific traditions relating to caregiving research can be distinguished. There has been theoretical and empirical interest in the burden concept and its measurement. Progress has been made in developing more sophisticated instruments and using burden as an outcome measure in mental health service evaluation. Theoretical findings on burden and expressed emotion have also been gradually incorporated into treatment programs with psychoeducational approach (Schene et al., 1996, 300).

2.2.2. Concepts of caregiving and burden

In the history of research on the impact of mental illness on the family, caregiving is a relatively modern concept that has come to describe the relationship pertaining between adults who are related through kinship. Caregiving needs to be distinguished from dependency relationships which are age appropriate and culturally expected. Most people begin and end their lives with a period of dependency during which it is crucial that others provide care and support. The institution that typically provides this care is the family, although expectations may vary from culture to culture, and from one historical era to another. In western industrialized societies, adults are expected to be independent on their family of origin and to care for themselves unless they are disabled by illness. The caregiving relationship is based on two roles. The caregiver assumes an unpaid responsibility for the care recipient, who is usually disabled and unable to fulfill the reciprocal obligations associated with normative adult relationships. Caregivers are bound by kinship obligations that go beyond those normatively associated with a family role at a particular stage (Schene et al., 1996, 297).

In the following, I will refer to the caregivers using several concepts. In Finnish, the term ‘omainen’ refers to family members (parents, children,

spouses), to relatives and sometimes also to other close persons (Arhovaara & Rinne, 1989, 23). In English, the use of the corresponding term in caregiving research has changed over the past two decades. In earlier studies, the researchers most often used concepts 'relative' or 'family member'. In recent studies, the terms 'caregiver' and 'carer' are most common. However, caregiver is not necessarily a family member, but may be another close person to the care recipient.

The concept of caregiving is a general term describing the relationship between caregiver and care recipient. Burden is a more specific concept, referring to a broad range of difficulties experienced by family members and specifically associated with the mental illness (Schene et al., 1996, 303; Baronet, 1999, 821). Burden is usually divided into two dimensions, objective and subjective burden (Hoening & Hamilton, 1966, 167–170). Objective burden refers to the negative effects of the illness on the household and the caregiving demands imposed on family members. Subjective burden refers to the caregiver's personal appraisals of the situation and the psychological consequences for the family (Baronet, 1999, 819–820; Maurin & Boyd, 1990, 99). The definition of burden concentrates on the negative aspects of caring. Although mental disorder may disrupt family life, not all relatives experience their caring role as burdensome. Therefore a more neutral term, caregiving consequences, has recently been suggested to be used instead of term burden (van Wijngaarden et al., 2000, 21).

The concept of distress has also been associated with burden. However, the distinction between distress and burden is important and the two concepts should not be used interchangeably. Distress is related to more general measures of family members' mental health, psychological morbidity, or life strain. The difference between distress and burden is that distress is not specifically attributed to the presence of the person with mental illness, but to one's overall life situation (Maurin & Boyd, 1990, 99).

2.2.3. Background and situation of caregivers

National statistics include only limited information on the prevalence of caregiving activities. Caring for a mentally ill relative is not systematically reported to the authorities, and family caregivers who get in touch with the mental health system and family associations represent a subgroup of all people involved in this type of care. A recent survey on the prevalence of caregiving in Canada indicated that approximately 15% of the adult population aged 15 to

64 provided informal care for an ill relative or a friend. In this survey, informal caregivers provided help because of chronic illness, old age, disability, mental retardation or mental illness (Cochrane, Goering, & Rogers, 1997, 2004). In the United States Ascher-Svanum and Sobel (1989, 844) have estimated that women are three times more likely than men to have a caregiving role for an adult mentally ill relative.

The corresponding figures in Finland are lacking. However, it has been estimated that in 1998 15000–20000 individuals were cared for at home by their relatives, who received an informal care allowance. When the estimates of the number of persons who would have been in institutional care if their relatives had not looked after them were proportioned to the population, 9 900 of those being looked after at home would have been in institutions countrywide. Had the carer not received the allowance, an estimated 5 600 such persons would have been in institutional care. For most of the persons (74%) the reasons for the need of care were the increasing frailty associated with old age or long-term disability or illness. Mental illness was the reason for care only for 5% of the persons cared for (Vaarama, Rintala, Eteläpää-Vainio, & Sinervo, 1999, 10–11, 32, 41–42).

The majority of research on family burden has been conducted in the United States, Canada, and the United Kingdom (Maurin & Boyd, 1990, 100). The respondents in the 28 family burden studies reviewed by Baronet (1999, 821) were mostly female (69%) with an average age of 52 years. Most of them were white (75%) and often resided with the ill relative (43%). Caregivers had usually graduated from high school and were often parents of a severely mentally ill child (55%) or spouses of the ill relative (22%). The situation is similar in Europe. Among 14 member organizations of the European Federation of Associations of Families of Mentally Ill People (EUFAMI) in ten countries the majority of the carers (73–88%) in every country were women, average age ranging from 51 to 66 years. The percentage of caregivers living with the mentally ill family member varied from 21% to 84%. Around a quarter (13–29%) of the caregivers were working outside the home. About half of them (48–61%) had been caring for 10 years or longer and 13–48% spent at least 31 hours a week in caring. The majority of people being cared for were male (56–80%) with a diagnosis of schizophrenia (29–92%) and average age of 34–42 years. In spite of the methodological problems in the EUFAMI survey these figures can be considered to be estimates of the situation (Hogman & De Vleeschauwer, 1996, 9–16).

The results in Finnish studies have been similar to the European results. Women comprised 81–87% of the caregivers, the average age was 55 years

and 28–33% were living with the ill family member. In Finland 40–46% of caregivers were working outside the home. Despite the larger proportion of working caregivers, the time spent in caring is similar: 27–38% spent over 32 hours a week in caring. The majority of people being cared for were male (54–61%) with a diagnosis of schizophrenia (46–54%) and average age of 38–44 years. The duration of caregiving was not available in the Finnish studies, but the average duration of the illness was 12 years (Salokangas, Stengård, & Perälä, 1991a, 25–27, 35–36; Jokinen, 2001, 12–19; Nyman & Stengård, 2001, 23–27, 34).

The reasons for providing care vary and include a multitude of psychological, political, and social factors. Guberman and her co-workers (1992, 615) divided the motives for caregiving into three groups. The first group had to do with the caregiver herself. These reasons were most important and they were associated with the caregiver's material, social, and psychological situation. These included love, maternal feelings, feelings of family ties; feelings of obligation, resignation and guilt; a profound need to help others; socioeconomic dependence; belief in the healing process; religious or anti-institutional convictions; personal characteristics, and family tradition. Second group of motives referred to the availability of family, community or institutional resources which could offer an alternative caregiving situation. The third group included reasons associated with the care recipient. These reasons included the dependent person's refusal to be placed elsewhere and his or her state of health and level of autonomy that made it possible to provide care at home.

2.2.4. Strain and gain experienced by caregivers

The majority of caregiving studies have concentrated on the negative consequences of mental illness on the family, the family burden. Hoeing and Hamilton (1966, 167–170) were the first researchers to differentiate subjective and objective dimensions of burden. Subjective burden relates to the psychological consequences for the family and is defined as individuals' personal appraisals of the situation and the extent to which people perceive they are carrying a burden. This burden includes a broad range of negative feelings and emotions i.e. guilt, uncertainty, ambivalence, hatred, anger, and feelings of sorrow (Platt, 1985, 384; Schene, 1990, 290; Maurin & Boyd, 1990, 99; Schene et al., 1996, 301–303). These negative feelings have been experienced by 6–87% of caregivers (Thompson & Doll, 1982, 383; Salokangas et al., 1991a, 46;

Reinhard, 1994a, 82; Östman & Hansson, 2000, 33; Magliano et al., 2002, 294).

Objective burden refers to the caregiving demands placed on family members. Several aspects of objective burden have been distinguished: disruptions of household routines and relatives' careers and leisure time, difficulties in the financial situation, strain on interpersonal relationships and a reduction of social support (Platt, 1985, 384; Schene, 1990, 289–290; Schene et al., 1996, 301–303).

Household routine. When one family member is mentally ill, the family reciprocity is often disrupted, and others have to take on a greater proportion of the formally shared tasks. Family members often provide a great deal of assistance for the mentally ill family member in activities of daily living: provision of personal care, cooking, doing household chores and laundry, shopping, and helping with transportation (Schene, 1990, 289; Schene et al., 1996, 302). The proportion of caregivers that reporting objective burden in household routine has varied from 5% to 43% (Test & Stein, 1980, 411; Thompson & Doll, 1982, 383; Reinhard, 1994a, 82; Stengård, 1998, 57; Nyman & Stengård, 2001, 36).

Leisure time and hobbies. Assuming more tasks and giving support or help to the ill family member diminishes relative's opportunities for pursuing hobbies, recreation and holidays (Schene, 1990, 290). This type of objective burden has been reported by 11–71% of caregivers (Test & Stein, 1980, 411; Salokangas et al., 1991a, 46; Provencher, 1996, 183; Stengård, 1998, 57; Östman & Hansson, 2000, 33; Nyman & Stengård, 2001, 36; Magliano et al., 2002, 294).

Work and employment. Caregiving may also compel relatives to work less or give up their jobs. Some family members retire early because of their caregiving responsibilities. Crisis situations at home may also interfere with working. Difficulties in working were experienced by 5–84% of caregivers (Test & Stein, 1980, 411; Salokangas et al., 1991a, 46; Provencher, 1996, 183; Stengård, 1998, 57; Östman & Hansson, 2000, 33; Nyman & Stengård, 2001, 36; Magliano et al., 2002, 294).

The financial situation of a family may deteriorate because the ill family member is not able to work at all or works fewer hours. There may also be added expensed related to psychiatric care and medication. The ill family member may have a very small income or disability pension and family members need to provide financial help to him or her in order to cover necessary expenses. Other economic difficulties may emanate from the patient's inability

to manage money or as a result of destructive behavior (Schene, 1990, 290; Schene et al., 1996, 303). The proportion of families reporting financial difficulties has varied from 20% to 63% (Thompson & Doll, 1982, 383; MacCarthy et al., 1989b, 730; Salokangas et al., 1991a, 46; Provencher, 1996, 183; Stengård, 1998, 57; Nyman & Stengård, 2001, 36).

Interpersonal relationships between family members may become strained, likewise those with relatives, neighbors and friends resulting in the lessening of social support and a profound sense of isolation. In the case of spouses, disruption of the marital relationship is common. Siblings receive less attention when their parents become more involved in the care for a mentally ill brother or sister. Siblings may also be under pressure to be more helpful and supportive and to take on extra tasks. The healthy psychological development of children of mentally ill parents may also be at risk if the needs of the children are neglected or parenting skills are impaired (Solantaus, 2001, 22–28). Relationships outside household may also be adversely affected, first by having less time to spend on social relations, and second by social stigma for the patient and family members (Schene, 1990, 290; Schene et al., 1996, 301; Phelan, Bromet, & Link, 1998, 120; Struening et al., 2001, 1637). Difficulties in interpersonal relationships have been reported by 12–84% of caregivers (Thompson & Doll, 1982, 383; MacCarthy et al., 1989b, 730; Salokangas et al., 1991a, 52; Winefield & Harvey, 1993, 621; Reinhard, 1994a, 82; Provencher, 1996, 183; Stengård, 1998, 57; Nyman & Stengård, 2001, 36; Magliano et al., 2002, 294).

Baronet (1999, 821–822) concluded in her review of family burden studies that highest objective burden was reported for providing transportation, help in money management, housework and cooking, need for constant supervision, restrictions in caregivers' personal activities and providing financial help. The highest subjective burden was reported for issues of safety and possible violence of the ill individual toward self or others, excessive demands and high dependency toward the caregiver, night disturbances, socially difficult behavior, symptomatic behavior, worries about the future, and uncooperative attitude leading to conflicts and family hardship. More objective burden was experienced as a result of the tasks related to the caregiving situation than because of the disruptive behavior of the ill relative. Conversely, more subjective burden was experienced as a result of the disruptive behaviors of the ill relative than because of the tasks related to the caregiving situation. These findings support the conclusion about objective burden being highest with assistance in daily activities and subjective burden being highest in supervi-

ing activities. Burden also tends to remain stable over time in the absence of specific family interventions (Magliano et al., 2000; Raj, Kulhara, & Avasthi, 1991; Brown & Birtwistle, 1998; Scazufca & Kuipers, 1998).

The association between caregiver burden and several sociodemographic variables has been studied. However, only caregivers' age, ethnicity, and residing with the ill relative have been associated with burden. The association between caregivers' age and overall burden has yielded mixed findings. Some studies have found that caregivers' young age was associated with high levels of overall burden. Being white has also been associated with increased overall burden. Replicated findings show that residing with the ill relative is associated with increased objective burden, but not associated with subjective burden. This finding suggests that caregivers who do not live with their ill relative still worry as much about them. Caregivers' gender, education, family income, kinship with the ill relative and clients' gender were not associated with burden (Baronet, 1999, 823).

Furthermore, caregiver burden has been positively related to the presence of symptomatic behaviors and amount of care, but not related to diagnosis of the ill relative. Among all factors associated with caregiver burden, symptomatic behaviors have presented the strongest and most consistent associations. Symptomatic behaviors which have yielded the highest levels of reported subjective burden in caregivers (e.g., issues of safety and possible violence of the ill individual toward self and others, excessive demands, high dependency on the caregiver) are not exclusively related to specific diagnoses, but usually appear in periods of crisis and exacerbation of severe psychiatric illnesses. It is possible that the stability of ill relatives' conditions in terms of psychiatric symptomatology is an important factor influencing subjective burden (Baronet, 1999, 833).

An important mediator between the ill relative's behavior and family burden are the illness related attributions of family members. Evidence is accumulating that high EE and low EE relatives may differ in their beliefs about patients and the problem behaviors associated with the mental illness. In particular, several studies have shown that critical relatives are more likely than noncritical relatives to hold patients responsible for their difficulties. Criticism and hostility have been shown to reflect the family members underlying beliefs that patients could do more to control their symptoms and problems. Levels of empathy and support shown toward the mentally ill family member appear to vary across cultures. High EE relatives can be found in all cultures, but high EE attitudes tend to be less prevalent in developing countries compared

to more industrialized countries (Barrowclough & Hooley, 2003, 850, 861, 865).

The caregiving literature has been criticized for having methodological problems including the inconsistent use of theoretical and operational definitions, reliability and validity issues in the measurement of burden, problems in sampling, lack of theoretical frameworks, heterogeneity of populations studied, the absence of longitudinal research designs, and the lack of simultaneous control of the various variables influencing burden. There has also been a lack of cross-cultural research since most of the studies have been conducted in the United States and the United Kingdom. These methodological problems may account for some of the inconsistencies and variability in findings among family burden studies (Maurin & Boyd, 1990, 102–104; Magliano et al., 1998b, 405–406).

However, some advances in the methodological issues in the family burden research have been made in the 1990s. Schene and his co-workers (1998, 614) have further analyzed the dimensionality of the caregiving concept and found four distinct caregiving domains: tension, supervision, worrying and urging. Tension points to the strained interpersonal atmosphere between the patient and the relatives: the quarrels, annoyances, and occasional threats. Worrying covers painful interpersonal cognitions, such as concern about the patient's safety, general health, and the kind of help he or she is receiving. Supervision has to do with the caregiver's tasks of ensuring and guarding the patient's intake of medicine, sleep, and dangerous behavior. Urging relates to activation and motivation of the patient to take care of himself or herself, to eat enough, and to undertake activity. The result has been replicated in a Finnish study (Nyman & Stengård, 2001, 32–34).

Other advances in family burden research include increased simultaneous control of variables influencing caregiver burden, the differentiation of objective and subjective burden, increased attention to validity and reliability issues and cross-cultural studies. Areas that need further attention from research include the use of theoretical frameworks, the use of longitudinal research designs, the heterogeneity of the caregiver population, the replication of single study findings, and the theoretical definitions of burden concepts (Baronet, 1999, 836–837; Magliano et al., 1998b, 405–406).

As real as the burden of mental illness is for families, consideration should be given to the fuller experience of what it means to have a mentally ill family member. Although the literature has paid less attention to positive aspects of the family experience, serious mental illness also offers families an opportunity

to change in constructive ways and to strengthen family bonds. Such responses are called resilience, which refers to the ability to overcome from adversity and prevail over the circumstances of life. The most common experiences of family resilience include close family bonds and commitments, family strengths and resources, and family growth and development. In addition, family members often experience personal resilience such as personal contributions, improved personal qualities, personal growth and development and enhanced coping effectiveness (Marsh & Lefley, 1996).

Caring for a relative with mental illness also brings a variety of other benefits and gratification. These gains may be defined very broadly as the extent to which the caregiving role is appraised to enhance an individuals' life space and be enriching. Gain may include any positive affective or practical return that is experienced as a direct result of caregiving (Kramer, 1997, 219). Caregivers may enjoy the company of the family member, feel he or she is an important part of their life, feel pride and experience happiness as a result of their continuing relationship (Bulger, Wandersman, & Goldman, 1993, 259; Tessler & Gamache, 1995, 10). Horwitz and his co-workers (1996, 155–157) studied caregiving as a process of mutual exchange and found that both patients and their family members reported relatively high levels of patient support, especially symbolic support represented by gift exchange, companionship, participation in family activities, and expressing affection. Furthermore, the amount of support patients gave parents and siblings was very strongly associated with how much support they received from family members. Parents' positive appraisals of their relationship with their offspring has also been shown to be associated with lower caregiving burden among families both with and without mental illness (Pickett, Cook, Cohler, & Solomon, 1997, 226).

Corresponding results were also reported by Greenberg and his co-workers (1994, 477; Greenberg, 1995, 418). Ill family members, especially those living with their families, provided substantial help by doing household chores, shopping, listening to problems, providing companionship, and providing news about family and friends. This type of help was given by 50–80% of ill family members who lived with their family and 5–52% of those who lived apart. However, in a Finnish study using the same measure, the corresponding figures for providing help were 22–71% for ill family members living together with their family and 6–36% for those living apart (Stengård, 2004). In addition, caregivers have frequently found their role meaningful and satisfying. Caregiving experiences have entailed emotional growth and personal strength, prompted a reappraisal of life priorities, and enhanced sense of being needed

and making valuable contribution to the well-being of the ill family member (Nyman & Stengård, 2001, 42–45).

2.2.5. *Coping with mental illness in the family*

Caregivers exposed to seemingly similar stresses are affected by them in dissimilar ways. The reason why some caregivers adapt poorly, whereas others appear to adapt well in the face of equivalent adverse conditions, has been the subject of much speculation. The mediating factors such as coping are usually called upon to provide the explanation for this variability. *Coping* is a stabilizing factor that helps individuals maintain psychosocial adaptation during stressful periods; it encompasses cognitive and behavioral efforts to reduce or eliminate stressful conditions and associated emotional distress that are appraised as exceeding the resources of the person (Lazarus & Folkman, 1984, 141; Pearlin, Mullan, Semple, & Skaff, 1990, 589).

At the general level, conceptualizations of coping may be categorized according to their assumptions about the primary determinants of coping responses. Dispositional approaches assume that relatively stable person-based factors underlie the selection of coping behaviors. Contextual approaches assume that more transitory situation-based factors shape people's choices of coping responses. Contemporary theories generally recognize that both enduring personal and more changeable situational factors shape coping efforts. Coping is regarded as a dynamic process that changes over time in response to changing demands and changing appraisals of the situation (Holahan, Moos, & Schaerfer, 1996, 25–26). The coping responses can be divided into four groups: problem oriented, emotional, cognitive and physical. The aim of problem oriented coping is to directly manipulate the stressful situation by changing either one's own behavior or environmental conditions. Emotion focused coping refers to dealing with emotional distress, e.g. sharing feelings with others. Cognitive coping means changing the attitude or perception of the situation by redefining the problem in more useful terms. Physical coping refers to minimizing the effect of stress by exercising, relaxing or other means (Spaniol & Jung, 1987, 98).

Families of people with mental illness frequently face problems requiring problem oriented coping skills in order to manage the situation at home. Many of these problems are associated with the symptoms and behavioral changes of the person with mental illness. Birchwood and his co-workers (Birchwood &

Smith, 1987, 12–13; Birchwood & Cochrane, 1990, 859–861) have described different strategies that caregivers use in coping with the symptoms of family member with schizophrenia. *Coercion* is a strategy where the relative adopts a punitive approach (criticism, verbal or physical aggression, threats, attempts to shame or embarrass) intending to provoke confrontation. *Avoidance* includes responses which minimize relatives' exposure to the behavior through withdrawing from the situation. *Indifferent reactions* are those where relatives do not respond because they do not perceive the behavior as a problem; because the behavior is accepted (as a part of the personality or illness) or because relatives have given up trying to influence the situation. *Collusion* includes those strategies where relatives actively condone or support the behavior. *Reassurance* is reported only in relation to positive symptoms where relatives present a calm and stable exterior, emphasizing the security of the home and their relationship, but nevertheless not agreeing with the individual's beliefs or experiences. *Disorganized responses* are those where relatives express feeling of desperation and helplessness, and engage in many strategies without consistency and without any clear dominant strategy emerging. *Constructive responses* represent special action taken by relatives to alleviate the problem (but excluding coercive tactics).

Spaniol and Zipple (1994, 136–139) have also reported coping strategies that have been tried out by the families and found to be effective in coping with symptoms of serious mental illnesses and other common problems. One of the coping strategies families used was learning to identify harmful or unacceptable behaviors and becoming more tolerant of symptom-related behavior. They felt that it was important to communicate clearly to the ill family members what behaviors were not acceptable. This was especially important in the case of aggressive, self-destructive and suicidal behavior. Family members felt that it was important to listen to the concerns of the ill family member and to work on the problems while family members were calm. Sometimes it was necessary to rely on the help of a crisis team or the police to manage severe aggressive behavior at home.

Another common problem in families was the withdrawal of the ill family member. This was experienced as painful rejection by the caregivers. Families suggested two approaches to coping with isolation. First, they advised against forcing the family member to be unreasonably social and active. Second, they found it helpful to gently and consistently encourage additional social activities. At times the physical appearance and hygiene of the family member with the illness also differed from the rest of the family. Families encouraged

increasing the tolerance for a broader acceptance of appearance and hygiene and indicated that frequent and gentle reminders about cleanliness were helpful (Spaniol & Zippel, 1994, 139–140; Mueser, Valentiner, & Agresta, 1997, 336).

Families were also very concerned about their ill family member's participation in recommended treatment, especially the use of medication. Caregivers indicated that willingness to take medication was the single most important variable in predicting whether the family member with the illness would function well in the home. They indicated that supportive reminders to take medication and helping the ill family member understand and manage the medication and its side effects were essential. Families also reported discussing how willingness to take medication can reduce symptoms or prevent hospitalization. They emphasized the importance of working collaboratively with professionals to support the ongoing cooperation with the treatment (Spaniol & Zippel, 1994, 140–141).

Family members often have a range of emotions throughout the course of their relationship with the ill family members (Terkelsen, 1987; Karp & Tanarugsachock, 2000). Part of the difficulty is the sheer volume of the emotions experienced. Family members have mixed feelings such as fear, confusion, hope, compassion, sympathy, love, frustration, sadness, grief, anger, resentment, and guilt and they need to learn ways to manage these emotions. In the case of negative feelings, family members often make the distinction between the person and the person's illness. It is not the person they hate, but the illness. This dichotomy is an invaluable tool for emotion management when a family members have distressingly negative feelings toward a loved one (Terkelsen, 1987, 155–156; Karp & Tanarugsachock, 2000). In the study by Nyman and Stengård (2001, 48–49) the caregivers identified altogether 118 different ways to gain strength and enhance their well-being. These included also emotional coping strategies. The most often mentioned sources of support were friends and family members. Praying and belief in God were quite often mentioned. Belonging to caregivers' support group was also important for some caregivers as a way of taking care of themselves. Corresponding results have also been reported by Salokangas and his co-workers (1991a, 58–59) and Spaniol and Jung (1987, 99–102).

In addition to problem solving and emotional coping skills, families also use cognitive coping strategies aiming to change their perception of the situation. These are especially important in situations where the ill family member has persistent symptoms and other problems despite the care and rehabilita-

tion provided. In circumstances where the difficulties caregivers face cannot be changed, the problem solving efforts are not only likely to be unsuccessful, but also may in fact increase rather than decrease stress. In these situations looking at things in a different light can be very useful (Lundh, 1999, 737). Pearlin and his co-workers (1990, 590) have called this type of coping management of meaning and divided it into three groups: reduction of expectations, making positive comparisons and constructing larger sense of illness. In the study by Nyman and Stengård (2001, 42) the majority of the caregivers reported using reduction of expectations: trying to accept the relative as he or she is (used by 88% of caregivers); trying to think about the present rather than the future (80%); and trying to keep a sense of humor (76%). Caregivers also frequently used construction of a wider sense of illness: trying to make sense of the illness (91%); praying for strength to keep going (66%); and reminding oneself that mental health problems are common (62%). However, making positive comparisons was used less frequently than the other coping strategies: reminding oneself that others are worse off (66%); trying to think about the good times one had in the past (33%); and looking for the things that one always liked and admired in the relative (59%).

Furthermore, families must also manage their own personal levels of stress and cope with the feelings and changes in their lives generated by the stress. Because the mental illness of a family member can be demanding of time and energy, many families recognize the importance of balancing their lives (Spaniol & Zippel, 1994, 141–143). About half of the caregivers have reported managing stress by reading, watching television, spending time alone or getting exercise. Eating was used as a way reducing stress by 42% of respondents. Smoking, drinking alcohol and taking medication to calm oneself were used only by 7–12% of caregivers. (Nyman & Stengård, 2001, 42, 48–49).

Orford (1987, 272–273) summarized the factors that may affect family members' adjustment to different disorders in the family. The exact nature of the family disturbance or difficulty is associated with the specific effects on the everyday life of family members. Disturbances of behavior or apparent changes in personality, e.g. rudeness, aggression or suspicion, are most disturbing and difficult to handle. A relative's interpretation of behavior and attitude towards the task of coping are important mediating factors in adjustment. Constructive family coping is made more difficult by attributing the person's behavior to personality constructs such as laziness; assuming behavior to be fully under the deliberate control of the person; thinking the person's behavior to be intentionally provocative or blaming oneself for causing the problems of

the ill family member. Constructive family responses are facilitated by adopting a positive attitude towards coping by recognizing positive change, stressing positive gains, re-ordering life priorities and living in the present, adopting positions such as taking one day at a time and being assertive about one's own needs. Furthermore, successful adaptation is more likely when pre-illness relationships have been satisfactory.

2.2.6. *Physical and mental health of caregivers*

Caregiving research has documented the burden experienced by families of the mentally ill, but the long-term effects of this burden on the physical and mental health of caregivers have not been thoroughly examined. As a consequence of chronic stress caused by caregiving the physical and mental health of family members may deteriorate. Family members may suffer from psychosomatic symptoms, infectious illnesses, or depressive or other psychiatric symptoms.

Most of the caregivers (47%–70%) of people with mental illness rated their physical health good or excellent (Salokangas et al., 1991a; Reinhard, 1994a, 83; Nyman & Stengård, 2001, 66; Jokinen, 2001, 13; Leinonen, Korpisammal, Pulkkinen, & Pukuri, 2001, 390). In Finnish population studies the proportion of working-aged subjects reporting their health to be good or fairly good was 66–68% and the corresponding figure for those aged 65 or over was 36% (Helakorpi, Uutela, Prättälä, & Puska, 2000, 12; Nenonen, Tuori, Pelanteri, & Kautiainen, 2001; Koskinen & Aromaa, 2002, 38). However, in several studies caregivers reported suffering physical illnesses at least partly attributable to the mental illness of a family member. In the study by Salokangas and his co-workers (1991a, 50–51) 22% of the caregivers felt that their illness came out because of the problems of the ill family member. Most often relatives reported having high blood pressure, gastric ulcer, migraine, diabetes, functional problems with thyroid gland or asthma. Corresponding results were found by MacCarthy and her co-workers (1989b, 730–731). Over half of their sample reported suffering from a physical illness. Many of their problems were chronic diseases associated with old age but also in some cases with poor material welfare and stress. Chronic lung diseases, high blood pressure, arthritis and diabetes accounted for the majority of reported illness.

Burdens associated with stigma and worries about the future have been found to be related to the physical health of mothers of adult children with schizophrenia after controlling for the mother's age, educational level, and

marital status; coresidence; level of objective burden; other life stressor; and the adult child's gender and severity of psychiatric symptoms (Greenberg, Greenley, McKee, Brown, & Griffin-Francell, 1993, 210). Caregivers reporting more distress have also used significantly more psychotropic medication and consulted their general practitioners more frequently (Schene, van Wijngaarden, & Koeter, 1998, 616). Furthermore, positive symptoms of the patient have been shown to be predictive of the presence of caregiver infectious illness. In the caregivers of patients with the highest score of positive symptoms, almost 80% had had an infectious illness episode in the past 6 months (Dyck, Short, & Vitaliano, 1999, 414–417). These health changes may be mediated by behavioral factors that require changes in the caregiver's lifestyle or represent responses to the responsibilities of caregiving. These include such factors as having less time to look after oneself, eating poorly, exercising less, not getting enough rest, smoking more, forgetting to take prescription medications and not finding time for medical appointments (Grant, 1999, 420; Burton, Newsom, Schulz, Hirsch, & German, 1997, 165).

Furthermore, caregivers have frequently reported having problems with their mental health. In the study by Salokangas and his co-workers (1991a, 31, 50) 65 % of caregivers assessed their mental health as good although at the same time 59% of them expressed distress. About a third of the relatives felt that their mental health problems were due to the mental illness of a family member. In other studies the proportion of caregivers reporting distress has ranged from 29% to 57% (Oldridge & Hughes, 1992, 250; Barrowclough, Tarrier, & Johnston, 1996, 695; Cornwall & Scott, 1996, 346; Jokinen, 2001, 13; Leinonen et al., 2001, 390; Quinn, Barrowclough, & Tarrier, 2003, 294). In all of these studies the distress was measured by the General Health Questionnaire (GHQ). The corresponding figure of distress for the Finnish adult population has varied from 15% to 24% (Viinamäki, Hintikka, Kontula, Niskanen, & Koskela, 2000, 178; Pirkola et al., 2002, 52). Furthermore, 17–40% of the caregivers have reported depressive symptoms indicating the presence of some level of depression (Oldridge & Hughes, 1992, 250; Reinhard, 1994a, 83; Struening et al., 1995, 107; Dyck et al., 1999, 414; Nyman & Stengård, 2001, 69). In a Finnish epidemiological study 13.5% of men and 20.2% of women had mild depression and 2.6% of men and 4.0% of women had moderate depression (Varjonen, Romanov, Kaprio, Heikkilä, & Koskenvuo, 1997, 334). Compared to the results from Finnish population studies, the caregivers of people with mental illness report more psychological distress and symptoms of depression.

2.3. Psychoeducational interventions

The impact of the family on the course of illness, as well as the effect of illness on family functioning, have become an important focus of research and treatment (Mueser, Bellack, Wade, Sayers, & Rosenthal, 1992, 674). In order to prevent relapses and to help the family members to cope with the illness, a variety of psychoeducational interventions has been developed.

Although the concept “psychoeducation” is widely used in the literature on family interventions, it is rarely defined and there seems to be little consistency in the way it is used. It has been used to refer to a wide range of interventions focusing on educating and supporting patients (Bernier, 1992, 126) as well as to family interventions varying from lecture series and support groups to family therapy (Hatfield, 1990, 62). Family interventions have been variously referred to as psychosocial, psychoeducational, family education, family management, family support, family-based, informational, or combinations of these terms. However, the term family therapy is rarely used in this literature, and generally refers to family interventions such as systems approaches (Fadden, 1998b, 293–294).

Barter (1984, 183) has defined psychoeducation as

“the use of educational techniques, methods and approaches to aid in the recovery from the disabling effects of mental illness or as an adjunct to the treatment of the mentally ill, usually within the framework of another ongoing treatment approach or as part of a research programme.”

Anderson, Reiss and Hogarty (1986, vii–viii), have described psychoeducation as

“a method of care that provides attention to the family system without sacrificing the potential contributions of biological, psychological and vocational systems” and which will “sustain patients in the community, and minimize relapse without undue stress on family members themselves”.

In the following, I will use the concept “psychoeducational intervention” as a general term referring to different types of interventions focusing on information giving and skill development. However, the literature review is

restricted to studies concerning family interventions and no results of individual psychoeducation interventions are presented here. The main types of psychoeducational interventions (family psychoeducation, family education, family consultation and support groups) will be described with research findings on the efficacy of each type of intervention.

2.3.1. Family psychoeducation

Family psychoeducation refers to those family interventions where the patient and family members are seen together, where there is a skills-acquisition component in addition to a didactic element and where the primary aim is reduction of relapse in the patient (Fadden, 1998b, 294). The predominant conceptual basis for these programs is derived from research on the diathesis-stress model and expressed emotion. However, Goldstein and his co-workers (1978) investigated an intervention based on crisis theory and McFarlane's and his co-workers' (1995) multiple family group approach combines elements from psychoeducation and social support. Psychoeducation includes both educational and therapeutic components. In the beginning of the intervention, much care is devoted to establishing a collaborative working relationship where the family and therapist together attempt to find new ways of coping and effective solutions to problems faced. There is usually an emphasis on sharing information about the etiology, prognosis and symptomatology of the disorder. The professionals bring knowledge to the sessions and so do the family members, and the person who has experienced the illness is seen as a particular 'expert' on the disorder (Goldstein, 1991, 123–124; Fadden, 1998a, 116–117; Solomon, 1996, 1364–1365; Grunebaum & Friedman, 1988, 1184–1187; Falloon, Laporta, Fadden, & Graham-Hole, 1993, 1–6).

The educational component is usually an introduction to more intensive family treatment. The intervention aims to help family members to acquire a range of coping skills which will help them to deal with the difficulties of having a family member with a serious mental disorder. There is an emphasis on communication, and an attempt to help family members to learn more constructive methods of interacting with each other. At the same time, it is acknowledged that there may be some feelings within the family such as anger, irritation and disappointment which may be difficult to express. Participants are encouraged to find ways of expressing these feelings and reducing the likelihood of their occurring with excessive frequency in future. In addition to the attention paid to shared family goals and difficulties, all family members

are encouraged to have their own interests and goals which they would like to achieve. These may include maintenance of social activities or personal hobbies which give individuals a break from others in the family (Goldstein, 1991, 123–124; Fadden, 1998a, 116–117; Solomon, 1996, 1364; Grunebaum & Friedman, 1988, 1184–1187).

Generally the programs are part of a comprehensive treatment package for the patient that includes medication and outpatient clinical management or in some cases social skills training. Families are generally asked to be involved in the intervention for a minimum of nine months, with some approaches asking as much as a two-year commitment. The interventions are typically initiated at a point of crisis for the patient and his family, for example, during the patient's hospital stay or on discharge. These interventions may vary in implementation strategies (group versus individual approaches); setting (home versus clinic); intensity and duration of the educational component; extent of involvement of the ill relative; credentials and qualifications of the providers, and whether the focus is on problem-solving skills, communication, or behavioral management (Solomon, 1996, 1364). Psychoeducation has been used most extensively with families of patients with schizophrenia (Fadden, 1998a, 118; Solomon, 1996, 1364), although it has also been applied to those with depression, bipolar disorders, anxiety disorders, chronic physical health problems and dementia (Glick, Burti, Okonogi, & Sacks, 1994; Goldstein & Miklowitz, 1994; Falloon et al., 1993, 11).

The research on family intervention began in the late 1970s, with the consistency of findings in controlled trials becoming apparent through a number of publications in the 1980s. The results of earlier studies were remarkably similar and striking in effect. In those families who received the psychoeducational intervention, the relapse rates in the patient at nine months' post-intervention ranged from 6–12% compared with rates of 41–53% in the routine treatment control group. While rates of relapse increased during the follow-up period, at two years' post-intervention these were significantly lower in the intervention groups (17–40%) compared with the control groups (66–83%). Until 1990, therefore, the picture was relatively clear: family interventions with the common characteristics outlined above were very effective (Fadden, 1998b, 296–297).

While critics of these studies argued that psychoeducational interventions simply delayed rather than prevented relapse, it became clear that the eventual outcome in schizophrenia is better the longer relapse can be delayed or prevented. Thus, the interest in family interventions grew rapidly as researchers tried to ascertain if the findings of the original studies could be replicated

across cultures, in different settings, with different disorders and by ordinary clinicians in routine clinical practice (Fadden, 1998b, 297–300).

The conclusions of recent literature reviews of family intervention studies conducted (Penn & Mueser, 1996; Fadden, 1998b; Dixon, Adams, & Lucksted, 2000; Bustillo, Lauriello, Horan, & Keith, 2001; Pharoah, Mari, & Streiner, 2001; Pekkala & Merinder, 2001; Cuijpers, 1999; Falloon, Roncone, Held, Coverdale, & Laidlaw, 2002) and a recent meta-analysis of research findings (Pitschel-Walz, Leucht, Bäuml, Kissling, & Engel, 2001) all concur that substantial evidence supports their effectiveness in reducing relapse. Family interventions may also decrease hospitalization and encourage compliance with medication. Furthermore, long-term family intervention is effective for reducing expressed emotion, and improving outcome among individuals with schizophrenia. The superiority of family intervention over customary outpatient care has also been demonstrated. Different types of comprehensive family interventions have similar results. The effects of family interventions and comprehensive patient interventions are comparable, but the combination of these two does not yield significantly better results than either patient or family intervention alone. There is also some evidence that family intervention reduces family burden and psychological distress, improves the relationship between patient and relative and enhances family functioning. The treatment gains of family interventions are fairly stable; gains may be maintained for as long as 2 years. However, the pioneering clinicians who first evaluated family interventions seemed to get better results than those who came later. It is feasible that family intervention is less potent in the hands of those who have learnt from past work rather than those who formulated the approach.

Although the specific elements and construction of the various programs differ, successful programs have several characteristics in common: they regard schizophrenia as an illness; they are professionally created and led; they are offered as a part of an overall treatment package that includes medication; they enlist family members as therapeutic agents, not patients; they focus on patients' outcomes, although family outcomes are important; they do not include traditional family therapies which assume that behavior and communication within the family play a key etiological role in the development of schizophrenia (Dixon et al., 2000, 6).

However, psychoeducational family interventions have several limitations, many of which are due to links between program design and the design of the research studies in which the interventions were investigated. Most interventions were designed to fit the requirements of random clinical trials, which had stringent eligibility criteria that limited the range of families who partici-

pated. Given the heterogeneity of families with an adult member with a major psychiatric disorder, the findings of these studies have limited generalizability (Solomon, 1996, 1365). Psychoeducation has also been criticized because of its primary focus on reduction in relapse in the ill relative, and for failing to address the needs and concerns of the family members in their own right (Hatfield et al., 1987, 223).

The identification of active ingredients for different interventions has had very limited success. Beyond the general advantage of sustained over brief interventions in terms of primary outcomes, little is known regarding the specificity of the various treatments. Even for family interventions, the construct of expressed emotion has not been clearly shown to underlie the efficacy for relapse prevention. Also, when two forms of family interventions are compared, the literature is consistent that no advantages are apparent. Little is also known about the characteristics of families and patients who do not benefit from family intervention. Because the effects of these interventions are mainly on relapse prevention, in populations of patients in which the base rate of relapse is already low (such as medication compliant persons early in their illness), there may be no advantage in adding family intervention. Future studies should concentrate on identifying the minimal intensity of services that will maintain the relapse-preventing effects and examining whether some subgroups of patients may benefit in particular (Bustillo et al., 2001, 172; Penn & Mueser, 1996, 612; Dixon et al., 2000, 14; Cuijpers, 1999, 282).

Despite the well-documented efficacy of family interventions for people with serious mental illness, the use of psychoeducation in routine practice has been limited. In the cross-cultural study by Magliano and his co-workers (1998a, 418; 1998b, 408, 411) the percentage of relatives receiving information about the patient's illness showed a wide variation across five European countries, ranging from 2% to 96%. However, psychoeducational interventions were provided to less than 15% of families of schizophrenia patients in each of these countries. However, Ruggeri and her co-workers (2003, 235) reported that family sessions were provided for 7–55% of people with schizophrenia in five other European countries and further 10–19% of them did not receive but wished for family sessions. Dixon and her co-workers (1999, 236) reported that in the United States 30% of families had received information about illness or advice or support.

Barriers at the level of the consumer and the family members, the clinician and the administrator, and the mental health authority reflect the existence of attitudinal, knowledge-based, practical, and systemic obstacles to implementation. Family psychoeducation dissemination efforts that have been success-

ful to date have built consensus at all levels, including among consumers and their family members; have provided ample training, technical assistance, and supervision to clinical staff; have maintained a long-term perspective. Success has also been more likely at sites where the treatment model has been viewed more positively at the outset, where real and perceived resource limitations have been addressed, and where attention has been paid to the difference between new and existing treatment methods (Fadden, 1997, 604–608; Dixon et al., 2001a, 907–908; Amenson & Liberman, 2001, 591; McFarlane, 2001, 939–940). Understanding and addressing the lack of penetration of these models into clinical practice is an important priority for future research in this area (Mueser & Bond, 2000, 29).

2.3.2. *Family education*

Unlike psychoeducation, which was developed to meet the needs of the ill relative, family education interventions have been designed primarily with the needs of families in mind (Solomon, 1996, 1365). The goals of family education programs are to provide information for the families, to reduce their stress and burden, to increase their coping skills, and to improve the quality of life for them and their ill relative. Such programs may be primarily didactic or may combine didactic and experiential elements, offering participants the opportunity to practice the skills they are learning (Solomon, 1996, 1366; Atkinson & Coia, 1995, 70). The inspiration for family education programs is found in health education, parent education for those with disabled children, and adult education rather than in family therapy (Hatfield, 1990, 56–58; Guerney, Stollak, & Guerney, 1971, 276–277). The conceptual framework for these programs is based on findings about stress, coping, adaptation, and social support (Hatfield, 1987, 65–81).

The function of family education is to develop long-term, organized bodies of knowledge and generic problem-solving skills that will help the family members to solve problems in their lives both in the present and the future. The focus in education is on the broad application of what is learned and its retention over time (Hatfield, 1990, 56; Solomon, 1996, 1365). The educational needs of relatives have been well established (Kazarian & Vanderheyden, 1992, 67; Salokangas et al., 1991a, 67–70). The relatives of patients with schizophrenia and affective disorder report needs similar to each other, and the few differences are limited to their interest in learning how to cope with char-

acteristic symptoms of each disorder (Stengård, Jokinen, Pajala, & Nyberg, 2000, 16; Mueser et al., 1992, 678; Pollio, North, Osborne, Kap, & Foster, 2001, 205). Family education usually provides information on diagnosis, etiology, symptoms, course, treatment and services available.

While many families may need immediate information and advice for the sake of efficiency, they also need to develop a background of information and general problem-solving and coping skills. For families of severely mentally ill patients, coping involves continual adjustments to frequent crises and disruptions in daily life (Hatfield, 1990, 56; Solomon, 1996, 1365). Learning better coping skills is likely to increase the family members' confidence or self-efficacy in managing their relative's illness and in reducing their stress and burden. In addition, supportive relationships are essential components of education for families. The professionals' task is to communicate interest and empathy for the painful dilemmas that the caregivers face; offer reassurance and hope, and express confidence in their strength and competence to solve the present problems (Hatfield, 1990, 59; Solomon, 1996, 1366; Atkinson & Coia, 1995, 70). Supportive relationships with professionals and other families with similar experiences may buffer stress (Crotty & Kulys, 1986, 183). Furthermore, learning new skills in a supportive environment may help the family to adapt to their relative's mental illness (Solomon, 1996, 1366).

Despite the similarity of the content, the way in which family education is delivered has been wide-ranging, including individual family sessions with the patient present (McGill, Falloon, Boyd, & Wood-Siverio, 1983), individual education for relatives with the patient absent (Berkowitz, Eberlein-Friess, Kuipers, & Leff, 1984; Berkowitz, Shavit, & Leff, 1990; Budd & Hughes, 1997), separate and then joint sessions (Barrowclough et al., 1987), relatives' groups (Smith & Birchwood, 1987; Abramowitz & Coursey, 1989; Cazzullo et al., 1989; Pakenham and Dadds, 1987; Cozolino, Goldstein, Nuechterlein, West, & Snyder, 1988; Kane, DiMartino, & Jimenez, 1990; Posner, Wilson, Kral, Lander, & McIlwraith, 1992; Cañive et al. 1996; Sidley, Smith, & Howells, 1991; Winefield & Harvey, 1995), separate groups for patients and relatives (Merinder et al., 1999b) and multi-family groups with patients (North et al. 1998; Mills & Hansen, 1991). The style of presentations includes lectures (Cazzullo et al., 1989; North et al., 1998), oral presentation and written handouts (McGill et al., 1983; Sidley et al., 1991), lectures, discussion and course manual (Atkinson & Coia, 1995), handouts alone (Smith & Birchwood, 1987), video (Birchwood, Smith, & Cochrane, 1992; Winefield & Harvey, 1995), and some have included homework (Birchwood et al, 1992; Sidley et

al., 1991). The groups are usually led by mental health professionals. However, sometimes they are accompanied by family members (Solomon, Draine, Man-nion, & Meisel, 1996; Lundwall, 1996).

The information has been given over varying amounts of time and numbers of sessions, ranging from one (Cozolino et al., 1988) to sixteen (Cazzullo et al., 1989). When patients are included, they are encouraged to talk about their experiences and psychotic symptoms to aid relatives' understanding (McGill et al., 1983). Relatives have been targeted at different times: during hospitali-zation of the patient (Berkowitz et al., 1984), as a part of aftercare when the patient has been stabilized on medication (McGill et al., 1983) or as a new serv-ice open to all (Winefield & Harvey, 1995). Furthermore, the target group has varied according to the diagnosis of the patients. Most interventions have been offered to the relatives of patients with schizophrenia (e.g. Sidley et al., 1991; North et al., 1998; Merinder et al., 1999b; Winefield & Harvey, 1995), seri-ous mental illness (Mclean, Creer, Scott, & Beck, 1982; MacCarthy, Kuipers, Hurry, Harper, LeSage, 1989a; Mills & Hansen, 1991; Lundwall, 1996; Stam & Cuijpers, 2001) and affective disorders (Daley, Bowler, & Cahalane, 1992; Bland & Harrison, 2000).

The value of family education as the sole intervention in effecting knowl-edge acquisition, change in attitudes and behaviors, and prevention of relapse has not been consistently demonstrated. However, their continued implemen-tation and evaluation seem justified on several grounds. Relatives participating in these programs tend to rate them as helpful and, in some instances, such programs seem to relieve guilt and self-blame in families. Family education programs, as components of long-term psychoeducational interventions, may prove to be important means of initiating support for relatives, establishing a partnership and therapeutic alliance with them, and engaging them in the long-term interventions. Furthermore, dismissal of family education programs as ineffective seems premature, as the nature of the content of these programs, their format and manner of delivery, and their interaction with such factors as expressed emotion status, type of patients, symptomatology of patients, and gender require further inquiry. In addition, the effective and non-effective components of the various family education programs have not as yet been isolated. The most effective timing for the implementation of family educa-tion programs and timing for the inclusion of the patient in the family edu-cation process is at best based on guesswork at present. Finally, the majority of the family education programs have been implemented and evaluated on relatives of patients with schizophrenia. Their extension to relatives of patients

with various other psychiatric conditions is warranted (Kazarian & Vanderheyden, 1992).

2.3.3. *Family counseling*

Instead of the group format used in family education, the family consultation model uses a one-to-one format in which a consultant meets with family members or the family unit without the ill relative present. The goal of family counseling is to offer support and information in the face of real environmental stresses. Family counseling involves minimal etiological assumptions and the adaptive capacities of the family are the focus of attention instead of pathologies. The goal is not to cure the illness, but to relieve as much of the stress as is possible and to increase the patient's and the family's ability to live with the illness successfully. The counseling sessions might extend from two to six meetings, but many clients maintain contact over the telephone for months or years, calling whenever a problem or a crisis arises (Bernheim, 1982, 635; Simon, 1989, 294–295; Bloch, Szmukler, Herrman, Benson, & Colussa, 1995, 415).

Although education may be the most efficient way to prepare families to cope with mental illness on the long haul, education may meet less well the needs of families in crisis or those families who prefer a one-on-one type of relationship. In the family counseling model, education is adjunctive to advice, support, and guidance. The consultative function is primary and the educational function secondary. An assumption of the consultative model is that families who develop the appropriate knowledge and skills will be able to solve their problems with minimal direction from the consultant. Families are seen as the experts on the problems they face. The consultant provides a supportive relationship and helps families obtain the information they need to define their objectives and develop strategies to meet them (Solomon, 1996, 1366; Hatfield, 1990, 60).

Central to consultation is an emphasis on establishing a collaborative role relationship as the framework for discussing and agreeing upon a plan of action (Warwar & Greenberg, 2000, 573). The clinician and the family collaboratively share information about the problem: the family has a wealth of observation to share with the clinician, and the clinician will have specialized experience and information to share with the family. The clinician takes stock of the situation with the family and considers options from as broad a perspec-

tive as possible, but the decision whether to take one course of action versus another is clearly up to the family (Wynne, 1994, 129–130). This approach leaves options open until a thought-out consensus about how to proceed has been reached.

A beneficial process of counseling passes through a number of stages that are not always clearly distinguished from one another. Mannion and his co-workers (1997, 558–559) divided the consultation process into three phases, feeling or connecting, focusing and finding. Even though the family usually comes with specific requests for information there is an even more compelling need to tell one's story of caring for the ill relative (the feeling phase). Many family members also express grief, guilt and a sense of inadequacy. These personal aspects cover needs and emotional states related to caregiving. These feelings need venting and have to be worked through with empathic understanding. Only when the air has been cleared about hidden anxieties and concerns can the family members assimilate information about the issues that have brought them to the counseling in the first place (Simon, 1989, 295; Bloch et al., 1995, 416).

Following the provision of general information about the illness (the focusing phase), the clients are introduced to a series of concrete principles and techniques for managing the patient (the finding phase). The topics discussed with caregivers include for example the negative role of stress in the course of schizophrenia, setting limits and dealing with specific symptoms like delusions. The clinician also helps the family to make decisions about the handling of various day-to-day problems (Simon, 1989, 296; Bernheim, 1982, 638–639). Other themes common in counseling include family and social dimensions of caregiving. The caregiver might be involved in multiple caregiver roles, providing help not only to the family member with mental illness but also to other members of the family who suffer from physical illness or other disabilities. The caregiver might also be burdened with conflicts within the family about how best to manage the patient. Other family members or relatives may criticize or fail to acknowledge the caregiver's efforts. Stigmatizing attitudes in the community and inadequate mental health services are also common themes in counseling (Bloch et al., 1995, 417–418).

Only little is known about the effects of family counseling, since these interventions have not been extensively studied. Szmukler and his co-workers (1996b, 149, 154–155; Bloch et al., 1995, 422–423) assessed the value of six weekly sessions of counseling for relatives of patients with schizophrenia in a randomized controlled study. The counseling had educational and problem-solving components and was conducted in the family home in the absence

of the ill relative. The family members brought out a wide range of concerns including personal feelings, coping difficulties, family aspects and problems with health services. The effects of the intervention were limited. Gains were in the area of a better understanding of the patient and in the perception of a more positive relationship. The latter included a sense of the carer having contributed to the patient's well-being. There was no evidence of a change in coping or of an alleviation of the negative experiences of caregiving. However, the intervention was highly satisfactory to carers, and all participants would have recommended it to others. The caregivers welcomed an individual approach in which their personal needs could be focused on. The authors concluded that the intervention was probably too short for many caregivers and in future counseling interventions should be organized within the clinical team instead of an outside counselor.

Mannion and his co-workers (1997, 558–560, 567) conducted a random field trial of two family interventions comparing the effects of a 10-week group workshop and individualized consultation with a 9-month waitlist group. The individualized consultation of 6–15 hours increased the family members' sense of self-efficacy or self confidence in handling serious mental illness in their ill relative. The group workshop was effective in increasing the self-efficacy of family members who had not participated in support groups before. Based on these results the authors modified their family group intervention into a group consultation model incorporating the advantages of both the group workshop and individualized consultation. A process evaluation on this new approach revealed that it was very well received and capable of meeting the diverse needs of family members. However, Glynn and Mueser (1997, 573) pointed out that the intervention described is very brief and therefore likely to be of limited use. Furthermore, not all family members are willing to participate in any group meeting and should be offered an option for individual family meetings.

Solomon and her co-workers (1996, 43, 47; 1997, 183) compared the effects of individual consultation and group psychoeducation with a waitlist. The individualized consultation increased the family members' confidence in one's ability to understand mental illness in a relative and to cope with its consequences. Group psychoeducation was helpful in increasing self-efficacy of family members who had never participated in a support or advocacy group for relatives of psychiatrically disabled individuals. While the positive effect for self-efficacy of both interventions was retained at six-month follow-up, the continued maturation of the control participants resulted in a lack of effect between the three study conditions. These results suggest that the natural

process of maturation over time improves families' self-efficacy, but that family education can hasten this process.

Families seem to be receptive to the family counseling model and its use may well improve the services for families, but further research is needed before conclusions about its effectiveness can be drawn.

2.3.4. Self-help and support groups

Self-help groups are voluntary, small group structures for mutual aid and accomplishing a special purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and personal change. The initiators and members of such groups perceive that their needs are not, or cannot be, met by or through existing social institutions. Self-help groups emphasize face-to-face social interactions and the assumption of personal responsibility by members. They often provide material assistance, as well as emotional support; they are frequently "cause" oriented, and promulgate an ideology or values through which members may attain an enhanced sense of personal identity (Katz & Bender, 1976a, 9).

The concepts of self-help group and support group are often used as synonyms. However, they differ from each other in three major aspects. First, self-help groups often use ideologies (e.g. AA) to achieve change, whereas support groups do not normally espouse an ideology. Second, professionals rarely play an active role in self-help groups, whereas professionals often facilitate support groups. About one quarter of the groups have been reported to be professionally led, 27 % peer led, and the rest have had shared leadership. Professionals have also been involved with groups in other ways, as consultants, referral sources, and sponsors (Wituk, Shepherd, Slavich, Warren, & Meissen, 2000, 157). Third, self-help group meetings are structured and task-oriented, whereas support group meetings are relatively unstructured (Schiff, 2000, 276). In the following the term self-help group is used to refer to peer led groups for relatives ("vertaisryhmä" in Finnish) and concept support group refers to professionally led groups.

In order to understand the self-help activities of the caregivers of people with mental illness, it is useful to distinguish between self-help groups and self-help organizations. The self-help groups are based on the direct personal contact with other family members in similar situations and struggling with similar problems. Many of these groups have gradually turned into formal

family organizations and gained additional new dimensions, provision of services and attempts to influence public opinion. This public-relations work mainly consists of organizing informational events, lectures, meetings, and media appearances in order to educate politicians, professionals and students in training about the needs of carers. Education is also aimed at the general public to raise the awareness of the problems of people with mental illness and their relatives, and to reduce the stigma, misconceptions and misinformation that surrounds mental illness. Some family organizations do not restrict themselves to exerting pressure on institutions and authorities to establish adequate new facilities and services, but establish services of their own (Katschnig & Konieczna, 1987, 194–195; Atkinson and Coia, 1995, 114–115, 117). In Finland, the family organizations provide a variety of support services for the family members including counseling, educational courses, self-help and support groups, vacations, and recreational activities.

The primary goal of caregivers' self-help and support groups is to help members cope with stressful life events and to enhance members' coping abilities so they can effectively adapt to and cope with future stressful life events. The helping characteristics of such groups can be divided into four domains (Wituk et al., 2000, 157; Atkinson & Coia, 1995, 115; Schiff, 2000; Orhagen & d'Elia, 1992b, 17; Kuipers & Westall, 1993, 563; Riessman & Banks, 2001, 173–174; Heller, Roccoforte, Hsieh, Cook, & Pickett, 1997, 190, 195–196). First, the accepting atmosphere of the group allows participants to air feelings, especially negative ones such as shame and guilt. Participants also help each other to carry out grief work. Seeing that others are coping with similar problems offers a sense of hope and strengthens a sense of control over the situation. Second, an important objective of these groups is interpersonal support and understanding received from other group members. The group offers an opportunity to meet like-minded people, and to discuss and share experiences with others. In the process of helping others, the participants also help themselves. Third, belonging to a group facilitates social interaction and provides opportunities to expand natural network. Relatives often report restrictions in their social networks because of the mental illness of a family member. The realization that others in the group are in a similar situation comes as a relief offering a feeling of not being alone. Another major contribution of support groups relates to the acquisition of experiential knowledge and learning coping and problem solving methods. Informal discussions with group members gives answers to questions and offers help with specific problems. New information and skills promote feelings of mastery and open up possibilities for constructive changes. Developing a sense of perspective about problems

and learning how to solve them helps both carers and patients to achieve an appropriate level of adult independence in the long run. Group members who feel that obtaining information from others' personal experiences and gaining support and self-understanding are more likely to derive benefit from belonging to the self-help group. A greater degree of perceived benefit from group participation is also related to a greater length of participation in the group (Citron, Solomon, & Draine, 1999, 25–26).

Katschnig and Konieczna (1989, 147–148) compared the goals of family therapy and relatives self-help. They concluded that the reduction and prevention of psychopathological symptoms is the main task of professionals, whereas the goal of improving the quality of life is mainly one for relatives' self-help groups. These two goals are intimately related to each other, and when either is reached, the attainment of the other will also be facilitated to some degree. When a professional succeeds in reducing the symptoms through medication or psychotherapy, this also improves the relatives' quality of life. Similarly, when relatives attain greater satisfaction in life through participation in self-help groups, domestic tensions will be reduced, and the risk of relapse diminished.

Hogan and her co-workers (2002, 391, 424–425) concluded that 83% of reviewed studies of social support interventions reported at least some benefits of support interventions relative to either no-treatment or active controls. Furthermore, it was noted that interventions that emphasized reciprocal support (both giving and receiving support) demonstrated more encouraging results, suggesting that merely receiving support may not be as potent as mutual exchange of support. However, because of the wide variety of existing different treatment protocols and areas of application, there is still not enough evidence to conclude which interventions work best for which problems.

In addition to various types of self-help and support groups, special family education programs have been developed by caregivers themselves. The best known peer-led programs are the Family-to-Family Education program in the United States, *Coping with Schizophrenia: 14 Principles for Relatives* developed in Australia and the recently launched Prospect Program in Europe.

The Family-to-Family Education Program (previously called Journey of Hope) is the most widely used family education program in USA. It was developed in the early 1990s by Joyce Burland and is sponsored by the National Alliance for the Mentally Ill. This 12-week program is taught by trained family member volunteers with the use of a structured manual. In weekly two- to three-hour sessions, family caregivers receive information about mental illnesses, treatments and medication, and rehabilitation. They learn self-care

and communications skills as well as problem-solving and advocacy strategies (Dixon et al., 2001b, 965–966).

Both versions of this family education program have been evaluated. The participants of the Journey of Hope Program reported better understanding of their ill relative's symptoms and managing difficult behavior. They felt that they got along better with their ill relative, and had more realistic expectations of what he or she could do. Participants reported increased awareness of the different mental health programs available to them, and knowing how to advocate for better care. They felt less guilty about their relative's illness, and less isolated. Finally, after taking part in the program, participants felt more empowered, took better care of themselves, and had a happier outlook on life. These findings suggest that the program may meet a diverse range of family needs which differ according to their relative's diagnosis. The program may help families cope better by helping them understand the etiology and treatment of mental illness and the service system and improving their morale (Pickett-Schenk, Cook, & Laris 1997, 28; 2000, 415, 422–423). Furthermore, the Family-to-Family Education Program has been shown to enhance family members' empowerment and to reduce their depressive symptoms, to reduce their subjective burden of mental illness by diminishing worry and displeasure. The benefits were sustained for six months after program completion. However, the program did not appear to affect the participants' objective burden of mental illness nor did it affect their self-esteem or sense of mastery (Dixon et al., 2001b, 965–966; Dixon et al., 2004).

The Australian family education program *Coping with Schizophrenia: 14 Principles for Relatives* was developed by Ken Alexander in the beginning of the 1990s (Alexander, 1991, 1995). The course material is based on fourteen principles Ken Alexander found in his first hand experience to be most effective aids to coping (Alexander, 1995, 3–5). The objective of the course is that the relatives become better able to cope with the impact that schizophrenia has on the family members and become better able to help the family member with schizophrenia. The full education program consists of 18 three-hour sessions, divided into four courses. The first three courses are for relatives, regardless of whether they aim to become group leaders themselves. Course 4 is only for prospective group leaders who may be either trained relatives of people with schizophrenia, or members of the helping professions who work in the field of serious mental illness. The sessions consist of talks given by the group leader, discussions and workshop exercises. Sessions are given either at the rate of 1 or 2 evenings per week, or 2 sessions per day on a weekend for a group of 12 to 25 people (Alexander, 1995, 10, 106, 118–119). The experi-

ences of the program are positive, but the effects of the program have not been scientifically evaluated.

The Prospect Program has been developed by the European Federation of Family Associations of People with Mental Illness (EUFAMI) with sixteen partner organizations from twelve European countries in 2002–2004. Prospect consists of three separate training programs for those with self-experience of severe mental illness, their families and friends, and health and social care professionals and a Common Ground Module bringing members of the three target groups together to discuss productive communication. Each training program is led by facilitators drawn from the target group. The aims of the Prospect training programs are to support recovery from mental illness and promote inclusion in the community for people with self-experience of mental illness, their families and friends. It trains and educates participants to develop their skills and competencies to create new opportunities for social integration and employment. In addition it seeks to sensitize social and health professionals to new approaches (<http://www.eufami.org/prospect>).

The Prospect Training Programme for Family and Friends stemmed from a need to provide a European family education course which not only addressed the needs of family members but was also developed in conjunction with them. Prospect aims to facilitate families and friends of people with mental illness to exchange and explore experiences and from this develop coping skills specific to their own situation in an atmosphere of understanding. The course is structured in modules allowing flexibility in the provision of the course. It may be run over a weekend or weekly over a number of months. Each module is designed to stimulate discussion between participants about how the illness has affected them. The group setting is used for delivery of new information and for exchange of experiences, problem solving, and diffusing misconceptions that people might have about themselves and mental illness. Participants can also offer one another hope and support in dealing with their family member's illness and thus improving their own quality of life. All facilitators are relatives or friends of people with enduring mental illness. They possess a unique understanding of the situations, feelings and emotions that participants will bring to the course (The Prospect Training Programme for Family and Friends Manual, 2004, 3–6). The Prospect Training Programme for Families and Friends has been tested on several test sessions in ten European countries including Finland. The experiences were promising, but as yet the scientific evaluation on the effects of the program is lacking.

The family education programs conducted outside of the service system clearly have a role when the patient is not in treatment or is unwilling to give

permission for the family to participate in it, making relatives ineligible for professionally led family psychoeducation. Although there is little research on these models, they may serve certain needs psychoeducation does not or have particular strengths because they are peer led and emphasize family well-being (Dixon et al., 2000, 16).

A comparison of the main features of psychoeducational interventions is presented in Table 1. The frameworks of these interventions differ somewhat from each other. Family psychoeducation is based on the diathesis-stress model, whereas stress-coping theory forms the common ground for other types of psychoeducational interventions. The main goal of family psychoeducation is to reduce the relapse rate of the patients and the intervention is clearly used as a part of the patients' treatment. There is usually an emphasis on offering information, practicing communication and problem solving skills and preparing a plan for future crisis situations. Family psychoeducation works best as an integrated part of mental health services, since the provision of this intervention requires formal education and professional skills. The other types of psychoeducational interventions have been developed to meet the needs of family members and the emphasis is more on providing information and support than on acquiring specific skills. These interventions are often used independently of the patient's treatment. This is beneficial in situations where the patient does not give permission to include the relatives in the treatment giving the family members an opportunity to obtain information and support for themselves when needed. In addition to mental health services, family education and family counseling might also be provided by family organizations. Self-help and support groups form a special type of intervention with its strength in the empowerment of the participants. These groups have traditionally been organized by voluntary organizations and provide an excellent complement to the official mental health services. Although there is still need for more studies on the efficacy of these interventions, they are well accepted and rated as helpful by families and therefore their continued implementation seems justified.

2.3.5. Caregivers' satisfaction with services

Caregivers' satisfaction with mental health services has been examined in three types of studies. Several studies on burden and caregiving have also examined caregivers' needs for support and help as well as their experiences of and satisfaction with psychiatric services. Second, users' and caregivers' satisfaction with

Table 1. Summary of psychoeducational interventions for caregivers

	Family psycho-education	Family education	Family counseling	Self-help and support groups
Theory, model, framework	Diathesis-stress, expressed emotion, crises theory	Stress, coping, adaptation, health education	Counseling theory, stress, coping, adaptation	Normalizing experiences, social support
Goals	Reduce relapse rate and stress, improve families' coping abilities	Offer information, improve coping abilities, reduce stress and burden, improve quality of life	Offer information and support, reduce stress, improve coping abilities and quality of life	Improve coping abilities and quality of life, facilitate social interaction, reduce stigma
Target group	Family including the person with severe mental illness	Family members with or without ill relatives	Family or family member without ill relative	Family members without ill relatives
Duration	9 months to 2 years, often started at crises situation	3 to 4 months, possible to start when needed	Open ended, determined by the family	From few times to several years
Content	Educational and therapeutic; used as a part of extensive treatment package	Educational and supportive, independent of treatment of the ill family member	Counseling and educational; independent of treatment of the ill family member	Supportive and experiential; independent of other services
Provided information	Etiology, diagnosis, symptoms, course, treatment	Etiology, diagnosis, symptoms, course, treatment, services	Mental illness, services	Experiential knowledge
Skills taught	Problem solving, communication, management skills	Management of the illness, coping skills	Coping skills, problem solving	Coping and management skills
Strengths	Strong conceptual basis, cost-effective, tendency to foster relationship between family and professionals	Strong conceptual basis, non-blaming, designed to meet family's needs, use of experiential knowledge	Meets specific needs of the family, open to all families	Experiential knowledge and peer support, option to both receive and give support
Limitations	Designed for clinical trials, limited generalizability to other groups, limited availability	Independence of treatment of ill family member, short duration	Independence of treatment of ill family member	Independence of treatment of ill family member
Efficacy	Established by several clinical trials	Established in some studies, results not consistent	Few studies, efficacy not established	Established in some studies, results not consistent

mental health services has been increasingly used as a measure of outcome and quality of care in service evaluation. Third, a few studies have compared the views of professionals, patients and caregivers on mental health services.

The interest in measuring users' satisfaction with health services has increased substantially in the past two decades, but researchers have paid less attention to caregivers' satisfaction. Users have generally expressed high satisfaction with mental health services and the proportion of dissatisfaction has fallen between 10% and 45% (Vicente, Vielma, Jenner, Mezzina, & Lliapas, 1993, 125; Greenwood, Key, Burns, Bristow, & Sedgwick, 1999, 160; Sandlund & Hansson, 1998, 309; Wray, 1994, 117; Ruggeri, Dall'Agnola, Agnostini, & Bisoffi, 1994, 270; Merinder et al., 1999a, 299). Caregivers have been found to be more dissatisfied with mental health services than patients, general practitioners, or social workers (MacDonald, Ochera, Leibowitz, & McLean, 1990, 192). Caregivers also have higher expectations of community psychiatric services compared to those of patients (Ruggeri et al., 1994, 270). The proportion of dissatisfied relatives with mental health services has varied between 3% and 61% (Ruggeri & Dall'Agnola, 1993, 518; Grella & Grusky, 1989, 833–834; Wray, 1994, 117–118; Merinder et al., 1999a, 299; Vicente et al., 1993, 125). In addition, carers have reported dissatisfaction with social work, day care services and emergency services (Wray 1994, 117–118; Morgan, 1989, 1268). In Finland, 25% of caregivers reported being satisfied with psychiatric services, 45% were partly satisfied and partly dissatisfied, and 30% were clearly dissatisfied (Salokangas et al., 1991a, 62).

With the emphasis on community care, relatives have a lot of responsibility for caring for people with mental illness. While this process demands close collaboration between mental health professionals and family members, patients perceive that relatives are not involved enough in the process of care (Ruggeri et al., 2003, 237; Merinder et al. 1999a, 300; Sandlund & Hansson, 1998, 309; Perreault, Paquin, Kennedy, Desmarais, & Tardif, 1999, 160–162). Caregivers have also expressed dissatisfaction with various dimensions of services. In Finland, 21–31% of family members were dissatisfied with the availability of professionals during crisis situations, the information they were provided, their involvement in treatment planning, the level of interest shown by professionals in the information family members could give about the patient, and the professionals' interest in the problems family members had with the patient. The corresponding figures of dissatisfied family members in the Netherlands were 19–48% (Schene & van Wijngaarden, 1995, 809–810). Relatives have also been dissatisfied with the amount of time spent talking with

the doctors and with the amount of sympathy and understanding of doctors (Leavey, King, Cole, Hoar, & Johnson-Sabine, 1997, 54).

Furthermore, families have expressed a need for emotional support, information and practical advice, help in problem solving and planning for the future, respite from caring, financial support, crisis services, continuity of care, and assistance in finding community services (Holden & Lewine, 1982, 628–629; Grella & Grusky, 1989, 833–834; Kuipers, 1993, 208–209; Stengård et al., 2000, 16–17; Salokangas et al., 1991a, 67, 77; Jokinen, 2001, 26; Ascher-Svanum, Lafuze, Van Dusen, & Fompa-Loy, 1997, 1074; Solomon, Beck, & Gordon, 1988, 112; Rose, 1998, 144–145). Caregivers have also worried about patients often being discharged from hospital before they are fully stabilized and about many treatments showing no results. Relatives have pleaded for more patient-care alternatives outside the official mental health care system (Schene & van Wijngaarden, 1995, 810). Families find dealing with new and different staff particularly frustrating, as care is likely to continue for many years and through many stages of the life cycle. In some cases, caregivers and ill family members are not be able to live together, however much respite is provided. In these situations reasonable alternatives for the patient, such as sheltered accommodation, might be needed (Hanson & Rapp, 1992, 188; Kuipers, 1993, 208–209; Friedrich, Hollingsworth, Hradek, Friedrich, & Culp, 1999, 512). Families also want help in locating people with similar experiences of mental illness, in order to reduce their experience of alienation (Wynne, 1994, 126).

However, studies have reported more positive findings since the late 1980s. Hatfield and colleagues (1996, 827) reported that caregivers rated all services in 1993 as having more value than in 1976. Families placed the highest value on medication, hospitalization, individual therapy, case management, residential care and crisis services. Biegel and co-workers (1995, 479) reported that two thirds of the caregivers in their sample were satisfied with their contacts with professionals. Nevertheless, caregivers ranked more communication with professionals as their greatest need. Mira and associates (1997, 126–127) showed that although the caregivers of severely ill patients saw therapists as competent, available, and polite, they found them lacking in skills for adequate communication with the patients and families. Tessler, Gamache and Fisher (1991, 932–933) found that 53–73% of the relatives were satisfied or very satisfied with the outcomes of past and current contacts with professionals. Relatives were most satisfied with their contacts with psychologists, followed by nurses,

case managers, social workers, and psychiatrists. Particularly interaction with the case manager has been found to contribute significantly to the extent of the families' satisfaction with the service system (Grella & Grusky, 1989, 833–834). However, in a recent study in Finland, only 37% of caregivers reported being satisfied with mental health professionals, 43% were both satisfied and dissatisfied and 20% were dissatisfied (Nyman & Stengård, 2001, 56).

Previous satisfaction research has been criticized on both theoretical and methodological grounds and their usefulness in generating change in health service provision has also been questioned (Williams, Coyle, & Healy, 1998, 1351). The findings suggest that respondents give positive satisfaction ratings for general statements, but more variable responses to specific items such as advice on treatment, information about the illness, ability to get speedy help and privacy and activities on the ward. It may be that patients and their relatives are reluctant to criticize services upon which they are so dependent (Leavey et al. 1997, 55). Williams and his co-workers (1998, 1354–1356) have shown that the clients' satisfaction is associated with their perception of the duties and culpability of the services. User might prefer home visits, but not request them because she believes that this is not a responsibility of the service. In addition, while users might feel that the service has failed in its duty, they may not evaluate it negatively because they accept that there are mitigating circumstances for this. If a patient with severe depression has to wait for an appointment for six weeks, she might find this acceptable because of the delay due to holidays and believing that there were many other users with more urgent needs. In these situations clients might be “satisfied” with the services despite the negative experiences with them.

Caregivers' satisfaction with services may vary from country to country, but in general what seems especially to generate dissatisfaction is a lack of emotional support and information, a low level of caregiver involvement, and poor efficacy of treatment. However, involving family members in the process of care and being prepared to take account of their needs are essential to successful community care provision (Ruggeri et al., 2003, 237). Community services should be developed into flexible systems which are necessary if families' needs are to be met (Fadden, 1998a, 120). However, the experience is unique for each family with a mentally ill member. This experience varies greatly at different phases of patient's illness, the stage of the individual and the family life cycle, cultural and economic variations as well as the extent social support from extended family networks are available (Wynne, 1994, 126).

2.4. A model of well-being of caregivers

Three major conceptual frameworks have been used to study the responses of family members to severe mental illness: family burden, expressed emotion and family stress and coping models (Rungreangkulkij & Gillis, 2000). The assumption underlying the family burden perspective is that caring for a family member with severe mental illness imposes a burden on the family and the degree of burden varies according to the background variables and mediating factors (Schene, 1990, 291; Maurin & Boyd, 1990, 105). However, the family burden framework has several limitations. This research has centered on the negative and detrimental aspects of the caregiving process and only recently have researchers noted that caregiving also includes gratifying and positive aspects. Further, the distinction of objective and subjective burden is not clear: most of the changes that are called objective burden are in fact experiences reported by the caregivers themselves, not measured objectively in any sense. It has also been difficult to find out which changes are in fact caused exclusively by the mental illness of a family member and not by other factors of the life situation. Although the framework of family burden is not comprehensive enough to cover all aspects of caregiving, the family burden studies have helped the mental health professionals to understand the effects of severe mental illness on the family members and develop interventions to meet family's' needs for information and support.

Another theoretical framework of family response to mental illness is the research on expressed emotion. Originally developed by Brown, Birley and Wing (1972), the expressed emotion framework studies the emotional environment of families as a factor influencing patient relapse. High EE has been found to be predictive of relapse, poorer response to treatment or disease severity in psychiatric and medical illnesses such as schizophrenia, depression, bipolar disorder, post-traumatic stress disorder, eating disorders, alcohol abuse, obesity, asthma and epilepsy (Kavanagh, 1992, 601; Wearden, Tarrrier & Barrowclough, 2000, 646, 657). Family intervention research also suggests that interventions designed to reduce high levels of EE in relatives also result in decline in patients' relapse rates (Hooley & Gotlib, 2000, 136–137). However, EE research does not imply that families are doing less than their best in coping with a severe mental disorder, given the duration and impact of the disorder on family life, the professional and social support available to the family, and the competence and knowledge base of the family. Expressions of criticism and overinvolvement may be indications of family stress and burden on

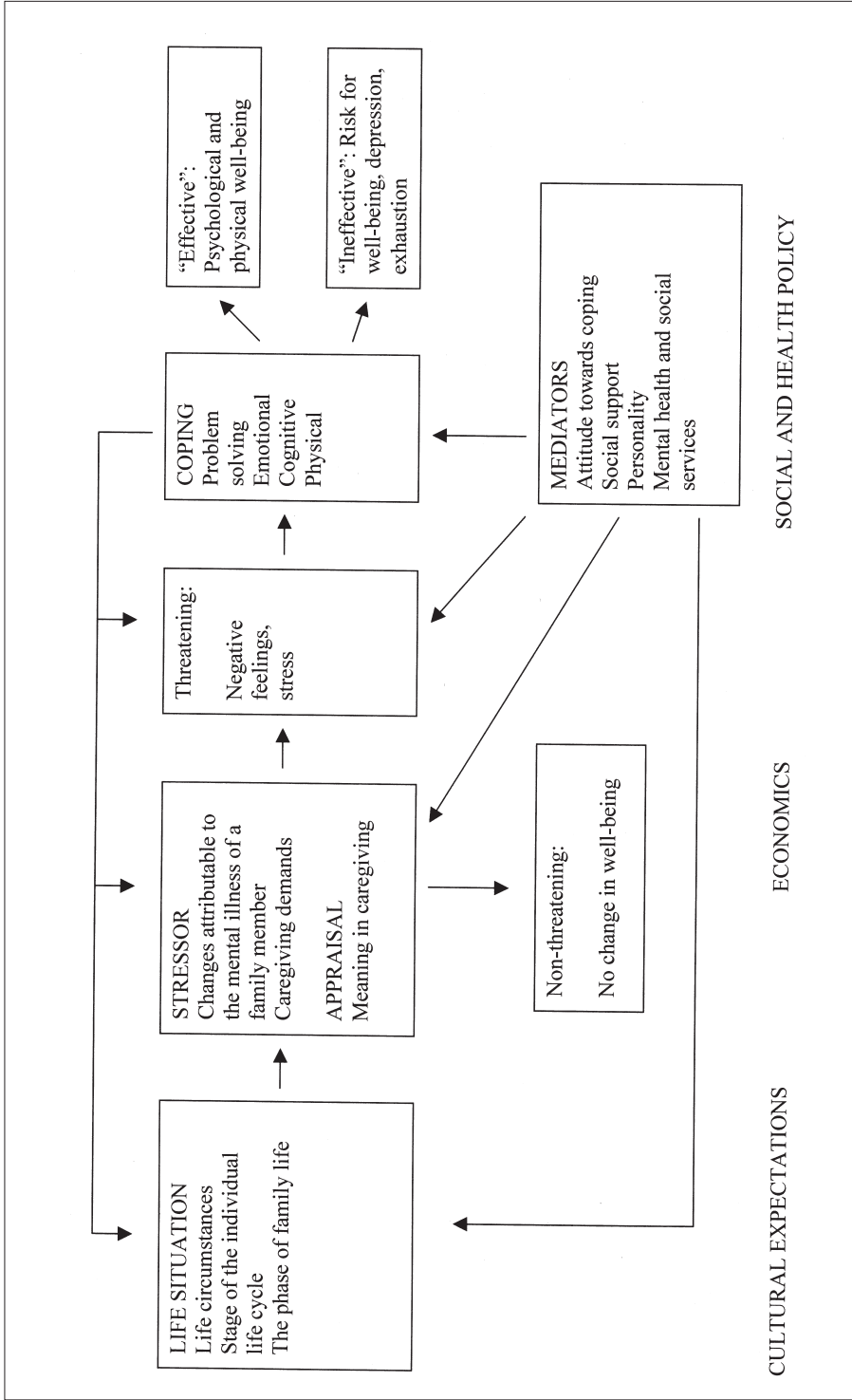
the part of concerned family members attempting to cope with the problems of caring for the ill relative (Mintz, Liberman, Miklowitz, & Mintz, 1987, 229). However, the expressed emotion framework is more usable in describing the well-being of the ill family members than the well-being of the caregivers.

The third commonly used conceptual framework is the stress-coping model originally developed by Lazarus and Folkman (1984) and adapted to the situation of caregiving by Hatfield (1987, 64–81) and Szmulker and his co-workers (1996a, 138–139). A modified version of stress-coping model based on the caregiving literature is presented in Figure 1. In this model it is assumed that family members experience stress as a consequence of responding to the mental illness of a family member. The life situation of an individual caregiver gives a unique context to the process of coping. The socioeconomic situation of the caregivers varies, as well as the phase of individual and family life cycle. A good financial situation provides safety and opportunities to buy the services that are needed. The mental illness affects differently family members depending on their role in the family. The experiences of mothers and fathers differ from those of spouses, siblings or children.

The ill family member's behaviors, disabilities, and perceived disruptions of the carer's life are the stressors appraised by the carer. Caregiving experience is conceptualized as an appraisal of these stressors and caregiving demands. Caregivers give different meanings to the caregiving (Noonan and Tennstedt, 1997). Some caregivers do not find the situation threatening to their well-being because they are not very close to the ill family member and do not have much responsibility for the caregiving or the affected family member does not need very much help and support. However, other caregivers find the situation taxing and appraise caregiving as a stressor threatening their well-being. In this phase, the coping abilities of the caregivers have a central role in attempts to regain balance in their lives. Coping refers to the problem-solving, cognitive and emotional efforts family members make to master the stressful situation. These different modes of coping are not mutually exclusive, and they can be applied simultaneously or sequentially to the problematic situation. Furthermore, the distinction between effective and ineffective coping strategies is not always clear-cut.

Mediating factors, such as the carer's personality, attitude toward coping, or degree of social support and available services may influence the appraisal and the coping strategies used. Outcome of well-being is the result of an interaction between the appraisal and the carer's coping strategies. When coping is insufficient to reduce the appraised stress, the result is psychological or physi-

Figure 1. Stress-coping model of caregiving



cal morbidity. The coping process takes place in the context of cultural expectations of caregiving, the economic situation of the society and existing social and health policy.

The stress-coping model is situated within the context of the individual and is inadequate to explain the family process. The corresponding family model is the Family Resiliency Model of Family Stress, Adjustment and Adaptation developed by McCubbin and McCubbin (1993). In this model family adaptation is seen as the outcome of the family's efforts over time to meet both the needs of individual family members to achieve their personal growth and also the functioning of the family system and its transitions with the community.

The ways families respond to mental illness vary as a function of time. The variation is due to the course of the illness and its treatment as well as other events and developments in the family that are not related to the mental illness. There are no longitudinal investigations of family response. However, based on the clinical experiences, longitudinal process of adaptation or recovery has been described as a series of phases (Terkelsen, 1987, 151–152; Spaniol & Zippel, 1994, 132–133).

Terkelsen (1987) divided the adaptation process into ten phases. The first phase is called “ignoring what is coming” since mental illness often starts with subtle alterations in the behavior of the affected person and family members tend to minimize these early changes by seeing them as normative variations of personality development or responses to stressful life circumstances. Because families approach unusual behavior as manifestations of temporary destabilization rather than as the first signs of an enduring condition, the psychological impact of the illness is still circumscribed. Emotional reactions are confined to intermittent anxiety and vague feelings that something might be seriously wrong. However, eventually the more severe manifestations of mental illness appear and can no longer be regarded as normal or temporary by the family members. At this time, the family is for the first time compelled to recognize the mental illness and to take action to help the afflicted family member. This second phase is characterized by the “first shock of recognition” leading to help-seeking behavior accompanied with intensifying anxiety and fear for future worsening (Terkelsen, 1987, 152–153).

Despite the family's efforts to get help for the ill family member, things do not always go well. The ill family member may reject any help or the family may find it difficult to obtain professional help because the situation is not felt to be as serious as they think. In these circumstances, family members feel confused, bewildered and helpless. Some family members may emotionally

distance themselves, while others become increasingly occupied with the welfare of the affected person. There may also be conflicts between family members regarding the affected person's problematic behavior that the family is no longer able to ignore, yet it is unable to act effectively. Thus the family finds itself in the third phase called "stalemate" (Terkelsen, 1987, 154–155).

Faced with a persistent disparity between evidence of a serious problem and inability to solve it, many families attempt to cope by limiting the implications. The common denominator in this phase, "containing the implications of illness", is the attempt to circumscribe the implications of the decline in functioning. During this phase, the notion of an enduring infirmity within the affected person that will not submit to available forms of help is still beyond comprehension. Family members may continue to experience high levels of anxiety, and may have a diminished interest in their own usual activities, yet they are still optimistic and hopeful. Before the diagnosis is given, family members are usually very confused by the behaviors of the affected person and do not know precisely what to feel. This reflects the bewilderment of a life that has moved rapidly from coherence and predictability to chaos and disorder (Terkelsen, 1987, 155–156; Karp & Tanarugsachock, 2000; Jeon & Madjar, 1998, 698).

Eventually something very compelling or sometimes disastrous occurs and the family moves to the next phase, "transformation to official patienthood". In this phase the affected person is officially identified as a psychiatric patient. Either suddenly or gradually, the family members are hit with the implications: one of the family has a mental disorder that will not go away. Family members usually hope that the diagnosis is given as soon as possible since it clarifies the situation and provokes feelings of hope, compassion, and sympathy. It also allows them to organize their fears around a specific medical entity. When the problem is named, there is hope that doctors can help the patient. Without a diagnosis, family members are left with misinformation and wishful thinking. The meaning of mental illness in the family now spreads throughout every aspect of the family's life (Terkelsen, 1987, 155–156; Thornton, Plummer, Seeman & Littmann, 1982, 36; Karp & Tanarugsachock, 2000).

As soon as the family accepts the presence of mental illness, the next phase, "search for causes", begins. The direction of the search depends on the family's preexisting beliefs about the nature of mental illness. Some families look for the causes in the history of family life, others seek a biological explanation. In this phase family members often experience guilt, especially if they feel that the causes of the illness lie in their interpersonal relations. Regardless of which

direction the search takes, the family is ultimately confounded by the absence of definitive answers often resulting to evolving of multidimensional views (Terkelsen, 1987, 156–157).

Once the family comes to accept the presence of mental illness in the family member, phase seven, “the search for treatment”, starts. This search is much influenced by three factors, the family’s level of acceptance of illness, their perception of the causes, and the treatment services available to the family. The family needs to learn about the mental health service system with psychiatric hospitals, community care services, supported housing, social security provisions and other support services and is searching for information from mental health professionals and books. Further, the family is confronted with the varying attitudes of the clinical staff regarding the role of family in the illness and its treatment. This phase is characterized by a strong obligation to help the affected person and emotions of love, empathy, compassion and hope. The difficulties are tolerated as long as they are seen as temporary manifestations of the illness (Terkelsen, 1987, 158–159; Karp & Tanarugsachock, 2000).

As treatment progresses, it becomes increasingly apparent to the family that the affected person is not returning to his or her previous level of adaptation and the phase of “the collapse of optimism” begins. In time, the family’s cumulative experience with the illness leads to the conclusion that the illness is not going to go away and that the whole family must make some accommodation to the prolonged, possibly permanent, disabilities of the affected person. The frame of permanency ushers in more negative feelings of anger, resentment, and even hate for the illness. While family loses its hope of a complete cure, it is apparent in most cases that the affected person has still the capacity for productive activities. Family members learn to trust their own expertise and judgments. However, valuing these capacities may be difficult as long as hope of a complete cure is retained. There is a danger that the caregiving task may become overwhelming and the needs of other family members are unmet resulting to reduction of contact with the ill family member (Terkelsen, 1987, 159–162; Karp & Tanarugsachock, 2000; Tessler, Killian, & Gubman, 1987, 11).

As the optimism collapses, “surrendering the dream” begins with mourning over the loss of the internal image of the afflicted family member, the dreams of his or her future developments, and the quality of the former relationship. This process resembles the grief process following the death of a loved one, but has major differences. It often takes several years for the family to realize that the illness is prolonged in nature and total remission is unlikely. Grief lacks

finality and is recurrent since the loss in relation to the afflicted person alters over time. The ill family member's potential for relapse is always there, and each relapse initiates a new response cycle of adaptation. The fluctuations in the level of disability of the ill person lead to changing of expectations on the part of other family members, keeping them in a state of uncertainty. Thus they can never be quite sure that their hopes for the ill family member's future are unrealistic. Some family members may undergo a delayed grief reaction reflecting the difficulty of mourning in a continuing and changing situation. In addition to grief, elderly family members may also fear the future because there may be no other relatives to take care of the afflicted after the parents' death (Terkelsen, 1987, 162–164; Jeon & Madjar, 1998, 699; Tessler et al., 1987, 12; Eakes, 1995, 78; MacGregor, 1994; Miller, Dworkin, Ward, & Barone, 1990, 1323; Davis & Schultz, 1998, 370; Thornton et al., 1982, 42).

To the extent that family members are capable of mourning the loss, they are able to learn to restore balance in the family's life, "picking up the pieces". The family learns to see the illness as one of the challenges in life rather than as the only problem or the central problem. This notion makes it possible for the family to rediscover activities unrelated to the illness and its concerns and take respite from the caregiving. Some family members conclude that none of their efforts can successfully change things and this recognition leads them to an acceptance of the other's condition. Acceptance can liberate the family members from the earlier burdensome belief that it is their duty to somehow solve the problem and the sense of obligation diminishes. The aim for the family in this phase is to achieve an accommodation through which the welfare of the afflicted person is brought into balance with the welfare of other family members (Terkelsen, 1987, 164–166; Karp & Tanarugsachock, 2000; Jeon & Madjar, 1998, 700).

There are some general characteristics of the family's recovery process. Recovery is a process of readjusting the attitudes, feelings, perceptions, and beliefs about ourselves, others, and life in general. It is a growth process in which the outcome may be the emergence of a new sense of self, and a greater sense of meaning and purpose in life. Each individual in the family recovers at his or her own rate. Family members may be in different phases of recovery at a given time and each phase has its own natural reactions and its own developmental tasks. The particular impact of the illness differs in family members. Recovery is not linear and family members may recycle through the phases as they gradually complete the tasks that will facilitate moving ahead (Spaniol & Zippel, 1994, 132–133). However, not all family members are able to reach

complete acceptance of what has happened. Those who do, are able to continue their own lives while appropriately assisting the ill family member when necessary. In addition, they are capable of setting clear limits for the ill family member and adhering to them. Others achieve partial acceptance and some family members do not accept at all that the affected person is ill but see his behavior as his or her fault (Thornton et al., 1982, 39–41).

3. AIMS OF THE STUDY

The aims of the study were:

1. To examine the gender differences of new schizophrenia patients in the premorbid stage and during the early stage of treatment (I).
2. To describe the well-being and need for information and support of caregivers according to living arrangements and kinship (II).
3. To determine whether the caregivers of discharged patients with schizophrenia are satisfied with their situation in general, and with the psychiatric services in particular, and to examine the factors associated with caregivers' satisfaction (III).
4. To identify the different types of caregivers and to examine whether the type of caregiving was associated with demographic characteristics, health and social disability of patients and caregivers, the coping strategies used by caregivers and their need for information and support (IV).
5. To examine whether a family education intervention: 1) would increase relatives' knowledge about the nature, course and treatment of schizophrenia, 2) would change the level of expressed emotion of family members, 3) would change relatives' objective burden and psychological distress, and 4) to compare the effect of two different methods of information delivery (oral presentation, video) (V).

4. SUBJECTS AND METHODS

4.1. Gender and short-term outcome in schizophrenia (I)

4.1.1. *Subjects*

The sample comprised all people between 15 and 44 who between 1 March 1983 and 28 February 1984 contacted public psychiatric services in six mental health districts in Finland for the first time in their lives in order to seek treatment for schizophrenia. Schizophrenia was defined by DSM-III criteria; the disorders included were schizophrenic, schizophreniform and schizo-affective psychoses.

During the 1-year period a total of 227 patients meeting these criteria contacted public psychiatric services. Both genders were equally represented in the sample (111 men and 116 women), and at entry the age and diagnostic distributions among men and women were similar. However, the paranoid forms of schizophrenia were a little more frequent among men than women while in schizophreniform psychoses the situation was reversed. At entry 80% of the patients had never been in psychiatric care before, and the remaining 20% had received treatment for a disorder milder than schizophrenia.

4.1.2. *Measures*

All patients underwent an extensive basic examination at entry, and individual treatment plans were drawn up for each patient. In addition, follow-up investigations were carried out 12 and 24 months after the initial contact.

At all stages the examinations were conducted by members of the psychiatric teams who were responsible for the treatment of the patients. During interviews with the patients and their relatives, the staff completed structured questionnaires. All questions were fully standardized, and instructions were included for each question separately.

The basic examination was conducted as soon as possible after the initial contact. In the interviews the aim was to trace the premorbid development

of the patients and to find out what kind of changes had occurred in their physical status, psychic symptoms, friendship and other human relations, hobbies, social and sexual interaction, school success and work history. A further concern was to study the process of admission to treatment and the duration of schizophrenic symptoms. The physicians working on the psychiatric teams completed the Comprehensive Psychiatric Rating Scale (CPRS) (Åsberg, Montgomery, Perris, Scalling, & Sedvall, 1978) on the basis of their own investigations and diagnosed the patients using DSM-III criteria.

On initial examination the teams registered 259 possible schizophrenia patients. The possible schizophrenia patients were re-examined when 6 months elapsed from the time of initial examination. Based on both examinations, all 227 patients fulfilled DSM-III criteria for schizophrenia.

On the basis of interviews with both patients and their relatives the psychiatric teams produced evaluations of the patients' total clinical status, working capacity and functional ability (the Global Assessment Scale, GAS, Endicott, Spitzer, Fleiss, & Cohen, 1976). Finally, the teams drew up an individual treatment plan, suggested it to the patient and registered how motivated he or she was to follow the plan put forward by the team. The treatment plan also included the teams' assessments of the need for treatment and predictions regarding the progress of the illness. The patients made their own evaluation of their life situation and were asked whether they anticipated any changes.

During the 2 year follow-up, monthly data were collected on the different types and amounts of psychotherapy that the patients had undergone, other treatment contacts, contacts by the patients' relatives, days spent in hospital, day hospital and hostels, days spent in sheltered work and occupational therapy, and use of drugs. Abridged versions of the basic examination schedule were also completed. In this study only the results of the second follow-up year are used.

4.1.3. Statistical methods

The differences between genders in the single variables were tested by the chi square test and t test. In order to find combinations of the variables, which separate men and women from each other, discrimination analyses were performed. In discrimination analysis, a linear combination is formed from the variables which together significantly discriminate the classes (men and women) from the criterion variable (Cooley & Lohnes, 1971). Data was analyzed using BMDP Statistical Software.

4.2. Well-being of caregivers of the mentally ill (II)

4.2.1. *Subjects*

Three family organizations for relatives of the mentally ill in three large Finnish cities (Tampere, Turku, and Oulu) participated in the study. These associations had a total of 371 members in the autumn of 1990, when the data was collected. Questionnaires were mailed to all members, and 249 (67%) were returned. Of these 249 members, 17 were mental health professionals, and 34 had no mentally ill relative at the time of the study. Thus the final study group included 198 caregivers.

4.2.2. *Measures*

The questionnaire included questions about patients' and caregivers' health, living conditions, social relationships, caregivers' experiences of psychiatric care, and the well-being of the caregivers. The well-being of caregivers was assessed on three scales measuring psychological distress, objective burden, and life satisfaction.

The caregivers' psychological distress was assessed using the General Health Questionnaire (GHQ; 12-item version, Goldberg, 1972). The summation of answers to all items in the GHQ-12 yields an individual sum score ranging from 0 to 12. When the score for each caregiver was dichotomized, 0–1 points indicated a "normal" level of mental well-being, and 2–12 points indicated lowered mental well-being. Cronbach's alpha for this measure was 0.91.

The caregivers' objective burden was measured with the five-item Objective Burden Scale (OBS) devised for this study. Item content was based on the family caregiving literature and validated by the representatives of the self-help groups. As an indicator of the objective burden of care, caregivers noted the areas of their life that were affected by the caregiving task. These areas included employment, leisure time, finances, social relationships, and overall routine. Caregivers reported the extent to which they had experienced burden in each item during the previous weeks. The score on this measure was the sum of the areas in which at least some burden was noted by the caregiver. The sum ranged from 0 to 5, with higher scores indicating greater levels of objective burden. Cronbach's alpha for this measure was 0.70.

The life satisfaction of the caregivers was measured with the 12-item version of Life Satisfaction Scale (LSS) (Salokangas, Joukamaa, Stengård, & Mat-

tila, 1989). The sum score ranged from 0 to 36, with higher scores indicating higher levels of life satisfaction. The sum score of the LSS scale was divided into three classes: less than 27 points indicated low satisfaction with life, 27–33 points indicated some satisfaction, and more than 33 points high satisfaction with life. Cronbach's alpha for LSS was 0.88.

The caregivers' need for information was measured by asking caregivers to rate their need for information of six specific topics on a two-point scale, with 1 indicating the presence of the need, and 0 indicating its absence. The topics included the patient's illness, psychiatric care, medication and its side-effects, social benefits, advice in difficult situations, and educational courses for caregivers. The total score of the scale was the sum of the needs ranging from 0 to 6. Cronbach's alpha for this scale was 0.85.

The need for support was measured similarly by six items including the need for domestic help, need for a personal support person, financial help, respite from caregiving, a better place to live, and the need for a place in a sheltered accommodation. The total score of the scale was the sum of needs ranging from 0 to 6. Cronbach's alpha for this scale was 0.63.

4.2.3. Statistical methods

Two-way analysis of variance (ANOVAs) were conducted to examine the relationship of patients' and caregivers' sex, patient residence, and relationship to variables measuring the well-being of relatives (GHQ, OBS, LSS, need for information and support). Data was analyzed using SPSS-X Statistical Software.

4.3. Satisfaction of caregivers of patients with schizophrenia with their situation and psychiatric services (III)

4.3.1. Subjects

The data were collected as a part of a national project designed to study the treatment and the life situation of deinstitutionalized patients with schizophrenia in Finland. The project's data set consists of patients between the ages of 15 and 64 years with a diagnosis of schizophrenia who resided in 19 mental health or health care districts and who had been discharged from psychiatric hospitals.

Three separate samples were constructed for the project. From hospital discharge registers, patients consecutively discharged in three waves – after January 1, 1982; after January 1, 1986; and after January 1, 1990 – were selected for the study until the three samples amounted to 30 patients per 100,000 inhabitants in each district. In one district the samples were half this size and in another twice this size. The diagnoses for the 1982 and 1986 samples were based on ICD-8 criteria, and those for the 1990 study on DSM-III-R criteria.

For this study the analysis were restricted to the 1,097 discharged patients in the 1986 sample, because only in this cohort were both patients and their caregivers interviewed at the three-year follow-up. Interviews were conducted successfully with 775 patients, or 71% of the sample. Forty patients, or 4%, declined to participate in the study interview but gave the researchers permission to use information collected during their previous visits to psychiatric hospitals or community mental health centers; for these patients the researchers answered the interview questions on the basis of this information. Another 137, or 12%, declined to participate in the study, though 78 of these patients gave permission for their caregiver to be interviewed. Ninety-six, or 9%, could not be located, and 49, or 4%, had died.

There were no statistically significant differences in sociodemographic factors between the patients who took part in the follow-up study and those who did not. At the time of discharge, the overall level of functioning according to the 10-point version of the Global Assessment Scale (GAS) used in Finland (Lönnqvist, 1984) was poorer and the daily dose of neuroleptic drugs higher among the patients undergoing follow-up than among the dropouts. The follow-up group also had used psychiatric services to a greater extent before and particularly after discharge.

The aim was to interview one caregiver for each patient. After excluding patients who had died ($n=49$), patients who could not be located ($n=96$), and patients for whom no one was close enough to qualify as caregiver ($n=39$), the sample consisted of 913 patients whose caregivers could be interviewed. Of these, 237 patients, or 26%, did not give permission to interview their caregivers, and 66 caregivers, or 7%, refused to be interviewed. Fifty-nine caregivers, or 6%, were not interviewed because the patients themselves had declined to participate in the study, and 6 caregivers were not interviewed for other reasons. Thus, altogether 545 caregivers, or 61%, were interviewed.

The patients whose caregiver was interviewed were more often single than the patients whose caregivers were not interviewed, and their age at onset of illness was lower on average. At the time of discharge, the patients whose care-

giver was interviewed were younger on average, had a lower functional status, were more often on disability pension, were more likely to use long-acting injection medication, and were more often discharged to live with their parents than those whose caregiver was not interviewed. During the three years following discharge, the patients whose caregiver was interviewed visited community mental health centers and used neuroleptic drugs and the day hospital more frequently than those whose caregiver was not interviewed.

4.3.2. *Measures*

Data were collected from psychiatric case records on the patients' psychiatric history and on their use of services during the three years before and after discharge. Data were also collected on the patients' overall level of functioning as measured by the 10-point GAS, somatic health, working ability, and medication at discharge. Three years after discharge the patients and their caregivers were interviewed separately by psychiatric teams using a structured interview schedule designed for this study. The patient interview included questions on the patient's psychosocial functioning, maintenance of grip on life, current living conditions, personal relationships, and use of and need for psychiatric, medical, and social services, including a detailed list of various services and treatments as well as the patient's satisfaction with the psychiatric care received.

Maintenance of grip on life is a global assessment measure devised to evaluate treatment outcome for patients with schizophrenia (Salokangas, Rakköläinen, & Alanen, 1989). The concept of maintaining a grip on life is characterized by the patient's efforts to achieve the goals and modes of satisfaction normally associated with the interpersonal relationships and the social life of an adult.

The caregivers were interviewed using a modified version of the Medical Research Council Practices Profile (Creer et al., 1982). In this version, 19 structured items included questions about housework, self-care (hygiene, use of toilet, eating, getting up, and going to bed), taking medicine, taking responsibility for one's own care, managing money, taking care of children, working, marital relationship, other interpersonal relationships, social contacts other than family, socially difficult behavior, social withdrawal, interest in events, activity, managing emergencies, and suicidal behavior. In each item, the caregiver was asked how much the patient required help and whether the caregiver was satisfied with the patient's behavior. The caregivers' satisfaction

with the situation in general was measured on a 6-point scale, and their satisfaction with the psychiatric services was measured on a 3-point scale.

4.3.3. *Statistical methods*

The differences between the proportions or the means were analyzed using chi square tests and t tests as appropriate. Logistic regression analysis (Fleiss, Williams, & Dubro, 1986) was used to select variables associated with two dependent variables – caregivers' dissatisfaction with the situation and with the psychiatric services. For the logistic regression the two scales measuring the caregivers' satisfaction were dichotomized, with 0 indicating satisfaction and 1 indicating dissatisfaction. The independent variables for the analysis were initially organized into six groups: the patients' background, the caregivers' background, the patients' functional and clinical status, the patients' social relationships, the patients' need and use for services, and the patients' satisfaction with the care received (III, Table 1).

The logistic regression analysis proceeded in two stages. First, each group of independent variables was entered separately into a backward stepwise logistic regression in which the probability criterion for removal was a p value greater than .1. In the second stage, the variables that remained in the models in the first stage (III, Table 1) were entered into the final models (III, Table 2 and Table 3). Since duration of illness as well as the patient's gender might interact with any other variable, these variables were forced into each model to control for their potential confounding effects. Data was analyzed using SPSS for Windows version 6.0.

4.4. Caregiving types and psychosocial well-being of caregivers of people with mental illness (IV)

4.4.1. *Subjects*

The study was conducted as a part of a larger research project designed to study the situation and needs of caregivers of the mentally ill in Finland. The data were gathered in two phases. In the first phase, the questionnaire was sent to a random sample of 100 members of each of the five largest family organizations in Finland (The Family Association Promoting Mental Health in the cities of Helsinki, Tampere, Turku, Oulu, and Kuopio) during the fall of 1996. Of the

500 questionnaires mailed, 353 (70.6%) were returned. In the second phase in March 1997, the questionnaires were delivered to 204 caregivers whose mentally ill family member was hospitalized in Pitkaniemi Hospital, which is the central psychiatric hospital for Pirkanmaa Mental Health District in Southern Finland. Furthermore, 81 caregivers whose ill family member visited the community mental health center in Tampere were also asked to fill out the questionnaire during the same time period. Of these 285 questionnaires 139 (48.8%) were returned. These two data sets were combined (n=492). However, 15 of the returned questionnaires were incomplete, 55 were answered by supporting members and 24 by other members who did not have a mentally ill family member at the time of the study, leaving 398 questionnaires that were usable for analysis.

The situation and needs of caregivers of patients with schizophrenia and major affective disorders were compared in the previous report (Stengård et al., 2000). Even though there were differences in the backgrounds of these two diagnostic groups, there were no differences between the caregivers in psychological distress, overload, coping with life problems or in caregiving competence. Because in Finland there has been the greatest need to develop support services for caregivers of patients with severe mental illness, the present study involved data from the caregivers of patients with schizophrenia or depression (n=284). The caregivers of patients with neurotic and personality disorders, mental disorders due to a general medical condition, as well as those with a primary diagnosis of alcohol abuse were excluded.

4.4.2. *Measures*

The questionnaire included a number of measures intended to address the backgrounds of the caregivers and the patients, the caregivers' and the patients' well-being and social disability, the caregiving consequences, coping with caregiving and caregivers' needs for information and support. Specifically, the questionnaire included the following measures.

The caregivers' social disability was assessed using a four-item scale developed for this study to assess the extent of caregiver's difficulties in transportation and housework (cleaning up, preparing meals and shopping). Responses were given in three ordered response categories: 0 = not at all; 1 = some; 2 = a lot. The four items were summed to derive a total score of the social disability of the caregivers, with higher scores indicating more disability. Scores ranged

from 0 to 8 with a mean of 1.5 (SD=1.8). For this study, Cronbach's alpha was .80.

The patients' social disability was assessed using a nine-item scale developed for this study (difficulties with housework, meals, managing money, self-care, taking responsibility for one's own care and medication, going to bed / getting up, shopping, social relationships, working). Responses were given in four ordered response categories: 0 = not at all; 1 = just a little; 2 = somewhat; 3 = a lot, with higher scores indicating more disability. The nine items were summed to derive a total score of social disability ($\alpha=.86$). Scores ranged from 0 to 26 with a mean of 11.1 (SD=5.2).

The caregivers' psychological distress was assessed using the General Health Questionnaire (GHQ, 12-item version) (Goldberg, 1972). The summation of answers to all items in GHQ-12 yields an individual sum score ranging from 0 to 12, with higher scores indicating more psychological distress. Scores ranged from 0 to 12 with a mean of 3.4 (SD=3.7) ($\alpha=.91$).

The overload felt by the caregivers was assessed by the Overload Scale developed by Pearlin and his coworkers (1990). The scale includes four items with four ordered response categories: 1 = not at all; 2 = somewhat; 3 = quite a bit; and 4 = completely. Individual items were summed to derive a total score of the overload experienced by the caregivers, with higher scores indicating more overload ($\alpha=.73$). Scores ranged from 4 to 16 with a mean of 10.3 (SD=3.0).

The management of situation was analyzed as four single items developed by Pearlin and his coworkers (1990) to assess some ways that caregivers use to make caregiving easier for themselves. Responses were given in four ordered response categories: 1 = never; 2 = once in a while; 3 = fairly often; and 4 = very often.

The management of meaning scale (Pearlin et al., 1990) is divided into three sub-scales. The first sub-scale involves the reduction of expectations (three items), the second the use of positive comparisons (three items) and the third the search for a wider sense of the illness (three items). Responses were given in four ordered response categories: 1 = never; 2 = once in a while; 3 = fairly often; and 4 = very often. In this study the three sub-scales were combined, summing the individual nine items, with higher scores indicating use of management of meaning as a coping strategy more often. Scores ranged from 15 to 36 with a mean of 26.7 (SD=4.2) ($\alpha=.71$).

As proposed by Pearlin and his coworkers (1990) management of distress was measured by eight single items. These items were designed to assess the individuals' efforts to lessen awareness of the situation or to decrease the

symptoms of stress that result from it. Responses were given in four ordered response categories: 1 = never; 2 = once in a while; 3 = fairly often; and 4 = very often.

The caregiving dimensions were assessed by the Finnish version of the Involvement Evaluation Questionnaire (IEQ) originally developed by Schene and van Wijngaarden (1992). A timeframe of the foregoing 4 weeks was used. All items were scored on a 5-point Likert scale with 1 denoting “never” and 5 denoting “(almost) always”. Factor analysis using principal component analysis with varimax rotation was carried out to determine the dimensional structure of IEQ using the following criteria: (a) eigenvalue > 1.0; (b) variables should load > .40 on a factor; and (c) the interpretation of the factor structure should be meaningful. The factor analysis on the 28-caregiving items of the IEQ revealed four distinct caregiving dimensions similar to those found by Schene and van Wijngaarden (1995; van Wijngaarden et al., 2000). Sub-scales were created by computing the sum of the items included in each factor, with higher scores indicating more caregiving consequences in each dimension.

Tension (9 items, $\alpha=.81$) refers to the strained interpersonal atmosphere between patients and relatives. Tension scores reported by the caregivers had a mean of 16.0 (range 9–34). Supervision (5 items, $\alpha=.80$) refers to the caregiver’s tasks of ensuring and guarding with regard to patient’s intake of alcohol and drugs, and hazardous behavior (mean 7.1, range 5–25). Worrying (6 items, $\alpha=.80$) covers painful interpersonal cognitions, such as concern about the patient’s safety, general health, and the kind of care he or she is receiving (mean 14.9, range 6–28). Urging (7 items, $\alpha=.80$) refers to activation and motivation, that is, stimulating patients to take care of themselves, to eat enough, and to undertake activity (mean 13.8, range 7–30). The four factors explained altogether 50.4% of the total variance.

Caregiving competence was measured using a four-item scale developed by Pearlin et al. (1990). The items ask the respondents to rate the adequacy of their performance as caregivers. Responses were given in four ordered response categories: 1 = not at all; 2 = just a little; 3 = somewhat; and 4 = very much. Individual items were summed to derive a total score, with higher scores indicating more caregiving competence. Scores ranged from 6 to 16 with a mean of 11.8 (SD=2.1) ($\alpha=.82$).

The measure of personal gain or enrichment was developed by Pearlin et al. (1990) to assess how much the caregivers had managed to find some inner growth as they faced the severe challenges of caregiving. The responses for this four-item scale were given in four ordered response categories: 1 = not at all; 2 = just a little; 3 = somewhat; and 4 = very much. Individual items were

summed to derive a total score, with higher scores indicating more personal gain. Scores ranged from 4 to 16 with a mean of 11.5 (SD=2.9) ($\alpha=.86$).

The Caregivers' Need for Support Scale was devised for this study. The scale has 24 dichotomized items (0=no need for support, 1=need for support). A timeframe of the foregoing 12 months was used. Factor analysis using principal axis analysis with varimax rotation was carried out to determine the dimensional structure of the Caregivers' Need for Support Scale using the following criteria: (a) eigenvalue > 1.0; (b) variables should load > .40 on a factor; and (c) the interpretation of the factor structure should be meaningful. The factor analysis on the 24 items of the Caregivers' Need for Support Scale revealed five distinct dimensions of support. Sub-scales were created by computing the sum of the items included in each factor, with higher scores indicating more need for support.

Need for psychoeducation (5 items, $\alpha=.89$) refers to the need to learn skills in problem solving, communication and managing stress and crisis situations (mean 2.5, range 0–5). Need for adjustment training (3 items, $\alpha=.90$) refers to the need to participate in adjustment training courses for the patients and caregivers to learn how to cope with mental illness (mean 1.0, range 0–3). Need for vacation (4 items, $\alpha=.84$) covers the need to participate in organized vacation activities (mean 1.3, range 0–4). Need for respite care (5 items, $\alpha=.78$) refers to the caregivers' need to have someone to take care of the patient while the relative takes a day off (mean 1.0, range 0–5). The need for support group (2 items, $\alpha=.86$) refers to the caregiver's need to take part in a support group and meet other caregivers with similar problems (mean 1.1, range 0–2). The five factors explained altogether 51.2% of the total variance.

The caregiver's need for information was assessed using a scale originally developed by Mueser et al. (1992). All items were scored on a 5-point Likert scale with 1 denoting "not interested" and 5 denoting "very interested". Factor analysis using principal component analysis with varimax rotation was carried out to determine the dimensional structure of the Need for Information Scale using the following criteria: (a) eigenvalue > 1.0; (b) variables should load > .40 on a factor; and (c) the interpretation of the factor structure should be meaningful. The factor analysis on the 45 items of the questionnaire revealed five distinct dimensions. Sub-scales were created by computing the sum of the items included in each factor, with higher scores indicating more need for information.

Rehabilitation (13 items, $\alpha=.91$) refers to the need to learn more about opportunities for day activities, alternative living situations, and social skills training (mean 46.1, range 13–65). Basic facts about mental illness (10 items,

$\alpha=.90$) refers to the need for information on mental illness and medication (mean 41.9, range 18–50). Coping with everyday problems (10 items, $\alpha=.90$) covers topics of stress management, problem solving and communicating with the patient (mean 38.8, range 13–50). Negative (5 items, $\alpha=.89$, mean 19.8, range 5–25) and positive symptoms (4 items, $\alpha=.86$, mean 13.8, range 4–20) refer to the need to learn more about the nature of these symptoms. The five factors explained altogether 58.6% of the total variance.

4.4.3. *Statistical methods*

Factor analyses using principal components analysis with varimax rotation were carried out to determine the dimensional structure of IEQ (Schene and van Wijngaarden, 1992) and the Need for Information Scale (Mueser et al., 1992). Factor analysis using principal axis analysis with varimax rotation was carried out to determine the dimensional structure of the Caregivers' Need for Support Scale.

K-means cluster analyses were used to identify homogenous groups of caregivers. Four variables were included in the cluster analysis representing caregiving dimensions as measured by IEQ: tension, worrying, supervision, and urging. The variables were standardized before performing the cluster analysis with three, four, five, six, seven, eight, nine, and ten clusters. To determine the optimal number of clusters three different criteria were applied. Visual inspection of the scatter depicting the relationship between the number of clusters and the sum of deviations showed that the marginal reduction in the sum of the deviations fell abruptly at the six-cluster solution. This procedure suggested adopting either a five or a six-cluster solution. Furthermore, accepting the 5-cluster solution as the optimal solution was supported by the fact that it gave the most meaningful results. The 5-cluster solution thus identified best five distinct caregiving types distinguished by levels of caregiving dimensions (IV, Table 1) found in the literature (Schene & van Wijngaarden, 1992). Moreover, when more than five clusters were extracted, only less than 10 caregivers constituted the new clusters.

A series of chi square tests and analyses of variance were conducted to test for differences among the caregiver clusters. Data was analyzed using SPSS for Windows version 9.0.

4.5. Educational intervention for the relatives of schizophrenia patients (V)

4.5.1. Procedure

The psychiatric teams responsible for the care of schizophrenic patients organized 20 groups for family members of patients with schizophrenia or schizophreniform disorder in a total of seven psychiatric hospitals, four community mental health centers and two family organizations in 12 cities in Finland. All group leaders ($n=45$) were mental health professionals (psychologists, social workers, psychiatric nurses) who were not involved in the care of the patients. In both family organizations and in one psychiatric hospital, some of the group leaders were involved in both the oral presentation group and the video group, otherwise the group leaders were different individuals in the oral presentation and the video groups. The group meetings were held every week or every other week except for one oral presentation group, which was organized as a weekend course. The group leaders took notes on every group meeting recording, e.g. which participants were present, the subject of the oral presentation, visiting lecturers and themes of the discussion. The group leaders of oral presentation groups felt that the questionnaire was too long and took too much time to complete during the first and the last meetings. Several relatives also found some of the questions difficult to answer. Therefore a shortened version of the questionnaire was used in the video groups. Furthermore, the video group participants were not followed up due to lack of resources. The participants served as their own controls as there were no control groups.

For oral presentation, eight groups were organized as a part of a Nordic multi-center study in the period 1992–1993 (Nordentoft, LaBianca, Haastруп, & Stengård, 1994). Every session consisted of oral presentation of information by a visiting lecturer or group leader and discussion (V, Table 1). The groups were also allowed to use any written material available to them. However, based on the notes recorded by the group leaders, written material was used in only one group. In this group, the participants were given a leaflet and some bulletins about the local family organization. The group leaders were present regularly, while the lecturers might vary from session to session. All the participants in the oral presentation groups, each consisting of eight sessions of 2 1/2 hours, were asked to complete questionnaires at the beginning of the first session and at the end of the last session. The follow-up questionnaires were completed by the participants six months after the intervention. In oral

presentation groups 86.9% of the participants attended at least six of the eight sessions (mean attendance 6.6., SD=1.7).

For video education, 12 groups were organized in the period 1994–1995. In these groups the information was provided through a video program called “Family course for patients with schizophrenia and their families” consisting of six lectures lasting 22–38 minutes (V, Table 1). The group leaders were regularly present, but no other lecturers were allowed to participate in the groups. Every session consisted of one lecture on video and a discussion, but written material was not used in the groups. All the participants in the 12 video groups, each consisting six sessions of 1–2 hours, were asked to complete shortened versions of the questionnaires at home before the first session and after the last session. In the video groups, 87.6% of the participants attended at least four of the six sessions (mean attendance 5.1, SD=1.4).

4.5.2. Subjects

Sixty-nine persons participated in the oral presentation groups and 128 persons participated in the video education. Of these 197 participants 166 (84.3%) were parents, 14 (7.1%) were spouses, 12 (6.1%) were siblings, one child and four others (aunt, sister-in-law, daughter-in-law and friend). The mean age of the participants was 55 years (range 24–84 years, SD=11.1) and 72% (n=143) were female. Thirty-six percent (n=71) of the participants were living with the patients at the time of the study. The participants were related to 147 patients – 97 male and 50 female. All the patients had a diagnosis of schizophrenia or schizophreniform disorder. The mean duration of the illness was 11.6 years (SD=8.1). Fifty-three patients (36.1%) were in psychiatric hospital at the time of the study.

Of the 197 participants who attended the groups, 175 (88.8%) completed both pre-intervention and post-intervention questionnaires. In the oral presentation groups, 63 of the participants (91.3%, n=69) returned their follow-up questionnaires. There were no statistical differences between participants who returned the pre- and post-intervention questionnaires (n=175) and participants who failed to return them (n=22) in gender, mean age, duration of patient’s illness, patient being in the hospital at the time of the study or participant living together with the patient. However, the participants who failed to return their questionnaires were more often relatives of female patients (chi square=6.03, df=1, p<0.05) and they attended the group on average one time

less than other participants (mean attendance 4.3/5.8, respectively; $t=-3.07$, $df=23,5$, $p<0.01$).

4.5.3. Measures

In addition to questions addressing the participants' background, the questionnaire included the following measures.

The Knowledge Test included questions about the symptoms, etiology of schizophrenia, relapse risk, criteria for commitment, social skills, factors that may influence the course of illness and family management. The questionnaire is a nine-item, multiple-choice instrument devised for this study (range 0–27, $\alpha=0.77$ in pre- and post-intervention).

The objective burden was measured on a six-item scale devised for this study (range 0–6, $\alpha=0.59$ in pre-intervention and $\alpha=0.57$ in post-intervention). The score on this measure was the sum of the areas of participants' lives in which burden was noted (social relationships, finance, employment, hobbies and leisure, practical help required by the patient and quarrels in the family).

The participants' psychological distress was assessed using the General Health Questionnaire (GHQ, 12-item version) (Goldberg, 1972). The summation of answers to all items in GHQ-12 yielded an individual sum score ranging from 0 to 12. When the score for each participant was dichotomized, 0–2 points indicated a "normal" level of mental well-being, and 3–12 points indicated lowered mental well-being ($\alpha=0.90$ in pre- and post-intervention).

The Family Questionnaire (Feinstein et al., 1988) was used to assess expressed emotion (EE) among the participants. It consists of 20 items (1=never, 2=sometimes, 3=often, 4=always) describing aspects of behavior related to criticism (CC, 10 items, range 10–40) and to emotional overinvolvement (EOI, 10 items, range 10–40). Cronbach's alphas for CC in pre- and post-intervention were 0.76 and 0.71, respectively. The corresponding figures for EOI were 0.57 and 0.52.

The group evaluation form contained 13 items describing the participants' feelings about the usefulness and atmosphere of the group (scores 1=yes, 2=no, 3=I don't know).

4.5.4. *Statistical methods*

The changes in outcome variables before and after the intervention were evaluated with chi square tests and Z-test for correlated proportions (Kanji, 1993) and, when appropriate, t test for dependent groups and repeated measures analysis of variance. The differences between male and female participants and method of information delivery in post-intervention scores of the dependent variables were studied by using two-way ANOVA using the pre-intervention scores as the covariates in the analyses. Data was analyzed using SPSS for Windows version 9.0.

4.6. Summary of data sets

The summary of data sets gathered in the five studies is presented in Table 2. Study I examined all new patients who during a period of one year sought specialized psychiatric treatment for schizophrenia in six mental health care districts. Studies II–V comprise a large study group of caregivers of people with severe mental disorder (n=1224). Caregivers were contacted through family organizations, psychiatric hospitals and mental health care centers. Most of the participants were women with an average age of 55–56 years. Over half of the caregivers were parents of persons with mental illness. The caregivers were related to 1174 persons with severe mental disorder, most often schizophrenia or major affective disorder. Over half of the ill family members were male. The average age of the ill family members in these studies was between 37 and 41 years and the duration of illness was 11–13 years on average.

Table 2. Summary of subjects in studies I to V

Study	Characteristics of the subjects	Diagnosis	Number of subjects	Age, range (mean)	Sex ratio % females	Response %
I	Patients	Schizophrenia	227	15–44 (27)	51	96 (follow-up)
II	Members of three family organizations, 62% parents	All mental illnesses	198	20–75+ (56)	83	67
III	Caregivers of discharged patients, 49% parents	Schizophrenia	545	17–89 (56)	66	75 (patients) 61 (cares)
IV	Members of five family organizations and caregivers of patients in psychiatric care, 56% parents	Schizophrenia, major affective disorders	284	22–84 (55)	82	70 (I phase) 49 (II phase)
V	Members of two family organizations and caregivers of patients in psychiatric care, 84% parents	Schizophrenia	197	24–84 (55)	72	89 (follow-up)

5. RESULTS

5.1. Gender and short-term outcome in schizophrenia (I)

Premorbid development. There were no significant differences between the genders in the amount or type of symptoms occurring during the youth. Male and female patients also had similar histories of friendship relations and hobbies. Men had done as well at school as women, and there was no significant difference between the genders in terms of educational level. The one area in which men had had far greater difficulty than women was that of sexual development: 52% of men, but 75% of women ($p < 0.01$) had an established relationship with the opposite sex by the time they reached the age of 16–23 years.

A tendency to withdrawal during youth correlated significantly with poor sexual development ($r = 0.42$) and with the absence of close friends ($r = 0.53$). In discrimination analysis gender differences were accounted for by the variables of premorbid development (somatic health, neurotic, psychosomatic and psychotic symptoms, tendency to withdrawal, suicidal behavior, behavioral disturbances, friendships, hobbies, sexual development and school success). The most discriminating combination of variables consisted of only poor sexual development and poor success at school; both poorer among men (I, Table 2).

Patients' life situation at entry and during the follow-up. At entry the proportion of women who were married was higher than the proportion of married men (I, Table 3). Women also had more ($p < 0.05$) children (0.6 children) than men (0.3 children). During the follow-up there was a slight increase in the number of divorced patients in both genders. Heterosexual interaction also declined in both genders: at the outset 21% of the men and 46% of the women had a permanent heterosexual relationship and 57% and 30% respectively had no heterosexual interaction ($p < 0.001$), but by the end of the follow-up only 16% of the men and 42% of the women belonged to the former category while the figures for the latter had climbed to 71% and 51%, respectively ($p < 0.01$).

By entry there were only minor differences between the genders in frequencies of social contacts and hobbies, housing situation, social group, employment situation, income level, and self-evaluation of life situation (I, Table 3). At the end of the follow-up, however, men tended to have fewer social contacts ($p < 0.01$) and lived more often with their parents. Men's view of their life situation was also more pessimistic than that of women.

In the discrimination analysis (I, Table 4) of the variables describing psychosocial behavior on entry into the study (marital status, housemate, occupation, employment situation, size of household and economical situation), the combination of factors having the greatest discriminating power consisted of housemate (not parents for women), occupational status (lower for women), and size of household (larger for women). At the end of the follow-up the most important discriminating combination (from the same group of variables) was formed by marital status (married for women), employment situation (good for women), and occupational status (low for women).

Men and women reported the same amount of general problems in life, both at entry and during the follow-up, but there were some differences in the type of problems they experienced. Women tended to report more problems that were related to secondary family ($p < 0.05$), whereas men suffered more often from career problems ($p < 0.05$) and alcohol problems ($p < 0.01$).

Planning of treatment and treatment given during follow-up. There were no differences between the genders either in the proportion of patients who had received psychiatric treatment (20% of the men and 21% of the women) before entry to the study or in the duration of earlier treatment. During the initial stages of treatment 81% of the men and 77% of the women were admitted to hospital ($p > 0.10$); 71% and 66%, respectively, were admitted regardless of their own will ($p > 0.10$).

The same amount of staff and relatives took part in the preparation of the first individual treatment plans for both genders; the proportion of patients who participated in this work was also the same in both genders. Similarly, the preparation work itself took up more or less the same amount of time for both male and female patients. There were, however, some clear differences in the contents of these plans, i.e., in the types of treatment that were considered necessary. The psychiatric teams felt that women were in greater need of creative therapy ($p < 0.01$) and home help ($p < 0.05$) than men. On the other hand, men were felt to be in greater need of training in basic social skills ($p < 0.05$). On the basis of their baseline examinations the teams recommended drug treatment equally often to men and women. The two most important forms

of treatment were individual psychotherapy and drug treatment. The teams' evaluation was that individual therapy would be most effective form of treatment in 41% of men and 57% of the women ($p < 0.05$). Drugs were recommended as the main method of treatment in 31% of the men and 17% of the women ($p > 0.10$).

In the discrimination analysis of the variables describing the teams' first evaluation of the need for treatment (crisis intervention, individual, primary family, secondary family, and group therapy, occupational therapy, neuroleptic, antidepressive, psychosedative drugs, long lasting injections, and different modes of sociotherapeutic and rehabilitative measures) the most discriminating combination of factors consisted of secondary family therapy (recommended more often to women), home help (women), group therapy (women), training in basic social skills (men), physical exercise (men), vocational guidance (men) and guidance in finding a suitable job (men) (I, Table 5).

During the follow-up women went to psychotherapy (counting all sessions in individual, family and group therapy) far more often than men ($p < 0.01$), and even at the end of the follow-up women were still going to individual psychotherapy more frequently than men ($p < 0.05$). On the other hand there were no significant differences between the genders in drug treatment, in care received in hospital, day hospital, or hostels, in the amount of sheltered work or occupational therapy, or in the number of treatment places during the follow-up.

According to the new treatment plans that were prepared at the end of the follow-up, men continued to need more occupational therapy ($p < 0.01$) and training in basic social skills ($p < 0.01$) than women. In the discrimination analysis (with the same group of variables as in the analysis of the first treatment plan (I, Table 5) the training of basic social skills (recommended more often to men) and help in finding a suitable job (men) formed the most significant discrimination combination. At this stage, it seemed that men were far less motivated to go along with the recommended treatment plan than women ($p < 0.05$). This lack of motivation was associated significantly with negative symptoms ($r = 0.38$) and disorders of speech ($r = 0.31$), which were also more common in men.

Predicting the future course of the illness. During baseline examinations the psychiatric teams predicted how their patients' status and need for treatment will develop over the following two years. It was expected that men would need more hospital treatment than women ($p < 0.05$); that they would spend less time at work than women ($p < 0.05$); that they would have a poorer grip

on their life than women ($p < 0.001$); and that their psychiatric status (GAS) would be poorer than that of women ($p < 0.05$). Regarding frequency of social contacts and psychotic symptoms, there were no gender differences. Finally, the male patients themselves had a more pessimistic picture of their own future situation than women ($p < 0.05$).

Changes in psychic and functional status. Upon entry into the study, men and women were in an equally good position with regard to their somatic status: in both genders 83% of the patients were healthy (no symptoms) and only 4%, again in both genders, had some illness requiring medical treatment. During the follow-up eight of the original 111 men died, five of them through suicide. There were no deaths among women.

There were no significant gender differences in the amount of psychotic symptoms experienced prior to admission, the duration of these symptoms, or in the acuteness of their outbreak. Likewise, the differences in clinical status at entry were only marginal. The evaluations made by the psychiatric teams of the patients' total clinical status were not significantly different for men and women (I, Table 6).

At the end of the follow-up men suffered more often than women from negative symptoms and disorders of speech (I, Table 6). Premorbid sexual development was significantly associated with negative symptoms both at entry ($r = 0.24$) and at the follow-up ($r = 0.30$). As for disorders of speech, the correlations were even higher ($r = 0.27$ at entry and $r = 0.33$ at the follow-up). A premorbid tendency to withdrawal was also significantly associated with negative symptoms at the beginning of the study ($r = 0.27$) and at the end of the follow-up ($r = 0.29$), as well as with disorders of speech at entry ($r = 0.31$) and at the end of the follow-up ($r = 0.25$).

At the end of the follow-up there was a higher proportion of men than women who suffered from depression, and at this point men also met the DSM-III criteria for schizophrenic symptoms somewhat more often than women (I, Table 6). By contrast, there were no significant gender differences in the proportions of those suffering from Schneider's first rank symptoms or psychotic symptoms, nor in the estimates presented by the psychiatric teams regarding clinical disturbance. In the discrimination analysis of clinical symptoms at the follow-up negative symptoms were the only significant distinguishing factor between men and women (with the former suffering more often).

At the beginning of the study no significant differences were found in the patients' working capacity or functional abilities, but by the end of the follow-up women were far ahead of men in this respect (I, Table 6).

5.2. Well-being of caregivers of the mentally ill (II)

Characteristics of caregivers and the patients. The caregivers were mostly female (n=164, 83%). The mean age of the 198 caregivers was 55.7 years (SD=12.3). Nine were more than 75 years. Almost two-thirds (n=125, 63%) of the caregivers were married. Less than half (n=83, 42%) of the caregivers were working outside the home; 101 (51%) were retired.

Half of the patients were male (n=110, 55%). The mean age of the patients was 37.5 years (SD=11.9). Most of the patients were single (n=149, 75%) and were pensioned (n=168, 85%) because of their mental illness. At the time of the study 30% (n=58) of the patients were hospitalized.

Most caregivers (n=122, 62%) were parents of the mentally ill person. Siblings comprised 12% (n=24) of the group, spouses another 14% (n=28), and the rest were other relatives or friends (n=24). One-third of the subjects (25 spouses and 41 parents) lived with their ill family member. Half (69 of 132) of the family members who were not living with their ill family member reported at least weekly contact. Female caregivers took care of 98 male and 66 female patients, and male caregivers took care of 12 male and 22 female patients.

Caregivers' well-being. Caregivers showed high levels of psychological distress. The mean score of the GHQ was 4.5, and when using the binary method of GHQ scoring, nearly 60% were rated as having psychological distress. There were no differences in psychological distress between the caregivers of male and female patients (II, Table 1).

Half of the caregivers (n=107, 54.3%) had experienced objective burden in at least one area of their lives. The caregivers reported that the caring task disrupted their lives on an average of 1.2 of 5 possibilities on OBS. The most frequently reported items were overall routine (37.5%) and social relationships (27.1%). The caregivers of male patients felt significantly more objective burden than the caregivers of female patients. The objective burden felt by caregivers was also significantly greater if the caregiver and patient were of different sex (II, Table 1).

About two-thirds of the caregivers (n=126, 64%) scored less than 27 points in LSS, showing low satisfaction with life. The mean LSS score was 23.7. Female caregivers felt significantly lower satisfaction with their lives (mean, 23.3) than male caregivers (mean, 26.1) (II, Table 1).

Need for information and support. Most (n=152, 77%) of the caregivers expressed the need for more information on at least one item. The mean of this scale was 3.2. The topics most often mentioned were need for advice in dif-

difficult situations (61%) and need for information about psychiatric care (60%) and medication (60%). Half (n=111, 56%) of the caregivers expressed the need for support in at least one item. Most often the caregivers needed respite from caregiving (30%) and financial support (25%). The mean of this scale was 1.3. There were no differences in need for information or support between the caregivers of male and female patients (II, Table 1).

Relationships between patient residence and relationship. Caregivers who lived with the patient expressed more psychological distress, objective burden, need for support, and lower satisfaction with life than caregivers who did not live with the patient. Furthermore, parents expressed more need for information (mean, 3.6) compared to other caregivers (mean, 2.6) (II, Table 2).

There was also a statistically significant interaction in analyses of variance between patient residence and kinship for psychological distress, objective burden, and satisfaction with life. In each case there was no difference between parents living with the patient and parents not living with the patient. However, other caregivers living with the patient expressed more psychological distress, objective burden, and lower satisfaction with life than other caregivers not living with the patient (II, Table 2). It should be noted, however, that other caregivers living with the patient were all spouses.

5.3. Satisfaction of caregivers of patients with schizophrenia with their situation and psychiatric services (III)

Caregivers' background. Two-thirds (n=359) of the caregivers interviewed were women. The mean age of the caregivers was 56 years (SD=14.6), with a range of 17 to 89 years. The caregivers of male patients were on average older than those of female patients (58.8 years versus 51.6 years; $t=5.7$, $df=448$, $p<.001$). Thirty-nine percent (n=211) of the caregivers were mothers of the patient, 10% were fathers (n=58), 5% were siblings (n=27), and 19% were spouses (n=103); 27% (n=146) were other caregivers or close friends. Sixty percent (n=322) of the caregivers were not employed at the time of the study. About 38% (n=207) considered their health good. At the time of the interview 10% (n=52) of the caregivers were using psychiatric services themselves; another 12% (n=67) had used psychiatric services earlier. Half of the caregivers (n=274) lived with the patient they cared for, and about the same proportion of patients (n=284) spent most of their days at home.

Patients' background. The group of patients whose caregiver was interviewed consisted of 308 males (57%) and 236 females (43%). The mean age was 37.3 years (SD=10.6), with a range of 17 to 64 years. The majority of the patients were unmarried (70%, n=379) and on disability pension (86%, n=467). The patients' mean score on the 10-point GAS was 4.6 (SD=1.4), with scores ranging from 1 to 9. The duration of illness was 12.7 years (SD=8.7), ranging from less than a year to 39 years.

Caregivers' satisfaction with the situation. Twenty-two percent (n=119) of the caregivers were dissatisfied with the situation in general. Five of eight predictors of caregivers' satisfaction with the situation remained in the final logistic regression model: living with the patient, functional status, the patients' social disability, the medication given in the previous year, and the amount of rehabilitation at the time of the study (III, Table 1 and Table 2).

According to the logistic regression model, caregivers who lived with the patient (n=272) were more likely than those who did not (n=269) to be dissatisfied with the situation (26% versus 18%, respectively). Furthermore, caregivers whose patients had a lower functional status according to GAS score or had more problems with social role behavior were more likely to be dissatisfied than those whose patients had better function and social capability. Caregivers also were more likely to be dissatisfied if the patients had been given less medication the year before and had undergone less rehabilitation at the time of the study.

Caregivers' satisfaction with the services. Thirty-four percent (n=188) of the caregivers were dissatisfied with the psychiatric services the patients received. Eight of 13 predictors of the caregivers' satisfaction with the services remained in the final logistic regression model: patients' psychotic symptoms; maintenance of grip on life; psychiatric care, rehabilitation, and social services supplied at the time of the study; physical examination and treatment given in the previous year; and the patients' satisfaction with community care and medication (III, Table 1 and Table 3).

According to the logistic regression model, caregivers were more likely to be dissatisfied with the services if their patients had severe psychotic symptoms or poor maintenance of grip on life. Thirty-nine percent of the caregivers whose patients had psychotic symptoms (n=316) were dissatisfied compared with 29% of those whose patients did not have psychotic symptoms (n=215). Forty-one percent of caregivers whose patients had a poor maintenance of grip on life (n=269) were dissatisfied as compared with 28% of those whose patients had a good grip on life (n=264). Furthermore, caregivers whose

patients were given less psychiatric care, rehabilitation, or physical examination and treatment were more likely than others to be dissatisfied. Caregivers whose patients had used more social services also were more likely than others to be dissatisfied.

The patients' attitudes toward the community care and medication they received were also associated with the caregivers' level of satisfaction with the services. Caregivers were more likely to be dissatisfied with the services if the patients were dissatisfied with their community care or if the patients felt indifferent about their medication. Forty-seven percent of the caregivers whose patients were dissatisfied with the community care (n=97) were dissatisfied with the psychiatric services compared with 31% of those whose patients were satisfied (n=402). Similarly, 48% of the caregivers whose patients were dissatisfied with their medication (n=119) were dissatisfied with the services compared with 31% of the caregivers whose patients were satisfied with their medication (n=395).

5.4. Caregiving types and psychosocial well-being of caregivers of people with mental illness (IV)

Characteristics of caregivers and patients. The caregivers were mostly female (n=233, 82.0%). The mean age of the 284 caregivers was 54.8 years (range 22–84, SD=12.4). About 70% of the caregivers were married (n=201, 70.8%) and 15.9% (n=44) had a university degree. Almost half of the caregivers (n=127, 45.8%) were working outside of the home, 3.6% (n=10) were housewives, 8.7% (n=24) were unemployed and 41.9% (n=116) were retired. Over half of the caregivers (n=159, 56.2%) were the parents of the mentally ill person. Spouses comprised 21.9% (n=62) of the sample, siblings 9.5% (n=27), and children 6.0% (n=17). The rest were other relatives or friends (n=18, 6.4%). About one quarter (n=83, 29.4%) lived with the mentally ill family member and another 136 (48.2%) met the patient weekly.

Over half of the patients were male (n=152, 54.7%) and unmarried (n=164, 59.0%). The mean age of the patients was 41.1 years (range 16–88, SD=14.1). Two-thirds of the patients (n=180, 63.4%) had a schizophrenia diagnosis and one third (n=104, 36.6%) had a diagnosis of depression using ICD-10 criteria. The mean duration of the illness was 13.5 years (range less than one year to 47 years, SD=10.0). At the time of the study 69 (24.3%) of the patients were in psychiatric hospital. Over 70% of the patients (n=207, 73.9%) were on a disability pension.

Caregiving types. K-means cluster analyses were used to identify five distinct caregiving types.

Cluster 1 was labeled “supervising” and had the least number of caregivers (4.1%, n=10). These caregivers had the highest scores on all the caregiving dimension scales. The caregivers in this cluster had the highest supervision scores, especially compared with the other four clusters. Supervision includes caregiver’s tasks of ensuring and guarding with regard to the patient’s intake of alcohol and drugs, and hazardous behavior. The caregivers in this group had a lot of responsibility for the well-being of the patient and they felt anxious about the relationship.

Cluster 2, labeled “anxious”, had the second smallest number of caregivers (11.9%, n=29). Caregivers in this cluster obtained the second highest worrying and tension scores, but had relatively low scores in supervision and urging. High tension and worrying scores refer to strained interpersonal atmosphere at home as well as caregivers’ concern about the patients’ well-being and the kind of care they were receiving.

Cluster 3 was labeled “coping” and had the largest number of caregivers (43.4%, n=106). Caregivers in this cluster obtained the lowest scores on all the four of the caregiving dimension scales. These low scores refer to less strained family atmosphere and fewer concerns about the patients’ well-being and life situation.

Cluster 4, labeled “resigned”, accounted for 20.5% (n=50) of the caregivers. Caregivers in this cluster had relatively high score on worrying, but low scores on all the other caregiving dimensions. These caregivers were mainly worried about the patients’ life situation, but they did not take a very active role towards the patient.

Cluster 5 was labeled “activating” and accounted for 20.1% (n=49) of the caregivers. These caregivers had the second highest score on urging, but relatively low scores on all the other caregiving dimensions. Urging refers to activating and motivating the patients to take care of themselves, to eat enough, and to engage in different activities.

The background of patients and caregivers. No statistically significant differences in the demographic background variables of patients or caregivers were found between the five types of caregivers. However, the caregiving types differed in their satisfaction with their financial situation. The proportion of satisfied caregivers ranged from 30.0% (n=3) among the supervising caregivers to 76.2% (n=80) among the coping caregivers ($\text{Chi}^2=16.4$, $\text{df}=4$, $p=0.003$).

The health and social disability of patients and caregivers. The caregiving types differed statistically significantly in patients’ mental health and social disability

(IV, Table 2). All of the supervising and anxious types of caregivers assessed the mental health of patients to be moderate or poor, whereas the corresponding percentage for coping caregivers was 69.5%. Patients' social disability was also assessed as highest in patients of supervising or anxious caregivers.

Coping caregivers reported better physical and mental health than other caregiving types (IV, Table 2). The supervising and anxious types of caregivers reported poorest physical and mental health. Furthermore, psychological distress and overload were highest among the supervising and anxious types of caregivers and lowest among the coping caregivers. However, there were no statistically significant differences between the caregiving types in social disability.

Coping by caregiving types. Supervising caregivers used all situation management techniques more frequently than the other types of caregivers (IV, Table 3). Resigned caregivers also quite often used obtaining information as a way to cope with the situation. Supervising, resigned and activating caregivers used management of meaning more frequently than the other caregiving types. However, the differences between the caregiving types were small.

Supervising caregivers tried to manage stress by spending time alone, smoking and watching TV more frequently than other caregiving types. Anxious-type caregivers used watching TV and taking medication to calm them. Activating caregivers also used medication to lower their level of stress.

There were no statistically significant differences between the caregiving types as to how much the caregivers had managed to find inner growth as they had faced the severe challenges of caregiving (personal gains) or in how adequate they felt they were as caregivers (caregiving competence).

Need for information by caregiving type. All types of caregivers expressed the need for more information on all topics (IV, Table 4). The coping caregivers had least need for information, whereas the anxious and supervising caregivers had most need for information on all topics. Resigned caregivers expressed the need to learn more about the basic facts of mental illness.

Need for support by caregiving types. The coping caregivers reported the least need for support while the anxious type of caregivers expressed the need for most types of support (IV, Table 5). Supervising caregivers expressed need for respite care and vacation and resigned and activating caregivers felt that they needed psychoeducation.

Even though the types of caregivers expressed the need for support, all the caregiving types had received only a minimal amount of support during the past 12 months. There were no statistically significant differences between the types in the amount of support received. Membership of a family organiza-

tion did not explain the differences in the support received since there were no statistically significant differences in participating in activities organized by family organizations.

5.5. Educational intervention for the relatives of schizophrenia patients (V)

Knowledge gain. The mean scores of the Knowledge Test increased significantly following the intervention in both groups (V, Table 2). The knowledge gain was also retained at six-month follow-up in oral presentation groups. A two-way analysis of variance was performed to find out whether there were any differences in post-intervention Knowledge Test scores between methods of information delivery or gender of participant. The Knowledge Test score before the intervention was included in the analysis as a covariate. There were no significant differences between male and female participants or between oral presentation and video education. Significant effect was found only for the covariate ($F=129.4$, $df=1$, 168 , $p<0.001$).

Criticism and emotional overinvolvement. Before the intervention 28.4% ($n=19/67$) of the participants of the oral presentation groups had high expressed emotion (EE). The proportion of high EE relatives in post-intervention and follow-up was 36.7% ($n=22/60$) and 32.3% ($n=20/62$), respectively. In the video groups the corresponding figures were 26.7% ($n=31/116$) and 14.7% ($n=16/109$), respectively. After the intervention, the criticism scores (CC) of the participants decreased in video education but not in oral presentation (V, Table 2). The EE status or the emotional overinvolvement scores (EOI) of the participants did not change significantly after the intervention.

A two-way analysis of variance revealed that there were no significant differences between male and female participants or between oral presentation and video education in post-intervention scores of CC or EOI. Significant effects were found only for the covariates in CC ($F=1681.6$, $df=1$, 163 , $p<0.001$) and in EOI before the education ($F=142.0$, $df=1$, 162 , $p<0.001$).

Objective burden. The family members had experienced objective burden on average in 2.4 ($SD=1.6$) areas of life (V, Table 2). The only statistically significant change in the objective burden was that the proportion of participants who felt that their social network had diminished because of the mental illness of a family member decreased during the six-month follow-up (48.3% in pre-intervention, 30.0% at follow-up; Z-test for correlated proportions between pre-intervention and follow-up, $z=2.33$, $p<0.01$).

Psychological distress. Before the intervention 48.5% of the participants (51.8% of women and 39.6% of men) were distressed (3–12 points in GHQ). The psychological well-being of participants improved statistically after the intervention in oral presentation and video education and this increase in well-being was retained at follow-up for the oral presentation group (V, Table 2). A two-way analysis of variance revealed that there were no significant differences in post-intervention GHQ scores between male and female participants or between oral presentation and video education. Significant effect was found only for the pre-intervention score that was used as a covariate ($F=150.9$, $df=1$, 168 , $p<0.001$).

Evaluations of the group. Most of the participants evaluated the usefulness of the educational intervention and the group atmosphere positively. The only item below 70.0% acceptance was “my relationship with the patient has become easier.” The participants in video education found the information presented more often useful in practice (85.7%) than the participants in the oral presentations (61.3%) ($\chi^2=20.5$, $df=2$, $p<0.001$).

6. DISCUSSION

6.1. Methodological considerations

Study I examined all new patients who during a period of one year sought specialized psychiatric treatment for schizophrenia in six mental health care districts. Since the units involved included both hospitals and outpatient services, the sample may be regarded as a representative one. Schizophrenia was diagnosed by DSM-III criteria, thus eliminating all patients aged 45 and over with similar symptoms. In the group of patients over 45 years there were more women than men and the proportion of married women (with good prognosis) in this group was higher than that of married men. This supports the view that the exclusion of patients over 45 years from the study group has attenuated rather than exaggerated the gender differences in outcome. The fact that the mean age of male patients in this study was very similar to that of female patients may also have had the same diminishing effect on the gender differences. Earlier findings of the international follow-up study of the World Health Organization (World Health Organization, 1979) showed that younger males have a poorer outcome than older females. Before entry to the study one fifth of the patients had at some point received treatment for a disorder less severe than schizophrenia and therefore this sample does not strictly consist of first-contact patients. However, the proportion of patients who had received prior psychiatric treatment was the same among men and women, and it is reasonable to assume that this factor did not have a significant impact on the gender differences.

One problem in data collection may be represented by the fact that the psychiatric teams who collected the research data had no special training for the job. However, the interview schedules they completed were fully structured and included detailed instructions for each question; this will certainly have eliminated any major mistakes or distortions. On the other hand it may also be argued that the psychiatric teams who are responsible for the day-to-day treatment of patients will learn much more about them in this process than an outside researcher could during just one interview. Although the reli-

ability of Study I may have been adversely affected by the large number of field researchers and the lack of special training, this was unlikely to have an effect on the gender differences. During the project the teams were not aware of the study hypothesis of the possible effects of patients' gender on the course of the illness.

The prospective research design in Study I and the use of the same indicators at baseline and after the follow-up contributed favorably to the accuracy of the measurement of gender differences. Gender differences were found with the standardized indicators (e.g., CPRS, GAS), even though the total evaluations made by the psychiatric teams suggested no significant differences. This result suggests that studies based exclusively on such total evaluations may easily overlook important differences.

The caregivers who participated in Studies II–V constituted a heterogeneous group of caregivers including both members and non-members of family organizations in Finland. Caregivers were contacted through family organizations, psychiatric hospitals and mental health care centers. The response rates in Studies II–IV ranged from 49% to 75% and can thus be considered to be quite high. The lowest response rate (49%) was on the second phase of the data collection in Study IV. The questionnaires were delivered by mental health professionals to caregivers whose ill family members were treated in psychiatric hospital or in a community mental health center at the time of the study. The low response rate of these caregivers may reflect their interest in participating in the study, the relevance of the questions asked for these caregivers or the ability of the mental health professionals to motivate the caregivers to participate.

The respondents of Studies II–V are similar to the samples of other studies, although the samples are larger and more representative of different groups of caregivers than most previous samples (Maurin & Boyd, 1990). Most of the caregivers were women and family members of persons with schizophrenia or major affective disorders. The greater willingness of women to participate in these studies is consistent with their general involvement in caregiving roles of all kinds (Wood, 1994). However, the results may not be representative of the situation and needs of male caregivers. In addition, the generalizability of the findings to other groups of caregivers in Studies II, IV and V is limited by the long average duration of the patients' illness. The caregivers interviewed in Study III comprised a group of carers whose mentally ill family members had been discharged from psychiatric hospitals and undergone three years of follow-up. Patients who remained in the program and were examined after three years were more severely disturbed and used psychiatric services more fre-

quently than the program dropouts. Thus the caregivers who were interviewed constitute a group of caregivers of severely disturbed, long-term patients with schizophrenia. In Study V the proportion of dropouts in follow-up was small and the caregivers who completed both pre-intervention and post-intervention questionnaires represent all participants very well. These characteristics of the study groups must be taken into account when evaluating the results of the studies.

In order to find a suitable instrument for Study II a literature search was conducted, but no suitable research instrument measuring family burden could be found. There were no instruments available in Finnish since this was one of the first studies on family burden in Finland. Instruments in other languages did not meet the researchers' conditions of short, self-administered instrument covering different aspects of caregiving. Therefore it was decided to develop a new questionnaire for this study. The items were based on the result of the literature review and supplemented by items emerging from discussion with participants of support group for caregivers. In addition to the scales devised for this study (the Objective Burden Scale, the Need for Information Scale and the Need for Support Scale), the questionnaire also included two standardized scales, the GHQ-12 (Goldberg, 1972) and the Life Satisfaction Scale (Salokangas et al., 1989). Most of the scales showed a good internal consistency (Cronbach's alpha) with values ranging from 0.70 to 0.91. The only exception was the Need for Support Scale, which had an alpha value of 0.68.

In Study III the patients and caregivers were interviewed by the psychiatric teams responsible for the care of the patients. The clinical and social outcome of patients was assessed by clinical interviews. Use of internationally standardized rating scales might have increased validity and reliability of the measurement. However, the caregivers were interviewed using a modified version of the Medical Research Council Practices Profile (Creer et al., 1982) that has also been used in other studies in Finland (Salokangas, Palo-oja, & Ojanen, 1991b; Stengård, Saarinen, & Salokangas, 1993). The major advantages of this schedule are the clear separation of objective and subjective elements, and the item-by-item approach to the measurement of burden (Platt, 1985, 391).

The questionnaire used in Study IV consisted of several internationally used ratings scales: the GHQ-12 (Goldberg, 1972), scales measuring overload, the management of situation, the management of meaning, caregiving competence and personal gain (Pearlin et al., 1990), the Involvement Evaluation Questionnaire (Schene & van Wijngaarden, 1992) and the Caregivers' Need for Information Scale (Mueser et al., 1992). The scales were translated by Finnish study groups. Need for support, patients' social disability and care-

givers' social disability were measured by scales devised for this study. The Cronbach's alphas of the scales ranged from 0.71 to 0.91 showing, good internal consistencies.

The Involvement Evaluation Questionnaire has been shown to be sufficiently valid and reliable instrument for the assessment of caregiving consequences. The factor structure of the IEQ in Study IV was very similar to those obtained in other studies. However, IEQ ratings are probably influenced by cultural factors, and comparisons have to be made against the background of these factors. This means that local norm groups should be formed to serve as culturally unbiased standards in the future (van Wijngaarden, Schene, & Koeter, 2002, 164–65). This is also the case with other international rating scales used in Study IV. The only exception is the GHQ-12, which has already been used in Finnish population studies (Viinamäki et al., 2000; Holi, Marttunen, & Aalberg, 2003).

Study V had several limitations. This study was not originally planned for comparison of the groups and therefore the participants were not randomly assigned to the oral presentation and the video groups. The participants also served as their own controls and no control groups were used. The data were collected in slightly different ways in the oral presentation and the video groups. In the oral presentation groups the participants completed the questionnaires during the first and last meeting, whereas the video group participants completed the questionnaires at home. However, since this procedure took most of the time at the first and last meetings of the oral presentation groups, both types of groups had six meetings for information and discussion. Furthermore, a shortened version of the questionnaire was used in the video groups and the video group participants were not followed-up due to lack of resources.

The oral presentation groups were organized as a part of a Nordic multi-center study (Nordentoft et al., 1994) and the Danish research group had designed the research instruments before Finland joined the study. In addition to the questions devised for this study, the questionnaire included two standardized scales, the GHQ-12 (Goldberg, 1972) and the Family Questionnaire, which has been validated using the Camberwell Family Interview as the gold standard (Feinstein et al., 1988). The questionnaires were translated at the University of Tampere by a Danish teacher. The internal consistencies (Cronbach's alpha) of the scales used in Study V were high (range 0.71–0.90) except those for objective burden (0.59) and overinvolvement (0.57). It should also be kept in mind that changes in the variables measured by the questionnaire may or may not correspond with changes in real behavior.

Assessing validity in areas in which there are few established measures and for which a gold standard or criterion of accuracy cannot be established is difficult. The assessment of the validity of the measure is essentially a joint measure of the validity of the measure and the validity of the construct itself. For this reason it is most problematic when it is most needed – for measures of newer, less validated constructs (Blacker & Endicott, 2000).

The central concept of the family caregiving tradition, family burden, is a negative concept in itself. Caregiving consequences (van Wijngaarden et al., 2000, 21) or caregiving are more neutral terms and using them would be advisable. The focus on detrimental caregiving consequences is somewhat consistent with the long trend in social science research of focusing on general measures of psychological dysfunction (e.g. depression, lack of health, anxiety). Mental health research has been weighted on the side of psychological dysfunction. Positive psychological functioning has been studied much less than the mental health problems. In fact, the meaning of basic terms, such as mental health, is negatively biased – typical usage equates health with the absence of illness rather than the presence of wellness. Clearly, there is more to mental health than the absence of pathology, and well-being should be assessed using multidimensional measures. Lack of attention to the positive dimension of caregiving seriously skews perceptions of the caregiving experience and limits the possibilities to enhance the theory of caregiver adaptation (Kramer, 1997, 218; Ryff & Singer, 1996, 14).

Ryff and Singer (1996, 15; 1998, 15) have proposed a formulation of positive human health that goes beyond the prevailing absence of illness criteria. Three principles underlie the formulation of human health. First, positive health is not a medical question but rather is fundamentally a philosophical issue that requires articulation of the meaning of the good life. Second, human health is at once about the mind and the body and their interconnections. Thus, a comprehensive assessment of positive health must include both mental and physical components, and the ways in which they influence each other. Third, positive human health is best construed as a multidimensional dynamic process rather than a discrete end state. Human well-being is ultimately an issue of engagement in living, involving expression of a broad range of human potentialities: intellectual, social, emotional and physical. Thus the core dimensions of the model of well-being are self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life and personal growth. Ojanen (2001) has also offered a comprehensive view of elements that embody lives well-lived. These include reasonable material conditions, but also more complex aspects such as mastery, love, self-esteem,

hope and faith. These dimensions of positive health and well-being should be incorporated into future studies on caregiving.

6.2. The situation and needs of caregivers

In order to understand the situation and needs of caregivers of people with severe mental disorder (e.g. schizophrenia), it is necessary to examine the symptoms and outcome of the disorder itself. Study I showed that the psychosocial outcome of male patients with schizophrenia was poorer than that of female patients. The gender differences in outcome seemed mainly to be due to differences in premorbid psychosocial development: to the tendency of men to be withdrawn, to their inability to establish satisfactory heterosexual relationships, and finally to the negative aspects in the profile of their illnesses which may be connected to early deviances in neurodevelopmental processes. These results have also been replicated in other studies (Usall et al., 2002; Roy, Maziade, Labbé, & Mérette, 2001). However, the research on gender differences in schizophrenia has been criticized for using a dichotomous comparison of male and female sex differences instead of examining the role of gender along a continuum of masculinity and femininity. Gender might also be more thoroughly understood through the concepts of gender identity and gender roles (Nasser, Walders, & Jenkins, 2002).

The psychiatric teams responsible for the treatment of the patients were aware of the difficulties of male patients and in their treatment plans emphasized the greater need of men for rehabilitation and for training in basic social skills. However, the rehabilitation provided was not very successful, because at the end of the follow-up the functional ability of men was far inferior to that of women and the need for further rehabilitation greater than in women. The poorer psychosocial situation of men was also confirmed by the patient's own subjective experiences. From the outset men tended to be more pessimistic about their life situations than women and at the end of the follow-up this difference was even more obvious. The gender differences in the outcome of schizophrenia might also be associated with the differences in experiences of the caregivers of male and female patients. The caregivers of male patients have been reported to experience more burden than caregivers of female patients (Stengård et al., 1993; Fadden, Bebbington, & Kuipers, 1987; Mors, Sorensen, & Therkildsen, 1992), but there are also contradictory findings (Baronet, 1999; Thornicroft et al., 2002).

The results of Studies II, IV and V showed that negative caregiving consequences were quite common among caregivers. A large proportion of family members reported experiencing psychological distress. Depending on the cut-off point for the GHQ, 48–60% of family members were rated as having psychological distress. Compared to the results of Finnish population studies, the proportions of caregivers reporting psychological distress is twice as high as that of Finnish adult population (Viinamäki et al., 2000, 178; Pirkola et al., 2002, 52). This result is consistent with earlier studies on the psychological well-being of caregivers (Quinn, Barrowclough, & Tarrrier, 2003, 294; Cornwall & Scott, 1996, 346; Barrowclough, Tarrrier, & Johnston, 1996, 695; Winefield & Harvey, 1993, 621), even though some studies have reported lower levels of psychological distress (Oldridge & Hughes, 1992, 250).

About half (55%) of the caregivers rated their physical health good (Study IV). The corresponding proportion in Finnish population studies is about 2/3 (Helakorpi, Uutela, Prättälä, & Puska, 2000, 12; Nenonen, Tuori, Pelanteri, & Kautiainen, 2001; Koskinen & Aromaa, 2002, 38). Caring for a ill family member is generally regarded as a chronically stressful process, with potentially negative physical health consequences. Vitaliano and his coworkers (2003) conducted a meta-analysis of 23 studies comparing the physical health of caregivers of family members with dementia with demographically similar noncaregivers. Caregivers exhibited a slightly greater risk for health problems than did noncaregivers and female caregivers reported poorer global health than did male caregivers. Although the results do not permit the definitive conclusion that caregiving is hazardous to one's health, these added risks are noteworthy because they may have clinical implications for millions of caregivers. To be of concern to society, caregiving does not have to cause illnesses, it only has to contribute to illness progression. Therefore the somatic health of caregivers should be understood as an important public health issue.

In addition to consequences to mental and physical health, caregivers had experienced objective burden in one or two areas of their lives (Studies II and V). Most often the caregivers found general supervision of the ill family member tiring, but the social relationships of the caregivers had quite often also become more difficult (Study II). These findings are consistent with previous studies (Thompson & Doll, 1982, 383; Winefield & Harvey, 1993, 621). The results suggest that many families experience burden in one area or another, but relatively few experience extensive burden in several areas (Fisher et al., 1990, 215).

The well-being of caregivers varied greatly according to their caregiving situation. Study II showed that the caregivers living with the ill family member expressed more psychological distress, objective burden, and lower satisfaction with life than caregivers living apart from the ill family member. The most distressed group of the caregivers were spouses living together with their mentally ill spouse. These results were replicated in the study by Nyman and Stengård (2001, 71, 88).

Study IV differentiated five types of caregivers: supervising, anxious, coping, resigned and activating caregivers. About 2/5 of the caregivers managed the situation well and reported low levels of burden and overload. Activating and resigned caregivers were also coping quite well, even though their well-being was somewhat lower and they expressed a need for information and support. However, supervising and anxious types, who comprised about 15 % of the caregivers, were the most burdened types. The situation of both the ill family members and supervising and anxious types of caregivers was more difficult than that of the other caregiving types. This result is consistent with those reported by Tennakoon and his co-workers (2000) who found that the caregivers of family members with first-episode psychosis increased supervision when their ill relatives displayed difficult behaviors. Reinhard and Horwitz (1995) have also shown that caregivers who reported higher levels of disturbing behaviors and provided more concrete and emotional assistance reported higher levels of burden.

Although the literature across illnesses consistently shows a moderate relationship between the level of patient disability and psychological distress of the caregiver, there is considerable variability in caregiver outcomes (Biegel & Schulz, 1999). Such outcomes are thought to be mediated by a variety of factors including meaning in caregiving and emotional support (Noonan & Tennstedt, 1997). In Study IV, there were no differences between the caregiving types in personal gain or reported caregiving competence. Despite this, it seems that it is the caregivers' subjective perceptions of their difficulties that is important in predicting stress, rather than the objective characteristics of the events. Many caregivers find their role meaningful and satisfying. As one of their life priorities they want to make a valuable contribution to the well-being of the ill family member. Even family members living in difficult and burdening caregiving situation have various ways to gain strength and enhance their well-being. The most important sources of support are close friends and family members, belief in God and belonging to caregivers' support group (Marsh & Lefley, 1996; Kramer, 1997; Nyman & Stengård, 2001; Salokangas et al.,

1991a; Spaniol & Jung, 1987). However, caregivers often need help in identifying their personal and social resources and taking them into use.

Since burden is associated with the social disability of the ill family member, treatment of the symptoms and improvement of the functional capacity of the ill family member may alleviate caregiver burden and enhance the well-being of caregivers (Szmukler et al. 1996a, 147; Taiminen et al. 2000, 124; Magliano et al., 2000, 112). The burden may also be alleviated by providing emotional, informational, practical and financial support for caregivers (Nyman & Stengård, 2001; Orford, 1987, 26). Thus all support interventions for families should aim to diminish the experienced difficulties and solve problems, but also at the same time aim to strengthen the positive aspects of life.

Caring is a very personal, ethical and existential question, since each of us has to decide whether to care for others who need our help (Koistinen, 2003, 168–172). On the other hand, caring is a very broad issue, one that has political, social, pragmatic, and philosophical aspects (Wood, 1994, 1, 11). While the trend toward community-based care has increased families' caregiving responsibilities for people with serious mental illness, the family's structural capacity to meet those demands is diminishing (Reinhard, 1994b, 70). Several social and demographic changes have altered kinship structures in ways that weaken its capacity for caregiving. Broad geographic mobility has led to the dispersion of extended families, thereby limiting availability of informal social support. The increasing proportion of female workers in the labor market decreases women's ability to perform traditional, ongoing caregiving roles. High divorce rates, growth in single-parent homes and small family size, compromise the structural caregiving capacity of families. Although high rates of remarriage create new kinship configurations with multiple options for close family bonds, the small size of accommodation restricts the development of new extended families. Further, one reality that will continue to play a key part in women's decision to give care is the absence of available or attractive alternatives (Guberman et al., 1992, 615; Julkunen, 1992, 135–136; Valta-kunnallinen omaishoidon uudistaminen, 2004, 27; Gray, 1985, 39).

Despite these trends, informal caregiving is still provided mostly in private homes and parents and their adult children still have close relationships and both give and receive help from each other. In Finland, adult children met their parents in 1994 more often than in 1986, whereas the trend in meeting siblings was the opposite. Parents helped their adult children by giving advice or money, providing transportation and help in child care, whereas adult children took care of their aging parents (Anttonen & Sipilä, 2000, 104; Melkas,

2003, 82, 92; Ritamies & Fågel, 1998, 65–71). Many adults also value quality of life and close relationships are seen as part of good life (Valtakunnallinen omaishoidon uudistaminen, 2004, 27). For those persons who do not have close family members living nearby the peer support groups might provide an opportunity to share experiences and receive emotional support and help (Koistinen, 2003, 113–114).

Informal caregiving has been and continues to be women's agenda and is thus closely connected to the social status of women (Anttonen & Sipilä, 2000, 135). As deinstitutionalization and home maintenance policies continue to be developed, women are becoming the key element in the development of government strategies to meet the needs of dependent adults (Guberman et al., 1992, 615). In the Nordic countries social and health services have typically been both financed and provided by the public sector, the state and the municipalities. These services have been available to all citizens. Even though the public social and health services still form the majority of services, the sociopolitical reform of the 1990s in Finland introduced several changes. One of these was the integration of private sector, third sector and informal family caregiving into the public service system (Julkunen, 2001; Valtakunnallinen omaishoidon uudistaminen, 2004).

One recent example of this integration process is that the Ministry of Social Affairs and Health appointed a rapporteur to draw up proposals for the measures to develop informal care. The rapporteur proposes 16 measures that would make informal care an important part of the service structure in social welfare and health care. Informal care will be supported by financial compensation and support for the carer and services for the person cared for. The developing measures proposed also include an informal care deduction in the Income Tax Act, a two-day leave per month, and a multiprofessional team and a contact person for informal care for the evaluation, implementation and monitoring of informal care. In addition, framework agreements and recommendations by labor market organizations should be used to enhance informal care by making use of job rotation leave, reduced working hours, accumulated holiday, provisions on compelling family reasons, telework and part-time solutions. The rapporteur also proposes that the expertise of organizations and the use of service vouchers in producing services and support should be utilized more actively. The total costs of the reform will be financed by central and local government. Developing informal care requires smooth cooperation and division of labor between the public sector, companies providing service and organizations (Valtakunnallinen omaishoidon uudistaminen, 2004). Thus, the well-being of caregivers is in many ways dependent on the sociopoliti-

cal decisions taken in society. The simultaneous trends of decreasing informal help and growing difficulties in the economy of municipalities may result in serious crises in informal caregiving in the near future if new solutions are not found (Anttonen & Sipilä, 2000, 145).

6.3. Psychoeducational interventions

Study III showed that most caregivers of people with schizophrenia are satisfied with their situation and with the psychiatric services in Finland. Nevertheless, one-fifth of the caregivers were dissatisfied with the situation in general and about one-third with the psychiatric services. Although previous studies have reported similar figures (Wray, 1994; Salokangas et al., 1991a), research on caregiver satisfaction has been criticized for reporting implausibly high satisfaction scores with little variation (Lebow, 1982). In this study the caregivers were interviewed by the psychiatric teams responsible for the care of the patients. As has been suggested in earlier studies (Leavey et al., 1997; Honkonen, 1995), the caregivers might have been reluctant to criticize the services on which they are so dependent.

Caregivers were more likely to be dissatisfied with the situation if they lived with the patient and if the patient's functional state was poor or the patient's use of services, particularly medication and rehabilitation, was low. This result may reflect the greater burden on caregivers taking care of family member with schizophrenia whose social role functioning is poor and whose needs for medication have not been adequately met.

Caregivers were dissatisfied with the services if the patients had severe psychotic symptoms or poor maintenance of grip on life and if they were given less psychiatric care, rehabilitation, and physical examination and treatment. The patients' use of social services and the patients' own dissatisfaction with community care and with their medication were also associated with caregiver dissatisfaction. These findings suggest that the caregivers of people with schizophrenia want rather basic things from psychiatric services. The most important factors in ensuring caregiver satisfaction seem to be rehabilitation measures that might improve patients' functional status and adequate medication, especially to control patients' psychotic symptoms. Persons with schizophrenia should also be adequately examined and treated for physical illnesses.

The satisfaction of caregivers of mentally ill persons appears to have two dimensions. First, as previous studies have reported, caregivers need to be accepted and treated as active partners in patients' care and rehabilitation

(Leavey et al., 1997; Wray, 1994; Biegel et al., 1995; Hanson & Rapp, 1992; Gasque-Carter & Curlee, 1999). Families want information about the illness and its treatment, and they want to know what they can do to help their ill family member. Second, the burden on the families of mentally ill people should be alleviated with long-term rehabilitation and care to help patients gain as high a functional state as possible. Caregivers need to be closely involved in the treatment process, and their need for information, support, and counseling should be carefully assessed and met.

Psychoeducational interventions have been shown to be effective in reducing relapse, decreasing hospitalization and encouraging compliance with medication. Long-term family interventions might also enhance family functioning and reduce expressed emotion and family burden (Penn & Mueser, 1996; Fadden, 1998b; Dixon et al., 2000; Bustillo et al., 2001; Pharoah et al., 2001; Pekkala & Merinder, 2001; Cuijpers, 1999; Falloon et al., 2002; Pitschel-Walz et al., 2001; Hazel et al., 2004). There is also some evidence that briefer family education interventions, family counseling and support groups are effective in knowledge acquisition and changing attitudes and behaviors of caregivers, although the results are not consistent (Kazarian & Vanderheyden, 1992; Szmukler et al., 1996b; Hogan, Linden, & Najarian, 2002).

Psychoeducational interventions also have other advantages. Education can be used as a powerful form of engagement of families in further interventions (Berkowitz et al., 1990, 219) and as a strategy for maintaining the gains of individually based family interventions (Mueser & Glynn, 1999, 23). Psychoeducation programs are non-stigmatizing and help families regain the capability to evaluate what is within or beyond their control and empower them to work collaboratively with health professionals (Van Hammond & Deans, 1995, 11). In addition to benefiting families, the intervention is an excellent way to train the staff to respect and appreciate the enormous strengths and abilities of family members (McLean et al., 1982, 568; Gingerich et al., 1992, 929).

The major limitations of psychoeducational family interventions are their limited availability and generalizability due to the stringent research designs in which the interventions have been developed. Since the families of people with serious mental illness form a heterogeneous group, more research is needed to find out how these interventions work in routine clinical practice (Solomon, 1996; Magliano et al., 1998a, 1998b). Despite the limited success in identification of the active ingredients for different interventions (Bustillo et al., 2001, 172; Penn & Mueser, 1996, 612; Dixon et al., 2000, 14; Cuijpers, 1999, 282), their continued implementation and evaluation seem justified. In

Finland, the use of psychoeducational family interventions is recommended as a part of comprehensive care of schizophrenia patients in the national Current Care Guidelines (Suomen Psykiatriyhdistys, 2001, 2650).

In keeping with previous studies (Smith & Birchwood, 1987; Sidley et al., 1991) the educational intervention described in Study V produced gains in knowledge about schizophrenia. Even though the information gains remained modest, most of the relatives felt that they had acquired new information. Another finding consistent with previous studies was that the psychological well-being of the participants increased after the intervention (Cuijpers, 1999; Birchwood et al., 1992; Cook & Heller, 1999), but there was no change in the objective burden felt by the participants (Orhagen & d'Elia, 1992a). However, the proportion of the participants who felt that their social network had diminished because of the mental illness of a family member decreased during the 6-month follow-up. Furthermore, there was a slight decrease in the criticism towards the mentally ill family member in the video groups, but not in the oral presentation groups. These findings reflect the results of previous studies that brief educational interventions may be well suited to the needs of families with low expressed emotion, while families with high expressed emotion may require more intensive involvement (Posner et al., 1992; Merinder et al. 1999b).

In conclusion, Study V demonstrated that brief educational intervention can yield significant benefits, even for relatives of long-term schizophrenia patients. Most mental health care facilities have resources to supply educational intervention but not intensive single-family treatment. This type of intervention can be implemented by community mental health agencies with existing personnel and a few additional resources. However, there are several factors in the content and delivery of psychoeducational interventions that should be taken into account in further development of the interventions. Family members are capable of specifying their own educational needs (Mueser et al., 1992, 674; Jokinen, 2001, 32–33), but their ideas may be different from those of professionals. Therefore family members should be involved in the development of the content of educational interventions which should be flexible enough to meet the needs of each particular member as well as to provide general information relevant to all members (Pollio, North, & Foster, 1998, 821; North et al., 1998, 43–44; Gasque-Carter & Curlee, 1999, 523; Perkins, Nieri, & Kazmer, 2001, 130). Particularly with etiological information, caregivers may be very selective about the aspect which they find relevant to their own situation. New information should be at least approximate to their existing lay-model for it to be assimilated (Sidley et al., 1991, 316, 319). However,

providing caregivers with information, rather than the teaching method, seem the crucial element in the intervention (Birchwood et al., 1992, 813).

Furthermore, the educational process does not cease after a brief exposition, but information should be offered consistently. Many family members want more detailed and sophisticated information as time goes on and their knowledge base increases (Goldstein, 1991, 126; Dixon et al., 2000, 17; Perkins et al., 2001, 122). Families also need enough time to integrate the educational material and gauge its relevance to their own experience (Cuijpers, 1999, 283; Mueser & Glynn, 1999, 92). The interventions are unlikely to be successful if they ignore the underlying complex belief system that pertains within the family (Barrowclough & Hooley, 2003, 875). The timing of the intervention also seems crucial. If educational intervention is left too late, the caregivers may have developed fixed views that might be difficult to change (Budd & Hughes, 1997, 123).

Providing information for the family members of people with mental illness requires that issues of confidentiality are taken into account. All disclosures to and exchanges with families should be preceded by discussing with the patient the values of these communications and by obtaining the patient's consent. The patient's choice to include or exclude other family members should be respected. However, from the clinical point of view, families who provide care and support for the ill family member need adequate information to successfully carry out this role (Petrila & Sadoff, 1992, 137–139). The practitioners can also assume the role of mediator and assist patients to explore their interests and to develop proposals for sharing information that meet both the patient's and family's interests. Frequently, the information needs of families can be met by providing them with information that is helpful but not confidential. The practitioner giving the information may be someone other than the care provider for the ill family member. This helps to protect the relationship between the practitioner and the patient (Zipple, Langle, Spaniol & Fisher, 1990, 538–543). Families can also be referred to educational groups provided by family organizations.

However, in some situations the practitioners have to consider the possibility of overriding the patient's refusal. Szmukler and Bloch (1997, 403) have proposed that justification for involving the family contrary to the patient's wishes is strongest when the harms to be avoided are serious and highly probable; no acceptable alternatives are available; the patient's capacity to make a genuine choice is impaired; the family's values embody mutual concern and assistance; and not recruiting the family may lead to even greater restrictions on the patient's liberty.

In Study V, the most important element of the educational intervention for the participants was probably sharing their experiences and feelings with other participants. This effect may have contributed to the increase in relatives' well-being even more than the providing of the information. Furthermore, the new information acquired might not be the facts presented by the group leaders but the ideas the caregivers shared in the informal discussions with other participants. As suggested in earlier studies (Heller et al., 1997; Citron et al., 1999), family support groups may have two distinct types of benefit factors, information benefit and relationship benefit. The relationship benefits include peer support, sharing similar thoughts, feelings and actions, and feeling understood and accepted by others. Psychoeducational programs may also help relatives to regain the capability to evaluate what is within or beyond their control, empower them to work collaboratively with health professionals (Hammond & Deans, 1995), and help them to acknowledge and accept their concerns about stigma and rejection by others (Phelan, Grommet, & Link, 1998).

The interventions should be based on the competence paradigm underscoring the positive qualities of families and tailored to meet the needs of different groups of caregivers (Marsh & Lefley, 1996; Määttä, 1999, 106–114). The families of mentally ill people live in different types of caregiving situations and their needs for information and support vary according to the disabilities of the mentally ill family member, the relationship to the ill family member, social support available and the financial situation of the family (Nyman & Stengård, 2001, 91–92). Elderly parents have special needs for financial and residential planning (Mengel, Marcus, & Dunkle, 1996) whereas the children of mentally ill parents need security and continuity in everyday life as well as supportive adult relationships (Solantaus, 2001, 25; Jähi, 2004). The majority of the participants of psychoeducational interventions have been women. Therefore inventions should be further developed in order to gain higher acceptability among men (Cuijpers, 1999; Pickett-Schenk, 2003).

The atmosphere of the intervention is also very important. The therapist should promote an atmosphere where families are acknowledged as experts of their respective situations, and allow them to share their individual skills and knowledge with each other (Perkins et al., 2001, 130). Professionals should expect to hear, without becoming defensive, expressions of strong negative feelings (grief and anger) experienced by the caregivers. Plenty of time needs to be allocated for sociable interactions within the group to generate peer support (Winefield & Harvey, 1995, 144–145). The research findings about grief in family members should be adopted by education programs to provide an

appropriate environment for an individual to review feelings of loss and grief (Davis & Schultz, 1998, 378; Miller, 1996).

Successful family psychoeducation dissemination efforts have built consensus at all levels, including clients and their family members. They have provided ample training, technical assistance, and supervision for clinical staff, and have maintained a long-term perspective. Therapists have been willing to see families outside normal working hours, to use strategies aimed at engaging families in therapy, and to see families with a co-therapist. However, successful implementation also requires changes at institutional level. Trained and motivated staff cannot effectively implement new interventions if the size of their caseloads remains the same (Dixon et al., 2001b; Amenson & Liberman, 2001; McFarlane, McNary, Dixon, Hornby, & Cimett, 2001; Fadden, 1997). Therefore the implementation of these highly acceptable and effective interventions also needs adequate financial resources. The personnel working in the health and social services of local communities also need training and supervision to be able to support the families of the mentally ill. The municipalities have the main responsibility for financing the mental health services as well as organizing the services for their residents.

6.4. Implications for service development

In the era of community care, the need for psychoeducational interventions for the families of people with mental illness is clear. Patients with severe mental disorders need comprehensive care and rehabilitation services as well as sheltered housing and employment. Families are able to support their mentally ill relatives in the community only if their needs for information, practical advice and support are met. Providing services that meet the needs of the patients reduces the caregiving responsibilities of the family members and alleviates their burden. However, family members have also needs of their own. Severe mental illness is a crisis for the whole family and provokes a wide range of feelings. Family members need support especially in dealing with feelings of guilt, shame, and grief. In long-term caregiving situations family members also need time for respite and vacations and opportunities to pursue interests of their own. There is an obvious need for more well-designed community support programs for the families of people with severe mental disorder. All services should be based on a thorough assessment of the needs of the ill family member and the caregivers. Well-designed research instruments as well as

clinical practices for identifying and assessing service needs of caregivers with several concerns and coping difficulties are urgently needed.

Table 3 describes the needs of family members and proposes a model for the distribution of tasks between the individual caregiver, his or her social support network, family organizations and services provided by society. Every individual can and should take responsibility for his own well-being as much as possible in the prevailing situation. Many caregivers are capable of coping well with their personal resources and support provided by their social network. However, caregiving might be a risk for the well-being of the caregivers in situations where the demands of the caregiving task exceed the coping resources of the caregiver (Nyman & Stengård, 2001). In these situations family members need help and support even for years. Service providers should also be sensitive to the needs of families and involve caregivers in the service planning decisions that so directly affect their lives.

It should also be noted that self-help and support groups have tremendous therapeutic potential (Davison et al., 2000, 216). In Finland, all recent national programs for the development of mental health work recommend that voluntary mental health organizations and health and social services should work in close collaboration in planning and providing services and peer support for people with severe mental illness and their families. Supporting the children as well as other family members of mentally ill persons is also an important part of mental health work and prevention of mental health problems (Mielenterveyspalveluiden laatusuositus, 2001; Mielekäs Elämä, 2000, 2003; Suomen Mielenterveysseura, 2003; Heikkilä, Kaakinen, & Korpelainen, 2003). All professionals in mental health and social services as well as in family organizations should continue to work toward the goal of reducing family stress, whether through family interventions or through lobbying of decision-makers and mental health policymakers and administrators to ensure that adequate services are available for patients and their families outside the home (Mintz et al., 1987, 233).

6.5. Implications for future studies

Studies II–V were cross-sectional, aiming to describe the situation and needs of caregivers at the time of the study. These studies documented the burden experienced by families of the mentally ill, but the long-term effects of the caregiving consequences on the physical and mental health of caregivers have

Table 3. Caregiving consequences and resources for support

Problems associated with caregiving	Self	Family and social network	Family organizations	Society
Emotional problems	Self-regulating emotions	Sharing and airing feelings	Normalizing feelings, offering hope for future	Providing psychotherapy and medication
Social problems	Keeping in touch with friends	Socializing with relatives and friends, engaging in activities as a family, encouraging additional social activities	Facilitating social interaction and providing opportunities to expand natural network in self-help and support groups, reduce stigma, empowerment	Supporting voluntary organizations, actively engaging families to services, positive attitudes towards persons with mental illness and their families
Financial problems	Good education, permanent job	Family's good socioeconomic situation	Providing free or inexpensive services, help in applying for social benefits	Providing social security benefits, informal care allowance, flexibility in work arrangements
Mental and physical health problems	Healthy way of life, taking vacations and respite from caregiving, enhancing well-being	Supporting healthy way of life, help in organizing opportunities for rest	Teaching ways to enhance well-being and taking care of oneself, providing and organizing vacations	Providing health care and mental health care services and home-help
Practical problems in management of the situation at home	Learning by trial and error, becoming more tolerant, searching for information and advice	Enhancing communication and problem solving skills, negotiating family rules	Providing practical advice and experiential knowledge, teaching coping and problem solving methods, promoting feelings of hope and mastery	Providing crisis services, home-based social and psychiatric services, advice and information, supported housing for the ill family member
Problems in finding and using services	Searching for information	Helping in search for information	Counseling, providing assistance in finding services, advocacy for better services	Providing case management

not been thoroughly examined. The situation of caregivers changes over time and there is a clear need to learn more about the adaptation process of family members that take place in the long run. Future studies should use longitudinal research designs with an emphasis on the physical and mental health of caregivers.

Caregiving research has traditionally concentrated on the negative consequences of caregiving. However, some advances in the research have been made in the 1990s and factors such as appraisal, social support, coping resources, family resilience, sense of coherence, meaning of caregiving and positive aspects of caregiving are emerging as important (Fadden 1998a; Noonan & Tennstedt, 1997; Szmukler et al. 1996a; Marsh & Lefley, 1996; Landsverk & Kane, 1998; Farran & Kuhn, 1998; Farran, Miller, Kaufman, Donner, & Fogg, 1999). Further, Farran (1997, 255) has proposed that the stress-coping paradigm of caregiving should be broadened by adding elements of the existential paradigm such as values, moral decisions and ability to discover and create meaning. These dimensions of positive health and well-being should be incorporated into future studies on caregiving.

More research is also needed about the situation and needs of different groups of family members such as male caregivers, siblings and children and those caregivers who provide help and support for several ill family members. Psychoeducational interventions should also be further developed. Although families on these programs tend to rate them as helpful (Kazarian & Vanderheyden, 1992), more research is needed on the aspects of the interventions that are experienced as helpful (McFarlane, 2003, 54) as well as well-designed, randomized studies investigating the efficacy of brief educational interventions.

6.6. Conclusions

The conclusions of this study are as follows:

- Family members should be involved in the care and rehabilitation of the person with severe mental illness. Families who provide care and support for the ill family member need adequate information, practical advice and support to successfully carry out this role.
- A majority of caregivers of people with severe mental illness experience some burden as a consequence of their caregiving task.

- For 15–25% of caregivers the caregiving situation is clearly a risk for their well-being and they need intensive help and support to cope with the situation. Research methods and clinical practices should be developed in order to identify these caregivers early enough to prevent and reduce their physical and psychiatric morbidity.
- The needs of all family members for emotional, informational, practical and financial support should be acknowledged and assessed as a part of the routine clinical practice in psychiatric hospitals and mental health care centers.
- Psychoeducational family interventions should be made more readily available in Finland.
- Family interventions should be based on the competence paradigm underscoring the positive qualities of families and tailored to meet the needs of different groups of caregivers.
- Psychoeducational interventions should be developed in order to gain higher acceptability among men, too.
- Service providers and policy makers should be sensitive to the needs of families and involve caregivers in the service planning decisions that so directly affect their lives.
- Voluntary mental health organizations and health and social services should work in close collaboration in planning and providing services and peer support for the people with severe mental illness and their families.

7. SUMMARY

7.1. Background and aims of the study

Over the past two decades, the deinstitutionalization movement has shifted the primary locus of care from psychiatric hospitals to community care in Finland as well as in most other Western countries. Many patients living in the community need a lot of practical help and emotional support in order to manage their everyday lives. Given the limited resources of community care, this support is often provided by the family members of the person with mental illness. As a result of the caregiving consequences, family members have experienced burden and distress and expressed a need for informational and emotional support. The purpose of the present study was to examine the short-term outcome in schizophrenia and to contribute to the understanding of the situation and needs of family members of people with severe mental illness.

7.2. *Subjects and methods*

Study I consists of 15-44-year-olds in six mental health districts who during a 1-year period between 1983 and 1984 contacted public psychiatric services for the first time in their life in order to receive treatment for schizophrenia. Schizophrenia was defined by DSM-III criteria; the disorders included were schizophrenic, schizophreniform and schizo-affective psychoses. During the study period a total of 227 patients meeting these criteria contacted public psychiatric services and were included in the study. All patients underwent an extensive basic examination at entry, and individual treatment plans were drawn up for each patient. In addition, follow-up investigations were carried out 12 and 24 months after the initial contact.

Studies II-V comprise a large amount of data on caregivers of people with severe mental disorder. The caregivers were contacted through family organizations, psychiatric hospitals and mental health care centers. Altogether 1,224

caregivers participated in these studies. Most of the participants were women with an average age of 55-56 years. Over half of the caregivers were parents of persons with mental illness. The caregivers were related to 1,174 persons with severe mental disorder, most often schizophrenia or major affective disorder. Over half of the ill family members were male. The average age of ill family members was between 37 and 41 years and the duration of illness was 11-13 years on average.

The data were collected by questionnaires in Studies II, IV, and V. All questionnaires included questions devised for each study as well as internationally used measures. In Studies I and III the data was drawn from national projects designed to study the treatment and the life situation of patients with schizophrenia in Finland. Data were collected from psychiatric case records and the patients (Studies I and III) and their caregivers (Study III) were interviewed separately by psychiatric teams.

7.3. Results

The purpose of Study I was to examine the gender differences of new schizophrenia patients in the premorbid stage and during the early stage of treatment. Men showed a poorer premorbid sexual development and they also tended to be more withdrawn than women. Following the onset of the illness, men still failed to establish satisfactory heterosexual relationships, they suffered more often from negative symptoms, and they displayed poorer working capacity and functional ability than women. At the beginning of the follow-up men had a more pessimistic view of the development of their life situation over the next 2 years, a prediction which turned out to be correct. The predictions made by the psychiatric teams were very similar. In their plans for treatment the psychiatric teams recommended primarily psychotherapeutic methods for female patients – and women actually went to psychotherapy more often than men – whereas it was felt that the rehabilitation of men should concentrate on working capacity and basic social skills.

Study II aimed to describe the well-being and need for information and support of caregivers according to living arrangements and kinship. Nearly 60% of the caregivers reported psychological distress and half of the caregivers had experienced objective burden in their lives. Most often the caregivers found general supervision of the patient tiring, but the social relationships of the caregivers had also quite often become difficult. The caregivers living with the patient expressed more psychological distress and objective burden and

lower satisfaction with life than caregivers living apart from the patient. The most distressed group of the caregivers were spouses living together with their mentally ill husband or wife.

Study III was intended to identify the factors associated with whether caregivers of patients with schizophrenia were satisfied with their situation in general and with the psychiatric services in particular. One fifth of the caregivers were dissatisfied with the situation in general and about one third with the psychiatric services. Three main factors were associated with caregiver dissatisfaction with the situation in general: patients' poor psychosocial functioning; patients' insufficient use of medication and rehabilitative services; and living with the patient. The patients' and caregivers' backgrounds and the patients' social relationships and satisfaction with their care had negligible roles in explaining the caregivers' dissatisfaction. Caregiver dissatisfaction with the services the patient received was associated with a set of factors different from those associated with their dissatisfaction with the situation in general. Caregivers were dissatisfied with the services if the patients had severe psychotic symptoms or poor maintenance of grip on life and if they were given less psychiatric care, rehabilitation, and physical examination and treatment. The patients' use of social services and the patients' own dissatisfaction with community care and with their medication were also associated with caregiver dissatisfaction.

The aim of Study IV was to identify different types of caregivers of mentally ill people and examine the differences between these types. Five types of caregivers were identified according to the caregiving dimensions: supervising; anxious; coping; resigned; and activating caregivers. About two fifth of the caregivers managed the situation well and reported low levels of burden and overload. Activating and resigned caregivers were also coping quite well, even though their well-being was somewhat lower and they expressed a need for information and support. However, supervising and anxious types, who comprised about 15 % of the caregivers, were the most burdened types. The mental health of patients of supervising and anxious types of caregivers was reportedly poorer and the social disability was higher compared with other types. These caregivers also reported poorer physical and mental health, more psychological distress and more overload than other caregivers.

Supervising caregivers used problem-solving, reappraisal and stress reduction more frequently than the other types of caregivers. The coping caregivers had least need for information, whereas the anxious and supervising caregivers had most need for information. Resigned caregivers expressed the need to learn more about the basic facts of mental illness. The coping caregivers reported the

least need for support while the anxious type of caregivers expressed the need for most types of support. Supervising caregivers expressed need for respite care and vacation and resigned and activating caregivers felt that they needed psychoeducation.

Study V was undertaken to examine the efficacy of a multifamily educational intervention. The educational intervention produced gains in knowledge about schizophrenia. Before the intervention a quarter of the relatives had high expressed emotion (EE). The EE status or the overinvolvement scores of the participants did not change after the intervention. However, there was a slight decrease in the criticism scores towards the mentally ill family member in the video groups, but not in the oral presentation groups. The psychological well-being of the participants also increased after the intervention, but there was no change in the objective burden felt by the participants. The intervention had a high acceptability among the relatives. The participants in video education found the information presented more often useful in practice than the participants in the oral presentations.

7.4. Conclusions

A majority of caregivers of people with severe mental illness experience some burden as a consequence of their caregiving task, but for 15-25% of caregivers the caregiving situation is clearly a risk for their well-being. Research methods and clinical practices should be developed in order to identify these caregivers early enough to prevent and reduce their physical and psychiatric morbidity.

Family members should be involved in the care and rehabilitation of the person with severe mental illness. Families who provide care and support for the ill family member need adequate information, practical advice, financial and emotional support to successfully carry out this role. These needs should be acknowledged and assessed as a part of the routine clinical practice in psychiatric hospitals and mental health care centers. Psychoeducational family interventions should also be made more readily available in Finland.

Service providers and policy makers should be sensitive to the needs of families and involve caregivers in the service planning decisions. Health and social services should work in close collaboration with voluntary mental health organizations in planning and providing services and peer support for the people with severe mental illness and their families.

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