

Recovery from Severe Mental Illness: a 5-Year Follow-Up Study After the 1995 Swedish Mental Health Care Reform

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ABSTRACT *The aim of this study was to follow up the target group of the 1995 Swedish Mental Health Care Reform, focusing on recovery. In 1995–96, in one area of Sweden, 602 people were surveyed and judged to be severely mentally ill. Five years later the number of people who had recovered was estimated and compared with the group still judged to be severely mentally ill. A sample of recovered people was interviewed in order to gain an understanding of the recovery process. Of those surveyed, 14% were estimated to have recovered to the degree that they were no longer considered to be severely mentally ill. Support from others, medication and healthcare contributed to recovery, sometimes in a complex and contradictory way. It was also found to be important that the person took an active role in his/her own process of recovery. The recovered person's locus of control could be internal as well as external.*

Scientific interest in people who have recovered from severe mental illness has been limited over the last 20 years (Torgelsboen 1999). However, the importance of taking the recovered persons' own experiences into account has been increasingly stressed (Chadwick 1997, Corrigan et al. 1999, Topor 2001, Torgalsboen 2001).

Harding (1988) summarized five large longitudinal studies of recovery of people with a diagnosis of schizophrenia. Between half and two-thirds of the groups examined were found to have made a total, or at least a considerable, recovery.

Shepard, Watt, Falloon and Smeeton (1989) observed clinical improvement in about half of the people after 5 years, with better results for women than for men. In a meta-analysis of 87 studies between 1919 and 1979 (Warner 1985) it was shown that the number of people who made a total or considerable recovery varies over time. The number of recovered people was higher during periods of strong economy in society and during periods of optimism in treatment (Topor 2001). On average, the percentage of socially

recovered people was between 30% and 40% and the percentage of people who were totally recovered was between 10% and 20%.

Yet another meta-analysis (Hegarty et al. 1994) showed similar percentages. In this meta-analysis the number of recovered people showed a connection to the criteria of diagnoses applied during different periods of time; the stricter the criteria for diagnoses; the lower the number of recovered people.

Harrison et al. (2001) reported a World Health Organisation (WHO)-study with 1600 patients from nine countries. Follow-up studies were made after 2, 5, 15 and 25 years. About half of the survivors were improved after 25 years, but the number varied between different countries. Between 15% and 20% were recovered to the extent that they did not need any treatment.

Sullivan (1994) interviewed 46 formerly severely mentally ill people about activities, attitudes and behaviour among themselves or among other people important to their process of recovery. Factors associated with a successful recovery were medication (71%), support from society (67%), the person's own willpower (63%), work and school (46%), spiritual dimension (43%), knowledge about the illness (35%), support from interest-groups and friends (33%) and important relatives (30%). Tooth, Kalyanansundaram and Glover (1997) found similar factors. Torgalsboen and Rund (1998) conducted a study based on an earlier study of 18 completely recovered people (Rund 1990). Factors such as willpower and a supportive family were discussed as positive contributors to the process of recovery. Topor (2001) stressed the importance of the patient's own efforts in the recovery process.

It is problematic to compare the results of different studies of recovery. The criteria of inclusion differ. People who are considered to be severely mentally ill could have different diagnoses, though the diagnosis of schizophrenia is most common. It seems that there are no fundamental differences in the process of recovery between groups with different diagnoses (Young & Ensing 1999, Topor 2001). But even within a group with the diagnosis of schizophrenia, it is not certain that the diagnoses are comparable. Earlier, the criteria for a diagnosis of schizophrenia were less stringent in the USA than in Europe, with the consequence that the recovery rates were higher in the USA (Warner 1985, Hegarty et al. 1994). During the last 20 years the criteria of diagnoses have become more uniform, but still differ from country to country and from doctor to doctor (Warner 1985).

Other difficulties in comparing studies involve different operationalizations of the concept of recovery and the length of the follow-up period. However, the results for some patients unanimously show a recovery that can be rather complete. The probability of this recovery was more difficult to estimate.

Aim of the Study

The aim of the study was to follow up a group of people who were considered to be severely mentally ill at the time of the 1995 Swedish Mental Health Care Reform, but not so 5 years later. The main objective of the study was to

generate knowledge about the number of recovered people and the process of recovery.

Methods

Sub-Studies

This study consists of two sub-studies, one based mainly on quantitative method and one based mainly on qualitative method.

The Quantitative Sub-Study

Sample of the quantitative sub-study. Connected with the 1995 Swedish Mental Health Care Reform, surveys were made throughout the country in order to identify the number of severely mentally ill people and their needs. Of the municipalities in Sweden, 85% were surveyed (corresponding to 93% of the population) (Stefansson & Hansson 2001).

The definition used in the surveys to identify “severely mentally ill people”, i.e. the target group of the reform, was “people with a mental illness that causes a disability to the degree that it influences daily life (social consequences), and where this handicap is estimated to be long-lasting” (National Board of Health and Welfare 1998:34). People below the age of 18 years, or with intellectual disabilities or age dementia were excluded.

The target group of the reform is described as a group of people with handicaps caused by mental illnesses and societal deficiencies (Sandlund 1997, Markstrom 2003). The concept of handicap described in the reform is based on the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO 1980, Sandlund 1997). In a revision of ICIDH the concept of handicap is substituted by concepts of activity and participation (ICF, WHO 2001). In the present study the concept of handicap was retained because it was a key component of the discourse when the 1995 Swedish Mental Health Care Reform was implemented.

The municipality of Jönköping, where this study was performed, has approximately 120,000 inhabitants. The Department of Psychiatry at the County Hospital of Ryhov and the social services at Jönköping municipality co-operated in 1995–96 in carrying out a survey of severely mentally ill people according to the definition in the Mental Health Care Reform. Other service institutions and interest groups were also involved. A total of 602 severely mentally ill people were identified and listed this way (0.67% of the population over 18 years of age). Of the sample, 51% were women. The mean age for women was higher than that for men (53.9 years compared with 48.6 years, *t*-test: $p < 0.001$). Of the 602 severely mentally ill people, 473 agreed to be interviewed using a form worked out by the National Board of Health and Welfare (1998). The form included a value of overall psychosocial functioning (GAF; American Psychiatric Organization 1994), needs-assessment according to Camberwell Assessment of Need (Phelan et al. 1995) and a

diagnosis according to ICD 10 (WHO 1996). The diagnoses were divided into six subgroups (Table 1).

One employee from social services and one from a psychiatric care organization interviewed the participants. The interviewers were mainly psychiatric nurses, occupational therapists or social workers and at least one of them knew the patient well. Following this interview the employees cooperated in recording their own Camberwell Assessment of Need (CAN) ratings and made a Global Assessment of Functioning (GAF)-rating (Arvidsson 2003).

Some characteristics of the interviewed sample can be found in Table 1. There was no difference in gender when comparing the total sample (of 602) and the group of people who did not participate in the interview, however the non-participating group had a lower mean age (47.5 years, standard deviation (SD) 13.7 compared with 52.3 years, SD 17.3, t -test $p < 0.001$).

A new survey using the same method and definition of severely mentally ill was performed again in 2000–01. This time 828 people were identified as severely mentally ill (0.90% of the adult population). A total of 224 people were identified in the survey in 1995–96 but not in the survey in 2000–01. These 224 people made up the target group of this study.

The concept of recovery in this study. In describing the target group of the reform “severely mentally ill people” were defined as people with mental illnesses that caused disabilities that had become handicaps. People who were identified as severely mentally ill in the survey in 1995–96, but not so in 2000–01, were considered to have recovered from being severely mentally ill and estimated to have recovered in the sense that their illness no longer caused any handicap.

Table 1. Some characteristics of the people surveyed in 1995–96. Diagnoses according to ICD 10

Variable	%
Women	51
Cohabiting with a domestic partner	11
Living with children below 18 years of age	5
Living in their own apartment	66
Living in group homes	17
Living in institutions	17
Working in an ordinary or sheltered work	12
Ongoing contact with psychiatric care	90
Given the diagnosis of schizophrenia or similar (F 20–29)	50
Mood disorders (F 30–39)	17
Neurotic, stress related or somatoform disorders (F 40–48)	14
Disorders of personality and behaviour (F 60–69)	13
Disorders due to psychoactive substance abuse (F 10–19)	2
Given other psychiatric diagnoses	5

One problem of definition was that some people were not considered to be severely mentally ill in 2000–01 because their care had been transformed from psychiatric care to other organizations or authorities, e.g. somatic care, dementia care, or care of elderly people. Their disabilities did not seem to have decreased; they had simply changed care provider. These problems were naturally more significant for the older people in the sample. For the elderly subjects it was also problematic to determine whether their psychiatric problems were the main reason for their care. A somewhat arbitrary age-limit was therefore imposed in the present study. People aged 65 years or over at the time of the 2000–01 survey, were excluded.

People in this study who were defined as recovered from being severely mentally ill were those who were surveyed in 1995–96 but not in 2000–01, and had an age of 64 years or less in 2000–01. They were still living in the county in 2000–01 and did not belong to the care of any other provider than psychiatry or primary care. According to this definition the recovered people could still be in contact with psychiatric care. The people in this study defined as “still severely mentally ill” are those who were surveyed in *both* 1995–96 and in 2000–01 and had an age of 64 years or less in 2000–01.

Use of registers. The number of visits to out-patient facilities, the number of occasions of in-patient care and number of days of in-patient care were calculated via the case-register used in the psychiatric clinic.

The national registration register was used to identify people who were no longer in contact with psychiatric care in order to determine whether they had moved from the area or if they were deceased.

The case records of people who were no longer in contact with psychiatric care were examined to determine whether they were looked after by care providers other than a psychiatric care organization.

Statistics. Based on the interviews in 1995–96, comparisons were made between the group of people who had recovered from being severely mentally ill and the group who were still considered to be severely mentally ill. Differences in the sum of needs (CAN) and GAF values were analysed using *t*-tests. When studying differences between those groups in variables that were discrete, the χ^2 -test was used.

A logistic regression (Wald, forward stepwise) was also made when comparing the groups. Independent variables were gender, diagnostic group (schizophrenia or not schizophrenia), cohabiting with a domestic partner, sum of met and unmet needs (CAN), GAF-value and the presence of abuse problems.

The Qualitative Sub-Study

The sample of the qualitative sub-study. In trying to gain knowledge about the recovery process, people who had recovered from severe mental illness and who had no contact or infrequent contact with care providers for their psychiatric problems were interviewed. This group of people might be a more

“totally” recovered group than the group “only” recovered from being severely mentally ill but still in frequent contact with care for their psychiatric problems.

People with infrequent contact with care for their psychiatric problems were those who had had contact with care providers for their psychiatric problems on, at the most, three occasions during the last 2 years. The cut-off of three contacts was set because nobody had between three and ten contacts. Those with ten or more contacts seemed still to be in regular psychiatric treatment.

Twelve people met the original criteria for the interviews. Of these, two people took part unidentified in the inventory in 1995–96 and were not available for interview. Two other people declined to be interviewed. These four people had no contact with psychiatric care in 2000–01. Furthermore, one person had a long history of eating disorders, which at the time of the interview had developed into somatic illnesses in a way that her former psychiatric disorders were not relevant to her present treatment. According to earlier definitions she should belong to the group of people whose disabilities did not seem to have decreased but who were treated by care providers other than psychiatric care.

Seven people, five females and two males, were interviewed. None had been treated in in-patient psychiatric care during the last 5 years. Still, six people had infrequent contact with open psychiatric care or primary care for their psychiatric problems and were on medication.

Short description of the seven people interviewed.

- *Person 1:* female, 58 years of age. Early retirement pension depending on psychiatric illness. Divorced for 12 years, two children and three grandchildren. Now cohabiting with another man. Diagnosed with schizophrenia. Hospitalized repeatedly, the last time in 1989. Since then frequent contact with open care and day-centre. Since 1999 only infrequent contact.
- *Person 2:* female, 60 years of age. Working for 25 years in an office. Divorced for 20 years. Two children. Has been diagnosed with schizo-affective psychosis. Long and frequent hospitalizations over a period of 20 years. The last 10 years only open care. Earlier almost daily contacts but infrequent contact in the last years.
- *Person 3:* female 56 years of age. Early retirement pension depending on psychiatric illness. The last few years cohabiting a male. Previously single. No children. Has had a diagnosis of obsessive-compulsive behaviour. Five long periods of hospitalization in the 1980s and early 1990s. Subsequent frequent visits to open care, infrequent in the last 3 years.
- *Person 4:* woman 62 years of age. Early retirement pension depending on a somatic illness. Hairdresser. Married for many years. Children and grandchildren. Long and frequent stay in hospital in the beginning of the 1990s. Diagnosis of depression. Frequent contacts with open care

between hospitalizations and after the last stay 5 years ago. The last few years only infrequent contact.

- *Person 5*: male, 60 years of age. Early retirement pension depending on a psychiatric illness. Married for many years, children and grandchildren. Diagnosed with personality disorders. Never hospitalized, but frequent contacts with open care and day centres during the 1980s and 1990s. The last years only infrequent open care.
- *Person 6*: male, 60 years of age. Early retirement pension depending on a somatic illness. Carpenter. Married for many years. Children and grandchildren. Diagnosis of depression. Long and frequent hospitalizations in the first years in the 1990s. Subsequent frequent contact with open care. Only infrequent contact in later years.
- *Person 7*: female 63 years of age. Widow for many years. Children and grandchildren. Office-worker. Diagnosis of depression. Long hospitalization and several years of close contact with day-centre and open care. No contact with care for the last 3 years.

Qualitative interviews. The planning, methodology and analysis of the interviews was based on methods described by Kvale (1996). The people interviewed were initially contacted by telephone and reminded of the survey and interview in 1995–96. They were also reminded that a new survey took place in 2000–01 and that at that point they were no longer considered to be severely mentally ill. They were asked if they were willing to be interviewed about this change and about their experiences with the care provided. The interviews were conducted by the first author. Each interview lasted between 1 and 2 hours and interviews were, with one exception, performed in the homes of the interviewees.

The interviews could be described as semi-structured. The interview schedule was based on a study by Topor (2001). The following areas were investigated in depth according to contribution to recovery: own contribution, type of treatment, medication, hospital care, out-patient care, contact with personnel in psychiatric and social services, family, friends and other people, contact with user organizations or people in private practice, the social situation. Concrete situations mentioned by the respondent as being important for their recovery were explored more fully (Topor 2001).

Each interview was transcribed in its totality. The categorization of sentences in the present study was based on the areas identified in the interviews as significant to the process of recovery. The categories found were similar to the areas in the interview-schedule according to Topor (2001). Another category that seemed relevant, which was found in the analysis, was similar to the concept “locus of control” formulated by Rotter (1966).

Locus of control refers to the extent to which individuals believe they can control events affecting them. Individuals with high internal locus of control believe that events result primarily from their own behaviour and actions. Those with high external locus of control believe that powerful others, fate or chance primarily determine events. An assessment was made as to whether the people interviewed had a mainly high external or high internal locus of control

of their view of the reasons for their psychiatric disorders. Those with a high external locus of control seemed to find the reasons for their illness mainly in circumstances beyond their control and those with a high internal locus of control thought that they could influence their disorders. The assessment was based on the number of sentences categorized as internal or external.

Results

Quantitative Analysis

A total of 224 people were listed in the survey in 1995–96 but not in 2000–01 and, of these, 120 people were 64 years of age or less in 2000–01 (or would be if they had been alive). In 2000–01, of these 120 people, 31 were deceased and 23 had moved to areas where it was impossible to study their consumption of care. Ten people were under the care of providers other than psychiatric care. Four people surveyed in 1995–96 were impossible to identify and follow-up. Fifty-two people remained who were recovered in the sense that their disabilities were no longer judged to be handicap-inducing. A total of 317 people were considered to be “still severely mentally ill” according to the definition. Of the people in the recovered group and the group considered to be still severely mentally ill together, 14% were considered recovered to the degree that their illness did not cause disabilities that constituted handicaps.

Based on the interviews in 1995–96, comparisons were made between the group of people who had recovered from being severely mentally ill in 2000–01 and the group who were still considered to be severely mentally ill.

There were no significant differences (*t*-test) according to number of needs and GAF-value between the group that was recovered and the group that was still considered to be severely mentally ill. There were no differences between the groups related to gender, but in respect to cohabiting with a partner ($\chi^2 = 6.3$, $p < 0.02$) and group of diagnoses ($\chi^2 = 13.1$, $p < 0.001$).

Considering different diagnostic groups: 18% in the group diagnosed with mood disorders (F 30–39), 20% in the group diagnosed with stress-related or somatoform disorders (F 40–48), 13% in the group diagnosed with disorders of personality and behaviour (F 60–69) and 6% in the group diagnosed with schizophrenia or similar diagnoses were recovered as defined.

Group of diagnoses (schizophrenia or not schizophrenia) was the only significant variable in a multiple logistic regression (odds ratio 0.24, 95% Confidence Interval (CI) 0.10–0.57). Insignificant variables were: cohabiting with a domestic partner; problems of abuse; gender; GAF-value; met and unmet needs according to the CAN (Table 2).

Qualitative Analysis

Could the interviewed people be considered having recovered? At the time of the interviews, the interviewees were no longer considered to be severely mentally ill and had no or only infrequent contact with psychiatric healthcare services. However, the infrequency of this contact may be due to reasons other than

Table 2. A logistic regression, odds ratios in a bi-variate analysis and a multi-variate analysis. Recovered and still severely mentally ill, based on the interviews carried out in 1995–96

Variable	Bi-variate analysis		Multi-variate analysis (Forward Wald)	
	OR	95% CI	OR	95% CI
Group of diagnosis	0.25	0.10–0.60	0.24	0.10–0.57
Gender	0.82	0.37–1.80		
Abuse problems	0.81	0.22–3.02		
Cohabiting	1.34	0.41–4.40		
GAF	1.00	0.97–1.04		
Met needs	0.88	0.74–1.06		
Unmet needs	0.97	0.79–1.17		

recovery. How did they describe their own mental health status at the time of the interview compared with earlier? Examples are given below (quotes are slightly edited to better conform with written language norms).

I feel much better nowadays Before I was in two worlds. In this world, and a zombie, and I was in another world. . . .now this is gone, but I have my moments of depression, I cry for no reason. Nowadays my life is quiet and peaceful, I have flowers around me, I have more money, I'm proud of myself. (person 1)

Thanks to the medicine I have had no psychotic episodes . . . It's going rather well. It really has. . . it is positive. But I have trouble with my knees . . . No, each day goes well. I have a positive view of life. (2)

I was compulsive and had obsessions, difficult thoughts kept coming about what I had to do and control, go back and repeat things several times. . . .It was the thoughts and the compulsion that made me not feel well, yes it was yes, nowadays I feel much better, I can handle myself, yes I can. . . .I am so glad and grateful, I feel much better today. (3)

I don't remember how it was I slept day and night, just sleeping and gaining weight. I'm asthmatic and that makes me handicapped today But mentally, I now feel very well Once in a while I get anxious and nervous. (4)

Since I got the new medicine, I feel much betterI had problems in going outside. I got panic attacks and such things Before I was depressed, but that part got easier with the new medicine. I feel much better today Sometimes I still get panic attacks, but the medicine helps so that I can go out and walk around in town, do weekly shopping and so on (5)

My mental health was in pieces Oh yes, in plain language it was a hell today I care about many people and I am grateful that I get along so well today. It is a great difference, it really is. (6)

I was deeply depressed, both body and soul were completely run down There's not much you can do when you are in that kind of a crisis with anxiety and want to hang yourself and cannot even buy a bottle of milk. There is nobody who can sit and hold your hand I was in a completely other world and I heard voices and hallucinated. Yes, when I look back at that period of my life, I was feeling very bad for many years, I just cannot understand I feel better now than ever before. In my youth I was more up and down. I have a neighbour who says, ooh what a gloomy and grey day! But that is no reason to complain, it's a good day anyhow. (7)

All people described their mental health as much better than it had been previously. However, most people reported that their illness still influenced their life. Only one person (7) described herself as completely recovered. This was the only person who had no contact with mental healthcare services and who was not on medication.

Own contribution to recovery and locus of control. All seven people reported that they themselves had made contributions to their recovery process. However, the nature of these descriptions differed considerably. In the analyses it seemed relevant to relate their different ways of coping with the consequences of their illness to the concept of locus of control (Rotter 1966).

Three people were judged to have mainly an external locus of control in explaining the reasons for their psychiatric disorders. They seemed to attribute the causes for their illness mainly to circumstances beyond their control. Examples of such circumstances were:

I was feeling fine before this came along. I didn't know what it was. I lived in two worlds when this came over me. I was in another world besides the world I am living in now. (person 1)

I guess you are born with these kinds of things. (5)

I think it is God's will. Yes, it is. That's simply how I see it. He puts me to test, and He helps me. (3)

These three people seemed to have a strategy for recovery in which they attempted to adjust their expectations of life to their problems and to avoid situations provoking distress.

I think I have adapted my way of life to what I am able to handle, I have accepted that. (5)

I am so glad and so grateful for being better, I am so glad for everything I can handle myself, even the smallest things. I know how it was earlier. (3)

Sometimes it is tough, my problems overwhelm me. One day I feel fine, but the next day I don't. I try to do my best Yes, before I was ill I was able to do more things than I do today. I think I now only do what I am expected to do. It is some kind of mental thing. (1)

These three people had a close relationship with a person of the opposite gender, but seemed to live rather isolated lives, with few friends and social activities. No one was employed.

Three other people exhibited a mainly internal locus of control in attributing causes for their psychiatric disorders.

I know some things about my illness The outpatient care has been very good and I now I have to., it depends on me. (2)

I simply needed somebody to pull me together. (4)

I like physical and psychological training. It is also a personal choice. I don't think I otherwise would have reached the level I have. (6)

Their strategy was described as a fight against the restrictions imposed on their life by their illness.

The fighting spirit, yes, everybody who wants to come back has it. (6)

I can handle my own problems. I don't want to sit there and complain [to the therapist] about my life. (2)

I think one wants to do things on one's own, to take care of things. (4)

These people reported closer contacts both with friends and society in general compared with people with a more external locus of control.

For the interviewee who was judged to be fully recovered, it was not possible to determine whether her locus of control was mainly internal or external.

I am an Aries [astrological sign], my eldest son is an Aries and we keep on working until we are finished. I stopped visiting the day centre because my life changed. Nowadays, I fill my life with so much other joy. (7)

Contribution from out-patient psychiatric care and social services. Six people reported that their outpatient care had made important contributions to their recovery through efforts aimed at initiating activities and breaking isolation.

I had a key worker who came to my home and talked to me. But then another person, I don't remember who it was, helped me so I came in contact with the day centre, because I was isolated here in my home. Then I got out from my home at least once a week. I met people and then it went on, step by step. I got X as my key worker. She helped me a lot in the beginning, came to my home and fetched me. I had difficulties leaving my home, there was something in the way every time I tried to go out. (person 1)

And the walks she [the key worker] took me on! It was just wonderful. In the beginning I could hardly walk. I walked like a . . . well, I don't know how I walked. In some kind of trance. . .so the cleaning had to wait and be done step by step. It looked terrible in my home. (4)

Specific staff seemed to be very important and at least equally important as the intervention itself.

I was in very bad shape, you know, but then I was helped by the team from the social services and especially by X. (4)

I then came to the day centre and met Y. That saved me, I think. (7)

I met Z [from the clinic] who was the first person who understood me. (5)

These staff were often described as making efforts beyond what could ordinarily be required of them.

She was extremely good, she told me she also had been bullied during her youth, I think she was overweight, so she knew how it felt... she lent me some of her books on human relations and about how people react and so on. (5).

One person described mainly negative experiences from both open psychiatric care, that did not help, and social services, that interfered too much.

There were many people around, but I did not dare to speak my mind. I was afraid that if I did, something even worse could happen. (3)

Hospital care contribution. Six of the seven people interviewed had undergone long and often repeated care in psychiatric hospitals. Three people described their care as having contributed mainly positively to their recovery process, but no one attributed the positive outcome to their actual care. The positive aspect of their care was described as a kind of asylum effect, where the hospital provided them with a quiet and peaceful haven and relatives were given a period of respite from worry.

I got out of the house and got peace and tranquillity. I was afraid when he [the husband] came home drunk. I knew I now [in the hospital] could sleep calmly at night. Nobody threatened me or beat me. (person 1)

They [the relatives] could relax then. They knew I was being helped by experts up there. (4)

It was peaceful to walk around and take a break for a smoke... I don't know if I was helped, I really don't know, but at least I was not alone. (7)

Three people described their care in mainly negative terms. One person described many humiliating situations:

Yes, it was terrible and you were medicated until you dropped, woke up chained fast on the bed with the belt. They stood around me singing. (2)

She summed up her experiences as follows:

It was terrible the way I was treated. I don't even want to think about that time. (2)

The other two people also described feelings of humiliation, but these feelings were more closely related to shame associated with having to undergo psychiatric care.

To walk around in the hospital and to be so ill that you needed to be in a hospital, that was very difficult... It was terrible to realise that I was so ill. (3)

They wanted to move me to the psychiatric clinic, I don't know why but I could not handle the situation and my feeling of, I don't know what to say, inferiority. I never had these feelings elsewhere, but there I did. I felt I was being watched and got insecure. (5)

Contributions from medication. All seven people reported that their medication had contributed to their recovery, but to very different degrees.

Thanks to the medicine I now lead a normal life. (person 2)

Then I got the happy pill. So now I'm feeling better (4)

I take some pills every day, so I hope they are of some use. (3)

The interviewees described not only the beneficial effects of their medication, but also its side-effects and the struggle to balance effects and side-effects.

When I was gaining weight too severely, I thought: what the hell shall I do? . . . but you know, I had to begin again. It just didn't work, I felt so bad so . . . ooh! (2)

And the pill was good for my sensitivity, so to say. So I could stay away from home more, but the side-effects were so great that I had to stop taking it. (5)

And I wanted to test another pill instead of x because it made me feel depressed. But at that time I had a lot to do. I was stressed then and without the pill I couldn't think straight and my head was hard as a brick. (6)

Some of the interviewees expressed a more balanced view of the effects of their medication:

It is not only the medication that heals depression . . . when you have driven yourself to the edge, it has to take its time. (7)

Contributions from relatives and friends. Contributions from relatives and friends were often described as complicated and ambivalent. One person reported that, although he had unreserved support from those close to him, i.e. wife, children, grandchildren and friends, even then the relationships were complicated.

My wife stood by me and helped me . . . but of course she is right when she says I have changed. It's not that I'm aggressive or anything, but I have changed my behaviour. For a long time I mostly stayed in bed, and that was for several years. So she had gone through a lot. And today I cannot live the same life with her. It's very tough for her. That's why it's not wrong for me to go away one or two weeks, once or twice a year. (person 6)

Ambivalence and feelings of guilt were also reported by others.

I wanted to get a divorce in 1988 when I realized that I was unable to get back to work. I was ashamed. But she did not want to divorce me. I still cannot explain to my wife how I feel. I have tried, but she begins to cry and that is the hardest thing I know. (5)

Interviewees explained that certain relatives had made important contributions to their recovery, while other relatives had significantly contributed to their illness. Two of the women had been married to violent alcoholics and one person had a grown-up son with a severe mental illness.

I think my problems began then. It took some years before my nerves collapsed, but finally I couldn't take anymore . . . I was afraid when he came home drunk and broke things and beat me. (1)

Yes, I have escaped from a marriage, he was an alcoholic, maybe it was my fault, too. He remarried and had a little boy. [sighs deeply] (2)

My son became psychotic when he was 20 . . . and my husband was ill a short while later. But I was so very strong, so I could handle the situation. My son is my problem. (4)

Only one person reported that relatives and friends had made important contributions to her recovery and that her relationships with them were uncomplicated nowadays:

I have the dogs and my children and grandchildren. Everybody who meets me tells me how glad they are that I am so well. They say it so often, they saw me when I was ill. It was chaos at home then. I have two children, one had just moved in with a partner. The other one stayed at home and it was probably not much fun for her to see her mother always in bed. (7)

Critical moments. Of the seven interviewees, two identified a dramatic, critical moment in their recovery process. Both described having had serious plans for committing suicide, but that they had at the last moment changed their plans for different reasons. These situations were described as a turning point in their recovery process.

I stood by my bed and debated whether to take my life or to stay alive. But then, somebody said, or I felt as if somebody said: try to go on fighting . . . I experienced something, I don't know what it was, it's difficult to explain. I thought of my little child. No, no I must go on living, I thought, at least I must try. And then I struggled, in the beginning little by little. (person 1)

I tell you, I went down to the cellar, I thought about getting rid of myself in some way. But somehow it seemed too brutal and you have to think of the people you leave behind, but when you're in such hell, I didn't know what I was to do . . . but then I tried and struggled against my intentions and was able to walk to a friend's and we had a cup of coffee. (5)

Another critical event that interviewees mentioned was breaking of destructive relationships:

We had been married for 20 years. But then I was so completely fed up that I got a divorce from him. I thought it didn't matter what happened to me, even if I had to live on the street, just as long as I could get some peace and tranquillity. (1)

Discussion

Rates of Recovery

There are major problems in defining the concept of recovery in such a way that it is possible to compare results from different studies. Distinctions have

been made between “cure” and “recovery with defect” (Kraepelin 1971) and between “social recovery” and “total recovery” (Warner 1985) in attempts to make the definitions more stringent and comparable. Yet, assessments of whether or not patients have recovered remain a subjective judgement on the part of the investigators conducting the study (Harding 1986, Topor 2001).

Still, remarkably few people in the present sample were considered having recovered. Only 14% were judged to have recovered in the sense that their disabilities no longer constituted handicaps. In the group diagnosed with schizophrenia, only 6% were considered to be recovered in this sense, compared with nearly 20% of the people with a different diagnosis.

The concept of recovery used in this study is reminiscent of the concept “social recovery” (Harding 1986). However, since this concept excludes people who have received any kind of in-patient care over the last years (Harding 1986, Topor 2001), it may be stricter than the definition applied in our study. For example, of the 52 people considered recovered according to our criteria, 10 had received in-patient care during the last 2 years. A review of the case records of this group raised the question as to whether a few of them should in fact belong to the group still considered to be severely mentally ill. On the other hand, the number of recovered people in this study did not seem to have been over-estimated, rather the opposite. The actual differences between the number of recovered people in this study and previous studies may be even larger.

The definition of the concept “severely mentally ill” could be one explanation for the relatively low rates of recovery compared with other studies. The most important factor in defining the present sample was not diagnosis but rather disability and handicap. Although the subjects in the sample had different diagnoses, the inclusion criterion was that the illness had caused a handicap. However, a handicap may appear many years after the illness debuts; in such cases early recoveries would be missed.

Recovery Rates and the Mental Health Care Reform

The concept of handicap used in the definition to identify the target group of the Mental Health Care Reform in Sweden in 1995 seemed relevant as a large majority of the mentally ill was still considered to be handicapped 5 years later. The target group of the reform thus seemed to be rather stable with respect to handicap. This is an important observation in consideration of the shifts in perspectives on handicap regarding treatment and legislation. Mental illness causes disabilities and the degree of the handicap depends on psychological and social circumstances. This fact was most evident in people diagnosed with schizophrenia and least so in people with mood and neurotic disorders. In the first annual report of the implementation of the reform, the National Board of Health and Welfare described the target group of the reform as people with schizophrenia (Markström 2003). In the surveys conducted in Sweden, however, the target group was broadened and consequently about half of the people in the surveys had diagnoses other

than schizophrenia. It appears that the concept of handicap was more relevant to the originally intended target group.

The reform has been criticized for leading to the closing of mental institutions and to putting severely mentally ill people out on the streets without providing them with any kind of support or assistance (Markström 2003). Interestingly, however, of those who had been identified as mentally ill in 1995 in the area investigated, only five people who still resided in the area did not have contact with care-providers for their psychiatric problems 5 years later. This fact can be seen as a failure if the goal is total recovery, but it can also be interpreted as a sign that the severely mentally ill were not abandoned.

Process of Recovery

One conclusion from the interviews was that there were many and varied paths to recovery. Each person described a different way from the others. Support from others, medication and care were important factors, confirming results from Sullivan (1994) and Tooth et al. (1997). The importance of significant others in the recovery process was indicated by the fact that all seven people interviewed lived in close relationships with other people. Only 11% of the people surveyed in 1995–96 were cohabiting with a domestic partner (Table 1). However, the contributions to the recovery process from family and friends were complex and sometimes contradictory. People described important contributions to recovery from relatives and friends but that they also sometimes had contributed to their illness. Even when the interviewees reported unreserved support from relatives and friends the relationships could be complicated and ambivalent, often with the occurrence of guilt feelings.

Contributions from hospital care were described as side-effects rather than intended effects, i.e. the opportunity to escape from an intolerable situation seemed more important than the actual care in the hospital. Topor (2001) also found that hospital care as a opportunity to have “time out” from a difficult life situation was mentioned as important by recovered people.

Medication was mentioned as important, but similar to the results from Sullivan (1994) and Tooth et al. (1997) the side-effects were often highly problematic.

In out-patient care the attitudes from the staff seemed more important than methods, and that they could sometimes make efforts beyond what could ordinarily be required of them seemed important. Topor (2001) stressed similar results.

The study indicated that, although the direction and aims of their efforts differed, interviewees stressed the importance of taking an active role in their own recovery process. Two major strategies to recovery could be identified in the interviews. One was to adjust one’s expectations of life to one’s disabilities. People using this strategy had a high external locus of control and believed that their ability to influence the consequences of their illness was limited. They had “accepted” their disabilities. They lived together with a domestic

partner, but otherwise lived rather isolated lives. The other strategy was to struggle against the consequences of the illness. The people who used this coping strategy had an internal locus of control and could be described as believing they could significantly influence the consequences of the illness through their own behaviour and actions. They lived in close contact with other people and society. They did not “accept” their disabilities. Naturally, there were also examples of mixed strategies. Interestingly, the only person who seemed to be fully recovered showed such a strategy, possibly suggesting benefits of balancing acceptance with struggle. Neither the victimizing attitude of acceptance nor the “it’s all up to me” attitude of struggle may be most effective in the process of recovery.

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