

Sustaining Full Recovery in Schizophrenia after 15 Years: Does Resilience Matter?

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Abstract

The main purpose of this study was to follow up a group of persons who, fifteen years ago were considered to be fully recovered from schizophrenia, in order to examine how many have sustained their recovery and to investigate the role of resilience in recovery. A semi-structured interview was designed for this 15-year follow-up study based on previous research related to the course and prognosis of schizophrenia. In addition to the interview, measures of psychosocial functioning and the degree of positive and negative symptoms were used. Remission and recovery were evaluated by consensus-based criteria. The Connor-Davidson Resilience Scale was chosen to assess resilience. The results show a significant correlation between resilience and present psychosocial functioning. There is also a significant difference between fully recovered subjects and those in remission regarding their resilience score. These results show that the majority of the subjects had maintained their recovery, and that subjects who are still fully recovered have not used medication for seventeen years and are more resilient. Thus, a sustained, full recovery without medication seems possible for a subgroup of schizophrenia patients characterized by high resilience.

Key Words: Healing, Recovery, Remission, Schizophrenia, Outcome, Resilience

Introduction

The clinical expression of schizophrenia is diverse, and this significant heterogeneity is still unexplained. Most likely, schizophrenia is not a single disease entity, and there are several etiological factors and pathophysiological mechanisms involved (1). Schizophrenia has a profound impact on the individual and may be considered to entail profound adversity. Depending on the degree of vulnerability, in addition to internal and external resources, the course of the illness and its outcomes will be different, as shown in the

results of the most important longitudinal follow-up studies, indicating that approximately 25 to 30% of people with this diagnosis may be considered as fully recovered during the follow-up period, with another 25 to 45% achieving significant improvement (2-9). As a construct, resilience represents positive adaptation in the face of adversity and has received increasing attention as a factor contributing to recovery in individuals with schizophrenia. By definition, resilience encompasses unusual processes in that positive adaptation is manifested in life circumstances that usually lead to maladjustment.

Other follow-up studies focusing on characteristics of persons who have fully recovered from schizophrenia reveal that the ability to endure setbacks without giving up hope is common (10, 11). This quality of recovery is referred to as resilience, a construct which means “bouncing back” from difficult experiences (12, 13). In the field of developmental psychopathology, resilience, a construct representing positive adaptation despite adversity, has received increasing

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Clinical Implications

To the best of our knowledge, this is the first 15-year follow-up study that has investigated the stability of a full recovery from schizophrenia, using operational criteria in a small group of subjects with a former diagnosis of schizophrenia to address the following questions: 1) is the recovery sustained; 2) did resilience play a role in sustaining recovery; and, 3) was anyone healed? Our findings represent potentially important clinical and research implications. Firstly, the possibility of being cured of schizophrenia will engender hope in patients and help destigmatize the disease, showing that persons with schizophrenia are not doomed to a life of disability. Secondly, the results demonstrate the importance of separating the person from the disease when studying recovery in schizophrenia. Optimism and willpower are personal attributes that characterize the recovered individuals in this study, which was reflected in their high scores on the resilience scale.

attention over the last decades. Resilience by definition encompasses atypical processes, in that positive adaptation is manifested in life circumstances that usually lead to maladjustment. Resilience is a superordinate construct subsuming two distinct dimensions—significant adversity and positive adaptation—and, thus, is never directly measured, but rather is indirectly inferred based on evidence of the two subsumed constructs. This conceptualization of resilience is relatively vague and does not lend itself to empirical study. However, Connor and Davidson (14) have developed a measure of resilience, the Connor-Davidson Resilience Scale (CD-RISC), which enables the empirical study of the effect of resilience on the recovery process. This enables us to describe possible associations between schizophrenia and resilience. There have been no studies focusing on the impact of resilience on the recovery process and, therefore, references to relevant literature are lacking.

Despite the increasing recognition of a remitted and high-functioning subgroup within the schizophrenia spectrum, research on this topic has been impeded by the lack of a consensus on the definition of recovery. When defining the concept of recovery in schizophrenia, it is important to bear in mind that recovery is not synonymous with a cure, although these concepts are frequently used interchangeably. Some would claim that being on medication is one factor that distinguishes recovery from cure (15). Bleuler (16) defined cure as “*restitutio ad integrum*,” which means a return to the state that existed prior to the onset of illness. Arieti (17) has correctly maintained that this concept loses some of its significance in schizophrenia because the so-called premorbid state is clearly morbid and strongly related to the subsequent condition. He argues that if by cure we simply mean the loss of manifest schizophrenia symptomatology, it is possible to be cured from schizophrenia. It is also possible if by cure we mean the “reestablishment of relatedness with other human beings, closeness with a few persons, love for spouse and children, a reorganization of the personality that includes a definite self-identity, a feeling of fulfillment or of purpose and hope” (17, p. 616).

However, cure is a medical concept and indicates a return to normal health with no relapse in psychotic symp-

toms (18). But this concept does not capture the individual's active participation in the recovery process and is, therefore, not a useful concept in schizophrenia. In recent times, more of an emphasis has been placed on recovery as a subjective orientation or attitude, suggesting that regardless of their state of illness or health, people can have hope, feel capable of expanding their personal abilities and make their own choices.

According to Jacobson and Greenley (18), the concept of recovery is perhaps better accommodated by the notion of healing, a process that has two primary components: defining a self apart from illness, and control. People who have mental disabilities often find that they lose their sense of self due to their illness. In part, recovery is the process of “recovering” the self by reconceptualizing illness as only a part of the self, not as a definition of the whole. Thus, the process of self-redefinition is central to recovery (19). The second healing process is control, i.e., finding ways to relieve the symptoms of the illness or reducing the social and psychological effects of stress to recapture a locus of control.

In 2002, Liberman and his colleagues proposed an operational definition of recovery based on a variety of international studies (2, 3, 11, 20) using various strategies to generate data that have provided construct and social validation for the definition of recovery. This definition requires an assessment of outcomes in the dimensions of symptomatology, vocational functioning, independent living and social relationships. Several lines of research, including my own, have demonstrated that a full recovery from schizophrenia is possible (2, 3, 21) in the sense of being free of symptoms, maintaining a high level of functioning, being off medication, being employed and enjoying healthy social and romantic relationships. At present, it is not clear how many or what percentage of patients with schizophrenia have the potential for recovery (5), or how many of those who are fully recovered have sustained their recovery. There are only a few studies that have followed patients diagnosed with schizophrenia for more than ten years, and even fewer that have applied recovery criteria to this population. To the best of my knowledge, this is the first 15-year follow-up study that has investigated the stability of a full recovery from schizo-

phrenia, using operational criteria in a small group of subjects with a former diagnosis of schizophrenia to address the following questions:

1. is the recovery sustained?
2. did resilience play a role in sustaining recovery?
3. was anyone healed?

Methods

Procedure and Participants in the Initial Study

The original sample consisted of 17 subjects. The present study is a 15-year follow-up of fully recovered schizophrenia patients who participated in a Norwegian study in 1989–1990 (21) with the purpose of examining the main characteristics of full recovery according to a strict definition. They were recruited by letters to the major mental health hospitals in Norway, asking clinicians to refer fully recovered patients to the study. “Fully recovered” was defined by the following criteria: the patient had a reliable diagnosis of schizophrenia at a previous time, did not fulfill these criteria at present, had been out of the hospital for at least five years, had present psychosocial functioning within a “normal range” (e.g., scores above 65 on the Global Assessment of Functioning Scale) and was not on neuroleptic drugs or a low dosage only (<1 DDD, “Defined Daily Doses”). The Norwegian Medicinal Depot (NMDP) defined DDD as follows: “The assumed average maintenance dose per day for a drug used on its main indication in adults.” Consequently, those individuals on medication who were included in the study were on a dose which was less than half of an average maintenance dose per day. In some studies, this group would be considered as significantly improved, though not recovered (2). During a four-year period, 20 subjects were referred to the project, and 17 fulfilled the selection criteria.

Each case was given three diagnoses at three different points in time: the first at the first admission to hospital, the second representing the “most severe” diagnosis ever given to the patient and the third at the time of the interview. This diagnosis was based on a semi-structured interview, case records and supplemental information from the patients’ therapists. The index diagnosis and the “most severe” diagnosis were based on information from case records and information from the patients’ therapists. Each of the cases was diagnosed according to the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)* criteria (22) by a senior clinician (the author). A subgroup of patients was randomly selected and given an independent and blind diagnosis by a second senior psychologist who agreed on the schizophrenia diagnoses for 13 out of 15 patients. Both diagnosticians based their assess-

ments on tape recordings of the semi-structured interview with the patients and were unaware of scores on other measures (present overall functioning and premorbid functioning) (23).

At baseline, there were seven females and eight males in the group. Twelve subjects were in full-time or part-time employment. All subjects had independent housing; six persons were married and four had children. Eleven of the subjects did not meet the criteria of any Axis I diagnosis at the time of interview, while four fulfilled the “schizophrenia, residual type” criteria. We found it adequate to include these four subjects, since they did not show any psychotic symptoms and symptoms did not influence their social functioning in a negative way. On the other hand, many years of schizophrenia illness had contributed to psychological impairments in these individuals, which created the basis for categorizing them as “residual type schizophrenia.”

At this first assessment, eight persons were not on antipsychotics, and seven subjects were on low doses of first-generation antipsychotics. Nine persons were in supportive psychotherapy.

Procedure and Participants in the 15-Year Follow-Up

Fourteen subjects from a baseline (T1) sample of 17 subjects who were diagnosed with schizophrenia at an earlier point in time based on the *DSM-IV-TR* (22) were available for reassessment (T2) with psychiatric and resilience measures after 15 years.

Of the 17 subjects formerly with schizophrenia included at T1, one was deceased and two refused to participate. Due to strict ethical codes for psychological research, we were not allowed to renew contact with these subjects. However, it was possible to obtain some information from one of the subjects from a letter that was sent to the principal investigator recounting the present situation.

Table 1 summarizes some demographic and clinical characteristics of the 15 subjects at first assessment and at 15-year follow-up. Table 2 shows treatment characteristics at first assessment and at 15-year follow-up.

Thus, the final sample at follow-up consisted of 15 subjects, eight females and seven males. Mean age was 52.1 years. Nearly 60% had completed higher and further education at the time of interview; eight subjects were married and had children and three were divorced. The majority of subjects had independent housing, and the interviews were conducted in the investigator’s office or in the subjects’ homes. The study was approved by the Regional Committee for Medical Research Ethics.

In this 15-year follow-up study, the recovery criteria used were a combination of the author’s (21) and the opera-

Table 1 Demographic and Clinical Characteristics at First Assessment and at 15-Year Follow-Up

	First Assessment			15-Year Follow-Up		
	Mean	SD	Range	Mean	SD	Range
Age (years)	37.33	8.64	27–55	52.07	7.55	40–62
Sex						
Male	8			8		
Female	7			7		
Education (years)	13.00	3.22	9–20			
Married	6			6		
Children	4			4		
Premorbid adjustment (SASPAS* score)	17	4.18	13–28			
Diagnoses						
None	11			8		
In remission				4		
Schizoaffective				1		
Schizophrenia, disorganized				1		
Anorexia nervosa				1		
Schizophrenia, residual	4			0		
No antipsychotic medication	8			8		
Duration of periods without medication during follow-up (years)				17.12	6.40	10–26
GAF score	72.80	5.87	60–79	72.87	12.31	50–90
PANSS score				63.21	14.2	43–87
Resilience score				61.28	13.3	30–80
Follow-up period (years)				15.33	2.09	13–18

*Social Attainment Survey Premorbid Adjustment Scale

tional recovery criteria developed by Liberman and his colleagues (15). To evaluate remission, the criteria developed by Andreasen et al. (24) were used. The remission criteria were based on the evaluation of eight groups of symptoms in the Positive and Negative Syndrome Scale (PANSS): delusions, unusual thought content, hallucinatory behavior, conceptual disorganization, mannerism and posturing, blunted affect, social and emotional withdrawal, and a lack of spontaneity. The score on these items must be mild or less (<3), using a range of 1–7 for each item with a duration of six months as a minimum threshold.

In addition, the subject must have fulfilled the following criteria concerning psychosocial functioning: working or attending school at least part-time, living independently of family supervision, and socializing at least once a week with peers for a duration of two years. The criteria used for resilience were high scores on items such as: “I tend to bounce back after illness or hardship” and “I have close and secure

relationships” on the Connor-Davidson Resilience Scale (CD-RISC) (14).

Instruments

A semi-structured interview was designed for the 15-year follow-up study. The content of the interview was based to a certain extent on themes used in the previous follow-up studies and factors identified as being central to recovery such as employment (full-time, part-time or disabled), social activities (hobbies, member of organization, religious or social), friends (how many close friends, frequency of meetings), family (quality of relationships, frequency of contact), close relationship (married), sex life (satisfactory, not satisfactory), psychopathology, treatment (continuity, coordination, comprehensiveness, quality, adherence), access to care, hospitalization and what they did to help themselves (factors of well-being).

To assess resilience, the Connor-Davidson Resilience

Table 2 Treatment Characteristics at First Assessment and 15-Year Follow-Up

Type of Treatment	Number of Subjects	
	First Assessment	15-Year Follow-Up
On medication		
First-generation antipsychotics/low dose	7	1
Second-generation antipsychotics		5
Support from general practitioner	2	6
Supportive psychotherapy	9	5
Group therapy		1
Treatment status		
Not in treatment	0	8
Outpatient	15	6
Inpatient	0	1

Scale (CD-RISC) was chosen. This scale was first translated into Norwegian and then back into English. The scale has demonstrated sound psychometric properties and distinguishes between persons with greater and lesser resilience, but has yet to be used with schizophrenia patients. The scale is comprised of 25 items, each rated on a 5-point scale (0–4), with higher scores reflecting greater resilience.

The Global Assessment of Functioning Scale (GAF), a well-standardized, widely used measure of outcome, was used to obtain an assessment of the present overall functioning of the subjects. All subjects were diagnosed according to the *DSM-IV-TR* criteria (22), with the current diagnosis, if any, based on the semi-structured interview and case records. The Global Assessment of Relational Functioning Scale (GARF) is analogous to Axis V (Global Assessment of Functioning Scale), which is provided for individuals in *DSM-IV-TR* (22). The GARF Scale can be used to indicate an overall judgment of the functioning of a family or other ongoing relationship on a hypothetical continuum ranging from competent, optimal relational functioning to disrupted, dysfunctional relationships.

The degree for the severity of the symptoms was measured with the Positive and Negative Syndrome Scale (PANSS) (25). The PANSS is a 30-item rating scale that comprises a wide range of positive, negative and general symptoms. It is scored after a semi-structured interview and rated from 1 (not present) to 7 (extremely severe), based upon the last seven days. In addition, subjects were asked to rate their

own subjective well-being on a scale from 1–10 where 1 is “feeling bad” and 10 is “feeling very good.”

Statistical Analyses

All participants were included regardless of recovery or unremitted status. Analyses were conducted using the statistical package SPSS for Windows version 16.0. The main statistical methods used were correlation analyses between outcome group and resilience with PANSS scores, as well as individual factors associated with recovery defined as an outcome (21). Level of significance was set at $p=.05$. Eight correlational analyses were conducted. To address the challenge of multiple comparisons, the Bonferroni method was used with threshold p value of $p=0.005/8=0.006$.

Results

Of the 15 subjects in this follow-up study, eight (47.1%) fulfilled the operational criteria for a full recovery, the majority of whom were women. Four subjects were in remission, one was suffering from a severe condition of anorexia nervosa and two were still suffering from schizophrenia. Forty-seven percent of the subjects did not use any neuroleptic medication and had not done so for an average of 17.12 years. The resilience score was $M=61.3$ (range 30–80), which is close to the mean score for the outpatient population ($M=68$).

Fifty-three percent of the subjects were working, 41% derived their primary income from a job, and as many as 29% had full-time jobs. The majority of the subjects had one or more friends and reported considerable support from their families. Nearly half of the subjects (41%) reported that their sex life was satisfactory. All the subjects reported having hobbies, and 53% were members of an organization. The majority of subjects had one or more friends, meeting with them once or twice a week. Nearly half of the subjects went to parties in addition to initiating social meetings with friends and family. The three most frequently mentioned wellness factors (what they did to help themselves) were: hobbies (41%), to reflect and analyze (29%) and to work (24%). On the subjective well-being scale, the mean score was 6.43 (range 1.50–9.00).

A positive correlation between subjective well-being and GAF score ($.60$, $p<.05$), as well as between subjective well-being and the score on resilience ($.80$, $p<.01$), was also found. A regression analysis showed that resilience and GAF score explained 67% of the variance in subjective well-being, with resilience being the factor that significantly predicts subjective well-being when psychosocial functioning is controlled for. These results indicate a robust relationship between the feeling of subjective well-being, resilience and psychosocial functioning. This relationship is also revealed

in that as much as 41% of the subjects had never experienced prejudice and stigma in connection with their mental illness.

When asked about significant factors in recovering from their disorder, the following three factors were the most frequently mentioned by the participants: their own optimism and willpower (35%), the treatment they had been offered (24%), and socializing with friends and family (18%).

A substantial correlation appeared between the full-recovery group and GAF score (.87, $p < .01$) and the remission group and GAF score (.97, $p < .01$). The correlation between GAF score and resilience was .87 ($p < .01$), and the correlation between the full-recovery group and resilience score was .69 ($p < .01$), revealing a significantly higher degree of resilience in the fully recovered subjects. Accordingly, there was an expected significantly negative correlation between present psychosocial functioning and negative symptoms on PANSS ($r = -.77$, $p < .01$).

A small sample like this makes comparison of those subjects without antipsychotics ($n = 8$) with those on antipsychotics ($n = 6$) difficult. Hence, the following analyses should be regarded as tentative pending future studies of larger samples. Correlational analyses showed that for those subjects on no antipsychotics, their GAF scores, GARF scores, and score on subjective well-being were all positively correlated with resilience at the 0.01 level. For those on medication, no such relationship was found, suggesting that resilience plays a role in sustaining recovery without antipsychotic medication.

The correlation between the GARF and GAF scores was .75 ($p < .01$) and between the GARF and resilience scores was .61 ($p < .01$), revealing a significantly better relational functioning and higher resilience among those who had sustained their recovery. When performing Bonferroni corrections and using $p < .006$ as criteria for significance, the correlation between subjective well-being and GAF score ($p = .021$) and resilience and GARF score ($p = .029$) were not significant.

Discussion

In this longitudinal study of full recovery from schizophrenia, the results showed that nearly half the participants maintained full recovery. These subjects did not use any neuroleptic medication and had not done so for an average of 17 years. These results are in accordance with other long-term outcome studies on schizophrenia (2, 3, 26, 27). A study of the long-term course and outcome for patients discharged from Chestnut Lodge between 1950 and 1975 allowed for the identification of a subgroup of schizophrenia patients who sustained good outcomes without neuroleptics over an average of 15 years. In a more recent study, Harrow and Jobe (7) identified a subgroup of schizophrenia

patients who did not have a relapse while off antipsychotics and experienced intervals of recovery. Like the people in the Harrow study, those not taking medication for psychosis in the present study were among the best in terms of outcomes and no longer felt the need for any treatment in relation to mental illness. Thus, from a research perspective, it may no longer be controversial to claim that not all schizophrenia patients need to use antipsychotic medications continuously throughout their entire lives. Taken together, the results from the Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) (28), which demonstrated that treating schizophrenia, even with newer second-generation drugs, is only partially effective and is associated with problematic side effects, suggest that a more circumspect recommendation concerning the duration of use of medication for schizophrenia patients may be warranted.

Thus, from a research perspective, it may no longer be controversial to claim that not all schizophrenia patients need to use antipsychotic medications continuously throughout their entire lives.

Many studies, including the present one, reveal the presence of a proportion of individuals, both early and late in the course of the illness, who appear to improve and even recover without the continuous, daily use of antipsychotic medication. The toxic effect of untreated psychosis proposed by some researchers has also been questioned (29). In a previous longitudinal study, we discovered that 50% were not using antipsychotic medication and had been off medication for many years (10).

Findings from the present study also indicate that some of those who have fully recovered from schizophrenia will later experience a recurrence of the illness at a given point in time. For those in remission, it seems that they experience an episodic course of having a good recovery between episodes. Even if these subjects have not clinically recovered, they are in recovery because they have reclaimed autonomy and self-determination. These results highlight the ongoing disagreement, even among proponents of recovery, as to whether full recovery is a realistic goal for everyone with a history of schizophrenia (30), or whether some people will continue to need significant, clinician-administered treatment services at some points in their lives.

The data from this study indicate that there are important relationships between symptom severity and recovery process variables. The fully recovered participants had significantly higher resilience scores and significantly lower symptom scores than participants in remission, and there

was a significant negative association between resilience and the PANSS negative subscale scores. Subjective well-being and psychosocial functioning did not show a significant correlation when subjected to the Bonferroni correction method, but the effect size of .590 ($p=.021$) indicates that there is a relationship, but that the sample is too small to detect a significant relationship. Another correlation that did not turn out to be statistically significant when corrected was the relationship between resilience and GARF score (effect size .604, $p=.029$). Given the fact that the sample is small, and that as much as six out of eight correlations are still significant after running the correction of Bonferroni, indicates that the relationship between resilience and sustained recovery is robust.

... disprove the traditional assumption that any improvements are temporary remissions and suggest that it is possible for more than just a few patients to return to normal functioning.

Those who had a sustained recovery also reported optimism and willpower as being significant factors in their recovery. In sum, these results provide insight into the possibility that resilience is a determining factor in a sustained recovery from schizophrenia. Even so, it is difficult to know if these persons have good attitudinal approaches because they are feeling better, or if they are better because they are more resilient. One cannot rule out the possibility that the well-functioning and favorable outcome of those with sustained recovery has influenced their attitudes and in this way influenced scores on the resilience scale. The results from a 20-year follow-up, in addition to this and previous longitudinal studies on maintaining full recovery in schizophrenia (31, 32), disprove the traditional assumption that any improvements are temporary remissions and suggest that it is possible for more than just a few patients to return to normal functioning.

Almost 50% of the subjects in the present study have sustained their full recovery for 15 years, fulfilled all the operational criteria for full recovery, re-established their relationships with others and not used antipsychotic medication for an average of 17 years. This is a return to normal functioning and, therefore, satisfies the criteria for being healed. In accordance with the components of healing, they did not lose their sense of self to mental illness. For the fully recovered patients in this study, the continuous therapeutic work that had been conducted earlier (10) cultivated their hope of recovery, gave them a perspective on their illness and some ability to separate a sense of self from the illness, i.e., they saw themselves as people with schizophrenia rather

than schizophrenics. When viewing themselves as people who used to have schizophrenia, their self-respect permits them to confront and overcome the stigma against individuals with mental illness which they may have internalized, thereby allowing for a further connection with the self. As shown by the majority of participants in the present study, they have gained control by becoming active agents in their own lives.

One possible limitation of this study is that the interviewer was not blind to the recovery status, which may have influenced the reporting of recovery rates. In addition, the study of small samples, such as fully recovered schizophrenia patients, raises methodological dilemmas. A low statistical power is inevitable, and the likelihood of making an incorrect no-difference conclusion increases when the sample size is small. This follow-up study represents a cross-sectional assessment of outcome, although the people participating in the study 15 years ago now provide us with a window to the ways people can and do improve and recover. The strengths of the study include the use of operational criteria for full recovery and remission, structured interviews, sound psychometric measures, time span for follow-up and few missing subjects. The paucity of studies in this area is partially due to the amount of time required for follow-up studies, as well as missing subjects during follow-up. One possible reason for a few missing subjects in this study could be that they had met the interviewer 15 years ago, thus helping to promote confidence through familiarity.

The findings in this study represent potentially important clinical and research implications. Firstly, the possibility of being cured of schizophrenia will engender hope in patients and help destigmatize the disease, showing that persons with schizophrenia are not doomed to a life of disability. Secondly, the results demonstrate the importance of separating the person from the disease when studying recovery in schizophrenia. Optimism and willpower are personal attributes that characterize the recovered individuals in this study, which was reflected in their high scores on the resilience scale.

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