



# Evidence of Recovery: The 'Ups' and 'Downs' of Longitudinal Outcome Studies

SRN Discussion Paper Series: Paper 4

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February 2006

Please cite as:

Dorrer, N. (2006) Evidence of Recovery: The 'Ups' and 'Downs' of Longitudinal Outcome Studies. SRN Discussion Paper Series. Report No.4. Glasgow, Scottish Recovery Network.

## About the Scottish Recovery Network and this series

The Scottish Recovery Network (SRN) is funded through the National Programme for Improving Mental Health and Well-being to:

- Raise awareness of recovery from long term mental health problems.
- Develop understanding about the things that help and hinder recovery.
- To build capacity for recovery by supporting local action and highlighting and encouraging innovation in services.

This is the fourth in a series of discussion papers designed to help generate debate on how best to promote and support recovery from long-term mental health problems in Scotland. A number of source materials were used to inform its development. Contact the Scottish Recovery Network for more details on the series.

For more information on the Scottish Recovery Network visit [www.scottishrecovery.net](http://www.scottishrecovery.net). For more information on the National Programme for Improving Mental Health and Well-being visit [www.wellscotland.info](http://www.wellscotland.info).

## About the author

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## Summary

This discussion paper provides an overview of some of the findings of longitudinal mental health outcome studies that have been conducted in the course of the few last decades in different countries and with different patient groups. The paper first discusses the findings of studies that have focused on the outcome of schizophrenia. It discusses changing trends in outcome rates and some criticisms of the research in this field. A comparison of more recent outcome findings for different mental health conditions leads to the conclusion that recovery rates as reported in psychiatric research are slightly less positive than predicted by the Vermont Longitudinal Study in 1987. However, a closer look at outcome patterns and measurements used reveals a much more complex picture.

The paper draws on evidence that suggests that despite the introduction of new drugs, relapse rates have not decreased. Recovery rates also appear to be higher in developing countries. The limitations of traditional outcome measures are discussed and the paper concludes that outcome tools need to be developed in correspondence with the experiences of people who describe themselves as in recovery or recovered.

*“Two to three years ago I realised that you really could recover... Cause I thought once you had it that was it - it was stuck, but you can recover. I find that quite an amazing fact, cause over the years psychiatrists and things, no one actually says “you can recover”, it’s never mentioned.”* SRN Narrative Research Respondent

## Introduction

The assumption that ‘mental illness’ is a lifelong condition that can only be managed through long-term medical treatment continues to be widespread. It is also reflected in health professionals’ reluctance to give a positive prognosis for ‘severe’ mental health problems, for example a prognosis of potential recovery that could capitalise on hope and raise expectations. Of course, health practitioners also carry responsibility for not installing unrealistic or false hopes in people. This is particularly the case when evidence appears to be inconclusive. Indeed, much debate has engulfed the findings of long term mental health outcome studies. Over the last century, average recovery rates of between five and seventy per cent for severe and enduring mental disorders have been reported in various international studies (see e.g. Warner [1994] for a review of outcome studies of schizophrenia between 1904 and 1991).

### What do longitudinal outcome studies tell us about recovery?

Longitudinal mental health outcome studies have primarily focused on schizophrenia. At the beginning of the century it was Kraepelin’s (1919) description of the deteriorating course of the condition that increased interest in the comparison of recovery rates of patients diagnosed with schizophrenia in different regions and countries. Only 13 per cent of Kraepelin patients, who, notably, were first admitted to a mental institution during the period of the great depression, were rated as having completely recovered. Complete recovery, in the majority of outcome studies, has been understood to mean a return to pre-illness functioning including a loss of psychotic symptoms. Long-term outcome studies following Kraepelin further distinguished between complete and social recovery, with social recovery generally referring to levels of economic and residential independence as well as interpersonal adjustment. Variations in the criteria used for the measurement of either social or complete recovery have made the comparison of outcome rates rather more difficult.

Despite variations in the criteria applied for the measurement of recovery and/or the selection of participants, it appears that the prognosis for recovery from severe mental health problems may have improved significantly since the beginning of the last century.

The study most frequently cited in this context is the *Vermont Longitudinal Study of Persons with Severe Mental Illness* conducted by Harding and colleagues between the mid-1950s and early-1980s (Harding et al. 1987). The findings of this 32-year longitudinal study revealed that two-thirds of the 262 previously long-stay patients had improved considerably or recovered 25 years after their first assessment and after having undergone a rehabilitation and community aftercare programme. Their findings (see Table 1 for key findings) constituted a challenge to the assumption that people who suffer repeated episodes of a mental illness would only ever be able to

regain marginal levels of functioning. Sixty-eight per cent of the study's sample were rated as functioning above a level of 'mild impairment' and fifty-five percent received a rating of 'slight or no impairment'. Assessed areas of functioning included not having been in hospital in the past year, experiencing slight or no symptoms, living independently, having close relationships, being employed and leading full lives in general.

**Table 1: The Vermont Longitudinal Study of Persons with Severe Mental Illness: Summary of key findings**

One third of "profoundly ill, long stay patients" of the Vermont State hospital were assigned to a comprehensive deinstitutionalisation programme and reintegrated into the community

**Key Findings:**

- ▶ After 10 years, 70% of these patients remained out of hospital but required continuous support from the mental health system;
- ▶ After 25 years, one-half to two-thirds had considerably improved or recovered;
- ▶ The results obtained at 25 year follow-up demonstrate the phenomenon of late recovery. Some psychiatric conditions require longer time periods to acquire an accurate picture of outcome.
- ▶ Well designed deinstitutionalisation programmes can make a significant difference;
- ▶ DSM III criteria (the contemporary diagnostic manual) for schizophrenia did not predict long-term outcome well, i.e. outcome was better than predicted.
- ▶ Functioning at outcome was marked by heterogeneity, for example some people did work but were socially isolated, others were well interconnected but did not work.

A number of long-term follow-up studies conducted within a similar time period have supported Harding et al's findings. Tsuang et al. (1979) and Coryell and Tsuang (1986) conducted forty-year follow-up studies with patients admitted to hospital with schizophreniform disorder between 1934 and 1944 in Iowa. They found that twenty per cent (Tsuang et al. 1979) and thirty-one per cent (Coryell and Tsuang 1986) of patients had fully recovered, with thirty-five per cent and forty-eight per cent respectively having recovered socially. An important long-term study (23 years) was carried out by Bleuler (1968; 1978) in Switzerland, who found that many of his chronic patients improved later in life and that between twenty-five and thirty-five per cent recovered from their illness. Other studies conducted between the 1940s and 60s in Europe (e.g. Huber et al. 1975; Ciompi and Müller 1976) found that between

one third to over half of the patients included in the study had significantly improved long-term.

Since the publication of these more positive outcome rates, a number of criticisms have been raised. Harding's sample was, for example, not based on a hospital cohort but included patients that had been recommended for a rehabilitation programme, often because they had been showing signs of recovery (Harrison and Mason 1993). In their review of evidence Harrison and Mason argued that due to significant variations in sampling criteria and a lack of consistency in the definitions of 'poor', 'moderate' and 'good' outcome it is difficult to make a meaningful comparison between studies. The authors point out that any "discussion of the outcome of schizophrenia inevitably involves widely differing concepts of what is meant by 'outcome' and indeed what precisely is meant by 'schizophrenia'" (Harrison and Mason 1993 p.536). Their review of evidence did not support the hypothesis that there has been a "metamorphosis in the course and outcome of the schizophrenia group of disorders" (Harrison and Mason 1993 p.540). However, the authors highlight two findings that they believe deserve further investigation. One is the finding that marked differences in outcome appear to exist between 'developed' and 'developing' countries; the other is the phenomenon of late recovery in chronic schizophrenia (e.g. Harding et al. 1987, see Table 1).

Warner (1994) reviewed eighty-five outcome studies of schizophrenia conducted between 1904 and 1991 and similarly concluded that recovery rates were not significantly better at the end of the 20<sup>th</sup> century than they were during the beginning of the century. For schizophrenia, complete recovery rates stayed at around 20-25 per cent and social recovery rates at around 40-45 per cent.

How do these recovery rates compare to other mental health conditions? For bi-polar depression good outcome rates appear to have been found at the beginning of the century while more moderate rates have been reported over the past 40 years. Lundquist (1945) followed-up patients for 11 to 30 years after first admission and reported that eighty-five per cent of patients socially recovered. Follow-up studies published over the last 40 years, on the other hand, report a good outcome for around forty per cent of patients and a poor outcome for twenty to thirty per cent (e.g. Hastings 1958; Bratfos and Haug 1968; Carlson et al. 1974; Harrow et al. 1990; O'Connell et al. 1991; Goldberg et al. 1995). MacQueen et al. (2001) reviewed studies that focused on psychosocial outcome in patients with bipolar disorder and concluded that in aggregate thirty to sixty per cent of patients had 'detectable psychosocial impairment'. Again it should be noted that marked variations in regard to the length of follow-up periods, the assessment measures used and the estimates reported make it difficult to evaluate these findings.

In the past unipolar depression, like bipolar depression, has been considered to follow a relapsing-remitting course, with few cases developing into a chronic illness (Kennedy et al. 2004). Outcome rates reported over the past 20 years however suggest that the progression to relapse and recurrences and chronicity is more common. Murphy and colleagues assessed the long-term outcome of depression during a 17 year cohort interval and concluded that fifty six per cent of those diagnosed with depression had a poor prognosis of recovery due to recurrent episodes during the follow-up period (Murphy et al. 1986). Angst (1999, p.5) judges

depression to be “a common illness with long duration of episodes, high rates of chronicity, relapse and recurrence, psychosocial and physical impairment”. He suggests that the lifetime prevalence of depression is around seventeen per cent and that the likelihood of recurrence is over fifty per cent. Other studies point to the persistence of subthreshold depressive symptoms after recovery from a major depressive episode (Judd et al. 2000; Kennedy et al. 2004).

What do these findings mean? Viewed in isolation and from a clinician’s perspective they might lead to the conclusion that a diagnosis of a serious mental health problem implies a lifetime of impairments in many areas of functioning for the majority of patients. On closer inspection, however, these findings tell us more about developments in psychiatry than recovery itself. Warner makes the important observation that recovery rates stayed the same despite the development of antipsychotic drugs just before 1955. In the United States the introduction of these new drugs was not linked to a decrease in the proportion of people in hospital at follow-up but to an increase in hospitalisation (Warner 1994). This finding runs contrary to the claim that the introduction of anti-psychotic drugs made community treatment possible.

More recently, the same finding has been made for depression and bi-polar disorder (Kessing et al. 2004). Kessing and colleagues calculated rates of relapse leading to hospitalisation of 9417 patients diagnosed with depressive disorder and 1106 patients diagnosed with bipolar disorder in Denmark during 1994 and 1999. Despite the introduction of new anti-depressive drugs during this period there had been no significant reduction of relapse rates. A study in Iceland (Helgason et al. 2004) that compared hospital admission rates and out-patient visits to the sale of antidepressants during 1989 and 2000 replicated the findings of the Denmark study. Despite a dramatic increase in the sale of antidepressants hospitalisation rates had increased.

Interesting outcome patterns also emerged from the findings of several WHO studies. Already in 1973 the International Pilot Study of Schizophrenia (IPSS; WHO 1973) reported better outcomes for patients in developing countries at two and five year follow-up. It appears that despite a lack of psychiatric services in developing countries recovery rates are higher than in the developed world. Two later WHO initiatives support these findings. The Determinants of Outcome of Severe Mental Disorders (DOSMeD) study (Jablensky et al. 1992; Craig et al. 1997) and the 15 and 25 year follow-up study (ISoS; Harrison et al. 2001) of three WHO cohorts (in 18 countries) revealed significant cross-cultural variations in outcome rates.

Global recovery rates reported in the ISoS study were high - over half of the people followed-up had significantly improved – and the authors stress that their documentation of a striking heterogeneity in the course of schizophrenia and recovery rates by location “challenges conventional notions of chronicity and therapeutic pessimism” (Harrison et al. 2001, p.516). Recent long-term follow up studies from the ‘developing world’ have found even higher recovery rates for schizophrenia. A 20 year follow-up study conducted in Singapore reports that nearly two-thirds of the people included in their sample had a good or fair outcome (Kua et al. 2003). Similarly the Madras Longitudinal study which followed up patients 20 years after a first episode of schizophrenia found that only five out of 61 patients had

been continuously ill, seventy-seven per cent had high scores (over 60) on the Global Assessment of Functioning scale and seventy-six per cent of the men in the study were employed (Thara 2004).

How should the finding be interpreted? Ever since the publication of the first WHO follow-up study researchers and health professionals have been looking for factors that could explain why recovery rates were better in developing countries. A common suggestion is that stronger familial supportive networks and less emphasis on individual performance in developing countries contribute to the recovery from mental ill health (Kua et al. 2003). Often however, explanations revert to a simplistic reduction of cultural factors along the dimensions of rich/poor and modern/traditional. Halliburton (2004) argues that such explanatory approaches overlook an important difference between the 'developing' and 'developed' locations included in the WHO studies. He argues that the crucial difference between the locations is the fact that so called 'developing' nations are more "medically pluralistic". The co-existence of multiple medical systems allows people to try out a variety of therapeutic options and to choose one that works best for them. In effect, it is 'goodness of fit' that contributes to better recovery rates in countries that are not dominated by a biomedical approach to care.

## Recovery and the problem of measurement

The issue of goodness-of-fit is an important one and has particular relevance also for the measurement of recovery. A fundamental insight gained from taking account of people's lived experiences of mental health recovery has been that 'recovery' is a deeply personal process (Lovejoy 1984; 1988; Deegan 2001; Unzicker 1989; Brown and Kandirikirira forthcoming 2006). Recovery, as it has been experienced by people around the world who have at one point in their lives been diagnosed with a 'long-term mental illness', is not about returning to a stable baseline or former level of functioning in the clinical sense, but is a "self-directed process of transformation" (Deegan 2001). For many, a significant marker of recovery may therefore be the discovery of a new self. Objective measures of clinical and social recovery used in the majority of outcome studies such as the ones cited above do not tap into these personal and existential dimensions of recovery Roberts and Wolfson (2004). An acknowledgement of the shortcomings of traditional outcome measures may be reflected in the increasing use of the concept of 'quality of life' in psychiatric research.

Quality of life (QoL) measures focus on some essential aspects of recovery. Whether they are administered in interviews or via questionnaires, QoL measures enquire about objective life circumstances and subjective life satisfaction. Thus they focus, for example, on social and vocational functioning and the integration of the individual into the community (e.g. Young 2004; Ruggeri et al. 2005).

Objective quality of life indicators have largely been derived from what has traditionally been measured as 'social recovery' (see above). Thus the aim is to assess a person's living arrangements, financial and vocational situation, contact to family, number of social relationships, leisure activities and health. In addition quality of life measures ask about people's subjective satisfaction in these life domains. These outcome criteria are important but there is the growing opinion that outcome

measurement tools should be based on the experiences of people who describe themselves as being in recovery or recovered. QoL measures are still structured according to the lines of traditional psychiatric research and thus overlook many important aspects of the recovery process. A comparison with recovery indicators developed by mental health service users, for example the Hamilton County (Ohio) Recovery Initiative (Ralph 2000) makes this deficit apparent.

The Outcomes Task Force, a culturally diverse group of 42 consumers, families, providers, researchers, evaluators and mental health staff in Ohio define outcomes as “indicators of health or well-being for an individual or family, as measured by statements or characteristics of the consumer/family, not the service system”(Stewart 2003). The top four recovery indicators identified in Ohio were: i) the ability to have hope, ii) trusting my own thoughts, iii) enjoying the environment, and iv) feeling alert and alive (Ralph 2000). Ralph proposes that recovery as it has been experienced by people with mental health problems can be divided into four dimensions: i) internal factors, ii) self-managed care, iii) external factors, and iv) empowerment (see table 2 for an overview).

**Table 2. Dimensions of Recovery**

<b>Dimensions of Recovery</b>	<b>Indicators</b>
Internal Factors	e.g. the ability to have hope, trusting my own thoughts, enjoying the environment, feeling alert and alive, increased self-esteem, knowing I have a tomorrow, increased spirituality
Self-Managed Care	e.g. consumer directed care, independence, self-advocacy, having choices, setting reasonable goals, idiosyncratic coping methods
External Factors	e.g. interconnectedness with others, professional support, love and care from friends and family, meaningful work, own space
Empowerment	e.g. self-determination and control, making a difference, a sense of self-worth, the authority to act as a free and useful person, self-actualisation, activism and social justice

As the above table illustrates there is a clear overlap between user defined recovery factors and QoL measures, particularly in relation to ‘external factors’. Factors such as a sense of hope, having choices, self-advocacy, leading a meaningful life, or empowerment are however rarely considered in traditional outcome studies.

From the perspective of user initiatives factors leading towards recovery go hand in hand with factors measuring the attainment of recovery. For example elements of self-managed care need to be realised so that opportunities for recovery can be optimised but they can also be indicative of a person's progression towards recovery. Relapse rates and incomplete symptom remission, the focus of much outcome research that seeks to establish rates of 'normal' and 'stable' functioning, after all can not tell one much about peoples' idiosyncratic ways of establishing a new life for themselves. The challenge therefore continues to be "*to make the important measurable, not the measurable important*" (Robert McNamara, quoted In; Roberts and Wolfson 2004).

## Conclusion

A review of recent studies focusing on the long-term outcome of severe mental health problems reveals slightly less positive recovery rates than previously reported by Harding and colleagues in 1987. Still, it should be pointed out that these clinical studies indicate that around 40 per cent of people diagnosed with a severe mental health problem do get significantly better with time, in some cases the time required for recovery is longer than for others. In addition evidence from developing countries raises a number of questions about the role of services and treatments in promoting recovery which merit further investigation.

Finally there are problems with the way recovery has been measured. Traditional ways of measuring recovery show little correspondence with the experiences of those who describe themselves as in recovery or having recovered. A comparison between user defined measures and measures used in psychiatric research demonstrates that there is a lot more to recovery than can be measured by most current assessment tools.

## Commenting and finding out more

If you have any comments to make on this discussion paper, would like to contribute to the work of the Scottish Recovery Network or would like to join the mailing list then please email [info@scottishrecovery.net](mailto:info@scottishrecovery.net). Alternatively phone 0141 240 7790 for more details.

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