Making sense of madness:
Perspectives on experience, treatment and recovery

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In Australia, treatment for people who are diagnosed with schizophrenia is framed around the idea of recovery. What recovery means is understood in different ways. This paper examines findings from a qualitative study to see how people diagnosed with schizophrenia who have had long stays in psychiatric hospitals understand their own experience of, and recovery from, mental illness.

The paper begins by discussing the concept of recovery, and identifies different ways in which recovery is understood in contemporary mental health practice. After introducing the current study, it describes how participants recounted their own experience, their views about treatment, and what they imagine recovery to be. The paper concludes by considering these participants’ views in relation to those of their treating clinicians, family members, and support workers.

Explanatory stories: illness and recovery

Experiences identified as ‘madness’ have been understood in different ways in different historical and cultural settings. Contemporary western cultures understand madness as mental illness, categorising varieties of experience by means of diagnosis. A person who perceives things that others do not, and holds persistently to beliefs that others regard as delusional, may be understood to be suffering from an illness called schizophrenia (Appignanesi 2008).
The relative importance of biological and social factors in contributing to mental illness has long been contested. A biomedical view of mental illness sees madness as a manifestation of biological dysfunction, arising from genetic or structural defect or from chemical imbalance. A patient’s aberrant behaviour is seen as a symptom of their illness (Henderson 2006). Critiques of a biomedical view have argued that patients’ symptoms might also be understood as rational responses to impossible situations: what psychologist Dorothy Rowe (2002:261) calls ‘the desperate defences’. A psychosocial perspective on mental illness seeks to encompass these disparate views, recognising the influence of life history, experience and environment as well as that of biology (Fossey 2007:47-49).

Treatment for mental illness may include a concern with patients’ capacity to manage daily activities. A psychiatric disability support sector has developed in Australia since the 1980s, when non-government agencies began to be funded to deliver practical services of a kind that had previously been provided on an unpaid basis by families and charitable organisations (Gray 2007:81-85). Psychiatric disability support varies in emphasis in different states, with some programs providing psychosocial rehabilitation (Wissman 2003), and others resembling attendant care.

The stated aim of treatment and support through mental health services is recovery, defined as ‘a way of living a satisfying, hopeful and contributing life … beyond the effects of psychiatric disability’ (Department of Health and Ageing 2003). Canadian sociologist Nora Jacobson considered the emergence of this concept as an organising principle for delivery of mental health services in her book *In Recovery*. Jacobson (2004:46-47) notes that in its earliest formulations schizophrenia was by definition a
disease of poor outcome, admitting the possibility of remission but not cure. Since then there have been cycles of optimism and pessimism about the possibility of recovery from this condition.

Jacobson (2004:58-62) argues that the current cycle of optimism is supported by findings from longitudinal studies showing that up to two-thirds of patients diagnosed with schizophrenia report a measurable reduction in symptoms over time, and the emergence of ‘psychiatric rehabilitation’ as a profession with a focus on developing strategies for improving functioning, while valuing the perspectives and promoting the autonomy of clients. Optimism is promoted also by the consumer / survivor movement that gained momentum in the US in the 1980s.

Where providers of clinical treatment and psychiatric rehabilitation see mental illness as a medical dysfunction, the consumer / survivor movement does not. Instead, it argues that madness is a legitimate part of human experience from which things can be learned, and from which people can and do recover. The movement challenged the authority of professionals to define mental illness and identify recovery, upholding the patient as expert in their own experience (Jacobson 2004:65-66). In this view diagnosis and treatment can act as an obstacle to recovery, as being ‘under the doctor’ involves accepting your psychiatrist’s view of your situation as more legitimate than your own. Recovery is understood as a process, not a destination. It has been defined most succinctly as ‘living well in the presence or absence of my madness’ (O’Hagan 2007).
Jacobson’s analysis identifies several different understandings encompassed within the concept of recovery as it is used in mental health services. Recovery may be seen as a condition or as a process. It may be brought about through treatment with drugs or other therapies; enabled by support provided through a psychiatric rehabilitation model; or initiated when an individual asserts the value of their own experience. The existence of recovery may be identified by professionals using objective measures such as improved scores on instruments measuring clinical symptoms, or observed improvements in social functioning; or self-identified by individuals using subjective criteria to assess what Deegan (cited in Jacobson 2004:83) called ‘the transformation from anguish to suffering’.

This diversity in ways of thinking about recovery is reflected in accounts created by participants in the present study.

**Out of the Institution: the study**

The project examines the experience of people who were discharged after long stays in psychiatric hospitals, with assistance from programs providing supported housing. Under these programs clients live (usually alone) in their own homes, and receive outreach support in relation to mental illness and medication from community-based clinical teams, and psychiatric disability support from a non-government agency.

Disability support is client-directed, with a clear rehabilitation focus. Each client’s support is guided by a plan that identifies areas of unmet need, articulates goals that the client wishes to achieve, and breaks those goals into achievable steps. Support is
flexible, with workers visiting clients as often as daily or as little as monthly. Support continues for as long as the client feels they need it.

The study is framed from a psychosocial rehabilitation perspective. It takes as evidence of the programs’ success their ability to support clients in maintaining their tenancies and improving skills in self-care and participation in the community. The study found, as have evaluations of similar programs in other Australian states, that people who continue to experience severe and disabling symptoms associated with mental illness can sustain tenancies and live successfully in the community over the long term, with this kind of support (Meehan et al 2007; Muir et al 2007; Carter 2008).

The study interviewed individuals in Victoria who had been supported under such a program for twelve years, and people in South Australia who had been recently discharged or were soon to be discharged from Glenside hospital in Adelaide. This paper considers the experience of the 25 clients interviewed in SA, of whom fifteen were living in their own homes and ten were in hospital, working with a support agency ‘in transition’ toward discharge. These participants ranged in age from twenty-two to fifty-six. Six were women, and most were born in Australia. Twenty-three had been diagnosed with schizophrenia, and two with schizo-affective disorder.

The study uses qualitative methods. I approached clients through their support agencies, and with their consent, interviewed first their support worker and then the client. If clients agreed, I sought information also from their clinical worker, and
from a family member. Clients received a $30 voucher as a thank-you for their participation.

Interviews with clients took place in clients’ homes, or in the office of their support agency or at Glenside. Most interviews were one-to-one. In some interviews the support worker was present, either at the client’s request or because I was advised not to visit the client alone. Interviews were audio-recorded with clients’ permission, and transcribed verbatim. I asked clients about their experience of leaving hospital, of living in their own homes with support, and about their aspirations and concerns for the future. Questions were open-ended, to allow respondents to identify and elaborate on aspects that were important to them. Data were analysed as a series of case studies, giving multiple perspectives on the experience of each client.

The next sections outline what clients said about their experience of mental illness, and their views about treatment and recovery.

**Perspectives on experience**

Throughout their accounts, most participants described their experience in terms of illness. A few asserted that while they had been ‘unwell’ it was not really serious, and a small minority rejected altogether the idea that they had been ill.

Most participants talked about the experience that brought them to Glenside in general terms as a ‘nervous breakdown’ or ‘mental illness’, rather than naming a specific diagnosis. Many described experiencing perceptions that are not real, most commonly voices. Several participants described particular beliefs that they become
convinced of when they are ‘unwell’, that at other times they regard as delusional. One said: ‘Some of the vivid thoughts that I have, are true. And some aren’t true. I have to investigate to see if it’s true or not’. Several clients described responding to these thoughts and perceptions with destructive behaviour or violence, directed toward property and people. ‘I get frustrated, angry and violent. I don’t know why I do it’.

A number of participants explained their ‘breakdown’ as resulting from trauma experienced in childhood, as teenagers, or less often, in the workplace. Several mentioned having used illicit drugs during their teens, usually marijuana. Some saw this as a precipitating factor for their illness while others did not.

While some participants described dramatic and life-threatening events associated with their illness, others felt that their condition was less serious than it had been made out to be. One said:

I think they overreacted a bit to my condition. I shouldn’t have been [in Glenside] that long. I wasn’t going around murdering people, you know, or even raping people or anything, it’s just a bit of an anger thing that I went through but I didn’t do any serious damage.

Some said they did not know why they had been in Glenside at all. One client said she was there because she had been homeless and had nowhere to go; another that she had gone there only to visit someone, but ‘they kept making me go back, and taking pills and stuff’.
Perspectives on treatment

When discussing treatment, most participants talked about prescribed medication. None mentioned having been offered counselling.

All participants talked about their time in Glenside, offering a range of views about the value of time spent there as a response to their experience of being unwell. Some were positive. One said he went there ‘to have a break from the world. It’s good to be looked after when you’re ill’. Several clients said they disliked being in Glenside because of other patients: ‘they have the complete psychos and the nice people just with problems, they had them all in the same area’. Some identified making friends with other patients as a good thing about being in hospital. Many said they disliked being in Glenside because they had been forced to take medication, or because of negative attitudes held by staff: ‘They put you down a lot. It’s no good for anyone really’. All who had been discharged from Glenside said they were very happy to have left.

Many clients said that while Glenside is not a good place to be, it provided sanctuary when sanctuary was needed.

It’s all right if they like you, then they are nice to you. If you are one of the patients they don’t like, they make your life hell. I don’t want to go back there. I will only go back there if I really, really know I am feeling unwell, then I will admit myself. When it gets to the stage that I want to start [problem behaviour] again, I will have to go back. I can’t afford to do it again. That’s why I have to go before it happens.
Most clients said their prescribed medications were effective in ‘taking the edge off’ their distressing thoughts, although many found them to be extremely sedating. Medications also promoted weight gain and other health problems. The following view was common: ‘To begin with I was a bit anti-medication but now I realise I do need medication and it might be an ongoing thing for a really long, long time. I’ve found that medication really helps me.’

**Perspectives on recovery**

Participants were asked in interviews about the nature of the support provided by their rehabilitation worker, and the activities clients did with them. Their responses framed these activities not as part of ‘treatment’, but as resources that promote strategies for staying well in the present, and planning for the future.

All described support provided by the agencies as important (‘We can talk about things. That keeps me even, and it stops you from being so lonely’), but several said they did not want to depend on it too much. One client said: ‘I can’t expect them to be coming all the time, they’ve got other people to see too’. Most participants said they valued being encouraged to do things for themselves. One said:

> If [support] was more intense I may not strive for independence so much. I don’t want to rely on people too much, otherwise I’d probably sit here all day saying ‘When are they coming to take me shopping?’

A common view among participants was that support has ‘given me hope that people with mental illness can achieve their goals and maintain a healthy lifestyle regardless
of having had a nervous breakdown or stuff like that’. For the future, the challenge will be ‘just getting off my butt and doing it I guess’.

Some of the younger clients said they would prefer to have things done for them, rather than being encouraged to do more themselves. One said: ‘I want easy guidance. Someone to accept that what I want to do is what I want to do. Not saying you can’t do this and all that.’

Most respondents described strategies they had learned for dealing with their illness. The most common was acceptance: ‘I’ve accepted my mental illness. I was sad about it and now I’m trying to accept it’; and ‘I’ve learned to come to terms with the illness. I don’t dwell on my thoughts any more.’ Other strategies include avoiding alcohol and illegal drugs, talking to people you trust, participating in regular activities, and ‘just deal[ing] with life day-by-day.’ ‘I’m sort of going at my own place. Just take life as it comes, see what happens’. Many identified independence as a goal. ‘I’d like to be self reliant, autonomous and independent. Relying on my own skills to get me through situations and not let them turn out to be big dramas’.

When thinking of the future several participants described fear associated with living in their own place. One said: ‘Sometimes I hear things that aren’t there. I see shadows walking past the window and I’ve got no-one to talk to about it’. When asked how could their housing situation be better, several mentioned locks. ‘It could be more secure, grilles on the windows and deadlocks. I always get sweaty palms where I live’.
Accounts created in interviews by these clients indicate that most see their experience in terms of illness, and accept the understanding of their condition that is put forward by their treating clinicians. In imagining their future, most were concerned first with moderating symptoms through use of prescribed medication, and learning and practicing strategies that will make it possible to live with those intrusive perceptions, thoughts and feelings that remain. The next objective is to develop skills in self-care, and learn to function better in the community. Although the word ‘recovery’ did not appear in participants’ accounts, the idea of ‘living well in the presence or absence of madness’ was implicit in many.

Making sense of madness

Clinical staff, support workers and family members who took part in this study presented diverse views about mental illness and recovery. Many clinical staff were pessimistic about their clients’ prospects, feeling that they would be unable to cope without supervision. Support workers felt that given the opportunity, their clients could improve their skills and develop independence. Families just wanted to be assured that their son, daughter or sibling would have adequate support so that the previous cycle of crisis and hospitalisation could be averted. Support workers were consistently more optimistic about prospects for recovery than clinical staff or families.

In making sense of their own experience, clients are caught between the disparate views of their workers and carers. Most clients describe their experience as mental illness, although some also hold their idiosyncratic perceptions as true. The experience clients have in common is repeated episodes of inability to cope with the
circumstances of their lives. Their common challenge is to find strategies to deal with intense and intrusive feelings, perceptions and thoughts, without causing harm to themselves or others. Most see prescribed medication as an important tool in achieving this, but for many its benefits come at a heavy price. Most clients express a desire to take time and learn to cope with their experience, with the safety net of ongoing support from their agency.

O’Hagan (2007) argues that taking responsibility for one’s own journey is a defining characteristic of recovery. Our findings show that providing long-term access to secure and affordable housing, plus ongoing psychosocial rehabilitation support, encourages clients to find the confidence to do this. As these clients leave hospital and live in the community with this support, they will have more opportunities to try and fail and try again and to learn from their mistakes. Their understanding of their experience is a work in progress, as they move from a hospital environment where expectation for recovery is low, to their own homes with intensive support from workers whose approach is centred on fostering hope.

References


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