

‘I have to Get Really Honest with Me’: Findings on Recovery from Mental Illness.

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Introduction

The primary focus in present day psychiatry on symptoms and their neurobiological basis, although of significant, is now increasingly viewed as insufficient (Hoffman et al., 2000). There has been a conceptual shift to view people with serious mental illness as consumers rather than patients, and to appreciate the need to understand their views as essential to the recovery process (Torgalsboen 2001). Psychosocial issues associated with care and recovery are now posited as of core significance (Yanos et al., 2001).

Consequently, increasingly there are calls in the literature for in-depth information on appropriate psychosocial care for individuals coping with a mental illness (Fenton & Schooler, 2000; Heinssen et al., 2000). As one response to these calls, this article presents insights gathered from an Australian qualitative research project with the primary aim of exploring factors that contribute to recovery in mental illness from a consumer’s perspective. Further findings from the study (McGrath et al., 2007), highlight many negative aspects of the drug imperative within the Australian psychiatric system. The present article focuses on the findings associated with consumers’ strategies for recovery that are not dependent on drug therapy.

The Research

The findings are from a sub-project of a larger research project funded by a Central Queensland University Merit Grant that followed up clients from Project 300, a mental health, disability and accommodation package established by Queensland Health in 1995 to assist 300 clients with psychiatric disabilities. The aim of the sub-project was to explore, through qualitative methodology, the factors that contribute to recovery from mental illness. This research involved interviews with individuals chosen because they were articulate about their recovery from mental illness. Qualitative research methodologies have been instrumental in ensuring that the voice of the consumer is heard in a way that contributes to changes in conceptual understanding of recovery in relation to mental health care practice (Mancine et al., 2005; Ramon et al., 2007).

Full ethical clearance was obtained for the research from the university ethics committee. The interviewees were provided with a written project description, informed verbally of their rights as a research participant and signed a written consent form at the point of agreeing to participate.

Methodology

The ten ($n=10$) participants for this arm of the study represent a purposive sample of individuals who were chosen on three criteria: first, they had an official DSM-IV psychiatric diagnosis for a mental illness; second, they were able to demonstrate recovery from that illness; and third, they were articulate and sufficiently motivated to express in words the experience of recovery. Each participant documented their own criteria for recovery which included evidence of remaining symptom-free, of maintaining a support and friendship network, of engaging successfully in meaningful occupation or study and of investing energy as a volunteer into assisting others coping with a mental illness. Participants were enrolled through the snowballing techniques of networking within the mental health consumer network. The intent behind such a purposive sample was to provide an opportunity for articulate mental health consumers to provide leadership in providing insights on recovery for those who were less able to express themselves.

Data was collected through a non-directive Rogerian interview that proceeded at each interviewee's pace, with constant checking by the interviewer that the material dealt with remained within the comfort zone of the participant. The interviews started with the question – “Could you talk about your recovery process, taking as much time as you need and talking about issues that you think are important?” At times the interviewer would ask for clarification of statements and would also make summaries of the progress of ideas to confirm that the interviewer understood the ideas expressed correctly. The interviewer did not impose a structure on the interviews but rather engaged with the flow of the discussion in the direction established by the interviewee. The interviews lasted for approximately two hours. They were audio-recorded and transcribed verbatim. The language texts were then entered into the NUD*IST computer program and analysed thematically. A phenomenological approach was taken to the recording and analysis of the data. The aim of phenomenology is to describe particular phenomena, or the appearance of things, as lived experience (Streubert & Carpenter, 1995). The process is inductive and descriptive and seeks to record experiences from the viewpoint of the individual who had them without imposing a specific theoretical or conceptual framework on the study prior to collecting data (Polit & Hungler, 1995). All of the participants' comments were coded into free nodes ('free nodes' is a technical term for the categories created on the QSR NUD*IST N5 program to store statements that relate to a similar topic), which were then organised under thematic headings. There were 141 free nodes created from the interviews of which the data from the free nodes on factors facilitating recovery are presented here.

Findings

Recovery takes time

A caveat to the following discussion is the idea that even with the right conditions recovery is a protracted process that can take years. As can be seen by the following, the participants emphasised this point:

It was a journey [and it] took some time to get it right.

It's taken me years.

You're just learning as you go along...

Factors initiating recovery

Personal crisis and significant life change as turning points

The participants gave detailed examples of personal crises they experienced and how the experience initiated or gave them the motivation for the recovery process. For reasons of confidentiality the details of these experiences will not be provided, but the point that a crisis can initiate recovery is recorded. As one participant explained:

When I went through that stuff, it was something I made a commitment to myself: That I would never, never, ever, ever walk down that road again.

There were also examples of positive life changes initiating recovery, such as finding a supportive partner and doctor, as one participant explained:

It's very hard. It takes a lot of determination, and you need some feeding and fortunately my feeding came from [remarrying] again. My current wife, and my doctor who at that time I was seeing weekly, he was just encouraging. Just straight out simple, non-scientific encouraging. And away I went.

For others, it was the responsibility of providing the best emotional environment for their children, for example:

What every parent wants is to know that they... have done... the best thing by their kids. I want to emphasise that, you know, that's probably one of my driving forces.

Taking personal responsibility for recovery

A key factor mentioned by all of the participants in relation to initiating and sustaining the recovery process is that of taking personal responsibility for dealing with their illness. As seen by the following, without self-responsibility recovery is seen as unlikely to take place:

Look, you should go to all the amount of lectures, and medication and psychiatrists, and courses. Yet till you are ready to accept something in your own mind, then it just won't work.

Accounts were provided of how previously participants had 'given away' their sense of control to others, for example:

... You know until I had my own hand there directing; you know all the other times... I gave my control over to the partner I was with, or the parents... The worst I was at was when I let other people [take control].

At the core of personal responsibility is the idea of 'owning' the illness, for example:

Put it this way, I owned the stuff that was my stuff.

Self-control incorporated taking advice from others, for example:

I made my own decisions about myself, and my life. And she'd give me some guidance at times, and different suggestions, and things like that. But it was always my choice.

Although discussed in full in findings published elsewhere (McGrath et al., 2007), it is important to note that participants stated that the mental health system does not adequately support this healing direction. For example, one participant who had been involved in the system for over six years with 15 hospital

admission before any health professional gave advice about the importance of taking personal responsibility for recovery, stated:

But one of the major criteria I feel, and I feel even more strongly now, is that the system has to be encouraging towards that [taking personal control of illness].

It was seen as possible for a sense of personal responsibility, albeit limited, to even be initiated during a psychotic phase of the illness, for example:

I guess when you're deep in a psychosis there's not a lot you can do... But you have to come to a bit of an insight that you're unwell.

Confronting mental illness

At the core of the process of taking self-responsibility is that of confronting and accepting the fact of one's mental illness, as one participant explained:

And being a real to the fact that it exists... and finding a way to think of it differently.

Fear is an emotion that can block such a process, as one participant expressed:–

... Sheer fear of it... I guess it's something that you've got to face and accept. And you know, I think... the reason I was able to do it, was because I wasn't afraid of losing anything.

It was noted that the act of confronting the illness helps to control it, for example:

... If you're going through something, handle it. Sit down if you have to. Handle it, and it goes away.

Self-awareness and insight

Participants indicated that self-awareness and insight are essential in the process of confronting the illness in order to initiate and sustain recovery.

... And it's using that word... which is quite vital within recovery: 'insight'.

As one participant explained, honesty with the self is a key aspect of insight:

And what I have to do is I have to get really honest with me.

The process is active and requires ongoing focus and attention, as the following example of mood control indicates:

I've been told... that I have a quite an insight into my moods. I don't let it get out of hand. I could bring it back down. I think I'm very aware of my mind.

Accepting the limitation imposed by the illness is also seen as a part of insight, for example:

I'm not over-confident. I don't want to be that. But I'm... more understanding than ever before that I still have to be mindful that there is... an inherent weakness. But it's not a handicap.

An important point made by the participants is that insight is not just restricted to the illness but must embrace an exploration of the whole person. As one participant explained:

So often I did a lot of my own logical thinking around, or rational thinking around some of the experiences I'd get on a daily basis... So I guess the thing that is going to help me along the way is working on myself, my human self. "Okay, that's just part of my illness."

Self-acceptance and self-forgiveness – getting over the mental illness label

Self-forgiveness is an important part of accepting the limitations of the illness, for example:

You look at some actions and behaviours that you do when you're ill, and they just don't fit into your self perception. But that's hard to accept. And that's where, if people want to get better, they have to... cut themselves some slack, and then forgive themselves for not acting the way they wish they'd acted all the time.

Along with self-forgiveness, there needs to be a sense of self-acceptance, for example:

And I used to lie a lot, about who I was, and because I... didn't feel like I was up to par with everyone else. And now it's like, 'Here I am, if you don't like me, that's fine'.

An important part of this process is the act of letting go of the illness label. Participants talked about how prior to recovery they had related to others through their 'illness label' but had to let go and embrace a sense of self-respect, for example:

And I really... wanted to be me...I didn't want to be known as 'the poor little schizophrenic; be nice to her because she's ill'.

As another participant explained, it is the act of redefining the self:

... Recovery to me is about understanding, and getting familiar the sense of self that I... had given away to somebody else to define, so redefining that for myself.

Obtaining useful information

Information on all aspects of the mental illness was noted to be of considerable assistance for the recovery process, as one participant expressed:

... Helpful information, I'm really loving it... there are concepts that are really helpful, and there are others that are really useless.

Information about how other 'consumers' deal with recovery was seen as particularly helpful, for example:

I do think another thing is that sharing information between consumers or advocates does help. Because I think that information helps you. Yes, and it's not something any professional would ever teach you.

Many of the participants indicated that they actively read a wide range of books to seek out the information they needed, for example:

I read a lot. I read stuff on the internet. I've got a folder full of stuff that I read over and over again, trying to find some similarity to what I experience.

Reading provided insights on mental illness, strategies for coping, hope and inspiration from the stories of others going through similar experiences.

People support – a safety net

The support of others was noted as vital to recovery, but a caveat is that it is important to be selective about the people to include in the support circle, as one participant explained:

But I actually found out that it's actually better to have many people in your life, [more] than just one in particular, but also be cautious and careful about who you have in your life.

In particular, it was seen as important to be cautious about sharing the diagnosis with others, for example:

I chose to disclose my diagnosis to about half a dozen people, the range of people I felt safe with.

Strategies found successful for moving forward

The participants discussed a wide range of strategies they found successful in assisting with their recovery. Focusing on aspects of their experience that they could control was one such strategy, as one participant explained:

I guess I break it down to things that you have control over, and things that you don't.

The strategy associated with taking control is to view obstacles with an openness of what to learn from the experience, for example:

... It's not seen as obstacles, but it is: 'Now what can I learn from this...'

An important part of the focus on control is goal setting, as one participant explained:

I started to set goals. I started to set goals of things I wanted to do.

Another strategy is to not dwell on negative thoughts or problems as this will re-enforce an inward focus, but rather to look outside the self:

And try not to dwell - if you find out you've got problems or anything, have a look around you. Don't dwell on what it is. Dwelling on your problems, some people might shut off, become reclusive, sit on a lounge all day smoking. If you dwell on negative thoughts, or... irrational thinking, then it's going to consume you.

Engaging in activities that affirm the person's strength assists with a positive focus, for example:

I used to swim a lot, and I was a fairly good swimmer. And that was another space, that's kind of where I knew I was okay. Because I had to have something I could work with, something I could do, something I could change... If you're just flat with schizophrenia... it's kind of like almost a death sentence, you know?

This may include any diversional activity, such as learning a new skill, for example:

Diversional [activities], taking my mind off my problems, onto more positive stuff. Like learning new skills, like playing tennis, or planning.

For some, their employment or studies helped affirm their positive sense of self and provided diversional activities.

Where possible, the participants found it important to keep in touch with positive feelings about the future, as one participant explained:

... I'll lay down here when I'm going through a hard time. I know that things are going to get better, and I'm going to have good times again. I had this sense that I'd get it right again.

Finding a meaningful perspective can re-enforce the positive, for example:

... I think the only thing I know... is that some of the people in my life that have helped me unpack it in ways that help me create meaning.

Looking back at the progress made also helps to affirm the positive, for example:

It's wonderful to be able to value how far you're coming.

Indeed, one participant found that to write their life story helped to put things in perspective:

Writing my story probably did it for me.

Humour

Humour was mentioned as a key ingredient in the recovery process for a variety of reasons including being a 'safe way' of talking about difficult issues, a medium for feeling good and a way of making aspects mental illness accessible to others.

Recovery reinforces recovery

Participants spoke of the positive perspective that the recovery experience gave them and how they felt nourished by their recovery journey, as one participant explained:

What it's taught me now, is that I don't feel that way anymore. And I love that. It's a complete new experience. I don't believe you ever gain back what you had. I think you just grow into something different. And better.

It was noted that the positive aspect of the journey of recovery is not widely recognised, for example:

The richness of the journey - people don't go into that. You don't see people going, 'Oh God, I wish I hadn't gone through that'. I think I've been very much blessed.

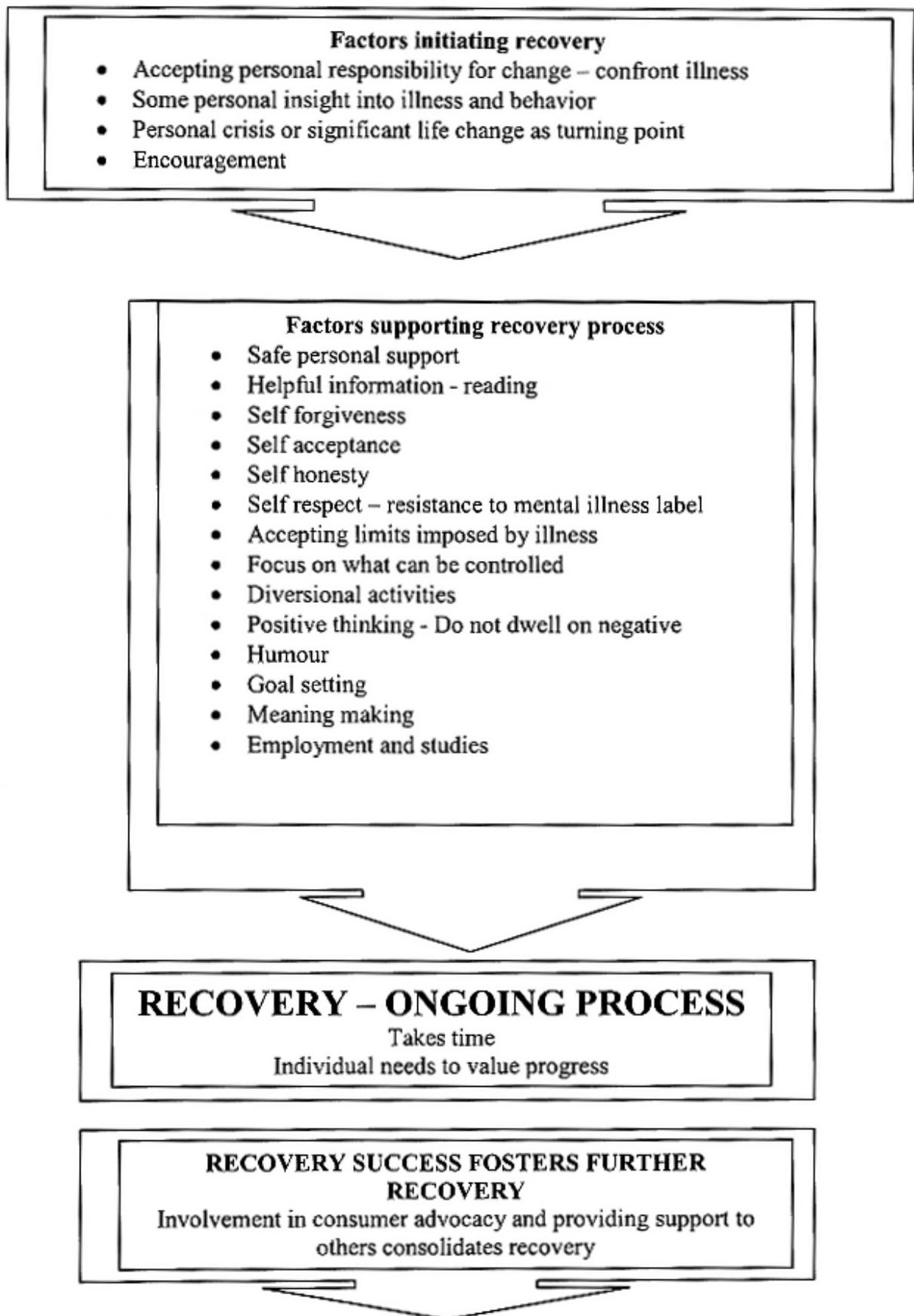
Most of the participants used the insights from their own recovery journey in their advocacy work in mental health. This advocacy work was seen as further strengthening the recovery process, for example:

Advocacy has given me a lot of satisfaction. It's wonderful to be able to value how far you're coming. You don't realise that till you see somebody who is just [been diagnosed] and all of a sudden you realise what a hole that they're in, and you remember how hard it was. Yeah... I tend like to think of it as turning your weakness into a strength.

Discussion

As outlined in Figure 1, the findings presented in this paper focus on the generic factors that participants perceived as facilitating their recovery process. This discussion needs to be set in the context of the notion that the process is protracted and can take many years.

Figure 1: Overview of Findings



The findings indicate that the process of recovery can be initiated by either a personal crisis or a significant positive life change such as finding a life partner or having children. Taking responsibility for the process of recovery by ‘owning’ the illness is seen as essential for

recovery. However, further published findings from the study (McGrath et al., 2007) indicate that this can be difficult in a mental health system that does not adequately support this healing direction. Part of the process of ownership is the act of confronting and accepting the fact of the mental illness, a process that can be blocked by the emotion of fear. Young and Ensing (1999) refers to this as 'stuckness' and the challenge in relation to recovery is to overcome 'stuckness' through self-empowerment.

The findings from the present study indicate that self awareness, insights and self-honesty are essential attributes initiating and sustaining the recovery process. Importantly, the findings indicate that recovery is seen to be an active process that requires focus and attention. A case study published from the study (McGrath & Jarrett, 2004) outlines in detail the focus and attention required for a therapeutic alliance to assist recovery. As Ridgway (2001) emphasises, recovery is a process of active coping rather than passive adjustment, in which the individual needs to move away from withdrawal in the disempowered role of psychiatric patient to engage actively with life. The present findings indicate that accepting the limits imposed by the illness and focusing on the strength of the whole person rather than just the illness are important dimensions of this process. In the literature this is referred to as the 'strengths perspective' where the focus is on the person's capabilities rather than on a limited illness model (Ramon et al., 2007; Rapp, 1998; Saleeby, 1992). The present findings indicate that this requires a degree of self-acceptance and self-forgiveness. The point is to focus on the whole person and re-define the self by moving beyond the mental illness label. Davidson (2003) refers to this process as living outside the illness and resonates with Ramon and associates (2007) concept of 'self-agency' which is increasingly being recognised as a key element in recovery.

Obtaining useful information on mental illness, and in particular on how other individuals deal with recovery, is noted as an important factor contributing to recovery. Hence, reading widely is valued as it provides insights on mental illness, strategies for coping, hope and inspiration.

The support of significant others is essential to recovery. The importance of connection and belonging are documented elsewhere (Laliberte-Rudman et al., 2000). However, the findings also indicate that a sense of safety and acceptance is essential so it is important for individuals seeking recovery to be selective about people included in the support circle and cautious about sharing information about their diagnosis and personal story.

The findings point to a number of successful strategies that can be used in the recovery process such as focusing on aspects of the experience that can be controlled; viewing obstacles with an openness; goal setting; not dwelling on negative thoughts; engaging in self-affirming and diversional activities; maintaining positive towards the future; seeking a meaningful perspective; and looking back on progress achieved. All processes are made easier by the use of humour. Making choice, maintaining control and goal setting are all factors affirmed in the literature (Dhillon and Dollieslager, 2000; Laliberte-Rudman et al., 2000). Willpower, as Torgalsboen (2001) demonstrates, is a potent factor contributing to recovery. The reverse has also been documented, with poor self-concepts, low expectations and external loci of control negatively influencing the individuals coping strategies and leading to hopelessness and chronicity (Hoffmann et al., 2000).

The positives gained from recovery are seen to further re-enforce the continuing process of recovery. The insights gained enable individuals in recovery to engage in mental health consumer advocacy, a process described as satisfying that provides further nourishment for the individual. A positive outcome of the recovery journey is reported to be a sense of evolving to a new person which includes feelings of achievement and appreciation. The work of Deegan (1996) affirms this idea – her writings describe recovery as a transformative process in which a new sense of self emerges.

Conclusion

The hope and expectation in sharing the insights from a group of individuals who have found successful strategies for recovery is that it will affirm the way forward and provide inspiration for others on a similar journey. As Hoffman and associates (2000) demonstrate, it is so important for recovery to maintain a positive approach and not give up. Increasingly, this message is being documented in the literature as we move into an era where consumers are showing the way forward to an exciting new

References

1. Davidson, L. (2003). *Living Outside Mental Illness: Qualitative Studies of Recovery in Schizophrenia*. New York: New York University Press.
 2. Deegan, P. (1996). Recovery as a journey of the heart. *Psychiatric Rehabilitation Journal*, 19:91-7.
 3. Dhillon A., & Dollieslager, L. (2000). Rehab rounds: overcoming barriers to individualized psychosocial rehabilitation in an acute treatment unit of a state hospital. *Psychiatric Services*, 51(3):313-7.
 4. Fenton, W., & Schooler, N. (2000). Evidence-based psychosocial treatment for schizophrenia. *Schizophrenia Bulletin*, 26(1):1-3.
 5. Heinsen, R., Liberman, R., & Kopelowicz, A. (2000). Psychosocial skills training for schizophrenia: lessons from the laboratory. *Schizophrenia Bulletin*, 26(1):21-46.
 6. Hoffmann, H., Kupper, Z., & Kunz, B. (2000). Hopelessness and its impact on rehabilitation outcome in schizophrenia – an exploratory study. *Schizophrenia Research*, 43(2-3):147-58.
 7. Laliberte-Rudman, D., Yu, B., Scott, E., & Pajouhandeh, P. (2000). Exploration of the perspectives of persons with schizophrenia regarding quality of life. *American Journal of Occupational Therapy*, 54(2):137-47.
 8. Mancini, M.A., Hardiman, E.R., & Lawson, H.A. (2005). Making sense of it all: consumer providers' theories about factors facilitating and impeding recovery from psychiatric disabilities. *Psychiatric Rehabilitation Journal*, 29(1):48-55.
 9. McGrath, P., & Jarrett, V. (2004). A slab over my head: recovery insights from a consumer's perspective. *International Journal of Psychosocial Rehabilitation*, 9(1):61-78.
 10. McGrath, P., Bouwman, M., & Kalyanasundaram, V. (2007). 'A very individual thing': Findings on drug therapy in psychiatry from the perspective of Australian consumers. *Australian e-Journal for Advancement of Mental Health*, 6(3). Accessed at: www.auseinet.com/journal/vol6iss3/mcgrath.pdf
 11. Polit, D., & Hungler, B. (1995). *Nursing Research: Principles and Methods*. Philadelphia: Lippincott.
 12. Ramon, S., Healy, B., & Renouf, N. (2007). Recovery from mental illness as an emergent concept and practice in Australia and the UK. *International Journal of Social Psychiatry*, 53(2):108-22.
 13. Rapp, C. (1998). *The Strengths Model: Case Management with People Suffering from Severe and Persistent Mental Illness*. New York: Oxford University Press.
 14. Ridgway, M. (2001). Re-storying psychiatric disability: learning from first person narrative accounts of recovery. *Psychiatric Rehabilitation Journal*, 24:335-43.
 15. Saleeby, D. (ed.) (1992). *The Strength Approach in Social Work*. New York: Longman.
 16. Streubert, J., & Carpenter, D. (1995). *Qualitative Research in Nursing: Advancing the Humanistic Imperative*. Philadelphia: Lippincott.
 17. Torgalsboen, A. (2001). Consumer satisfaction and attributions of improvement among fully recovered schizophrenics. *Scandinavian Journal of Psychology*, 42(1): 33-40.
 18. Yanos, P., Primavera, L., & Knight, E. (2001). Consumer-run service participation, recovery of social functioning, and the medicating role of psychological factors. *Psychiatric Services*, 52(4):493-500.
 19. Young, S., & Ensing, D. (1999). Exploring recovery from the perspective of people with psychiatric disabilities. *Psychiatric Rehabilitation Journal*, 22(3):219-31.
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