

Understanding Psychotic Experience and Working Towards Recovery

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This paper will describe the process of making sense of psychotic experiences and promoting recovery for people who are receiving psychiatric treatment. It will focus on some of the concepts, therapeutic strategies and actions that are likely to help the recovery process. I am a clinical psychologist who has spent the last 9 years working psychosocially with people whose problems have been diagnosed as psychotic. I have also had the experience as an 18-year old of receiving psychiatric treatment for psychosis and being diagnosed with schizophrenia. I will consider some of the basic principles we can learn from the growing recovery literature in order to better promote self help and recovery for the person who has psychotic experiences. I will envisage the different ways that we as professionals and patients might understand psychotic experiences as meaningful events in the context of people's social lives. I will argue that rather than attempting to reduce psychotic experience the focus of our work should be on reducing the debilitating nature of the experience so that people can freely get on with their lives. I aim in this chapter to reflect on practical considerations for working with psychosis that derive from both subjective wisdoms as well as the usual professional sources.

My Experience of Psychosis

From September 1986 to November 1987, I was treated for psychosis. This included several involuntary hospital admissions. Initially, I had experienced sleep deprivation and was very confused holding some grandiose and paranoid beliefs involving espionage and science fiction theories. I perceived the television and radio as having interactive messages for me. I also entertained spiritual beliefs focussing on battles between good and evil and having special powers of communication. My concentration was extremely poor. I was in a high state of vigilance, fear and tension, leading to chest pains. Perhaps due to having a family history of problems diagnosed as schizophrenia, clinicians quickly made a diagnosis of schizophrenia. My parents were informed and told I would need to take medication for the rest of my life.

However, 14 months after my initial psychiatric admission I stopped taking my depot injection of medication and disengaged with psychiatric services. I have not since received or used psychiatric services.

As a patient, I did not receive any specialist psychological interventions. The main interventions I received were pharmacological, ideological ('you must accept you have a serious mental illness') and eventually occupational therapy. I believe that I came very close to developing a long-term sick role as a 'schizophrenic' because the expectation all around me was that I would not be able to rebuild my life. Rather, I was encouraged to passively adjust to a serious 'mental illness' with a maintenance style medication regime. The belief held by hospital staff was that I would be powerless to influence the return of psychotic symptoms that could at any moment strike again. For me to escape this prophecy it felt like wading through miles and miles of swamp. This was an incredibly lonely journey. I had no guides, no specialist support, and no stories of success. With hindsight, my own understanding of my initial psychotic reaction is that my drift into a psychotic world was the result of dissociative psychological strategies that allowed me to escape from a social reality I felt alienated from. Motivated by the poor care I received and witnessed, I decided to train as a psychologist so that I might influence change in therapeutic approaches in the mental health system.

I now work in Bradford mental health services in England as a Clinical Psychologist. My aim in this chapter is to reflect on how recovery from psychotic experience, can be best promoted given the evidence from personal accounts and clinical research. In another publication I have reflected on what was and what was not helpful to my recovery process (May, 2000). In retracing my route to recovery I highlighted enabling personal narratives (stories of success and possibility), meaningful activities, and social inclusion opportunities (housing, work and educational opportunities) as being important turning points. I would like here to reflect on four areas which are important for practitioners to address if they are to be helpful in enabling people's recoveries. These areas are clinical language, the recovery process, medication and a whole-person approach.

1. Clinical Language

Being given a diagnosis of schizophrenia was not helpful for me. It created a learned hopelessness in me and my family who resigned themselves to the established belief I would always be ill, unable to work and always need antipsychotic medication. There is a deeply held assumption that schizophrenia is a disease-like degenerative process. Thus the category of schizophrenia is associated with a failure to recover and a gradual deterioration in social functioning (Blackman, 2001; McGorry, 1991; White, 1987) It is more helpful to see each individual's mental health as a unique and evolving story, which is importantly influenced by social and relational experiences.

Compared with traditional diagnostic categories, a focus on individual experiences provides a better framework for understanding psychosis on both empirical and practical grounds (Bentall, 1990). The British Psychological Society Report Recent Advances in Understanding Mental Illness and Psychotic Experiences, suggested individual formulations may be more useful than diagnostic categories (BPS, 2000). Moreover there is generally a practical benefit to moving away from clinical language and the concept of mental illness to a more holistic flexible language about 'mad' experience. Traditionally clinical language has risked colonizing people's experiences and beliefs (Dillon & May, 2002). The danger of clinical language is that it objectifies the individual concerned, presenting them as a passive victim of an active pathology. Therefore, the use of traditional clinical language risks compounding the sense of anxiety and powerlessness that the patient will experience. Consequently, there are strong arguments for an increased emphasis on valuing the subjective experience of psychosis and the meanings people attach to their experiences. I find it helpful to use terms such as *voices* and *disturbing or alternative beliefs*, rather than the terms hallucinations and delusions. This more inclusive language helps to increase understanding of client's perspectives of their experiences and ways they might best enhance their coping abilities. This *demedicalizing* of the experience also highlights the fact that it is not the voices or unusual beliefs that are the problem, rather the person's relationship with these experiences that will determine how distressing they are (Morrison, 1998; Romme & Escher, 2000).

2. Recovery Processes

The concept of schizophrenia was unhelpful to me. A more helpful concept would have been recovery, but unfortunately this was never discussed. In discussing recovery I am not implying the medical concept of 'cure'. Rather I am using the definition made by Anthony (1993) who suggests that recovery from serious mental health problems is a multi-dimensional concept: social and psychological recovery processes are seen as being as important as clinical recovery (Coleman, 1999). Clinical recovery is defined by reduction in 'symptoms' (e.g. voices and unusual beliefs). Social recovery describes the development of meaningful social relationships and roles, vocational activities and access to decent housing. Psychological recovery describes the process of developing ways to understand and manage psychotic experiences and regain some sense of structure in one's life. These distinctions are important as currently services and research focus too heavily on clinical recovery. However, if someone can recover socially and psychologically, clinical recovery may be irrelevant to the quality of their life. For example, there are many people who live successful lives who hear voices. They have ways of managing their voices so that their experiences do not hold them back from getting on with their lives. Anthony's (1993) definition of recovery includes dimensions of self-esteem, adjustment to disability, empowerment and self-determination.

The recovery concept being discussed was originally used by the physical disability movement in America. It has since then been used by mental health service users internationally. A recovery vision looks at the whole person from their own point of view. It focuses on people's strengths, hopes, wishes and achievements, as well as ways to manage difficulties.

'For some of us Recovery means learning to cope with our difficulties, gaining control over our lives, achieving our goals, developing our skills and fulfilling our dreams' (Ron Coleman, 1999, p. 103). Anthony (1993) described the following eight principles as important in understanding a recovery-based approach to serious mental health problems:

Some important points about recovery (adapted from Anthony, 1993):

1. Each person's recovery is different.
2. Recovery requires other people to believe in and stand by the person. Other people / opportunities play an important part in enabling the person to make this recovery journey.
3. Recovery does not mean cure. It does not mean the complete disappearance of difficulties.
4. Recovery can occur without professional help.
Service users hold the key to recovery.
5. Recovery is an ongoing process. During the recovery journey there will be growth and setbacks, times of change and times where little changes.
6. Recovery from the consequences of mental distress (stigma, unemployment, poor housing, loss of rights etc.) can sometimes be more difficult than recovery from the distress and confusion itself.
7. People who have or are recovering from confusion and distress have valuable knowledge about recovery and can help others who are recovering.
8. A Recovery vision does not require a particular view of mental health problems.

a) Recovering Social Identity

Initially when a person realizes that they have been identified as psychotic and are therefore different to others, a sense of loss of one's normality often follows. This can feel very threatening. Cast as psychotic one has entered a taboo identity in Western society, with connotations of being socially, morally and genetically inferior. A real sense of social failure and despair can set in. In addition one may feel disabled by the psychotic experiences themselves. At the time of hospitalization I found it useful to see myself as 'burnt out' - that I needed rest but that I could make a full recovery. However I knew that I could not go back and undo the fact that I had 'gone loopy'. It took me some time to come to terms with this. Consequently, there may be a period

of time when one has to mourn the loss of a former identity and reassess one's expectations and values (Ridgeway 2001). Many people going through this will value the information in the normalizing literature (Kingdon & Turkington, 1996). It is often useful to challenge traditional prejudices about psychotic experiences. For example, many people find it useful to see their experiences not as pathology but rather as a meaningful and adaptive response to adversity (Read & Harre, 2001). Some will benefit from reading accounts by people who value or have found meaning in their psychotic experiences (e.g. Barker, Campbell & Davidson, 1999; Read, 2001; Romme & Escher, 1993,).

b) Recovery and Narratives of Possibility

My recovery was about gaining other people's confidence in my abilities and potential. Behind that there was the physical recovery, which required rest, therapeutic activities and good food. However the toughest part was changing other peoples' expectations of what I could achieve. It involved seeking out contexts where my contribution was welcomed and valued. To approach new settings with confidence it was important for me to resist adopting an identity dominated by an illness model (see Deegan, 1996; Thornhill, Clare & May in press for other accounts). In another paper I have focused on how combating a 'mental illness'-saturated view of myself required access to some alternative positive stories about my identity (May, 2000). For example in planning my recovery I found it helpful to remember a teacher from my childhood who had said about me 'this boy will do well'. The literature on narrative approaches illustrates the benefits of creating spaces where people who have had psychotic experiences can explore enabling narratives about themselves and their lives (e.g. White, 1996; White, 1987; White & Epston, 1987).

c) Recovery Themes

From the studies that have looked at personal recovery accounts I will describe some recurrent themes (see Davidson and Strauss, 1992; Ridgeway, 2001; Young & Ensing, 1999):

1. *The importance of supportive others.*

A consistent theme in accounts of recovery is that there is always at least one person who has stood by that person, treated them with dignity and valued them. Having

people around you who give you space but who also believe in your abilities and potentials is a huge asset. We may be able to learn from stories of recovery in the disability movement where the importance of support networks or 'circles of friends' is described (e.g. Pearpoint, 1998). These structures both reduce the likelihood of burden on any one person and gives the individual a range of relationships within which one can enhance and rebuild one's confidence and social skills.

2. *Hope*

Hope is a key ingredient in successful recoveries. Traditionally this has been lacking in mental health services. Therefore stories of success are important ingredients in both information given to service users and training for mental health workers. From my own experience positive stories written by people who have made good recoveries would have been very hope-giving and inspirational. Therefore every Early Psychosis services should have a 'recovery library', containing positive media and personal accounts of experiencing psychosis and getting on with one's life. Involving mental health workers who have experienced psychosis in early intervention programmes is another excellent way to promote positive expectations of people's outcomes.

3. *A coherent account of experience*

Ridgeway's (2001) review of recovery accounts concluded that whilst denial may be an important initial coping strategy (Deegan, 1994), coming up with a way of understanding one's difficulties, is an important aspect of recovery. However Ridgeway (2001) observed that adopting an illness model is not necessary for recovery. Recovery does not require a singular view of psychosis. This fact challenges traditional approaches that assume there is a correct and insightful way to understand psychotic experience. Organized understandings of unusual experiences and mind states may be developed in diverse set of frameworks (Romme & Escher, 2000). For example, as alternatives or complements to medical or psychological frameworks many people find spiritual, paranormal and socio-political frameworks useful to make sense of their experiences. A coherent account may not see psychotic experiences as wholly negative, many people who function well socially, find their voice hearing or alternative beliefs informative and metaphorically meaningful.

4. *Spiritual beliefs*

Spiritual beliefs and activities are reported widely to be helpful in people's recovery stories (Young & Ensing, 1999). Mrs M. L. is a Rastafarian living in England who described the importance of faith in her recovery:

My problem was that I could not be myself living in a country that does not accept black people. But through the voices I found myself – my identity, which has everything to do with my racial history and my own past.... How have I come through my particular fire? Because I trusted completely in JAHOVIAH! All my thoughts are inside my head now. (Romme & Escher, 1993, p. 124).

Acknowledging the importance and validity of spiritual belief systems and activities, allows the person to maintain authorship of their life in the way that works most fruitfully for them. There is scope for good partnership work with local religious organizations, which have a different yet often valuable wisdom about healing and recovery processes.

5. *Building a Positive Personal and Social Identity*

This is about gaining access to conversations and activities that enable one to feel good about oneself. However this is not about promoting a relentless self-awareness. It includes having opportunities to carry out valued activities that contribute to and introduce one to the world of others so that one is less preoccupied with one's own inner world (Harrop & Trower, 2001). For example doing voluntary work and later paid work with adults with learning disabilities was significant in my own development of a more positive sense of identity. This was an activity that enabled me to be less preoccupied about my own deficiencies and inadequacies and instead focus on connecting to and assisting in others lives. Harrop and Trower (2001) also observed the dangers of psychological preoccupation with deficits of thought and behaviour. Thus services are likely to be more motivating and appealing if they have a solution focus, rather than a deficit focus, focusing on strengths, competencies, achievements and abilities (O'Hanlon & Rowan, 1998). Such psychological assets do not exist in a

social vacuum. For many people progressing in their social recovery may be about searching for contexts where their abilities and attitudes are noticed and appreciated. Voluntary and community-based projects are often of value here, with less of a clinical focus than health-based services. Therefore, Early Psychosis services that are not based in the voluntary sector would do well to make strong links with more community based organizations (e.g., colleges, community centres, voluntary organizations, employers etc.). 'Recovery groups' where members are encouraged to share stories and learn skills together (e.g., personal development, social awareness etc) and exchange self-help strategies, are effective at building morale and competency for many. A key principle in my work that I make explicit with members of Recovery groups is that everyone in the group has wisdom and expertise about their lives (see Dillon & May, 2002). How successfully services promote recovery for individuals will be determined by their ability to truly collaborate with this wisdom and expertise. Young people are more likely to engage in such Recovery groups if they are positive lively events that are relevant to their interests. I would suggest that the young people involved are invited from the start in planning of the aims, the content and the ground rules of such groups.

6. *Becoming Active; the individual moving to a position of taking responsibility for, and active involvement in his/her recovery.*

Traditionally mental health services have to some extent encouraged passive adjustment to an assumed 'illness'. The recovery literature suggests this is only likely to foster dependence and passivity. Rather, the challenge is to create environments that recruit the person as an active agent in their recovery. This is likely to evoke a more functional sense of self (Davidson & Strauss, 1992). Thus a recovery oriented service needs to offer accessible information and choices to the people they are working with; share decision-making; negotiate care; encourage the use of advance directives; support people to take informed risks. Ron Coleman, ex-psychiatric patient and mental health consultant, described how recovery requires one to invest in personal agency;

We must become confident in our own abilities to change our lives; we must give up being reliant on others doing everything for us. We need to start doing these things for ourselves. We must have the confidence to give up being ill so

that we can start being recovered(Coleman, 1999 p. 16).

Respectfully challenging a person who is showing signs of passivity to take greater responsibility is a very important skill in working with some young people with psychotic presentations. It is important to build strong rapport. Furthermore, this will require the worker to be very open about who they are, what their feelings are and what their role is, if they are to challenge the person they are working with. Challenging someone has to be done in a non-aggressive way emphasizing the long-term benefits of becoming more active and responsible as well as creating space to acknowledge difficult feelings involved in interpersonal interaction.

There are many reasons why a person will show signs of passivity.

Sedative effects of medication can encourage a lazy approach to life. Inner thoughts or internal dialogue may also be very seductive, avoiding the need for outside interaction. An outward appearance of disengagement with the world will act protectively against the possibility of social rejection and loneliness. Subjectively the person may feel some sense of power and security in their social silence.

People who exhibit passivity (often clinically described as negative symptoms) will benefit particularly from an approach that is assertive, creative and persistent. I recommend using a range of mediums to engage with the person and if possible engaging family members and or friends in this process. These can include: reading poetry, discussing topical ideas, story-telling, discussing and listening to music, going on countryside walks, outdoor activities and sport. One young man I worked with was willing to engage with me once I had asked him if he felt more powerful since he talked less. He nodded that this was the case. Our recovery work together then consisted of thinking about how he could interact with the world more without losing that sense of power and control he got from his socially withdrawn state. As I have indicated a range of physical and creative activities may help facilitate the person to recover a more active role in their lives, but as ever these always need to be carefully negotiated with the person themselves. Retrospectively one man has described to me how he understood his passive state as a state of shock about traumatic life events. Interestingly he described how he was always listening to what was being said to him,

despite his comatose presentation. Traditionally many clients who present in such withdrawn states have been over-medicated and this may often exacerbate the problem of relating to the world.

d) Emotional Recovery

Traditionally, professionals' approach to psychosis has prioritized thought disorder over the emotional content of psychotic experiences. Whilst it has been assumed some empathic work takes place, this has not been emphasized sufficiently. I would like to suggest that emotional work is crucial to consider in addressing psychotic problems. Firstly for many it is about emotionally validating clients' experiences. This is equally important in relation to psychotic experiences themselves, the experiences of receiving mental health services, and the social consequences of these experiences. For example, giving clients space to express their angry feelings about prejudice they have experienced has in my experience often been a valuable part of building a good relationship with them.

Evidence suggests that persecutory delusions act in an emotionally protective manner to protect a low self-esteem (Bentall et. al., 1994; Lyon et al., 1994). In my experience if you can help clients build up their sense of personal resilience and social value, the influence of persecutory ideas can be greatly reduced. A persecutory idea, though distressing will also make one feel important and responses help structure one's daily routine. In other words these beliefs provide one with a sense of meaning and purpose. If, as therapists, we want people to give up such ideas they will need to be replaced by beliefs that provide people with increased meaning and purpose.

Cognitive belief modification techniques for paranoid beliefs that teach people to think more rationally using guided discovery techniques are in danger of being over-valued in psychological approaches. Cognitive work which endeavors to shift persecutory beliefs, risks undermining the emotionally protective function provided by the persecutory belief. Such interventions are in danger of firstly alienating the client from the therapist and secondly increasing their vulnerability to a depressive state. The solution is to give people the choice about the best way to proceed. For example, whether they should explore the reality of their beliefs or pursue ways to live with the

paranoid ideas. In my experience clients are very able, given informed choices, to make good decisions about the course of their recovery work.

Drayton, Birchwood and Trower (1998) carried out a study that looked at the relationship between co-morbid depression and recovery coping styles for people with psychosis. Depression was found to be related to more frequent psychotic relapses and poorer social functioning. This was also related to perceptions of poorer parenting in childhood. It is therefore of key importance to address these emotional aspects of the lives of people with psychotic experiences. This can include self-esteem work for some. Others will benefit from counseling that addresses significant past emotional experiences. For example, one client I worked with, was preoccupied with disturbing ideas about being related to a mass murderer. After engaging in a course of supportive counseling relating to the loss of a child who had been taken from her by social services, she became far less preoccupied with and bothered by her disturbing ideas. The traditional emphasis in clinical work on prioritizing thought disorder for intervention, needs to be replaced by a paradigm which acknowledges the emotional and psychological functions of psychotic experience.

e) Psychosis as a Post-Traumatic Reaction

Romme and Escher (2000) described how for voice hearers the emotional processes recognised as important to recovery from trauma are extremely relevant. Romme and Escher's work suggested that many psychotic experiences are linked to earlier experiences of trauma. Many studies have found a high correlation between psychotic experience and past experiences of adversity and trauma (e.g., Greenfield et al. 1994; Mueser et al., 1998; Ross et. al., 1994). Many personal recovery accounts report finding emotional explanations useful in making sense of their experiences. Jasna Russo (2001) describes her journey into madness as one of protest against her past experiences of oppression and abuse:

I was meant to be a manufactory of pleasure – you touch me and I enjoy.... I was meant to belong to one man and feel secure with him, because he was my father.... Madness was about all the suppressed feelings and fears and disgust coming out at the same time...Being crazy was also about wanting everything

at the same time and having to have it immediately. I can't say I miss that intensity, but it gave me the feeling that change is possible. I discovered how much I wanted to want and that my life could change into something I wanted...I'm glad I didn't remain the one who was able to stand it all, the one behind the walls of an impermeable world all on my own, all unhappy(Russo, 2002, pp. 38-39).

An advantage of the post-traumatic explanation of psychosis is that it gives the psychotic process a functional role. Rather than being just an affliction, such psychological processes as splitting off from experience and dissociation, can be seen as adaptive strategies that have enabled the person to survive adversity (Warner, 2000). For many this is a more coherent and enabling story than the bio-medical narrative about psychosis. Therefore it is worth reflecting on the circumstances which aid recovery from trauma. Lewis Herman's (1998) work focusing on recovery by traumatized war veterans and sexual abuse survivors, described the value of the following four stages in healing processes:

1. A healing Relationship.
2. Safety.
3. Remembrance and mourning.
4. Reconnection.

It is important to note that many people may not be prepared to explore past distressing events. Making sense of past emotional experiences is therefore only relevant for some. For others, psychological or group work might be about focussing on resources, coping strategies and meaningful activities. My work with people suggests that clients have a wisdom and expertise about what line of inquiry might be most helpful to them at what time, therefore the important principle is to offer people choices about directions of therapy and recovery work. In my experience clients once they feel safe and trust the therapist or group they are attending are able to make good decisions about the course of their recovery work.

f) Living and Coping with Alternative Beliefs

Kaffman (1981) in a study of 34 families where there was a 'paranoid patient' found that firstly, there was always an element of truth and reality underlying persecutory belief systems and secondly, that past and present relationships played an important role in generating and activating the beliefs. Exploring the meaningfulness of people's persecutory beliefs and their relevance to their social lives and past experiences is often an extremely helpful and validating process. Persecutory beliefs that appear delusional to professionals often have significant metaphorical and affective value for the person. Thus they may represent real experiences of persecution and powerlessness. As an alternative to the conventional view of paranoid belief systems as pathological cognitive states, in applying a developmental perspective, persecutory ideas can be seen as understandable responses to past threatening experiences. Persecutory frameworks can be adaptive in eliciting safety behaviors in times of emotional adversity.

Rather than challenging the rationality of their alternative beliefs, many people find it useful in their recovery work to accept the possibility that their unusual beliefs are correct and develop appropriate coping strategies that enable them to improve their social functioning and sense of wellbeing. An example from my own work is Ben who in a Recovery group brought the problem that he was being persecuted by the local bus drivers shouting abuse at him as they drove past his home. Some group members felt that he might be paranoid, whilst others looked at how he was coping with the experience. Ben was asked 'it seems there are two ways forward with this problem, you can check out the reality of the experience to see if you are correct or not, or you can accept from your point of view the reality of the experience and focus on ways to not let these experiences stop you from getting on with your life in the way you want to.' Ben chose the latter solution; he was much keener to build up his self-esteem and coping abilities than focus on whether or not he was making perceptual errors.

A psychologist, Tamasin Knight (2002) described the personal benefits of working within the reality of unusual belief systems: At 16 years old, I became convinced that many things, including food packaging and my hands, were infected with a fatal disease. A couple of years later I became convinced that

the water supply had been contaminated so was refusing to drink. Resulting from the first of these experiences I was referred to clinical psychology...my beliefs were very strong so cognitive approaches were unable to shift them. On both the above occasions hospital admission was seriously considered and perhaps it was the fear of this that motivated me to try and find effective ways of helping myself. By this method I accepted my beliefs, and eventually found ways of overcoming or getting round them – by saying to myself statements such as ‘yes, my hands are infected with disease so I must find ways of eating without touching the food with my hands, if the food packaging is contaminated, can I find ways of decontaminating the packaging?’ and ‘OK, the water supply is contaminated so I’ll only drink imported water’(Knight,2002, pp. 4).

Knight’s own success using such techniques allowed her to avoid psychiatric admission and go on to higher education. At the time of writing, Knight is in the process of carrying out a piece of national research looking at service-users’ coping strategies within alternative belief systems. The literature on coping strategy enhancement is also relevant to this approach (Yusupoff & Tarrier, 1996).

Therefore, it should not be automatically assumed that persecutory beliefs themselves are the primary problem, as they might be part of the solution. Rather it is the person’s relationship with the persecutory idea that should be focused on. If individuals can find ways to cope within belief systems this may be part an important way to take back more control over their lives and decrease their sense of powerlessness. The following questions may be useful to consider:

- 1) How can we as helpers support someone to decrease the disempowering nature of disturbing ideas in a way that is most helpful to them?
- 2) How can the person relate to such ideas in a way where they are able to feel safer and negotiate wider social realities?

Whilst rationalizing techniques may help some people I suggest that it is important to present the person with a range of options in how best to psychologically manage their relationship with alternative belief systems and ideas. What is clear is that people require safe places to make sense of socially taboo experiences and ideas, in the context of their wider social experiences.

3. Medication

The psychological effects of neuroleptic drugs are important to consider in any psychological approach with people being treated for early psychosis. Though these drugs are often described as antipsychotic, neuroleptic (meaning 'nerve seizing') may be a more accurate description of their action. What is the experience of taking neuroleptic drugs like? David Healy (1997) in his book 'Psychiatric Drugs explained' described how in the 1950's the original understanding of how neuroleptics worked concluded that they produced a feeling of detachment - of not being bothered by what had previously been bothering. This description very much fits with my own experience of neuroleptics. Unfortunately this 'feeling of detachment' not only applied to my disturbing ideas but also to recovery processes such as creative thinking, problem solving and motivation to pursue purposeful activities. There is a danger that if anti-psychotic medication is used in a long-term fashion, its dissociative effects may suspend individuals' abilities to recover complex psycho-social abilities.

It was very difficult for me as an 18-year old man to do all the learning one needs to do about social skills, emotions, about career skills and about ones sense of identity and drive, on medium doses of neuroleptics. Six months after my third psychiatric admission I was at Art College trying to not let hand tremors effect my painting, always feeling half a second out of time with the other students. People observed how when I came off medication, how much more in touch with myself I seemed, both emotionally and intellectually. I was suddenly able to express more complex thought processes again. My decision to cease taking medication received no support from the psychiatrists. My actions were seen as non-compliance and no supportive services were offered to me. I was left to cope with the withdrawal effects alone. This was risky - the first two attempts to withdraw resulted in re-admissions, which were at least partly contributed to by mania-like withdrawal effects. Withdrawal syndromes often produce psychotic experiences and are often mistakenly assumed to be the 'illness' returning (Thomas, 1997; Warner, 1997). This misattribution can increase helplessness in the person concerned.

If people choose to move beyond maintenance medication as part of their recovery from psychosis, it is important to provide them with specialist support. For example, this could include:

- How best to gradually reduce doses. Research suggests that gradually titrated withdrawal produces the most successful outcomes (Breggin, 1999).
- Education about what withdrawal effects to look out for.
- Education about how these effects are caused.
- Strategies to deal with withdrawal states (e.g., temporarily increasing the reduced dose, temporary doses of benzodiazepines or other short-term medication, relaxation techniques, alternative therapies).

At present this type of support rarely occurs making successful withdrawal less likely and recurrences more traumatic. Whilst the current trend in treatment approaches is towards the use of low-dose 'atypical anti-psychotics, these drugs are not without their problems. They can lead to significant weight gain, which can undermine morale and reduce confidence levels, as body-image is important source of self-esteem for most people. Emotional and generalized cognitive blunting, increased sleep and lethargy are common. The widespread long-term 'maintenance' approach to the use of these drugs is concerning. The risks of disability caused by medication need to be considered and compared to the risk of increased level of psychotic experiences. Each person will have to make informed decisions about what suits them best in the management of their recovery. For example, in my own case, I may experience more unusual ideas than if I were taking neuroleptic medication but I have learned ways to incorporate them into my life so that they are life enhancing. If I took a maintenance dose of medication my overall level of motivation and cognitive abilities would be reduced so that I would be unable to function socially and professionally at the level I currently do.

It is important to shift the ideology of services so that psychopharmacology is seen as just one of the tools people can use to recover from early psychosis. In Finland, psychosis services operate according to psychotherapeutic principles. Alanen (1997) described the 'needs-adapted treatment' approach where medication is seen as an adjunct. Medication treatment strategies are seen as time limited and are constantly reviewed as part of a broader approach to recovery. People in early psychosis

programmes can make very good long-term recoveries from early psychosis with no or minimal neuroleptic treatment (Martenson, 1998; Mosher & Conti, 1994; Warner, 1995). The therapeutic superiority of drug-based treatment regimes has been questioned when compared with long-term drug successfully services promote free therapeutic programmes. Examples of the latter include The Soteria project in San Francisco and the Sater project in Sweden which both demonstrated superior long-term outcomes compared to control groups given standard treatment (Martenson, 1998; Mosher & Conti, 1994). In the first 2-3 years the drug-free patients required more care and services but after this time period they showed significantly better outcomes on both clinical and social measures of performance. Warner (1997) presented a detailed review of drug-free approaches and suggested that adults with well-developed social networks prior to psychotic episodes fare better without any neuroleptic treatment, whatsoever. Despite the evidence western state-funded services rarely offer drug-free therapeutic services. Unfortunately drug companies sponsor many psychosis training events and appear to have a vested interest in promoting a biomedical understanding of psychosis and maintenance style medication regimes. Hopefully in the future we will move to a more collaborative approach to drug management, which uses anti-psychotic medication in a less pervasive, more flexible style.

An important part of the engagement process should be in involving the client in a 'partnership manner' in making informed decisions about prescribing strategies. Healy (1997) produced a study showing that people with psychosis could be trained to 'cleverly self prescribe' their medication, which included stopping it completely and using increases according to stress levels. The people who were self managing their medication achieved more socially without clinical deterioration in comparison to their controls, who were on maintenance drug regimes. Clearly a collaborative approach to prescribing where one can make informed decisions about how best to use medication or not, to get on with life is the way forward.

4. Working with the whole person

Valuing the person's subjective perspective and wisdom

A recovery oriented approach suggests a move away from observing the person's behaviour and trying to interpret it in terms of clinical models to an approach that starts from valuing and respectfully understanding the person's experiences from their perspective. This is about a whole person approach, working on the problems that the client presents in the way they want to work with them.

Adopting a whole person approach means that a consideration of the person's present difficulties with psychotic experiences, needs to be balanced with an appreciation of important non-clinical aspects of personhood. These include a consideration of the person's developmental life experiences, their achievements, their abilities and potentials. Social references of personhood also need consideration. For example, the gender, family, peer, aesthetic and cultural contexts that the person defines themselves within.

Culture and a whole person approach

It is important to consider the impact of different cultural expectations on how clients might want to respond to their difficulties. For example as a young western man it was very important for me to demonstrate autonomy and preserve my newly acquired physical attributes. It meant that I experienced the psychiatric treatment I received as emasculating as it made me physically weaker, sexually impotent and encouraged a dependent relationship with psychiatry.

Veronica Dewan described how a cultural understanding demystified what had been seen as a problem only medicine would solve:

During my first admission to a psychiatric ward in 1990, I resisted all three White English male psychiatrists who told me that drugs were the only treatment that would help me. The fourth psychiatrist had an Indian partner and children of dual heritage. Within minutes of meeting me she asked if I had ever been offered psychotherapy...I now have a psychotherapist who is a black woman of African Caribbean and English heritage. She works in a way that

takes account of the whole of me. She understands the damage caused by racism, and how the process of assimilation has profoundly and painfully distorted my identity and truth. She gives me hope that my identity can have its own meaning. My psychotherapist is now the only mental health professional involved in my care (Dewan, 2000 pp.46).

Thus to relate to the person we really need to be creative in how we move beyond the illusory focus of the 'clinical gaze'.

Conclusion

Psychosis is not just an individual problem. My own 'madness' was about disconnecting from a world I struggled to identify with. Therefore in my work with people I am keen to consider how can we make the world around them one that is worth connecting to and negotiating with.

Traditionally the problem with being seen to be psychotic is that one is isolated with this experience, set aside as fundamentally different and inferior. The way to combat this isolation is to create safe spaces where unusual experiences can be shared and made sense of. As soon as we start to share commonalities the power of the isolation of the experience is broken down. Meaningful accounts of psychosis that allow us to connect with others and make choices about our lives are essential to any recovery process. In sharing unusual experiences and different ways of making sense of them we are no longer mad. The experience that is identified as psychotic can be incorporated into social identity, using a range of explanatory frameworks, including emotional, spiritual and psycho-social paradigms. Therefore being prepared to think flexibly about our approach to people with psychotic experiences on an on-going basis is an important part of developing recovery-oriented services. Services for psychosis have traditionally employed overly medicalized and didactic treatment approaches. Creating a more enabling approach involves recruiting the expertise of personal experience into therapeutic services. Recovery stories are an important source of hope and motivation for people with psychotic experiences. Recovery accounts demonstrate that people benefit from being able to make sense of their psychotic

experience in the context of their past and present social experiences, in the way that feels most comfortable to them. Making sense of psychosis and engaging in meaningful activities also requires reliable and enabling community networks. Truly helpful services enable people to take an active role in their recovery. Such services are likely to be those which avoid imposing clinical labels and definitions, stress the possibilities for recovery, adopt a collaborative approach to decisions about therapies and relate to the person rather than the 'symptoms'.

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