

The relationship between ideas of reference and unusual beliefs;
a personal reflection by Rufus May
(paper given in Maastricht in May 2005)

Marius has asked me to talk about the relationship between my different psychotic experiences, when I was a young man. When I was eighteen I was treated as an inpatient in East London for my unusual beliefs and bizarre behaviour. I was diagnosed with Hebephrenic Schizophrenia. After 14 months of treatment I stopped taking the neuroleptic drugs (against medical advice) and found other ways to cope with my experiences, recover and get on with my life. I used drama, dance, art and part-time employment as well as the support of a close friend to recover. After a number of different jobs I eventually studied psychology and trained as a clinical psychologist, gaining my doctorate six years ago. I now work as a clinical psychologist with people with severe mental health problems in both hospital and community settings.

As well as being a clinician I train mental health professionals on ways to work with voice hearing. During the training we use a hearing voices exercise developed by Ron Coleman where one person whispers in the other person's ear while they try to have a conversation with someone else. We then ask the people who did this exercise to say how they might respond to this experience if it was happening frequently. People describe how they might feel anxious, paranoid, agitated, like they are being watched, they might avoid others, or they might get angry. Many of these thinking styles and behaviours are assumed to be symptoms of mental illness yet this exercise suggests that many psychotic symptoms may be normal ways of responding to abnormal experiences.

I will now look at how a similar relationship might exist between other apparent psychotic symptoms.

Ideas of Reference and their relationship to delusions

Ideas of reference refer to the experience of taking general information in the environment and interpreting it as a personally significant direct communication. For example if I am doing a presentation and I am nervous and I am using someone else's computer and the computer says to me 'your batteries are now fully recharged' I can choose to interpret this as a message to me personally, rather than just an automatic general communication. This may help me feel more confident. This is an example of an idea of reference. Most people will experience ideas of reference in moderation, for example thinking your name was called when it was not, or hearing a love song that feels personally significant during a period of falling in love. If a bus arrives just when we need it we may feel destiny is smiling on us. Also many of us will have had the realisation that we have incorporated real sounds from the environment into the content of our dreams. For example a car alarm could be interpreted in a dream as an air raid warning. I know that many people who are practicing Christians find messages when they look randomly at religious texts and assume this to be spiritual guidance, a message from God. Tarot readings and the I Ching are other more structured practices that encourage the possibility that our environment can contain special personalised messages that if listened to will aid our personal life journey.

I have thought about how when I was eighteen my ideas of reference might be related to the unusual beliefs I developed that clinically were seen as delusions and symptoms of schizophrenia. The following account shows the interrelationship between ideas of reference and delusions/unusual beliefs I had after a few years of emotional problems in my teenage years. I have divided my history into stages to show how one psychological development was linked to another more clearly.

At the age of eighteen I found myself in a boring job as an office junior. I was anxious about my future, I had failed in my education and I had failed to get into the advertising business. On top of this emotionally I was struggling to adjust to the fact my first girlfriend who I had been with for a year had left me. This left a big hole in my life. In hindsight this emotional loss echoed an earlier experience of abandonment I had when I was eleven years old. Also socially I felt left out in the cold. My ex-girlfriend and all her friends were planning to go to University, while I seemed to have chosen a very boring career as a trainee draughtsman.

Stage 1. Communicating with God via Bible

Feeling a sense of emptiness and loss I began searching for meaning in my life. I started this process by experimenting with praying and then opening the Bible randomly to see if I could receive messages from God. This was fruitful.

Stage 2. Communicating with God via Advertising Billboards

I had also heard about people receiving answers to prayers in other ways for example via bill board posters. For example on one occasion I was praying for guidance about whether or not I should stick with my boring job I then saw the advertising slogan saying 'Don't miss it' which made me think there might be a hidden opportunity at my apparently boring work-place. Because I began to get messages in this way I started to feel special, chosen even.

Stage 3. Search for a theory to explain my special mission

If I was chosen I wondered what my mission might be. My work started to send me on delivery journeys from London to Manchester. When I lost my ticket at the station I then had to avoid the ticket collector for the 200 mile journey. I explored the idea I might be a trainee spy that my ticket had been pick pocketed to test my ability to deliver a parcel in difficult conditions.

Stage 4. Looking for communication from spy agency on radio

Nobody had openly contacted me to tell me I was a spy so I assumed that it was my job to uncover clues to tell me more about my new identity as a trainee spy. If I could find clues I could be more sure about my new identity. I therefore looked for special messages for me on the radio (as I had seen spies do in films). A famous quote from the bible says 'seek and thou shalt find' and by tuning the radio I found strange warnings telling me to "watch out" and "be careful".

Stage 5. Conspiratorial theories to explain radio communications

The relevance of the messages I picked up on the radio to my situation made me suspect my home must be bugged. Otherwise how would the people sending me messages know of my whereabouts? I asked my neighbours who were more technically knowledgeable to help me check the radio for bugs. When they could not find anything, this evidence along with their smug attitudes made me think they must be spies too.

Stage 6. Collection of more evidence to support my espionage theories

I looked for more evidence to support my theory that my work was a front for a spy agency and when I discovered my predecessor (as office junior) had had an alleged motorcycle accident and would not be returning I felt this was evidence to support my theory. He must have been unable to carry out a dangerous mission and had been hurt in the process, I thought. One of the other staff had heart problems. I assumed this was an understandable response to the stress of being a spy.

I started to sleep less as I was extremely excited about this new world I was uncovering and I found it difficult to sleep with the knowledge I was under some sort of surveillance. I am sure (from my clinical work experience) that it is a lot easier for many people to experience ideas of reference when they are sleep deprived; Without regular and sufficient sleep one is in a different mind state that is closer to dreaming, where the mind is more susceptible to selecting personally significant information from the environment. I therefore feel that due to this sleep deprived state my mind became more tuned into interpreting information in this 'ideas of reference' style.

Stage 7. Intensification of ideas of reference due to sleep deprivation and consolidation of espionage/conspiracy beliefs

Turning on the television I found that the characters seemed to be referring to my thoughts this was disturbing how could they read my thoughts? I assumed there must be a camera inside the television this would explain how characters in television programmes could deviate from their script and refer to my situation. This is another example of how the experience of ideas of reference - a dialogue from the television being experienced as referring to one's own thoughts -can then lead to the person developing a theory about this experience. This theory for example that cameras are watching the person clinically is seen as a paranoid delusion a primary symptom of Schizophrenia when in actual fact it is a rational attempt to make sense of a strange experience.

Many of my ideas about the espionage world I was assuming I was involved in developed from my experiences of ideas of reference as I have explained, they were also influenced by spy and science fiction stories I had read when I was younger. For example I felt safer when I walked the streets with my dog so I then assumed he might be a robotic dog with cameras for eyes, in the book *Bladerunner*, most animals are robotic automatons. When I visited my Uncle's house he had a picture of animals cleaning Noah's ark this seemed to be a tacit acknowledgment of my belief that domestic animals were intelligent robotic accomplices pretending to be dumb pets.

One person I have met described how he assumed his neighbour who lived above him must be spying on him after he found the television and radio started speaking to his thoughts and situation. He approached his neighbour to challenge him about this and was only satisfied when he saw the inside of his neighbour's flat. This is another example of how delusions can be understood as logical attempts to make sense of the illogical experience of finding messages referring to your thoughts in the environment.

Voice hearing can also have a similar effect on the formation of conspiratorial beliefs. A young man I am currently working with talks about how the voices he heard seemed to be coming from the walls so he assumed they were coming from wires in his flat which he consequently set about dis-mantling. It would be a mistake to assume his paranoid thoughts/delusions are a primary symptom of schizophrenia when they are actually an attempt to rationally explain the bizarre experience of his voice hearing.

It seems to be enormously beneficial for people who are experiencing ideas of reference or voice hearing to be able to hear other people talk about similar experiences, so therefore I try and create this opportunity in the group work I do in in-patient psychiatric hospital. If people can explain how their delusions are a logical attempt to make sense of a bizarre experience this can help them demystify their 'psychotic' experience and help increase understanding both in themselves and in the people trying to help them and care for them.

I will return to my own experiences. I found that the content of radio and television broadcasts had a relevance to my own personal situation. For example there was a drama about a Native American who was being warned he needed to hide as he was in grave danger of being found out, by a hostile tribe. I found this very frightening, firstly because I interpreted as a personal message from my spy superiors that I was in danger of being targeted by a rival espionage force (probably Russian communist). Secondly because it led me to assume there were sophisticated gadgetry that was able to monitor my movements and respond very quickly using the media of radio and television. For example I have already explained that I had assumed there must be a camera watching me in the television set.

When I began to get chest pains (which I now think were stress induced) I then decided that perhaps a control device had been inserted into my chest and that at the touch of a button I could be shocked or if necessary terminated by enemy spy agents.

Because of my chest pains I was taken to see my GP when I told her of my explanation for my chest pains, she said you need to see a specialist. I thought she meant a chest specialist. She did not. During the two mental state examinations I then was interviewed by Doctors who dispassionately listened to my explanations, without entering into dialogue or empathising with me. This form of interview was very unnerving and I began to speak more hesitantly and reluctantly. I know from the notes that this was judged to be poverty of speech. In this way problems of communication can be mistaken for the psychotic symptom poverty of speech. My ideas of reference were not discussed with me by the nurses nor were the conspiratorial beliefs. This re-inforced their value, as they were left unchallenged I assumed my beliefs must be true. But it also meant I learned to keep quiet about them, to bury them.

Social influences on my clinical presentation

I was in shock in my first admission. I found the environment very unstimulating and the neuroleptic medication very powerful in its ability to weaken my mind and body. I felt intense agitation when I was taking one particular neuroleptic; whilst I appeared very calm on the out-side, inside I felt like jumping out of my skin and if I had not had been able to negotiate a change of medication I may have tried to end my life. I have met many people being prescribed neuroleptics who do not realise such feelings of agitation are side effects of neuroleptics and assume it is part of their illness, many people suffer in silence and like me there is a strong risk of them acting suicidally because of these effects.

I think similar problems exist with the simple idea that negative presentations are negative symptoms of Schizophrenia. I can relate to the way many people being treated for psychosis withdraw socially and emotionally from connecting with the world around them. When I was in hospital important friends did not visit me making me feel ostracised. I felt alienated and socially devalued. This made me feel demoralised. Also being highly sedated on neuroleptic medication meant I would sleep 14 hours a day. I found myself in a state of mind where I could not concentrate properly. This was due to the mind blocking effect of the medication, and partly due to not being able to see any meaning in my life. Therefore there were times when as soon as I had woken up I would look forward to going back to bed again. I spent many weeks like this. Were it not for some unusual opportunities that eventually became available to me I could quite easily have got into a long term pattern of staying in bed and doing very little apart from smoking cigarettes eating and sleeping.

Therefore in my own work where people are seen as having 'negative symptoms' I am keen to explore the possible relation both to medication and to feelings of demoralisation. I have also discovered that other people with negative presentations have withdrawn their attention from the world in order to cope better with their voice hearing experiences. I think it is therefore unhelpful to assume passivity is a primary negative symptom of Schizophrenia. Rather I find it more useful to look at the history of this pattern of behaviour and the possible relationship with feelings of demoralisation, medication and as away of coping with internal experiences. I think it is important to assume so-called 'negative symptoms' are meaningful and responsive behaviours rather than arbitrary products of a disease process.

If I had accepted the diagnosis of Schizophrenia with the prediction I would always need to take medication I would have given up my sense of hope for a better future. I decided to not accept this diagnosis and prognosis. For a long time my family and I were divided on this matter and they saw me as lacking insight into the knowledge of the doctors and the benefits of medication. Clinicians also saw me as lacking insight. It was only after many years of my recovery journey without medication that they accept now some of the problems with the schizophrenia diagnosis and the limitations of neuroleptic medication. In my work I am therefore keen to help families and individuals move away from a diagnostic categorical approach to one which looks at the range of experiences the person is having and their possible relationships (with each other and the social environment).

During the second admission I became more aware that some of my fellow patients were potentially violent. I was the youngest person in the hospital and one of the skinniest. I developed a manic sounding laugh that I copied from two other dangerous appearing patients. I also developed a way of staring with bulbous glaring eyes. I found these techniques were quite an effective in making me feel safe in an unsafe environment. However I know they were seen as symptoms of my illness by clinicians in charge of my care. This is an example of how a learned behaviour that is adaptive can be mistaken for signs of the psychiatric symptoms of mood disorder and inappropriate affect.

My third admission happened when I came off medication in an unsupported way I experienced sleep deprivation and became more restless, impulsive and manic in my behaviour. My admission was seen as a relapse of Hebephrenic schizophrenic illness however I have always believed my hypo-manic presentation was at least in part caused by neuroleptic withdrawal effects.

My life's direction definitely began to change when a close friend of mine came back to London from travelling and started visiting me almost daily. Around this time I also saw a majestic sky that seemed like an omen of hope. I say this to illustrate that ideas of reference can also be helpful in building faith in a better future. But my friend standing by me and having faith in me was most important; it made me feel recognised and validated I began to struggle to rebuild my life. Focussing on activities that gave me a sense of self worth meant that the ideas of reference became less important in defining the meaning and value of my life.

A few words about my social economic background

My ability to challenge the way I was treated and seek alternatives were partly based on a privileged background. For example, being from a middleclass background I think it was easier for me to attempt to negotiate around my medication than some of my less well educated fellow patients. Also it meant that Doctors listened to my parents who knowing I hated hospital admission always argued for short admissions. This was despite the clinical preference recorded in my notes to use longer admissions.

Psychosis as a spiritual experience

My experience of being hospitalised and medicated against my will, being categorised as Schizophrenic and being socially seen as mentally ill, a moral failure, was a sobering experience. At the same time spiritually I felt although my experiences had made me act in a confused way, they had shown me there is more than one way to experience reality. This gave me hope that given the right opportunities I could find new ways to live in what had often seemed in my teenage years as a depressing world. I decided that in order to escape being locked up again psychiatrically, in the future I must offer something back to society and the cosmos, a kind of moral trade off. It was not long before I felt a calling to get involved in care work. I use this example to again show that ideas that may seem irrational can also be helpful if you can find a good way to relate to them.

Final words

A number of self help groups are now developing in the United Kingdom to help people talk about and relate to ideas of reference and unusual belief systems. Writing this piece has made me more aware of the need for self help material relating to ideas of reference. Firstly this could be very useful for people who are having these experiences to know they are not alone in having this experience which is not often talked about, yet like voice hearing is fairly common for both psychiatric service users and the general public. Secondly it would be useful for people to share coping strategies. Thirdly seeing that there are different ways to understand these experiences, would help many people make sense of their 'ideas of reference' experiences in less persecutory and frightening ways. To conclude I think that if we can develop a meaningful language about the experience of ideas of reference this will play an important role in developing the emancipatory approach to psychotic experience.