

Living with psychosis

A report on research
involving service users
with a foreword by Will Self

Researching Psychosis Together

November 2012

Brunel
UNIVERSITY
L O N D O N

This research was undertaken by Researching Psychosis Together, a collaborative research group based at Brunel University, Uxbridge, London, UK. The members of the group are mental health service users and occupational therapy academics, practitioners and students.

The group members who designed and implemented this research are:

John, Lucia, Christine, Adrian, Judith, Jackie, Lana and Wendy.

The group would particularly like to thank those who got involved in the research and all our supporters, who are listed at the end of this report. Thanks and best wishes to Lana Makdisi who worked with us for her MSc Occupational Therapy research.

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Foreword

Psychosis is probably the most frightening thing that can happen to us: a complete betrayal of the mind, by the mind. So comprehensively undermining of any certainties that we may attach to the world and its interpretation is this malady, that it is unsurprising that over the centuries different cultures have come up with both explanations of, and therapies for psychosis that are wildly divergent. The voices of God or gods; the speech of the ancestors or their totemic representatives - we may now regard these characterisations of psychosis in societies separated from our own in time and place nowadays as being in themselves culturally determined, but in fact we indulge in such deterministic formulations when it comes to both diagnosing and treating psychoses in our own society. Against the plethora of theoretical models - neurochemical, experiential, psychodynamic, psycho-social, cultural - what is required is not a panacea nor a catholicon, but an understanding of what in its most basic sense is workable: what makes people suffering from psychoses feel, quite simply, better. I commend this careful and unostentatious study to you as several steps in this right-minded direction.

Professor Will Self, Brunel University

Short summary of the report

The experiences of people living with psychosis are an important source of knowledge that was explored by the Researching Psychosis Together group, based at Brunel University. Starting from their own personal experiences, the group designed this research to find out what is helpful and demystify psychosis. Two focus groups were held, involving 15 people who discussed what it is like to experience psychosis. They talked about what to do, the importance of talking to others and not avoiding problems. Many people agreed that finding ongoing skilled help was important, to feel safe and more receptive when unwell. The findings suggest that services should give priority to understanding individual experiences of psychosis, so support can be more effective and focused on practical problems in life. Doing this research as a group had benefits for everyone involved: details of how to be involved in the next stage of the Researching Psychosis Together group's work are provided on page 22.

Why we did this research

Experiences of psychosis vary from person to person but it is possible to find common ground. Psychosis can give people different experiences of reality, which are questioned by others. It is not easy for people to speak about psychosis. Their experiences might not be believable, or thought strange, or ignored altogether.

Yet the experience of psychosis is much more than what goes on in people's heads. Living with a serious and often long-term mental health problem affects every aspect of life, including using mental health services.

The Researching Psychosis Together researchers believed that mental health services can be improved if experiences of service users are taken seriously. When this project was initiated in 2007, most information about psychosis was written by academics and professionals. The voices of service users were not obviously included in self-help guides. They were absent altogether from articles in professional journals. So this research was designed with particular aims in mind.



What we aimed to do

To find out what helps people living with psychosis so that those in helping roles can be more informed about what they can do. Those experiencing psychosis could be reassured that they are not alone in what they feel and need.

To demystify psychosis as many people struggle to understand what it is like to experience psychosis, and don't know what is helpful, especially as it can have such devastating impacts on people's lives.

To do the research as group, so that the research process was influenced by people working together, rather than just one person's agenda. Working together as service users, students and occupational therapists has brought different voices to the process and interpretation of the findings.

To gain support for the research from Brunel University and other external bodies, to confirm that our research is taken seriously.

How we did the research

Research has different phases, developing ideas into a practical plan for action. We started our discussions in 2007, and by 2009 we had a design which we took to university and NHS committees for approval. At last in 2010 we were able to do the research with local people, and since then we have been analysing the findings and sharing them with others.

One of the first decisions we made was to concentrate on people's experiences, which meant that we would be working with words rather than numbers. This is known as qualitative research. What people say about their lives is thought to be very important and often this is captured in interviews. We decided to bring people together in groups, as it can be easier to think of what to say when you're with other people with similar experiences. We also offered people the option of writing about living with psychosis.

When it was all approved and we had some funds, we told as many people as we could about the research. We had a launch event, with lunch provided, which was attended by 15

people. The next week we held two focus group meetings, which were attended by 13 people, 8 in one group and 5 in the next.

We worked together, as service users and mental health professionals, at every stage. The focus groups were led by service users and our occupational therapy student at the time, Lana. She recorded the discussions, wrote them down word-for-word and then carefully analysed what people said. Her findings are written up in an MSc dissertation which is available on request.

Lana found out important things about how people live with psychosis and we have included some of her findings here. We discussed her ideas and developed them for this report.



What we found out

The people in the focus groups shared their experiences, thoughts and ideas with each other. For this report we have organized them into three main themes:

1. What it is like to experience psychosis
2. What to do and what not to do
3. Other people

What it's like to experience psychosis


It is difficult for anyone to know what is happening with psychosis:

"Nobody knew what was going on, I just had bizarre behaviour and saying bizarre things"

"I was experiencing the symptoms, so frightened ... I would've liked someone to talk me through it and say this is what is really happening."

"when you're going through that [psychosis] you think that's what the reality is, so your perception is not accurate ... the communication line gets dead."

"people are saying it's not real but when you are in that situation it is very real. The whole thing is so real"



"I had an episode and I was in the ocean all night swimming ... they're so up with worry that they lose reality of what's really happening to you ... it must frighten the family as well"

It is important to find treatment that works:

"I'm on [name of medication] which has helped a lot so I haven't experienced any episodes lately."


"the treatment may not always suit you"

Life is affected in many different ways:

"It can happen anytime so you can't plan... and when you get into that stage you don't really feel like doing anything"

"I just take things day by day, I don't make plans, well cause plans always get..."

"there's a lot of people worried about losing their benefits, and that can be something that plays on your mind and that can be something that triggers off cause you don't know if it could be taken away from you"



“I’ve never totally recovered ... learnt to live with it”

“you can feel better about yourself, that you’ve done something or achieved something”

“It’s difficult to understand psychosis unless you’ve experienced it yourself.”

What to do and what not to do

Several people had learned to spot the triggers which made them feel worse:

“if I don’t sleep or I don’t eat, warning bells go off”

“My brother, who’s a trigger in my illness... it just cracked me up. I wasn’t sleeping. I know what my triggers are ... it’s a marvellous thing”

Talking to other people was important because:

“a lot of things are relied on by word of mouth”

“It’s best to express yourself and not keep it inside you”

“they [professionals] decide ... otherwise if they haven’t got any knowledge and you don’t talk ... and you think you’re always right ... so the whole situation should be coming out in the open, what is happening.”

“I’ve talked to them for five hours at a time. I’ve come out from what I was going through, gone to sleep, phoned

the next morning and said thank you for getting me through the night”

“She said “straight through that alley way” and that’s the best walk I ever took” [to the counselling service run by MIND]



It’s also important to find interesting things to do, for example:

“my writing does help, it’s very cathartic and gives me something to focus on”

“structure [to the day] is the key for me to feel better. I need things to do”

People advised that avoiding psychosis did not help:

“I hide, I tend to put up a barrier”

“I just keep fighting it and fighting it until it goes and it doesn't work sometimes ... but I try to ignore it, that's not a good idea.”

“When I'm on my own all I do is think and get more and more paranoid”

“I stopped going [to Mind] and I was spending more time by myself and it was disastrous.”

It was also pointed out that services should not be under-resourced, making it more difficult to get help:

“The mental health services are not cutting the mustard, it's under resourced and underfunded”

“people have to go through this person and that person... they need help soon, soon, soon, not to wait for another referral”

Other people

Some other people were not much help:

“they were about as much help as a tin of bananas”



“Negative people. People that are going to hold you back ... I gotta move on from them and realise I can do a bit more.”

“they [GPs] should have more training in mental health”

“people get insensitive and don’t understand your suffering, that you’re very unwell and say ‘oh snap out of it’ or ‘come on, come on, come on’”

On the other hand, good friendships were really helpful:

“My brother was the most important person. He was on the phone to the people in the hospital and I couldn’t ... I’d be dead if it wasn’t for him”

“you get real friendships with people with mental issues like yourself”

“I’ve now got friends, people to confide in and I know there is help out there and nothing to be ashamed of”

People who knew what to do were helpful:

“if you are bad, [name] will talk to you and she will get somebody to help”

“I had this one particular nurse who used to reassure me ... she’d sit there for about half an hour, but that’s very rare to get someone like that”

“you can’t expect a family to diagnose a mental illness ... but they will be able to support them if they know, educated about the symptoms”

What could be different for people living with psychosis

1. Being listened to
2. Being taken seriously
3. Being reassured
4. Having skilled help, to respond to acute moments of need and stop things getting worse

These all help to make people feel safe and more receptive to help when unwell.



Time, reassurance and understanding were needed to help people get in touch with reality and the wider world. This meant that those trying to help needed to give time to listen to the person's experiences and reassure them by offering guidance as to what was real, and what wasn't. This was most helpful when there was time to talk things through and consider how psychosis impacted on everyday life, in a practical way.

Changes in routine, such as sleeping and eating, could be useful signs that people were getting unwell. It took time to recognise the importance of these signs. Having knowledgeable and reliable services was crucial for getting help quickly. Knowing the language used by professionals when talking about psychosis was helpful for communication. But professionals should make an effort to understand the language and experience of people living with psychosis.

Why our findings could be useful and important

To support people living with psychosis, services and other people have to review their priorities and actions all the time. Our findings suggest that it is important to give priority to spending time with a person, to find out more about their experience of psychosis and try to agree the best action. Greater understanding means that people can be more effectively supported.

Taking a practical approach means being interested in how psychosis is impacting on every aspect of life. This means that practical solutions can be explored. It also means that the language used to communicate about psychosis can be more reflective of service users' experiences and less dominated by professional concerns about symptoms.

The way we worked together as researchers

To do this research, we had to be open with each other, with mutual respect. We built our working relationship through listening to everyone's stories and ideas. As each challenge came along, we shared our ideas about how to overcome it. This meant everyone learned about research through doing it together, gaining really useful knowledge and skills.

Going to another level

We have written more about this experience of growth, suggesting that by doing research differently we have progressed beyond all expectations. If you would like a copy of our paper, contact Dr Wendy Bryant using the details on page 22.

Bryant W, Parsonage J, Tibbs A, Andrews C, Clark J, Franco L (2012) Meeting in the mist: key considerations in a collaborative research partnership with people with mental health issues. *WORK: A Journal of Prevention, Assessment, and Rehabilitation*, 43, 1, 23-31

Researching Psychosis Together

We meet at Brunel University in Uxbridge, West London, every 3-6 weeks. Each meeting lasts about an hour and a half, with refreshments provided. You can come along and listen in, and we welcome people's ideas and thoughts about how to do more research. There are opportunities to be involved in research, teaching and interesting events such as public lectures at Brunel.

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Living with Psychosis

What it is like:

“when you’re experiencing this psychosis it IS happening to you ... I’ve still got memories like it really happened”

What to do about it:

“it helps to have constant people you are in touch with”

What not to do:

“people shouldn’t treat people as a mental health sufferer, a person lives their life and then suffers a mental health problem”

Other people:

“you need someone to talk to you, be patient, have an understanding, spend time with you”