

Lived experiences of psychosis: understanding the gap between perception and reality

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Word count: 1314

The study was not funded.

The Author has declared that there are no conflicts of interest in relation to the subject of this study.

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Introduction

Psychotic experiences and hallucinations have often been explained to be the result of the physical interaction of chemicals (1), and all such episodes have often been reduced to the malfunction of physical connections in the brain (2); such frameworks which explain mental ill-health have the potential of undermining the *lived experiences* of such events (3).

Theories that explain the cause of psychosis are often linked to application of the medical model which places primacy on the physical interactions in the brain causing mental illness (1). The medical model explanation often discounts other causative theories for mental illness such as psycho-social explanation (4), psychological theories (5), and spiritual causes (6). In addition, novel ways of investigating the *physical* symptoms of hallucinations and psychosis have been explored through simulated virtual immersive reality (7) to try to understand the impact of such experiences.

To connect with the needs of people with mental ill-health, it is my contention that it is important to understand the *lived experiences* of psychosis to gain an insight into mental distress; thus, as a service user and social work academic (8, 9), I share a short reflection to illuminate understanding of this experience.

Reflection

In my mind there is a gap between perception and reality. Remembering back. I was desperately in love and desperately longing to be loved. I pretended that *he* undertook

actions to make me jealous. He went off with somebody to make me jealous – to make me love him even more. I remembered making clever retorts to his replies, but these were words that weren't said. As I experienced psychosis, and delusions, I became less and less of a person. I was shrinking within myself. I developed a sense of learned helplessness. The victim. But in truth, nobody noticed. I would cry myself to bed at night as my self-esteem shrunk. My identity shrunk.

I pretended to myself that I had had a clever conversation with this person. That I had had a clever witty exchange – when, really, I had remained silent. The simulation that I fed myself, presented me being attractive. But I must have remained silent, not saying anything. I'm sure that the gap between reality and the pretended simulations in my head didn't match, but by the time I had pretended to myself what had been said, I had no understanding left of reality.

The emotions I experienced were very much like the abuse of controlling behaviour that many domestic abuse survivors experience. Except I pretended that mind games were happening, when probably nobody even noticed me. I believed that I was being oppressed, teased, but probably this was the pretence of my mind. The excuses I fed myself about this man, are the same excuses those who have experienced domestic abuse experience. They couldn't help themselves. They didn't know how it affects you. This behaviour is typical of any man. You squash your emotions, you accept behaviour. But for me it was all played out elaborately in my head. An elaborate psycho-drama – but I believe it was nothing. This is the difference between perception and reality. In my head, there was perception, but, in reality, there was nothing. I experienced the controlling behaviour in my head, I experienced

the shame of abuse in the gap between reality and perception. There was no connection between perception and reality.

As someone with a mental health need, it was difficult to differentiate between perception and reality: the world in my head was true even if it wasn't in actuality an accurate representation of the world. I experienced these encounters as real, and the impact of victimisation as real, even if it wasn't. I thus *experienced* the nature of controlling and oppressive behaviour in my mind, as a direct and perceived occurrence, even if it wasn't real.

Discussion

This reflection underlines the visceral and punishing nature of psychosis in its lived experience and how it can impact directly on the emotional wellbeing of a person experiencing mental distress. However, many clinicians, operating from the medical model of care, diagnose and identify the perceptions of people who experience hallucinations and paranoia (1,10) as eminently untrue and false representations of the world, based on illness criteria. However, a limitation of much research in this area (11: S67) is the dominance of operationalized definitions and measurement tools to maximize reliability and simplify diagnostic criteria. Thus, *lived experiences* of psychosis are often reduced by clinicians to be understood as inaccurate representations of reality emanating from minds of people who are confused and damaged; sometimes their thought patterns are merely pathologized as faulty connections between the physical and chemical processes of the brain (1).

However, in postmodern research it is acknowledged that there are different realities, and nobody holds a true representation of what that reality is, because everyone's perception of

that world is different. Each person holds a different recollection of a memory that is shaped by his/her perspective and by his/her current experiences, thus, it is very hard to argue that there is a true representation of an event (12). The dichotomy between a philosophy that claims there is no true representation of the world, and the belief in scientific explanations of reality, suggests that it may be difficult to dismiss the content of hallucinations and psychosis as merely inaccurate and false recollections of events manifested through the experiences of mental illness. While the emphasis on operationalization of diagnostic criteria may help to achieve reliable and interpretable data (11), it risks a premature simplification of psychopathology; not realising the complex content of these lived experiences.

However, is there ever an accurate representation of psychosis? The traditional Cartesian dualism has dominated the mind-body split in mental and physical health posited in Western thinking and the division between the physical and the mental has been rejected (13). There are many different and distinct explanatory models for the experiences of mental distress in different cultures (13) and it is important to understand how people from diverse cultures and ethnic backgrounds respond to mental ill-health. Western medical models and clinical language (11) often fail to supply the words or concepts for people to relate subtle and fluctuating forms of experience, potentially restricting the psychiatric phenomena that are reported by patients or attended to by clinicians. This links also to the increasing impact of racism on the delivery of care (14), as service users from ethnic minorities often perceive mental illness as distinct forms of experience, often unrelated to physical disease. Moreover, people from minority cultures often experience increased coercive treatment and the negative labelling of mental health diagnoses, highlighting the potential nature of mental health services as institutionally racist (15).

Conclusion

This discussion has led us to consider how we can relate to the perceived reality of these psychotic events. In my reflection it is acknowledged that unreal events were perceived as a true representation of actual encounters with reality. I have argued how the medical model reduces these symptoms to the malfunctioning of chemicals in the brain (1) and rejects the validity of these experiences.

User-led models of care prioritise the importance of user perspectives and user interpretations of their lives; for example, as expressed through such care models as the Hearing Voices Networks (16) and the development of peer-support led services (17). These innovations emphasise the primacy of user led knowledge and perspectives of care, underlining the need to access the lived experiences of service users through application of their own knowledge and relationship to their encounters with psychosis and hallucinations.

In this article it is therefore argued that it is important to relate to and connect with the lived experience of mental distress, rejecting the primacy of the clinicians' roles in defining the meaning and status of the lived experience of delusions and hallucinations, all combined under the umbrella of psychotic episodes.

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