1 UNDERSTANDING PSYCHOSIS AND SCHIZOPHRENIA

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Background

Psychosis is the generic name given to a range of illnesses that can affect the mind and interfere with how a person thinks, feels and behaves. The term psychosis covers several different conditions, for example, drug-induced psychosis, psychotic depression, schizoaffective disorder and schizophrenia spectrum disorders. The precise name used can change over time and will depend upon the pattern and length of difficulties that an individual has. A diagnosis of schizophrenia is considered the most severe type of psychotic illness and almost one person in every hundred people will be diagnosed at some point in their life. It used to be thought that schizophrenia was a discrete illness that was quite separate from other psychotic illnesses such as depressive psychosis.

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However, we now have a much clearer understanding of how these illnesses can merge into one another without clear boundaries. For example, some people will receive a diagnosis of schizoaffective disorder to reflect the presence of symptoms of schizophrenia and mood disturbance. For such a person, it will not be uncommon or unusual to present with symptoms and experiences which are suggestive of a diagnosis of schizophrenia on one occasion, but schizoaffective disorder or even bipolar disorder on another.

For some people, psychosis will typically have its first onset in late adolescence and young adulthood. This can usually be a time when a young person is navigating significant developmental and social milestones, such as going to college, embarking upon new relationships or employment. The first onset, however, can also occur during middle age and older adult (60+) years. People from all different sections of society, including all social classes and levels of wealth, can develop psychosis. Evidence has shown that reported rates of psychosis can vary substantially across different populations, countries and regions. For some, psychotic illnesses might be a single, one-off, episode, whereas for others it can be a longer-term condition characterised by alternating periods of remission and relapse, and for others again there may be continuous symptoms even when taking treatment. Psychosis is a complex condition that can often be misunderstood and associated with high levels of stigma and social exclusion. It can also be associated with high levels of distress for the person living with the diagnosis, but also for their families and friends.

Key Common Symptoms

A person living with psychosis may experience a range of symptoms, which are typically described as *positive* or *negative*. Positive symptoms refer to experiences that have been *added* to an individual's functioning and will include symptoms described as delusions, hallucinations, disorganised speech or thinking, and confused or disorganised behaviour. Delusions are considered as unusual and bizarre beliefs that are typically based on a misinterpretation of perception or experience. These beliefs can and do vary significantly from one person to another, in terms of

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their content, associated distress and the impact on different areas of their lives. In persecutory delusions, for example, individuals have beliefs that another (or others) is conspiring against them. In turn, this can lead to feelings of suspicion, fear and emotional distress, and adopting behaviours they believe will keep them safe and protect them from perceived harm. Hallucinations comprise felt experiences in any of our five senses that are not truly there but are experienced exactly as if they are. Hallucinations can be auditory (hearing voices or sounds); visual (seeing things); olfactory (smelling odours); tactile (feeling sensations on the body); and gustatory (experiencing different tastes). Thought disorder and disorganised speech can make it difficult to organise and articulate one's thoughts in a clear enough way for others to make sense of. These types of difficulties can also prevent logical decision-making.

In contrast to the added quality of positive symptoms, negative symptoms describe experiences that are absent from a person's usual functioning. It refers to the loss of ability to function in everyday tasks, such as bathing and self-grooming, cooking, cleaning and being employed or in education. These types of symptoms also include significant difficulties in establishing, maintaining and actively participating in social relationships and activities. Those affected by negative symptoms will tend to lack motivation and the wherewithal to engage in any activities. They will isolate themselves from others and social situations, including family and friends, and will experience a loss of emotions and emotional expression. Negative symptoms, compared to positive symptoms, tend not to receive as much attention from mental health services, professionals and researchers, and can seemingly present as being less distressing to the individual, who may appear to not even notice them. They will, however, be very noticeable to others in their network, including their families. These types of symptoms can be extremely upsetting to observe and may not always be readily understood as being part of the mental health problem. Instead, they can frequently be misunderstood as examples of laziness, rudeness and not caring, which can often lead to conflict with others, including families and the professionals they might work with.

Mood disturbances, such as anxiety and depression, are also common in individuals living with schizophrenia and related psychosis conditions.

For example, approximately more than half of those affected will experience a depressive condition at some point over the course of their illness. Like negative symptoms, mood difficulties can often be overlooked as our attention is focused on positive symptoms. Cognitive skills, such as memory, attention, concentration and processing speed that people require to function and complete day-to-day tasks, will often be disrupted in psychosis. In addition, sleep disturbances (e.g., spending less time asleep, nightmares) can be common, with some individuals being awake and asleep at opposite times to most others. For example, they might be awake through much of the night and have short episodes of sleep during the day.

The experience of an individual symptom (e.g., hearing voices) does not automatically mean that someone has a psychotic illness. This is because individual symptoms are more common than a diagnosis of psychosis and many people experiencing an individual symptom may not experience any related difficulties that bring them into contact with services. When psychosis symptoms first develop, many people can become preoccupied with specific issues and lose interest in key areas of their lives such as friendships, study, employment and previously enjoyed activities. They may behave in ways that increasingly appear odd and out-of-character, and are gradually of concern to those closest to them. Initially, the symptoms may seem to come and go and will often be noticed first by family or friends, while the person themselves would not share their concerns. In the absence of accessing the appropriate supports, treatments and care, most people will become more impacted by their symptoms and experience what is commonly called an acute episode or a breakdown.

Causes

Anyone can develop a psychotic illness and some groups can have an elevated risk of doing so. In schizophrenia spectrum disorders, evidence suggests that men have a greater likelihood of being diagnosed and will tend to be slightly younger at the time of the first onset of the illness. Based largely on data from regions such as Europe and North America, a higher risk of difficulties also exists in racial and ethnic minorities and migrant

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groups, particularly those from Black communities, a higher risk of difficulties also exists. If someone in a family has a diagnosis of psychosis, there is, statistically, an increased probability of developing it. This risk, however, varies significantly depending on how closely related the family members are. Thus, most people living with a diagnosis will have no family history of psychosis. Living in larger cities has been linked to higher risk, and the longer the individual has lived in the city, the greater the risk.

There is no single identifiable cause of psychosis. It is widely understood to be attributable to a range of different factors that will vary, in relevance and degree, from one person to another. We know that people may become more susceptible to developing psychosis if they have been exposed to a combination of risk factors, which can be psychological, social or biological. Schizophrenia spectrum disorders, for example, are believed to be partly a neurodevelopmental condition. This means there are likely to be factors present in an individual's early life and childhood that affect how the mind and brain develop and render a person more vulnerable to developing schizophrenia-related disorders at a later stage.

In the last few years there has been considerable progress made in increasing our understanding about the causes of psychosis. A range of early environmental factors can also elevate the risk of developing schizophrenia spectrum and related psychosis conditions. Some of these include viral infections, pregnancy and birth complications, stress, trauma and substance (mis)use (e.g., cannabis, cocaine, amphetamines). For example, there is consistent evidence that supports an association between cannabis use and schizophrenia spectrum disorders, with a five times greater likelihood of developing psychosis in people who smoke high-potency cannabis (e.g., commonly described as skunk in some countries) compared to those who do not. The dangers of cannabis are particularly important in adolescents since cannabis use typically predates the development of psychosis rather than being something that people living with the illness use to manage their symptoms.

There has also been some progress in genetic and biochemical research, particularly in identifying genes that might leave an individual more vulnerable to developing psychosis and in understanding how variations in brain chemistry can explain key symptoms. For example, we know that during an acute psychosis episode, an individual releases

excessive dopamine (a neurotransmitter) in some brain regions and the degree of dopamine release is related to the severity of positive symptoms that an individual displays. The origins of psychosis do not lie in dopamine anomalies, but such anomalies can help to explain the mechanisms and common pathway underlying positive psychotic symptoms. They may also play a role in the development of negative and cognitive symptoms.

In people living with schizophrenia and related psychosis conditions, nerve cells in parts of the brain may develop faulty connections with other cells. This results in a picture that can almost be likened to a computer with a problem with its wiring. The computer works well most of the time, but when it is overloaded, it can run into difficulties. In a similar vein, when the person living with psychosis is exposed to certain stressors, their brain systems might become overloaded, malfunction, and lead to difficulties such as misreading signals and failing to tell the difference between real and imaginary events. Magnetic resonance imaging (MRI) studies have demonstrated subtle differences in the brain structure between some people with lived experience of schizophrenia spectrum disorders compared to those without.

Health Outcomes and Key Issues

The life expectancy in people living with psychosis conditions is considerably shorter than in the general population. Though exact figures can vary, depending on the study, reduced life expectancy rates can range approximately between 15 and 30 years. The premature mortality in early years is primarily due to higher rates of death by suicide and accidental deaths. However, overall, more premature deaths are caused by physical illnesses, the seeds of which may also be sewn in these early years of illness. High rates of smoking, poor nutrition and inactivity may combine with adverse effects from antipsychotic treatments to increase the risk of dying prematurely from future heart disease, stroke, diabetes and respiratory disease. Tackling these physical health problems requires a 'whole-person' approach from early in the course of psychosis and its treatment – equipping individuals and their families with the knowledge and skills to adopt healthy routines and seek help early if things go

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wrong. Research efforts focused on improving life expectancy through identifying and minimising risk factors for suicide as well as physical health problems such as diabetes, heart disease and tobacco dependence are ongoing.

Contrary to sensational and stigmatising media headlines (which can fuel discriminatory behaviours and deter people from accessing support), most people with a psychosis diagnosis have not and do not engage in violent and aggressive behaviour. It is often overlooked that they are more vulnerable to being the victims of crime and exploitation by others. However, away from media headlines, we do know that involvement in violent and aggressive behaviours, typically towards people already known to them such as a relative, can be a problem for some people living with psychosis. The factors that can contribute to this risk are varied and, as noted in other areas, differ from one person to another but can include not taking prescribed medication, alcohol and illicit drug (mis)use. It can also relate to specific illness symptoms such as auditory hallucinations, where the voice content might include commands about what the person should do. Developing a detailed understanding of these risk factors can help to support better treatments that can be delivered at an early stage to improve outcomes for those living with psychosis and their families.

Treatments

Psychosis disorders are treatable mental health conditions. The recommended treatments which can be accessed in hospital and community settings aim to support and reduce the negative impacts on those living with psychosis and their families. The aims of treatment have evolved over time: previously, most emphasis was given to reducing positive symptoms. However, contemporary approaches, which are more comprehensive, also aim to focus on the negative, cognitive and mood symptoms, the social impacts of experiencing a mental health problem, and the needs of families.

Across the world, medications (frequently described in services and research as antipsychotics) represent the most common treatment approach used and can play an important role in helping individuals live

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with psychosis. Thus, at some stage over the course of the illness, those with lived experience of psychosis will be offered and encouraged to take some type of medication to reduce the negative impact of psychosis on their functioning. Medications, their precise names, dosage and how they are administered (e.g., via oral tablets, injection, liquid, nasal spray) will vary from one person to another and across different countries and regions. These variations are influenced by different factors, including the type and pattern of symptoms experienced, individual preference, the degree of understanding, agreement or acceptance of a need for treatment an individual might have, and health systems and medication availability in specific countries. In some countries, for example, an individual living with psychosis and considered by professionals to be significantly impacted by their experiences to such a degree that it affects their functioning might be required to receive medication treatment that they do not, themselves, consent to. Hence, the medications they are offered and might receive will be influenced by the degree to which they consent and agree to take them.

Not dissimilar to medications for any other health condition, medications used in the treatments for psychosis can have some unwanted and/or unintended side-effects. For example, unwanted effects might include experiences such as fatigue, weight gain, excess salivation or disturbances in sexual functioning. Identifying and managing unwanted side-effects are important, as individuals with psychosis (much like anyone else) might be less likely to continue with their prescribed treatments when they have unwanted and unmanaged side-effects. People will often be advised to take medication for an extended length of time that will typically extend beyond a time when an individual feels (or reports feeling) better. The idea is that medications are designed to help people maintain their wellness and reduce the risk of future acute episodes. However, it is not uncommon that people with lived experience of psychosis can find it difficult to continue with their prescribed medications when they feel well or when they have unwanted side-effects, because it no longer makes sense to do so and can feel unnecessary. Stopping medications can also occur when a person does not share the view of others that they have a mental health problem per se or a mental health problem that medication can help with. Unfortunately,

not taking medications regularly as prescribed, particularly in the early stages, can often lead to an increased risk of further episodes or exacerbation of their illness experiences and negative impacts for themselves and their families. It can take several attempts to find the right medication (including dose) that best suits an individual and this can often be a difficult process for the individual with psychosis and their families. Over time, the need for medication treatments may lessen and, for some people, the prescribed doses may be decreased or even stopped; however, this should be a slow process with very careful monitoring. These decisions will largely be influenced by how well individuals living with psychosis are getting on in their lives. In other cases, people may benefit from longer-term medication treatment. In these cases, staying on the lowest effective dose of the drug helps to lessen side-effects while also helping with symptoms.

Psychological treatments, which are frequently described as talking therapies, are designed to help people to deal with the symptoms (e.g., delusional beliefs) and/or the common problems associated with symptoms and having a mental health problem such as emotional distress, stigma, and isolation. Different treatments, which can be offered at different points during the illness course, can include individual psychological therapies such as cognitive behavioural therapy for psychosis (CBTp), which is cognitive behavioural therapy, specifically adapted for psychosis. Therapies can also include family therapies and group-based therapies. The groups might include those designed to help with a particular symptom such as coping with voice hearing or an educational and support group, designed to support families and carers and advance their understanding about psychosis. Therapy approaches will vary within their focus, strategies adopted, format, and target group. Moreover, the content of discussions will also vary from one person and one family to another depending on their specific presenting needs and therapy goals. However, despite these variations, psychological therapies are aimed at improving coping efforts and reducing the risk of further acute episodes and crises.

Other types of treatment and interventions that individuals living with psychosis might be offered, are those designed to improve skills needed for everyday living, which are usually negatively impacted by

their experiences of psychosis. Such skills might include those involved in attending to self-care, shopping, preparing meals and help in managing their finances and time. Cognitive remediation therapy (CRT) is a form of treatment designed to improve neurocognitive abilities (e.g., organisation and planning skills) among people living with schizophrenia and related psychoses. The goal of cognitive remediation therapy is to improve everyday functioning in people with schizophrenia and related psychoses by improving cognitive processes. Individuals living with psychosis might also receive help and support with developing skills that can assist with securing and/or maintaining voluntary or paid employment roles or undertaking further education and training.

Alongside the important contributions of medications, psychological therapies, life and vocational skills, in the treatments and recovery of people with lived experience of psychosis, are the relationships with close others. Families and informal carers will often remain in close contact with, and/or live together with, the person with psychosis, and their involvement will often continue long after a service or different healthcare professional has ceased contact. They can provide a range of different support functions, including companionship, advocacy and responding to areas of unmet need. Their contributions to improving outcomes and supporting recovery experiences for individuals living with psychosis can be invaluable, but their own experiences and needs can often be hidden and overlooked.

Aisha: A Lived-Experience Account of Psychosis

I dodged the scooter and looked up into the man's face. Hooded and talking, as if to himself, I thought. But it would be his earpiece. His handsome brown face displaying character and vigilance as he weaved amongst the traffic. How magnificent we are, I mused. Black people, all this beauty and culture. Yet here I am, under the 'system', a statistic, another lost soul wandering the halls of a too hot building with bars on their windows. Let out, only to go to the local shopping centre, sometimes accompanied by staff. And what do I buy? Chocolates and fags of course. All that good stuff.

I berate myself for not being healthier, and wonder where this path will lead. Stretching exercises in the garden as people shout, moan and wail. Contorting their bodies to express emotional pain.

My case notes read *aggressive, disillusioned* and *paranoid*. I now remember to sit with my legs folded and hands on my lap, and back up straight. But I am a person, I am a civilised being, and I am not your statistic.

The reasons for my decline are both simple and complicated. An aggressor that I speak nothing of to the mental health team. I don't trust them. They are clinical and seem to only smile at you during lunchtime. Stressed perhaps, or stressed definitely. What difference does it make that they have seen others like me, and they will see more? I glance at my palms looking for a fingerprint, and I laugh, since looking is supposedly a first sign of madness.

What makes me unique? My love of poetry, nature and family. My family, who seem to sit in their middle-class world mocking me, afraid and worried? Mocking is the part of the mind that isn't functioning; all this love I could no longer accept, and it became twisted, dark and fantasised. All I had built had crumbled: my properties, my close group of girlfriends and my love. Shattered, and in ruins. Perhaps this exclusive, elusive world I had occupied was just that, a fragile net waiting for someone to pull at its joining; and there was me, I fell out into a world of poverty, drug-fuelled companions and restless nights. Homeless and nameless. All the heart I had always given to those who suffered, who would give their heart to me now, it is me who is suffering?

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I dreamt wildly and manically of all the things that I would do once I was healed. Yet, I pondered, was there one kick too many to the stomach, and could it be reversed? Could I be loving to all again? This question played with me, but jaded and bitter was not an option. So slowly but steadily, I put one foot on the bottom of the ladder and began to climb. Here, today, I go up and down this ladder, but I am again loving, giving and whole. My brain plays tricks, my therapist calls it the 'Tricky Mind', and I have to catch myself when that happens. Yet, in stillness, and the silence of my flat with its pretty plants and the park outside with children filled with joy, it brings me peace and stability. And I realise, it doesn't really matter what I do or what I have in terms of a career, money or fitness. What matters is that I am good. I cringe at the ones who brought this into question and fear their bullying at times. Sometimes, what you stand up against and object to throughout your life, like bullying, can become the very thing that brings you down. However, I stand tall as an oak tree in knowing recovery happens, that health is real and beauty lies in the open hands of waiting and patient family.