

Module:

Mental health in the community

Week 3

The epidemiology and burdens of mental disorder

Topic 2

The burden of mental ill health for the individual – Part 1 of 2

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Lecture transcript

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In this talk, I'm going to talk about the burden of mental ill health from the perspective of the individual, the person suffering from some form of mental disorder, and, a little bit, from the perspective of the people around them.

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If you look at the personal impact of mental disorder, schizophrenia is the paradigmatic disorder. So, schizophrenia can cause symptoms such as delusions, hallucinations, thought disorder, so-called negative symptoms, affective, and anxiety symptoms. These are sort of things that get psychiatrists, like me, excited. Schizophrenia also causes functional impairments, the inability to carry out day-to-day tasks. And partly, this is due to significant cognitive impairments that are found in some people with schizophrenia: effects on memory, attention, language, and executive functioning (that's the thing that, for example, gets us around the shops when we're going shopping in a logical order).

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But it also does other things. So, people with schizophrenia often end up in hospital, and, when they do, that's often under compulsion. They're treated with medication, which provides them with a burden of side effects, potentially. Schizophrenia is associated with premature death, which is due partly to lifestyle, partly to suicide, and partly to metabolic effects of medication, and finally, partly possibly to do with other things that we don't quite understand.

Schizophrenia can impact one's self identity, and people with a diagnosis of schizophrenia experience stigma, and indeed self-stigmatization, and at times, quite gross discrimination.

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If we look more at the social effects, schizophrenia results in unemployment. Indeed, the employment rate for people with the diagnosis of schizophrenia in the United Kingdom is worse now than it was in the 1950s. Partly, as a result of that, poverty is a common factor. Homelessness is also much commoner in people with schizophrenia than the general population. Social isolation is common, and people have smaller, social networks, which tend to be non-reciprocal. That's to say, people with schizophrenia may not be giving as much as they're taking. They're less likely to be married or cohabiting, and less likely to have children, and if they do have children, to have the care of them. People with schizophrenia are at increased risk of being victims of crime, and also as perpetrators-- so there's increased contact with the criminal justice system. Finally, as we already implied, there's a significant burden of premature mortality amongst people with the diagnosis of schizophrenia.

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And I mentioned carers. So what are the impact on carers? Well, these are emotional impacts, practical impacts, financial impacts, and social impacts. Remember I mentioned stigma? Well, stigma attaches itself to family members as much as to the person suffering from the disorder. We now know that the burden that carers experience can be much reduced by appropriate policy and service interventions.

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Let me look at the personal impact of mental disorder. I'm going to introduce a phenomenological approach. What's it like to become severely mentally ill? How do people escape the illness identity? And what constitutes, for people who have been mentally ill, recovery? Now, in a very seminal book, *Living Outside Mental Illness* by Larry Davidson, published in 2003, Davidson describes in detail the processes of becoming ill, and escaping that illness identity. His book is based on phenomenological inquiry, and by that, we mean inquiry of people about their actual experiences.

And he's got a nice graphic in his book about the processes of falling into the world of severe mental illness, and then, escaping it. And, I think, the metaphor that he uses in that graphic is a black hole. You fall into the black hole. But, unlike physical black holes, there's a way out.

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So, Davidson describes people moving from a life before illness to experiencing cognitive intrusions and disruptions, experiencing decline in functioning, experiencing overt delusions and hallucinations, having a decreased sense of agency, increasing social withdrawal, and then becoming demoralised and despairing. But, as I said, for some people, at least, getting out the other end.

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Now, some mental disorders can readily be described in pictures. Others, of course, can't. If we think about the personal impact of mental disorder, there's a huge 'first person' literature about the experience of becoming, or being labelled as, mentally ill, which dates back, at least, to the 18th century. It's important to be aware of this literature, but impossible for me to do justice to it in this brief account. This literature's particularly important as part of the contemporary recovery narrative in mental health: pathways, the personal pathways, people have experienced to live a good life despite that mental illness diagnosis.

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And, as I said, there's a big literature-- there are many books, for example, on this; written, either by direct experience or taken from the words off the statements of people interviewed about psychosis. There's a notable book by Professor Marius Romme, *Living with Voices*, which provides 50 stories of recovery.

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I want to mention disability. There is big iconography related to disability, which is, almost solely, related to physical disability. So people in wheelchairs, blind people with guide dogs, people with walking sticks. But not every disability is visible.

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WHO tells us, 'disabilities is an umbrella term covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body-functional structure. An activity limitation is a difficulty encountered by an individual executing the task or actions, while a participation restriction is a problem experienced by the individual involvement in life situations. Thus, disability is a complex phenomenon reflecting interaction between features of a person's body, and features of the society in which he or she lives'.

You'll see that definition (WHO) is essentially designed for people where there's an obvious body dysfunction. Disability is, in fact, a fashionable term in popular discourse. But it's very, very

unfashionable in the mental health world.

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WHO provides us with very striking statistics about the extent of disability, and its impact across the world. According to the figure, one billion people living with disability out of a world population of seven billion.