Stigma and the carer

Introduction

I want to talk to you about -

- The myths surrounding mental illness
- Where stigma comes from
- Its impact on the user
- Its impact on the carer

And then the 64 dollar question:

- How do we eliminate, or at least minimise, stigma.

Myths surrounding mental illness

There are many myths and misunderstandings about schizophrenia in particular and other severe mental illnesses and their treatment. These myths have been with us for a long time. Here are my top four - you may have others of your own to add to the list.

- Myth Number One - schizophrenia is hereditary
- Myth Number Two - schizophrenia means having a split personality
- Myth Number Three - schizophrenia is the mother's fault
- Myth Number Four - All schizophrenia sufferers are knife-wielding madmen putting society at risk

Behind all these myths lie two dangerous assumptions - the first is that schizophrenia is someone's fault. And that someone is the carer and the carer's family - Not true.

The other assumption is that the mentally ill are all a danger to society -Not true.

You are many many times more likely to be harmed by a sane individual wielding a lethal weapon like a car than you are by the tiny minority of the mentally ill who are a danger to others. The vast majority pose a risk only to themselves, if they pose any risk at all.

These myths generate stigma on a massive scale, which brings me to my point.

Where does stigma come from?

- It comes from - the media - especially the tabloid press
- It comes from - the institutions of society - not least the criminal justice system
- It comes from - those health-care professionals who fail in their duty of care
- And lastly it comes from - the bulk of the population who have never personally come into contact with mental illness

What's the impact of stigma on the user from a carer's perspective?

There is a need for tolerance towards those who exhibit odd behaviour. People with mental illness are stigmatised but those who come from the black and ethnic minorities with a mental illness are doubly discriminated against.

Recovering from schizophrenia or any other severe mental illness, with dented self-confidence, the user is discriminated against when he or she attends the psychiatric hospital rather than the general hospital or a medical health centre thereby perpetuating the stigma.

- Stigma comes from families who can be hurtful, although well meaning
- Stigma derives from lack of proper work opportunities
- Stigma makes people angry, lose self worth and feel cheated , inadequate and excluded
- Stigma causes the user to feel an outcast in his or her own family
- Stigma causes users to tell lies and cover up their illness
- Stigma is created by the taboo of mental illness which can bring upon users and their families a feeling of shame
- Stigma arises as much from the physical side effects of drugs as from the illness itself
- And lastly, stigma can be almost worse than the illness itself

The impact of stigma on the Carer -

is that we hide behind white lies such as -

If your daughter is in the psychiatric hospital you are tempted to tell people that she's gone away because she's so upset about the break up of her relationship with her boyfriend.

Or - even more seriously -

If a suicide is attempted it again is covered up with a story such as the break-up of a relationship and not the truth that she couldn't cope with hearing voices.

One carer told me that after her son was diagnosed with schizophrenia, his friends' parents wouldn't speak to her and wouldn't let their kids come round to her house any more.

Another carer said that many of her friends had treated her differently and would not now talk to her in the same everyday kind of way (sharing news about how their respective families were getting on).

I met a carer from Belgium, who had long suffered the emotional impact of her husband's mental illness. She was asked to appear on a TV programme to give her view of how it was to live with someone who is ill. As a result there was a positive response from viewers, but her own family disowned her.

They claimed that she had brought shame on to herself and more significantly on them. This was despite the fact that her husband (who has schizophrenia) thought it a good thing to talk openly about it.

I have met other carers who are involved in the field of mental health and some, as I have done today, use a pseudonym when speaking about their personal situation, but use their given name and working title when talking in general and wider terms. Although this is an unhappy compromise, it is at least a start in the fight against stigma.

My personal story began with stigma, prejudice and ignorance. Our son fell suddenly ill during his first term at a university in England. Later he was diagnosed as having schizophrenia.

Out of the blue, we received a phone call from the wife of the warden of his hall of residence, telling us, with some considerable distaste, that he had behaved in a bizarre manner and had been taken to hospital.

In the short period of time he was at university, our son had made friends, but after he fell ill no-one, other than his tutor asked after him. This made my role harder to cope with as I was in a strange city and feeling totally traumatised. I didn't know where to turn and l was so afraid of stigmatising him that I told family that my son had had a nervous breakdown but was getting better -and no - they didn't need to visit because we would be home soon.

My ignorance was fed by the professionals because they didn't help me by providing me with adequate information. Perhaps when the user is very ill and is seen by family, friends and neighbours in an acute stage of illness then any attempt to hide the truth is useless. Here is an opportunity to learn for oneself and to pass on to others the knowledge that mental illness is not catching.

I use a pseudonym, not because I am ashamed or guilty or all the other myths placed upon me but because of stigma. There is a need to protect the person with the illness as well as their family. And yet at the same time I know that this does not help to alleviate prejudice and discrimination.

When the user is quote 'recovered' and is trying to quote 'fit into society', it is particularly difficult for the carer to cope with questions from friends and neighbours about him because they perceive him to be just another young man scrounging on benefits and making no real effort to get back into the work place.

How do I explain that my son who looks perfectly well is genuinely incapable of full-time work without telling them the truth and bringing upon him the very stigma I am trying to avoid.

Therein lies the heart of the paradox of stigma.

By bringing it out into the open, instead of helping to defeat stigma, it has the opposite effect on a personal level.

However, slowly, one at a time, family and friends are told a little about the illness then more if they wish, and so a wider circle becomes less ignorant, better educated and a few small steps are taken towards mitigating the fears and prejudices that mental illness arouses.

But that is as far as one can go on a personal level. One way I have sought to make a difference is by meeting other carers and joining forces to campaign on a local and national scale where the personal connection may be broken.

As a carer, I am afraid to be me. I know that the people who may shrink from me or call me names are not worthy of my friendship, but I live in a society that discriminates.

To put a new twist on a well known saying -

'Sticks and stones may break my bones but words . . . will always hurt me'.

Result: Stigma simply makes a bad situation worse

So how do we eliminate stigma?

It is the most intractable problem of all, and one which requires partnership between those directly affected by mental illness and the public at large.

It's no use saying that they should do something about it.

We are they.

We must play our part.

Remember the Big C? - (Cancer). That was a source of stigma for two reasons:

- First, fear - fear of the unknown and fear that somehow you might catch it by being near someone with the disease
- Second - the lack of a cure

And what's happened over the years? Cancer is talked about more openly and now - this is the key point - because it is more treatable, people are no longer so afraid of the disease.

Now we have the Big S (Schizophrenia). The causes of the stigma are the same. It is an unknown quantity and there's a fear that you might âcatch' it if it comes near you.

And the solution? A Cure.

Hang on, though, that's something of a tall order. No substantial progress has been made over the years. Instead of a physical straitjacket, patients have been given a chemical straitjacket, sometimes with pretty nasty side effects.

But there's another aspect, too. Prevention. If we can identify those at risk and intervene before a florid episode occurs or things have gone too far, then at least some of the suffering can be mitigated.

Remember mental illness is a curse which can last a lifetime, which has horrendous costs - and not just in mere financial terms.

And if the law has created Acts of Parliament which have shaped public opinion and actions in the context of race and gender, why not mental illness?

It will take medical advances and a long term public awareness campaign to defeat stigma in mental health. And carers need to come out and talk about mental illness as I am doing, by using a pseudonym if necessary, to get the message across.

Thank you

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