

SCHIZOPHRENIA: A SIBLING'S TALE

A diagnosis of psychosis can have a devastating effect on close family members of the person concerned. Stephan Kirby introduces Leanne Bowman's account of living with a brother who was diagnosed with schizophrenia five years ago

Summary

Stephan Kirby suggests that mental health professionals need a greater insight into the effects a diagnosis of serious mental illness has on family members. Leanne Bowman's account explains how her brother's diagnosis was received and how living with him since then has introduced new challenges to her life.

Keywords

Serious mental illness, schizophrenia, siblings, advocacy

AS AN occasional user of mental health services, and a mental health nurse of many years' standing, I have some insight into the needs, requirements and problems facing mental health professionals and the users and carers we come into contact with. But the one thing I have never given much thought to over the years, apart from as an academic or professional requirement, was how my own mental health issues were affecting and had affected loved ones around me.

As professionals, we know it makes sense to foster relationships with service users, based on listening and understanding. But from political and common-sense points of view it is vital to remember to listen to our patients' carers, their parents, siblings, children and other loved ones, and understand what the experience of mental illness is like for them, as well as for the patient in our care.

I met Leanne, a mental health nursing student, when she was embarking on her final year of study.

When preparing some work for me, Leanne was open and honest when discussing her brother's major mental illness and the effect it had and was having on her family life and her training.

We hope this paper offers readers an insight into the trials and tribulations faced when a close family member has a serious mental illness. We hope readers will gain an understanding of what it is like to have a sibling diagnosed with schizophrenia.

In what follows there is a discussion about the feelings, isolation and stigma encountered by Leanne when she learnt that her brother 'was schizophrenic', a term we accept is not politically correct. It shows the importance of appropriate support from mental health services and professionals to enable families to cope effectively with the situation.

Leanne Bowman's story

'I am a third-year mental health nursing student and by no means an expert on schizophrenia. But I can explain how the condition affects the family because my brother Jamie (not his real name) was diagnosed with this severe and enduring mental illness when he was 18 years old. Our mother is his primary caregiver and I am the secondary, but no less involved, carer.

'When Jamie was diagnosed in 2003 I experienced a mixture of feelings and emotions. First, I felt a great sense of loss, almost like a bereavement. In a sense it was a bereavement because, while Jamie looked the same, he acted very differently from the brother I knew. This process is described by Kuipers *et al* (2002) who identify two types of loss: the loss

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Leanne Bowman



of the person we knew and the loss of the hopes and aspirations we had for them. I also experienced “survivor’s guilt” (Kuipers *et al* 2002) because I was the “normal one” and had managed to escape the suffering of being mentally ill. I felt that because I was the older sibling I had a responsibility to protect my brother from suffering, but I had somehow failed him. I also felt frustrated because my mother and I seemed to be doing everything we possibly could to help Jamie, but it was never enough.’

Stigmatisation ‘I had a basic understanding of the term schizophrenia, but probably like many others I had misconceptions and was even scared of the term and its connotations. In society in general there is a stereotyped view of people with mental health problems, especially in the case of schizophrenia. The common misperception is that these people are violent, exhibit sexually inappropriate behaviour and have a split personality (Kuipers *et al* 2002). Corrigan and Watson (2002) refer to this stigmatisation as “the double misfortune of the mentally ill”. It occurs because of discrimination in areas such as work and independent living and, second, due to the effect of a culture steeped in stigmatising images that are exacerbated by headlines in the national media, such as “Schizophrenic man chops off his mother’s head” (Anon 2004) or “Schizo cabbie knifed six” (Moult 2005).

‘In the five years since my brother was diagnosed we have encountered our share of stigmatisation and isolation. When Jamie first came out of hospital the positive symptoms of his illness (Box 1) appeared to be under control but he was suffering with the negative symptoms and often stated that he felt depressed. As a result, he would often use socially inappropriate coping strategies to lift his depressive state, which more often than not involved taking illicit substances.

‘When Jamie was taking them he became violent and aggressive towards our mother, towards me and his friends. At first, we turned a blind eye and tried to deal with it ourselves because we wanted to protect him and did not want him to get into trouble.

But the violence and aggression escalated until it reached the point where we had to call outside help every week to have him removed from the house.

‘This sort of behaviour does nothing to promote a positive image of people with schizophrenia, but I understand that Jamie acted this way because of the substances he was taking. When he is not taking anything, he is a gentle and loving human being, but I do not think our neighbours understood that.

‘Schizophrenia can be devastating not only for the person who is ill, but also the entire family. Among the most vulnerable and most affected are siblings (Friedrich *et al* 2008), as the unremitting stress affects many aspects of their lives, including relationships, roles and health. I can relate to this because my life has changed dramatically since Jamie’s diagnosis. As a result of his changeable moods and unpredictable behaviour, I stopped inviting friends over because I often felt embarrassed because I did not know what sort of mood he would be in from one minute to the next.

‘I was lucky because my friends understood when I had to cancel plans or if I was late. They knew it was because Jamie’s needs had to come first. On the rare occasions when I managed to meet friends it was hard to focus on the conversation because I was worried something might be happening at home. At times my friends’ problems, such as boyfriend troubles, seemed unimportant compared with what was happening to our family. Chapman (2004), a carer herself, says she was reluctant to mix socially because her son’s illness was always uppermost in her mind.’

Carer experience ‘The relationship with my mother also changed. We had always been close and in some ways we became even closer. But there were times when we would disagree about the best way to deal with a situation. For example, if my mother and I had arranged to go shopping, but Jamie wanted to go somewhere different, his needs came first. If I disagreed with my mother and said we should do as we had planned, neither of us would have been able to enjoy the shopping because we would have worried about how Jamie had reacted to taking second place, so we would cancel our arrangements.

‘The *National Service Framework (NSF) for Mental Health* Standard 6 states that “carers play a vital role in helping to look after service users of mental health services particularly those with severe mental illness” (Department of Health (DH) 1999).

‘The National Institute for Health and Clinical Excellence (NICE) (2002) also acknowledges that “carers of someone suffering with schizophrenia have an integral role in community mental health care”. Their experiences need to be taken into

Box 1 Positive and negative symptoms

As a general rule, positive symptoms are an *additional* experience, whereas negative symptoms are a *reduction* in normal experiences:

Positive symptoms

- Hallucinations.
- Delusions.
- Thought disorder.
- Catatonia.

Negative symptoms

- Lack of volition.
- Lack of excitement.
- Poverty of thought.
- Poverty of speech.

(Brennan G (2009))

account for their own wellbeing and to ensure they can give their loved ones relevant community support. NICE makes it clear that intelligible information about schizophrenia and the possible role families can have in promoting recovery and preventing relapse should be made available to service users and their families.

'But as a carer I feel let down by mental health services. After Jamie was first admitted to a psychiatric unit under the Mental Health Act 1983, where he spent 28 days, I kept asking to speak to the mental health nurses on the ward to find out how he had been or if they were any closer to a diagnosis, but they always seemed to be too busy to talk to us. On the last day of Jamie's detention, my mother and I were to our surprise invited to the ward to discuss Jamie's progress and plans. But the mental health professionals seemed to be talking among themselves and the only time they made eye contact or paid us any attention was when they told us that Jamie's diagnosis was schizophrenia, that we could take him home and that we would get some support from a mental health team specialising in psychosis.

'I wanted to shout: "What does that mean?", "Why did this happen?", "What can we do to help?" But we were not given the opportunity to ask any questions.

'The Mental Health Policy and Implementation Guide (DH 2001) states that early intervention in psychosis teams (EIP) are there to support people aged 14-35 years with a first presentation of psychosis and to offer support for the first three years. The guidelines also state that EIP teams should involve families and carers in the assessment and treatment process, as well as offering family therapy and maintaining regular contact with carers.

'The EIP team did give us some useful information about schizophrenia and had regular contact with Jamie. But I felt that I was disregarded as a carer because I was not the parent or the primary carer. It is important to recognise that the bond between siblings is distinct and can be the longest lasting relationship in some families (Barnable *et al* 2006). Even if they are not involved in care, siblings can still experience stress by being part of the same household and because of the chronicity of the illness.'

Expressed emotion 'Despite initial promises, my mother and I were not offered any family therapy. There were times when my brother and I were constantly arguing and being hostile towards one another, due to his unpredictable behaviour. At these points, it would have been useful to have had some knowledge of the stress-vulnerability model (Zubin and Spring 1977), which the EIP teams use to underpin care. But I had not heard of it - or the

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concept of expressed emotion (EE) (Brewin *et al* 1991) - until I started nurse training.

'The theory of EE (Thomas *et al* 2004) correlates certain family communication patterns with an increase in symptoms and relapse in patients with schizophrenia. I support the idea of EE, but in practice, it is difficult not to make negative comments and to be critical when your sibling is constantly being demanding, and is hostile and aggressive towards you, especially when there has been no offer of support or family interventions to help deal with the situation more positively.

'My brother too received little help, and was offered only antipsychotic medication. We were told by the mental health professionals that as long as he continued to take his medication he would be "under control". The drug Jamie was prescribed, amisulpride, is an atypical antipsychotic drug that is a first-line treatment in people newly diagnosed with schizophrenia (NICE 2002). I do not dispute its effectiveness in alleviating some of the positive symptoms of his illness, but he still has auditory hallucinations - even though he will deny this to his mental health worker - and he continues to suffer with the negative symptoms of schizophrenia, particularly a lack of motivation.

'Jamie's lack of motivation has a major impact on the family because we constantly have to prompt him to attend to even simple things such as self-care, or to make doctor's appointments to get his prescriptions, and then remind him to take his medication twice a day, every day. I feel that badgering him to take his medication takes away his freedom of choice. When I am at home my role as a sister is over-ridden by a nursing role, so it feels that I never get a break from mental health and mental illness and the professional caring role I am training for.

'I think it would have been beneficial for Jamie to have tried interventions such as cognitive behaviour therapy (CBT), which can work in conjunction with medication to try to normalise his experiences of hallucinations. Evidence suggests that therapies such as CBT can be part of treatment to reduce the impact of the positive symptoms of schizophrenia (Turkington *et al* 2006).

'Another thing never mentioned by the professionals who have worked with us is the word "recovery", which the US National Institute of Mental Health (NIMH) (Darton 2002) defines as the "act of

Implications for practice

- Staff caring for a person with schizophrenia must be aware not only of the patient's experiences but also that of family members, who have to live with the crisis phase of the illness.
- Staff should seek and acknowledge family members' accounts, recognising that they are as much experts on the illness as the patient, especially in terms of relapse triggers and coping strategies.
- It should be remembered that true collaborative working necessitates the involvement and experience of the family.

claiming and gaining the capacity to take control of life that is personally meaningful and satisfying..." despite "...the limitations and challenges invited and imposed by distress, its treatment and the personal and environmental understandings made of them".

'But, despite the lack of support from services, Jamie has always had and will always have our support. It is almost five years since his diagnosis. He has not been hostile or aggressive for at least a year since he gave up taking illicit substances. He is demanding at times and does not always understand that I cannot drop everything because he says so.

'Jamie has a long-term girlfriend with whom he is very happy and he feels mentally well enough to find employment. He is an intelligent, thoughtful, insightful and creative young man. And he has had recognition for his talents as a budding DJ.

'At times I lost sight of what it must be like for Jamie. He still hears voices when he is particularly stressed; he has lost friends and being labelled "a schizophrenic" has affected his self-confidence. But no matter how difficult it is for his carers, it is worth to reminding ourselves now and again that we are not the ones with schizophrenia.

'My mother has been a tower of strength and she has kept me strong. I have the utmost respect for her: she is a fantastic role model. I am not sure what

the future holds for me as a carer and I think there are likely to be more difficult times ahead, but we will face them as a family.'

Nurse training 'Three years ago, I started my mental health nurse training because I wanted to help other people with mental illnesses and to be able to pass on my negative and positive experiences to other professionals, academics, carers, fellow students and, most importantly, service users. During clinical placements I have had the opportunity to work with people with a variety of mental health problems.

'I find myself drawn to working with young men: I find in them the qualities I see in my brother. They do not usually open up immediately about their fears and it takes time to build a therapeutic relationship and gain their trust, whereas the women I have worked with generally find it easier to express their feelings and are more willing to "engage".

'One thing I find difficult about being a nursing student is how my experiences and viewpoints are frequently challenged, albeit unconsciously. I often hear staff nurses saying things such as "there is so much high EE in that family, no wonder he is back in hospital". But I don't think I am judgemental and I will always make time to speak to service users' families, offering as much support, information and, perhaps more importantly, hope for the future, which I believe is an integral part of the nursing role. We need to walk a mile in their shoes to appreciate fully what it is like to have a family member with a serious mental illness.

'Now that I work in mental health services I am more positive about the future. Services have improved since 2003, with more nurses being trained in psychosocial interventions and putting them into practice. I hear the word "recovery" a lot more than I did five years ago. I have worked with some excellent nurses during my training. I hope that when I am qualified I will never be too busy to talk to a carer as I know only too well the unrelenting stress of being a carer of someone with a mental illness.'

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Ms Bowman's brother has consented to this article being published

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