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IMPROVING MENTAL HEALTHCARE

How stigma and over-use of restrictive practices affect the wellbeing of those with severe mental illness

Mental health-related stigma and the over-use of restrictive practices, such as seclusion and restraint, impact negatively on the wellbeing of those who have been diagnosed with severe mental illness. Positive and proactive interventions such as de-escalation and positive behavioural support have been designed to reduce the need for restrictive practices. In this article, I discuss these issues and describe the research evidence for improving mental healthcare. I will start with a definition of the term 'severe mental illness' (SMI).

Though this term is used inconsistently in research, policy and clinical practice, definitions of SMI usually combine significant duration of mental health service use and impairment of functioning. Psychotic and major depressive disorders are commonly classified as SMI. For the purpose of this article, I will also include another group of mental health conditions, personality disorders (PD), since people with these diagnoses are highly impacted by stigma and the use of restrictive practices. Ignorance and misunderstanding of SMI and PD are common, the following brief overview may help facilitate comprehension of the care needs of those affected. More detailed information about causes, symptoms and treatment are available on the MIND www.Mind.org.uk and the Royal College of Psychiatry health advice www.rcpsych.ac.uk/healthadvice websites.

Psychotic disorders and major depressive disorder

Psychotic disorders cause disordered thinking and perceptions. They are associated with several mental illness diagnoses such as schizophrenia, bipolar disorder (previously known as manic-depressive illness), puerperal psychosis (a severe

episode of psychosis which begins suddenly following childbirth), major depressive disorder, and sometimes also with drug and alcohol misuse. Psychotic disorders most commonly appear between the ages of 15 and 35 years. Prevalence estimates for psychosis vary according to how it is defined and measured, but total population-based annual prevalence rates are commonly reported to be approximately one to four per thousand. Common symptoms include 'delusions' which are false beliefs or impressions which are held despite evidence to the contrary and 'hallucinations' which are sensory experiences of things which do not exist outside the person's mind.

People with schizophrenia may also develop blunting or incongruity of emotional responses, apathy and paucity of speech. These 'negative symptoms' can result in reduced quality of social interaction. Bipolar disorder is characterised by repeated episodes during which the individual's mood and activity are substantially disturbed, alternating between elevated mood and activity and decreased energy and activity. Some, but not all, people with a diagnosis of bipolar disorder also experience psychotic symptoms. The type and severity of symptoms varies greatly between individuals with the same diagnosis.

A minority of people diagnosed with major depressive disorder may also experience psychotic episodes. However, the main symptoms of major depression are persistent depressed mood and a loss of pleasure or interest in things which the person previously enjoyed. Depressed people commonly experience low self-esteem and feelings of self-blame. Depression is the commonest mental illness; lifetime prevalence estimates range from three to seventeen per cent.





Commonly-held negative perceptions [of mental illness] include incompetence, beliefs about dangerousness, attributions of blame, expectations of poor prognosis, negative emotional responses and a desire for social distance (avoiding contact with people with mental illness)



Personality disorders

Personality disorders (PD) are characterised by patterns of behaviour, cognition, and inner experience which differ from societal norms and expectations. People diagnosed with a personality disorder may experience difficulties in cognition (understanding), controlling or expressing emotions, relating to other people and in controlling their impulses. There are several types of personality disorder, each with their own diagnostic criteria. At any one time, it is thought that about one in twenty people will have some kind of personality disorder. Living with any personality disorder makes life harder and people with these diagnoses often experience other mental health problems such as depression or anxiety disorders or substance abuse.

A lack of understanding of SMI is associated with mental health-related stigma which in turn has a range of negative consequences for those affected. I discuss this next.

Mental health-related stigma

A well-established and accepted model of mental health-related stigma is that proposed by Thornicroft (Thornicroft *et al.*, 2007). It proposes three important components: ignorance (lack of knowledge), prejudice (stigmatising attitudes) and discrimination (treating people unfairly). Components proposed by other models vary, but most agree that negative stereotype endorsement is important. Commonly-held negative perceptions include incompetence, beliefs about dangerousness, attributions of blame, expectations of poor prognosis, negative emotional responses and a desire for social distance (avoiding contact with people with SMI or PD).

Mental health-related stigma is generally acknowledged to be widespread. One method of studying this is to test public reactions to case descriptions of people with schizophrenia and major depressive disorder. Studies using this methodology worldwide have found large percentages of the public reporting being unwilling to work closely, or even to socialise, with people with schizophrenia or depression. Similarly, across countries, a high

percentage of people with schizophrenia report negative discrimination from friends and family members, and in finding or keeping a job; and in intimate or sexual relationships (Thornicroft *et al.*, 2009).

Arguably, people with a diagnosis of a PD experience the worst stigma. A recent review (Sheehan *et al.*, 2016) found that public knowledge of these conditions is poor, and that people with PD are often seen as purposefully misbehaving rather than experiencing an illness. In addition, people with SMI and those with PD often come from, or end up in, as a result of their illness, other groups or situations which also face stigma such as black and ethnic minority groups, being lesbian or gay, asylum seeking, homeless or in poverty.

Stigma has a major adverse effect on the lives and wellbeing of those living with SMI or PD. This includes receipt of poorer physical healthcare than the general public. It is well-established that people with SMI on average die 15 to 20 years younger than the general population. The reasons are complex, but there have been many reports by people with SMI of poor relationships with healthcare professionals, including GPs, which reduces their access to and engagement with health services. For instance, people with SMI have an approximately 30% higher fatality rate from cancer compared with the general population; partly this is due to late presentation by those with SMI (Kisely *et al.*, 2013). In qualitative work conducted by myself and others (Clifton *et al.*, 2016) stigmatising attitudes and behaviour by health professionals were cited as one barrier which prevents access to national screening programmes which can provide early detection of cancer. The situation may be even worse for those with PD as health provider stigma has been found to be particularly high, resulting in people with PD being treated less compassionately, even by mental health professionals, than those with SMI (Sheehan *et al.*, 2016).

Discrimination and prejudice can also result in 'self-stigma' where people with SMI or PD feel negatively about themselves and behave in self-sabotaging ways. For instance, people may use strategies of avoidance and concealment,



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which may further contribute to social exclusion and poor quality of life. In a systematic review (n=48 studies) which I conducted with colleagues (Brohan *et al.*, 2012) expectation or experience of discrimination was a factor in non-disclosure of mental health problems in the workplace. Whereas the decision to disclose is personal, under the Equality Act 2010, protection from discrimination is dependent upon the employer knowing about the disability. So fear of the negative consequences believed to be associated with disclosure can result in individuals missing out on the help they need.

In addition, families and others close to a person with SMI or PD can experience 'courtesy stigma' or 'stigma by association'. Society is damaged by mental health-related stigma when communities are deprived of the contributions that people with SMI or PD could make if they were unimpaired by stigma. Societal-level stigma also contributes to a lack of 'parity of esteem' between mental and physical health as highlighted by the previous government's Minister for Care Services, Norman Lamb (Department of Health, 2013). This applies to the resources allocated to mental health services and to research. For instance, approximately four times the amount of funding is provided for cancer research compared with mental health research. Whereas huge advances have been made in the field of cancer, few have been made in terms of understanding and treatment of mental illness. Finally, mental health-related stigma also contributes to prevent help-seeking by those experiencing mental health problems and accounts for the reduced potential for early intervention and prevention of mental illness. Negative media reporting compounds this by promoting a perceived association between mental illness and violence or aggression which I discuss next.



Violence and restrictive practices

Media stories of violent assaults by those with mental illness are impactful since they often appear motiveless and the consequences may be devastating. Sensationalised coverage helps to promote a strong association in the public mind between violence and SMI. However, in reality such incidences are rare and people with SMI are considerably more likely to be a victim of an assault than members of the general public (Varshney *et al.*, 2016). Nevertheless, in a minority of people diagnosed with SMI, symptoms may include a reduced ability to manage emotions, including aggression, which sometimes escalate into violent behaviour. Violent behaviour may be towards others, such as carers, but is most often directed towards the patient themselves in the form of self-harm, including suicide attempts. It is worth noting that suicide is among the three leading causes of death among those aged 15 to 44 years, and of those who die from suicide, more than 90 per cent are found to have a diagnosable mental disorder (Bertolote and Fleischmann, 2002). Violence, including self-harm, is an important driver for hospital admission and an important care outcome is the safety of both patients and carers.

Interventions used in the management of disruptive and violent behaviours in psychiatry include a range of 'restrictive practices'. These are defined as 'making someone do something they don't want to do or stopping someone doing something they want to do' (Department of Health, 2014). Interventions range from simple acts such as only allowing cups of tea at certain times or restrictions regarding leave under the Mental Health Act, to the use of physical restraint or seclusion. The term 'restraint' has no standardised definition but 'involves measures designed to confine a patient's bodily movements' (Sailas and Fenton, 2012: 2). Seclusion is 'the placement and retention of an inpatient in a bare room for containing a clinical situation that may result in a state of emergency' (Sailas and Fenton, 2012: 2).





De-escalation techniques involve the use of verbal and non-verbal techniques, such as personal space, body language, and listening skills, to help the person exhibiting disruptive behaviour to calm themselves

Restraint and seclusion are sometimes necessary to prevent injury and reduce agitation. However, they can have deleterious physical or psychological effects. For instance, positional asphyxia during restraint may occur as a result of alcohol, substances or medication (Mind, 2013). The higher incidence of physical health problems, such as heart disease or diabetes, in people with mental illness increases this risk. Experience of restraint may trigger recall of previous traumatic experiences and thereby exacerbate anxiety symptoms. Family members or carers who witness restrictive practices may also experience distress.

It is accepted policy that restrictive practices should only be used as a 'last resort'. However, there exists a lack of clarity around this term which may contribute to the fact that seclusion and restraint have been overused. A report by Mind (Mind, 2013) and investigation by the UK Department of Health in 2012 into abuses at Winterbourne View Hospital (a private hospital in Gloucestershire where evidence of abuse had been exposed by a BBC programme) showed that these terms have been used to inflict pain, humiliate or punish. The scale of the problem is unclear, but in 2012, there were almost 1,000 incidents of injury following restraint (Mind, 2013). There is huge variation in restraint use across England with one National Health Service (NHS) reporting 38 incidents while another reported over 3,000 in the same year (Mind, 2013). This suggests that there are differences between NHS Organisations in their approach to managing violent incidences and that some approaches may be more effective. Accordingly, interventions to reduce the use of and need for restrictive practices have been developed in an effort to improve patient and carer safety. Two such interventions are 'de-escalation' and 'positive and proactive care'.

De-escalation

Sometimes people with SMI or PD who are experiencing an acute episode and healthcare staff may disagree over how necessary it is for the person to be in hospital. People with SMI or PD may sometimes therefore be kept in wards, which may be noisy and frightening, against their will. This can lead to arguments and aggression, including self-harm and suicide attempts. How staff talk to patients who are experiencing distress can influence whether or not behaviour escalates into violence. NHS mental healthcare staff have mandatory training in effective communication and in calming strategies known as 'de-escalation techniques'. De-escalation techniques involve the use of verbal and non-verbal techniques, such as personal space, body language, and listening skills, to help the person exhibiting disruptive behaviour to calm themselves.

De-escalation techniques should be the first-line intervention for imminent violence in mental health settings. However, this is not always the case and, even when used, de-escalation techniques may not always be successful. Factors which contribute to the use and success of de-escalation include the severity of the threat; staff experience and training; staff attitudes to restrictive practices and accountability for their use; staff emotional regulation skills; and ward culture and procedures. For instance, incidences of violence are reduced where ward culture promotes respect for patients by promoting psychological understanding of behaviour and by reducing power inequalities and social distance between staff and patients. Nevertheless, it is not fully understood what techniques work best for which patients in which situations. At the time of writing, the National Institute for Health Research (NIHR) is calling for bids for funding for research to determine this and to develop an evidence-based staff training for roll out across the NHS.



Positive and proactive care

Positive and proactive care is a means of reducing the need for restrictive practices as well as providing a template for their safe, compassionate, ethical and lawful application. The safe and effective use of de-escalation techniques is part of this, but a further key principle is positive behaviour support (PBS). This is a behavior management system used to understand what maintains an individual's challenging behaviour. Disruptive behaviours are difficult to change because they generally serve a purpose for the individual. Once nurses understand the individual's needs, they can be dealt with before behaviour becomes challenging. There is a range of initiatives in the UK to promote PBS - Skills for Care guide, Tizard Centre service specification on the use of PBS, National Institute for Health and Care Excellence (NICE) quality standards on preventing and managing violence and aggression, and NHS England is currently working to improve the quality of the data reported on the use of restrictive practices. There is a lack evidence for the effectiveness of PBS interventions in mental healthcare settings.

Recommended positive behavioural support interventions include having a lead for restrictive practice within each NHS Trust, ward 'champions' and the use of 'Positive Behaviour Support Plans' (PBSPs). A PBSP can be used by nurses to identify how and when to intervene to prevent an episode of disruptive behaviour and to promote good physical and mental wellbeing. The UK's Department of Health guidance is that PBSPs should be 'person-centred' and include primary, secondary and tertiary strategies. A comprehensive assessment of each individual's biological, psychological and social needs will be necessary to ensure that the care planned is fully holistic. However, though more common in learning disability environments, few studies have been conducted to support the use of positive behavioural support interventions in mental health settings. Furthermore, there are no agreed standards for the content or implementation of PBSPs.

Working in partnership with West London Mental Health Trust (the organisation providing services in West London on behalf of the NHS), I have recently received funding from the General Nursing Council Trust (a charitable organisation) to develop and evaluate the positive behavioural support work implemented by the Trust lead for Restrictive Practice. This research will examine mental health nurse training in the use of PBSPs in order to understand how training may best be designed to affect nurse behaviour change. We will also ask staff and carers of patients admitted with a mental illness crisis which aspects of the PBSPs they find helpful and unhelpful. The findings of this work will help inform future changes to training and the use of the PBSPs.

Conclusion

A large body of research exists which demonstrates the extent and negative consequences of mental health-related stigma. This stigma can contribute to people missing out on the good quality care they deserve. There are many challenges for professionals working in mental health services including well-documented shortages in funding and staffing. Positive and proactive approaches to care designed to keep patients and carers safe have been developed. However, considerably more investment in mental health research is needed before we can understand what works for whom in what situation so that professionals are able to deliver the best possible care. True 'parity of esteem' for physical and mental health will only be achieved with significant investment in mental health services.



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