

Reading about

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Psychiatric stigma

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Although there is agreement on what 'stigma' is (a mark of disgrace or discredit that sets a person aside from others), definitions differ in the breadth of experiences they describe. Stigmatisation is the process wherein one condition or aspect of an individual is attributionally linked to some pervasive dimension of the target person's identity (Mansouri & Dowell, 1989). It is the negative effect of a label (Hayward & Bright, 1997), or the process of establishing deviant identities (Schlosberg, 1993). For Corrigan & Penn (1999), stigma is another term for prejudice based on negative stereotyping. The clear inference is that the 'negative' aspect reflects not only unfavourable stereotypes, but also the negative attitudes and adverse behaviour of the stigmatiser. Clausen (1981) saw stigma as "a buzz word, arousing more emotional reaction than words like devaluation and discrimination". Other writers have questioned the usefulness of the word to describe a range of adverse experiences. Sayce (2000) argues that the focus should move from the receiver of stigma (the psychiatric patient) to the people or agency causing the stigma. To be marked as 'mentally ill' carries internal (secrecy, lower self-esteem and shame) and external (social exclusion, prejudice and discrimination) consequences, all of which are written about under the 'stigma' heading. The stigma literature is further divided on the basis of the background or discipline of researchers and their vision of how to reduce the stigma and discrimination against people who have had, or currently endure, mental disorders. One example of this diversity, and an excellent place to begin studying this subject, is the *Lancet* series (1998, 352, September 26) on stigma. This series has contributions from users and professionals, with writers who are both. It coincided with the launch of the Royal College of Psychiatrists' 'Changing Minds' anti-stigma campaign

(White, 1998; Crisp, 2000; www.stigma.org).

Stories and histories

The first and last words on stigma belong to people with mental disorders. Shaw (1998) quotes the knee-jerk reaction to her book about her postnatal depression: "how can we believe this person's account to be credible when she says herself she was suffering from severe depression at the time". Thankfully, only a minority of psychiatrists ignores such narratives. The seminal work by Goffman (1963) is annotated with the experiences of people who had been marked by a variety of stigmata. Barham & Hayward's project (1995) to tell the stories of people with schizophrenia living in the community is reminiscent of Goffman's work with asylum inmates. Read & Reynolds (1996) & Sayce (2000) provide longer accounts of what it means to have a mental illness. The reality of US psychiatric careers forms the major part of Fink & Tasman (1992) and Wahl (1999). The common themes of all six books are social exclusion, financial hardship and discrimination. A recent report, based on responses from 556 UK users, shows that 70% have experienced discrimination in some form: 47% in the workplace, 44% from general practitioners and 32% from other health professionals (Mental Health Foundation, 2000).

For an historical perspective, the most readable book is Porter (1991). It is a valuable record of contemporaneous attitudes and (often indefensible) treatments. Full of highly readable personal accounts, it begins with playwright Nathaniel Lee's famous quotation: "they called me mad, and I called them mad, and damn them, they outvoted me" (Porter, 1991). Stigma across time and diverse cultures is also described in Section 2 of Fink & Tasman (1992). The most comprehensive and scholarly

work in this field is by Fabrega (1990, 1991a,b). These articles, extensively referenced, provide valuable insights into the multiple historical, religious, ethnic and cultural influences on stigmatisation. Western societies have always linked ideas of morality and virtue with health and reason, and early Christian societies tainted madness with images of the demonic, the perverse, the promiscuous and the sinful (Schlosberg, 1993). Knowledge of these associations is necessary to understand the origins and perpetuation of psychiatric stigma.

Historical perspectives are important, but it would be folly to regard stigma as merely an historical problem, or to assume that stigma, like the poor, will be always with us. Despite scientific advances and the rise of the medical model, stigma has not gone away (Read & Law, 1999; Byrne, 2000). Angermeyer *et al* (1987) compared perceptions of stigma of German in-patients in an isolated state hospital with those of in-patients in a large university hospital unit, where they frequently met people with general medical conditions. Against the predictions of both staff and the researchers, and controlling for diagnoses and individual stigma-reduction strategies, the university hospital group perceived higher levels of stigma: they would have preferred to be in-patients in secrecy and isolation (Angermeyer *et al*, 1987). Other researchers have also re-evaluated public attitudes in the light of community care (Taylor & Dear, 1981; Brockington *et al*, 1993; Wolff *et al*, 1996a,b,c). Closing the asylums – the 'relocation of madness' – has brought about a community backlash and the reality of former patients leading isolated community-based existences (Barham & Hayward, 1995).

The psychiatric literature

Accepting that stigma plays a negative role at every stage of mental illness – presentation, diagnosis, treatment and outcome (Byrne, 1997) – it is surprising that psychiatric textbooks omit stigma as either subject or indexed item. This may be partly explained by the fact that psychiatric articles addressing the same range of problems do not mention stigma directly. In a review of the literature, Avison (1996) concluded that social networks (actual and perceived) predict the onset and recurrence of mental illnesses. Lack of social networks is, in effect, social exclusion (stigma). Manning

& White (1995) reported UK employers' reluctance to hire someone with mental illness, but found more tolerant attitudes to depression than to schizophrenia or alcoholism. Using standardised measurements with matched controls, Brown *et al* (1999) have reported a more unhealthy lifestyle (poor diet, smoking and lack of exercise) in a cohort of 102 people with schizophrenia. Their findings, which controlled for social class, may reflect the low priority that psychiatrists and general practitioners assign to the physical health of these patients. Levenson & Oldbrisch (1993) surveyed US transplant units and reported that controlled (*sic*) schizophrenia was a relative contraindication to transplant among two-thirds of renal and liver teams; 63% of cardiac and liver units deemed a history of affective disorder a relative contraindication to transplantation (Levenson & Oldbrisch, 1993). Dembling *et al* (1999) calculate that the median age of death is 66 years for people who had been treated by state mental health facilities, compared with 76 years for controls. These and many other similar studies are part of the stigma literature and should drive the arguments to improve current practices (Wahl (1999), Sayce (2000) and the Mental Health Foundation (2000) provide comprehensive listings of widespread discriminatory practices in the health services and beyond).

Ghodes *et al* (1986) highlight unfavourable attitudes in medical and nursing staff to patients who overdose, and these are even worse when there is perceived alcohol or drug dependence. Measuring the attitudes of health professionals, Fleming & Szmukler (1992) found that patients with anorexia were seen as "less likeable" than other patients and as being responsible for their illness. Lefley (1987) reported that 90% of mental health professionals who had a family member with mental illness, frequently heard colleagues make "negative or disparaging remarks" about patients: the majority of these professionals stayed silent and did not disclose their relative's illness (Lefley, 1987). Schwartz & Schwartz (1977) criticised psychiatry by identifying practices that contribute to stigma, principally an overinclusive definition of mental illness and overinvolvement by the profession in the justice system. Schlosberg (1993) argued that psychiatrists, often oblivious to stigma, have a clear choice of role: to be either stigmatisers or destigmatisers of their patients. He cautioned against

further stigmatisation of an "undesirable" patient group – those who have other stigmas (e.g. old age, poor educational status), are treatment resistant, or reject medical authority (Schlosberg, 1993). The relatively new profession of psychiatry did not cause stigma, but many of its former and current practices perpetuate it (Byrne, 2000).

Hayward & Bright (1997) reported a fall in interest in stigma publications in the 1970s, noting that this has reversed during the past decade. Previously neglected topics, for example the stigma of dementia or substance misuse, have now been addressed. Benbow & Reynolds (2000), writing about the stigma of Alzheimer's dementia, comment about ageist attitudes and therapeutic nihilism, and the fact that once the illness was deemed *psychiatric*, this brought its own additional stigma. Negative social meaning placed on stigmatised behaviour (for example, addiction) can often be a more important barrier to change than the behaviour (alcohol or drug misuse) itself (Ritson, 1999). Ritson's article is one of a 'stigma series' in the *International Journal of Clinical Practice*. Both dementia and alcohol and drug addiction have been included in the 'Changing Minds' anti-stigma campaign (Crisp, 2000). Along with this resurgence in publications come broadly based articles, challenging medicine to 'put its own house in order' (White, 1998). The best work in this area has been published relatively recently: Wolff *et al* (1996*b,c*), in a controlled trial of community education, have shown individually tailored local initiatives as the way forward. In a related study, the same group quantified the tarnished image of community psychiatry, but also showed that there is a demand for information and education among (potentially hostile) residents' groups and argued that these concerns should be addressed (Wolff *et al*, 1996*a*).

Other perspectives

In addition to personal, historical and psychiatric perspectives, other disciplines have added to current concepts. Much of Goffman (1963) is still highly relevant today, and sociologists have taken these ideas forward, especially in the literature on the nature of prejudice and stereotypes (Byrne, 1997). While some writers have considered attribution theory (certain negative traits can discredit the person to whom they are ascribed) to explain stigma, labelling theory (symptoms and behaviour are seen as

violations of social norms or products of situations rather than as the expressions of psychopathology) has been advocated by most (Schlosberg, 1993). Link *et al* (1991) describe individual responses to labelling (defence, attack or adaptation) as secondary deviation, believing that these efforts are bound to fail. Although not directly referenced in this review, both nursing and social work journals have consistently shown a broader interest in stigma than the psychiatric literature (Byrne, 2000). Anthropology and cultural studies provide a wider context within which stigma operates. Prejudice against people with mental illness has parallels with racism and racial discrimination: one particular challenge is the coincidence of mental disorder and minority ethnicity, so-called double discrimination. Ethnicity is also an important factor in anti-stigma initiatives, and Wolff *et al* (1996*b*) reported key attitudinal differences in ethnic groups.

Social psychology has made a major contribution to stigma research, although the methodology is quite different to that of medical research. Measuring stigma remains problematic: prejudiced people tend to play down these attitudes, and behaviour is more difficult to study in real settings. Amerigo Farina has been at the forefront in fieldwork studies examining the complex precursors of adverse behaviours, and has integrated anti-stigma strategies into treatment programmes (Farina, 1998). Bruce Link has also contributed to current thinking, with his modified labelling theory and work showing stigma to be at least as important as socio-economic variables in determining symptomatology and outcomes (Link *et al*, 1991). Angermeyer *et al* (1987) used Link's 29-item Perceived Stigma Questionnaire to record perceptions of and coping styles for stigma. Younger patients were more aware of the social costs of their illness, and people with higher professional status were more likely to be encouraged by mental health professionals to keep their psychiatric status secret (Angermeyer *et al*, 1987). Mansouri & Dowell (1989) report that stigma is a significant source of distress in, for example, people with severe enduring mental illness in a community-support programme, where it correlates with self-esteem. Their study is unusual in that the majority of social psychology research has been conducted among volunteer students rather than users and carers. The key question is whether attitudes, and more importantly changes in attitudes and

behaviour, in undergraduates can be generalised to other populations. None the less, Desforges *et al* (1991) provide a useful examination of the contact hypothesis, that is, contact with someone with mental illness predicts less prejudice and more positive behaviour. Using students as subjects, they make a case that optimum contact should revolve around shared and multiple tasks (Desforges *et al*, 1991). Corrigan & Penn (1999) believe that contact will be productive only if there is equal status between the stigmatised and stigmatisers.

Capturing public opinion

There is no agreed instrument to measure stigma, but measuring public opinion about mental disorders is central to understanding and reducing it. Public opinion surveys identify levels of awareness, belief systems, fears and stereotypes of these disorders but they can be criticised for underestimating antipathy, as those unaffected or disinterested may refuse to participate in a survey and many give socially desirable responses. Taylor & Dear (1981) have developed a valid and reliable scale, the Community Attitudes to Mental Illness (CAMI), which measures attitudes across a number of key parameters. It was developed specifically for use in the community (in the context of the emptying of the asylums) and refined to quantify attitudes across four scales: authoritarianism, benevolence, social destructiveness and community mental health ideology. Hayward & Bright (1997) concluded that medical researchers tend to ask closed questions and obtain positive answers, while sociologists ask open questions, uncovering negative stigmatising answers. This is certainly untrue of recent medical research. Brockington *et al* (1993) measured UK residents' attitudes using a modified CAMI. They related fear of those with mental illness to factors such as increased age, lower occupational class and having no acquaintance with mental illness: increased age was associated with greater benevolence, and students (under 25) had the least benevolent attitudes. Within studies of this type there are many contradictions. Benevolent attitudes ("best possible care for people who are ill") may coexist with higher levels of fear: Wolff *et al* (1996b) report mostly positive attitudes in adults with young children, but high fear and exclusion scores. Identifying specific components of public opinion is essential in directing educational initiatives. Penn *et*

al (1999) describe an educational programme designed specifically to address perceived and actual dangerousness, which has had encouraging results.

Another entry into understanding the nature of stigmatisation is through the media, a single but very important source of information about issues such as mental illness. Their currency is stereotype, and the common stereotypes of mental illness correspond to the four CAMI scales above (Byrne, 1997; Wahl, 1999). Wilson *et al* (2000) have studied 128 children's television programmes, the majority made in the USA. Of these, 46% referred to mental illness references using derogatory terms (nuts, bananas, twisted, wacko, cuckoo, freak, etc.) and six had characters labelled consistently as ill, with no other redeeming characteristics. According to labelling theory children learn these stereotypes at an early age (Byrne, 1997). Read & Law (1999) comment that the mental illness stereotypes held by journalists are similar to those of mental health professionals. Clausen (1981) saw media misrepresentation as perhaps the only issue in stigmatisation, but others play down its influence:

"the public shows a remarkable capacity to enjoy the cavalcade of hypocritical, frivolous or malicious entertainment served up to it... people can be intelligent and discerning, and still chose to enjoy rubbish" (Radford, 1996).

McKeon (1998) argues for a comprehensive stigma-prevention programme, which should challenge the negative media depictions and promote a balanced portrayal of mental illness in the media. Thus, in revealing, protesting against and reducing stigma, the media is an excellent starting point. Penn *et al* (1999) devised an educational programme for young people that used written case vignettes, but these may not have the same impact as the latest tabloid headlines or 'psychokiller' film. Recent trends, for example, celebrities' disclosure of their depression and the twinning of mood disorder with creativity, may be counterproductive (McKeon, 1998). Equally psychiatrists 'coming out' may perpetuate the notion of the infectivity of mental illness. Salter & Byrne (2000) argue for a greater interaction between psychiatry and television, but on the latter's terms, acting and reacting quickly by using powerful human interest stories and restoring positive images of people with mental illness. Professionals need to continue to object to media inaccuracy: one established news-paper health correspondent commented

that he has had more complaints from dentists than from psychiatrists (Salter & Byrne, 2000). The US-based National Alliance for the Mentally Ill website, www.nami.org includes 'Stigma Busters' which provides subscribers with free e-mail updates of ongoing battles for fairer media coverage.

Solution-focused work

Everyone writing about stigma, directly or indirectly, offers ready solutions, summed up by Corrigan & Penn (1999) as: protest, education and contact. We must protest at all discriminatory practices and media misrepresentations. However, in doing so we need to keep in mind the 'rebound' phenomenon, where suppression of prejudice, insensitive protest or foisting unrealistic stereotypes onto the public may lead to a backlash (Corrigan & Penn, 1999). Educational campaigns – collaborative, culture-sensitive and comprehensive – show best results when locally based and focused on the anxieties of their target groups. There is a compelling argument that psychiatrists should extend existing psychoeducational programmes into the broader context of public education (Byrne, 2000). But education needs to be something more than psychiatric training for the lay public. People with mental illness (who have a greater than average knowledge of mental disorder) tend to be *more* negative to others who are ill (Hayward & Bright, 1997). Read & Law (1999) believe that propagation of the medical model will perpetuate stigma: information on genes and 'chemical imbalances' implies that those with mental illness have no control over or responsibility for their actions. In a study of the effect of a public education campaign on mental illness, Wolff *et al* (1996c) showed that even though knowledge about mental illness remained unchanged in their study group, attitudes and behavioural intention towards those with mental illness did improve. In addition to educational programmes, contact needs to be carefully planned (see above). All studies quoted in this paper strengthen the argument that the measures of success in treating psychiatric patients should extend beyond dopamine receptor occupancy and should include quality of life indices, markers of physical and psychological well-being and wider social contexts. Others take the arguments even further, and see this as a civil and human rights issue, advocating a

disability inclusion model (Sayce, 2000). Stigma may be topical and trendy, but it is more than exam fodder or a passing fashion. Ann Beall (quoted in Sayce 2000, p. 78) wrote:

“we are truly an outcast people. Anti-stigma work is about rediscovering common ground. Otherwise we'll always be the 'other'. We led the parade to the death camps and no-one questioned”.

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