

Combating the stigma of schizophrenia

RICHARD WARNER

The recent report on mental illness from the office of the US Surgeon General (US Department of Health and Human Services, 1999) found that the most significant obstacle to the treatment of mental disorders is stigma. Mental health professionals, people with mental illness and their family members are not likely to be surprised by this finding, having lived with this knowledge for years. But would society so readily tolerate such a situation if stigma were the greatest obstacle to the treatment of tuberculosis or cancer? Doubtless, we would mount a massive educational campaign to dispel the ignorance, the stereotyping and the negative attitudes about these disorders, much as we did when the early response to AIDS created widespread public hysteria. It seems only reasonable that we should do the same for mental illness, but in so doing, we must confront centuries of mystery and magic which surround madness, especially schizophrenia, and combat a media industry which perpetuates numerous myths.

People with schizophrenia can achieve greatness. The 1994 Nobel prize for economics was awarded to John Nash, a man with life-long schizophrenia (Nasr, 1994). One of the greatest American composers and jazz artists of our time, Theolonius Monk, suffered from the same illness (see the 1988 documentary film *Theolonius Monk: Straight No Chaser*, produced by Clint Eastwood). But achievements such as these are not what come to the mind of the person in the street when he or she thinks of schizophrenia. The modern media perpetuate a stereotype of people with schizophrenia as being violent, unreliable, lazy, unpredictable and always irrational, and of the illness as being permanent and progressive.

Mad scientists, demented doctors and crazed killers are stock-in-trade for Hollywood. The psychotic killers

in such films as *Psycho*, *Silence of the Lambs* and *Nightmare on Elm Street* perpetuate the image of the mentally ill as dangerous. Rather than present accurate information about mental illness, films often distort the truth for dramatic effect. In the psychiatric hospital scenes in *Terminator 2*, a 1991 Hollywood film viewed by 160 million people, gray-clothed patients were herded by burly attendants wielding truncheons (Wahl, 1995). Although the 1975 Academy-Award winning film, *One Flew Over the Cuckoo's Nest*, was filmed in Oregon State Hospital, the producers rejected the idea of using actual inpatients in walk-on roles because they felt they did not look strange enough (Wahl, 1995).

Two decades of content sampling of US television reveal that as many as ten percent of programs portray someone with mental illness (Fruth & Padderud, 1985). Over 70 percent of these characters are portrayed as being violent, more than half are seen as villains and a fifth are killers (Gerbner *et al.*, 1981; Signorelli, 1989). A recent prospective study of British television programs for children (primarily cartoons) found that all of the mentally ill characters portrayed were devoid of positive attributes; all exhibited bizarre behaviour, physical characteristics and dress, and half were evil (Wilson *et al.*, 2000).

One of the myths perpetuated by the media is that mentally ill people are likely to be violent. More than half of the references to mentally ill people in United Press International newspaper stories deal with someone committing a violent crime (Shain & Phillips, 1991). «Hospital Bungle Releases Beast for Sex Spree», screamed a 1996 British newspaper headline (Wolff, 1997, p.149). «(Greenwich) Village Beast May Go Free», proclaimed another in 1992 in New York City (Wahl, 1995, p. 46). In fact, people in treatment for mental illness are no more likely than members of the general public to behave violently; abusing drugs or alcohol and not being in treatment elevates the risk that a mentally ill person will act violently (Monahan & Arnold, 1996), but this level of detail is overlooked by the media. Consequently, out of fear, people often resist having treated mentally ill peo-

Indirizzo per la corrispondenza: Professor R. Warner, Mental Health Center of Boulder County, 1333 Iris Avenue, Boulder, Colorado 80304 (USA).

Fax: +1-303- 449 6029

E-mail: dick_warner@compuserve.com

ple live in their neighbourhoods. In Britain, over two-thirds of mental health service providers report encountering such «Not In My Backyard» campaigns (Repper *et al.*, 1997). As many as 50 percent of the attempts to establish group homes for psychiatric patients in the US fail because of community opposition (Piasecki, 1975). In one American city, residents objected to the placement of a group home in their neighbourhood on the grounds that there were too many young people and too many old people living there who, by inference, would be victimised by the mentally ill residents (Wahl, 1995). In a similar incident in Hong Kong, the neighbours claimed that a projected group home would be too close to a butcher's shop where the sight of knives would drive the mentally ill people to a frenzy (personal communication, Yip, 1998). The origins of violence in our society, in fact, are alcohol and drug use, poverty, male gender, youth and the availability of firearms. The most dangerous of citizens is the drunk driver; but it is the mentally ill person, not the drunk driver, who is demonised by the press.

The media sometimes portray people with mental illness as inhuman animals. Mentally ill villains on television and in films are routinely depicted as having a bizarre appearance - glassy eyed, grimacing, giggling and snarling. Under the headline «Monster Masked as a Human Being», a New York newspaper article about the trial of a man with paranoid schizophrenia expressed amazement that the accused appeared normal in the courtroom. «He clasped his hands and coughed like a normal person», ran the article, «He shifted his seat and slouched down and even dozed off, just like a human being» (Bolinger, 1994, p.1).

People with mental illness are shown as a breed apart, without family or normal connections to the fabric of society. Several surveys of US primetime television programs have shown that characters with mental illness are rarely married or have a specific job (Wahl, 1995; Fruth & Padderud, 1985; Signorelli, 1989). They are «a special, distinct class of people characterised primarily, if not exclusively, by the illnesses they suffer» (Wahl, 1995, p. 43).

The media portrayals of the mentally ill perpetuate many myths about schizophrenia; that people never recover from the illness, for example; that it is caused by poor parenting or weakness of will. In part because of the common misuse of the term «schizophrenic» in the press to mean «of two minds», two-thirds of the American public confuse schizophrenia with multiple personality disorder (Wahl, 1995).

HOW DOES STIGMA INFLUENCE OUTCOME?

How does stigma handicap people with schizophrenia? Clearly, some people refuse to accept that they have the illness because they are unwilling to see themselves as incapable, feckless or near bestial. Consequently, they reject the label and delay or evade treatment. Family members may wait months or years before bringing mentally ill relatives in for treatment, unable to conceive that he or she could fit their stereotype of mental illness and unwilling to suffer the shame.

On the other hand, those who accept the label of mental illness may unconsciously adopt the public image of the mentally ill person, seeing themselves as dependent and incompetent and functioning less well than expected, as a result (Warner, 1994). This formulation is confirmed by Doherty's (1975) study of self-labelling by psychiatric inpatients; those who accepted that they were mentally ill were rated as showing the least improvement and those who denied that they were mentally ill did better. A study by Warner *et al.* (1989) adds further support. Outpatients with psychotic disorders who accepted that they were mentally ill had lower self-esteem and lacked a sense of control over their lives. Those who found mental illness most stigmatising had the worst self-esteem and the weakest sense of mastery. The study suggests that patients can only benefit from accepting that they are ill if they also have a sense of control over their lives. Such patients are few and far between, however, since a consequence of accepting the illness label is loss of a sense of mastery. Thus, stigma puts people with schizophrenia in a paradoxical situation - accepting the illness can mean losing the capacity to cope with it.

In addition, stigma leads to discrimination against people with schizophrenia in employment, housing, access to treatment and community tolerance. Post-war US studies found that only 13 percent of employers reported they had knowingly hired a person with mental illness and a quarter of them flatly stated they would never do so (Olshansky *et al.*, 1958; 1960). A more recent US study, in which a researcher posed as an unemployed worker, revealed similar discrimination in employment (Farina & Felner, 1973). In present-day Greece, over 40 percent of the public would refuse to employ a person with mental illness, although over 90 percent would employ a physically disabled person (Parashos, 1998). A label of mental illness makes it more difficult to find accommodation (Page, 1977); a recent American study found that 40 percent of landlords immediately reject applicants with a known psychiatric disorder (Alisky & Iczkowski,

1990). Citizens fight to exclude treatment facilities and living quarters for the mentally ill from residential neighbourhoods, even though group homes for the mentally ill have been shown to have no adverse effects on communities (Boydall *et al.*, 1989). A British study documented that half of the mentally ill people surveyed reported unfair treatment by general health care services and a similar number reported being subjected to verbal and physical harassment in the community (Read & Baker, 1996).

HOW CAN WE FIGHT STIGMA?

Use of language

At an individual level we can help fight the stigma of mental illness by encouraging people to watch their language. For example, many people sensitive to stigma have stopped using the term «schizophrenic» and instead refer to «a person with schizophrenia». The concern here is that if we call someone by the name of his or her illness we negate the person within. We do not call someone a «pneumoniac» or «cancerous» because we recognise that there is more to the person than his or her illness. By using «person-first» terminology we recognise the human being behind the label.

Similarly, we can encourage people to avoid derogatory terms like «nutcase», «loony-tune» and «whacko». We have long since stopped using terms like «cripple», «nigger» or «queer» in decent company. That we continue to use derogatory terms for the mentally ill is one more illustration that mental illness is one of the last remaining bastions of prejudice in civilised society.

Neighbourhood campaigns

When neighbours of a new group home for people with mental illness in south London were surveyed, two-thirds expressed a willingness to help the new facility and showed interest in learning more about mental illness (Reda, 1995). Organisers found that this goodwill could be mobilised by a focused education campaign which encouraged neighbours to initiate social contact with mentally ill residents (Wolff, 1997). During the campaign, informational packets (video-tapes and written materials) were distributed, and social events and informal discussion sessions were organised. The campaign decreased fearful and rejecting attitudes and increased contacts between group-home re-

sidents and their new neighbours. Thirteen percent of the neighbours made friends with patients or invited them into their homes, whereas no neighbours did so in an area that was not exposed to the educational program. Campaigns which increase contact with patients can be expected to improve attitudes, since personal knowledge of someone with mental illness is associated with greater tolerance (Penn *et al.*, 1994).

Social marketing

Efforts to reduce the stigma of mental illness in the 1950s were notably unsuccessful (Cumming & Cumming, 1957), but public education methods and techniques for health promotion have improved dramatically since that time. «Social marketing» campaigns, as they are known in the communication field, have been used successfully around the world in reducing infant mortality, AIDS prevention, family planning, improving nutrition, smoking cessation and a variety of other causes. Carefully designed campaigns can have substantial effects on behaviour (Rogers, 1995; Rogers *et al.*, 1995). Effectiveness is increased by «audience segmentation» – partitioning a mass audience into sub-audiences that are relatively homogeneous and devising promotional strategies and messages that are more relevant and acceptable to those target groups (Rogers, 1995; 1996).

In developing such campaigns, it is important to gather information about cultural beliefs, myths and misapprehensions, and the media through which people would want to learn about the topic. The needs assessment method may incorporate focus groups, telephone surveys and information from opinion leaders. A pre-testing mechanism is then established which allows the initial promotional strategy – the objectives, target groups, messages and media – to be continuously refined (Rogers, 1995).

Entertainment media, such as popular songs and soap operas, can heighten awareness and provide information and are especially useful for socially taboo topics such as mental illness. Soap operas have been successful in advancing social messages in several countries. For example, a TV soap opera in China called «Ordinary People», which promotes smaller family size and AIDS education, began broadcasting in 1995 and will, in due course, reach 16 percent of the world's population. A radio soap opera encouraging AIDS awareness and family planning gained a wide audience in Tanzania and was effective in changing attitudes and sexual behaviour (Rogers, 1996).

Lobbying the news and entertainment media

Through advocacy groups, we can educate people who work in the news and entertainment media. Such groups can lobby the entertainment media to include positive characters with schizophrenia with the goal of educating the public and changing attitudes toward the illness. In the US, a group calling itself the «Soap Summit» analyses the content of soap operas (looking at such topics as teenage sexual behaviour), lobbies script-writers to change the content of their programs to create positive social messages, and measures the impact of their lobbying on content. A character with schizophrenia was recently introduced into the most widely watched program in Britain, «EastEnders.» The National Schizophrenia Fellowship reports that this story-line attracted unprecedented attention and did more to reduce stigma than any number of worthy media appeals. The program humanised the illness and exploded the myths that schizophrenia means someone has a split personality and or that it is likely to make someone violent (Frean, 1997). In Australia, a character with schizophrenia was inserted into the TV soap opera «Home and Away» in response to lobbying by a consumer group.

Local and national advocacy groups can also lobby the news and entertainment media to exclude negative portrayals of people with schizophrenia. Such groups are known as “stigma-busters” or “media-watch” groups. The stigma-busting approach calls upon members to be alert to stigmatising messages in any medium and to respond appropriately. The National Stigma Clearinghouse, begun in 1990 by the New York State Alliance for the Mentally Ill, is an example of such a program. The Clearinghouse collects examples of negative portrayals of people with mental illness from across the United States, from television, advertising, films and the print media. Members of the organisation write or phone the responsible journalists, editors or others in the media, explaining why the published material is offensive and stigmatising, and providing more accurate information about mental illness (Wahl, 1995).

An example of a successful stigma-busting intervention was the response co-ordinated by the National Stigma Clearinghouse to the advance publicity for the November 1992 issue of Superman comic reporting that the issue would reveal how Superman was to be killed by “an escapee from an interplanetary insane asylum” (Wahl, 1995, p. 145). The Clearinghouse and other advocacy groups lobbied DC Comics, explaining that depicting the

killer of the superhero as mentally ill would further add to the stereotype of mentally ill people as evil and violent. When the death issue hit the news stands the killer was no longer described as an escaped mental patient or a “cosmic lunatic”, nor depicted wearing remnants of a strait-jacket (Wahl, 1995).

The National Alliance for the Mentally Ill, in the US, moved to eliminate a similar negative image in 1984, when Hasbro Toys produced, as part of its G.I Joe series of action figures, a new villain, Zartan, with two faces and two identities, described on the box as an “extreme paranoid schizophrenic”. The National Alliance pointed out to the manufacturer that the toy communicated to children a tie between mental illness and criminality and perpetuated the inaccurate perception of schizophrenia as a form of multiple personality. Hasbro withdrew the toy with apologies (Wahl, 1995).

A national anti-stigma campaign

Building on advances in communication technology, the Defeat Depression Campaign was conducted in Britain between 1991 and 1996 with the goals of reducing the stigma associated with depression, educating the public about the disorder and its treatment, encouraging people to seek treatment early and improving professional treatment expertise. Campaign media directed at the general public included newspaper and magazine articles, television and radio interviews, acknowledgement by celebrities of their own episodes of depression, press conferences, books, leaflets in multiple languages, audio cassettes and a self-help video. A program to educate general practitioners, which included conferences, consensus statements, practice guidelines and training videotapes, was also launched (Paykel *et al.*, 1997).

Knowledge about and attitudes towards depression and its treatment were tested before, during and after the campaign and showed progressive improvement of around five to ten percent. Attitudes towards counselling and antidepressants improved during the campaign. By the end, members of the general public regarded people suffering from depression as being more worthy of understanding and support, and were more likely to acknowledge the experience of depression in themselves and in close friends. They saw depression as more like other medical disorders and were increasingly positive about general practitioners’ capacity to treat the disorder (Paykel *et al.*, 1998).

A global anti-stigma campaign

Using similar communication technology, the World Psychiatric Association, in 1997, initiated an educational program on schizophrenia focusing on social aspects of the illness, effective and humane treatment, and rehabilitation. The project aims to reduce stigma and increase awareness of the public health importance of schizophrenia. The program, which is being distributed throughout the world, is sensitive to differences between cultures, combining internationally and locally produced materials (Sartorius, 1997).

The first pilot project of this global campaign was launched in Calgary, Alberta, a city of nearly a million people, in 1997 (Warner, 2000). The local action committee, made up of representatives of consumer and family organisations, mental health professionals, health policy makers, researchers and representatives of the press and the clergy, selected the following target groups: health care professionals, teenagers, community change agents such as journalists; and the general public.

For each target group, messages and appropriate media were selected. In the case of the teenage target group the messages were

- No-one is to blame for schizophrenia
- People recover from schizophrenia
- People with schizophrenia are people with schizophrenia.

The media included

- a speakers' bureau of people with mental illness, family members and professionals which addressed high school classes across the region;

- teaching guides for health teachers;

- an internet web page (www.openthedoors.com) with information on schizophrenia;

- a competition for students to produce anti-stigma materials; and

- posters in the high schools.

Outcome results were positive. The proportion of students achieving a perfect score in a knowledge test about schizophrenia doubled to nearly 20 percent, and attitude scores also improved substantially.

The campaign to target information to journalists was also a success. Positive coverage of schizophrenia and mental illness in the local newspaper, including human interest stories, research advances and funding and program needs, increased by 35 percent in the months following the start of the campaign. Ironically, because of the co-occurrence of several major news events involving mentally ill people during this same period (such

as the trial of the Unabomber in the US and the shooting of two police officers at the US Capitol) the number of column inches of news coverage with negative content increased by 44 percent. The campaign-generated positive news stories helped offset the negative coverage.

Campaign activities targeted toward the general public in Calgary included a radio advertising campaign, newspaper stories, news conferences involving people with schizophrenia, and TV coverage of campaign events. Radio advertising was conducted for over a month over five local stations. A random-digit telephone survey of the general public was conducted before the campaign launch in 1997 and 18 months later, after airing the radio spots. More than a quarter of those contacted during the second survey, reported hearing a radio spot; however the impact on the general public was negligible. There was no improvement in knowledge or attitudes among those surveyed. In fact, there was a slight worsening of attitudes, perhaps because of the negative news events which had coincidentally occurred during the period of the campaign (Warner, 2000).

The lesson from this campaign is that efforts targeted to circumscribed groups, such as high school students and journalists, are more likely to be successful and will be more affordable, than attempts to reach everyone in the general public. Appropriate target groups might be neighbours of group homes (Wolff, 1997), general practitioners, local police, emergency room staff, families of people with schizophrenia, landlords, potential employers, and so on. The selection will be determined by local needs, but the approach is one that is basic to the concept of social marketing – segmenting the audience into small, relatively homogenous subgroups and delivering a well-honed message, relevant to the target group.

A stigma-reducing campaign need not be expensive. Many of the interventions used in Calgary were low-cost, and more expensive media, such as radio advertising, were only used to the extent that funding was available. The two-year budget for the Calgary project, including the limited media campaign directed at the general public, was under US\$ 150,000 (plus a good deal of volunteer time).

Similar local campaigns are feasible in any locality, and advice on how to conduct one is available from the World Psychiatric Association. Those who are interested in launching a similar campaign may contact Prof. Norman Sartorius at the World Psychiatric Association Programme to Reduce Stigma and Discrimination Be-

cause of Schizophrenia (Hôpitaux Universitaires de Genève, Département de psychiatrie, Belle-Idée, Bâtiment Salève, 2 chemin du Petit-Bel-Air, 1225 Chêne-Bourg, Geneva, Switzerland), for instructions on developing a local program.

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