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# The patient's perspective

*Kay Redfield Jamison and Adam Ian Kaplin*

## Introduction

It is difficult to be a psychiatric patient, but a good doctor can make it less so. Confusion and fear can be overcome by knowledge and compassion, and resistance to treatment is often, although by no means always, amenable to change by intelligent persuasion that leads to better healing. The devil, as the fiery melancholic Byron knew, is in the details.

## Delivering the diagnosis, prognosis, and plan

Patients, when first given a psychiatric diagnosis, are commonly both relieved and frightened—relieved because often they have been overwhelmed by pain, anxiety, and hopelessness for a considerable period of time, and frightened because they do not know what the diagnosis means, what the treatment will entail, and their likelihood of obtaining a meaningful response. They do not know if they will return to the way they once were, whether the treatment they have been prescribed will or will not work, and, even if it does work, at what cost it will be to them in terms of their notions of themselves, potentially unpleasant side effects, and the reactions of their family members, friends, colleagues, and employers. Perhaps most disturbing, they do not know if their depression, psychosis, anxieties, or compulsions will return to become a permanent part of their lives. Caught in a state often characterized by personal anguish, social isolation, and confusion, newly diagnosed patients find themselves on a quest to regain a sense of mastery of themselves and their surroundings. One of the main goals of therapies of all types is to empower the patient and give them some control back over their world and rechart the meaning and purpose of their lives under altered circumstances.

The specifics of what the doctor says and the manner in which he or she says it are critically important from the start and will colour the patient's ongoing treatment course for years to come. Most patients who complain about receiving poor psychiatric care do so on several grounds—their doctors, they feel, spend too little time explaining the nature of their illnesses and treatment; they are reluctant to consult with, or actively involve, family members; they are patronizing and do not adequately listen to what the patient has to say; they do not encourage questions or sufficiently address the

concerns of the patient; they do not discuss alternative treatments, the risks of treatment, and the risks of no treatment; and they do not thoroughly forewarn about side effects of medications.

Most of these complaints are avoidable. Time, although difficult to come by, is well spent early on in the course of treatment when the manifestations of confusion and hopelessness are greatest, the risk of non-adherence is highest, and the possibility of suicide substantially increased. Hope can be realistically extended to patients and family members, and its explicit extension is vital to those whose illnesses have robbed them not only of hope, but also of belief in themselves, their future, and the very meaning of their lives. The hope provided needs to be tempered, however, by an honest and realistic explication of possible difficulties yet to be encountered: unpleasant side effects from medications; a rocky time course to meaningful recovery which will often consist of many discouraging cycles of feeling the progress of marching towards wellness, only to stumble and slide temporarily backwards towards illness again; and the probable personal, professional, and financial repercussions that come in the wake of having a psychiatric illness.

## Importance of doctor-patient communication

It is terrifying to lose one's sanity or to be seized by a paralyzing depression. No medication alone can substitute for a good doctor's clinical expertise and the kindness of a doctor who understands both the medical and psychological sides of mental illness. Nor can any medication alone substitute for a good doctor's capacity to listen to the fears and despair of patients trying to come to terms with what has happened to them. A good doctor is a therapeutic optimist who is able to instil hope and confidence to combat bewilderment and despair. Great doctors are able to provide the unwavering care to their patients that they would want a member of their own family to receive, blending empathy and compassion with expertise and confidence.

Doctors need to be direct in answering questions, to acknowledge the limits of their understanding, and to encourage specialist consultations when the clinical situation warrants it. They also need to create a therapeutic climate in which patients and their families feel free, when necessary, to express their concerns about treatment or to request a second opinion. There must also be a willingness by

doctors to collaborate across medical disciplines in the care of their psychiatric patients because of the influence and, likewise, the impact of somatic diseases on mental illness—for example, there is evidence that depression predisposes people to conditions such as myocardial infarction, diabetes, and multiple sclerosis, all of which conversely increase the likelihood of depression. Moreover, persons with major depression and schizophrenia have a 40–60% greater chance of dying prematurely than the general population, due to physical health problems that are often left unattended or exacerbated by the side effects of psychotropic medications. Doctors are also frequently called upon to advocate for their psychiatric patients who are frequently stigmatized and therefore at great risk of being discriminated against by being deprived of their professional, economic, social, and cultural rights. Particular care must be taken by doctors to prevent their patients from receiving substandard care by refusing to share, against their patient's better judgement, important aspects of their mental illness with non-mental health medical practitioners.

Treatment non-adherence, one of the major causes of unnecessary suffering, relapse, hospitalization, and suicide must be addressed head-on. Unfortunately, doctors are variable in their ability to assess, predict, and facilitate adherence in their patients [1]. Asking directly and often about medication concerns and side effects, scheduling frequent follow-up visits after the initial diagnostic evaluation and treatment recommendation, and encouraging adjunctive psychotherapy or involvement in patient support groups can make a crucial difference in whether or not a patient takes medication in a way that is most effective. Aggressive treatment of unpleasant or intolerable side effects, minimizing the dosage and number of doses, and providing ongoing, frequently repetitive education about the illness and its treatment are likewise essential, if common-sense, ways to avert or minimize non-adherence.

### Communication in the digital age

The ever-expanding availability of health information technology, ranging from assistive devices (that permit regular tracking of symptoms and reminders to facilitate treatment adherence such as automated texting and telemedicine) to therapeutic tools (that provide interventions such as online cognitive behavioural therapy), will continue to improve the ease with which care can be delivered. But in the end, it is the therapeutic alliance between patient and clinician, honed and proven over two and a half millennia since the time of Hippocrates, that will and must remain central to the healing process. Technology can assist and enhance, but not replace, the doctor-patient relationship.

### Doctor as teacher

Education is, of course, integral to the good treatment of any illness, but this is especially true when the illnesses are chronic and shrouded in the secrecy that is caused by both social and personal stigma. The term 'doctor' derives originally from the Latin word for teacher, and it is in their roles as teachers that doctors provide patients with the knowledge and understanding to combat

the confusion and unpredictability that surround mental illness. Patients and their family members should be encouraged to write down any questions they may have, as many individuals are intimidated once they find themselves in a doctor's office. Any information that is given orally to patients should be repeated as often as necessary (due to the cognitive difficulties experienced by many psychiatric patients, especially when acutely ill or recovering from an acute episode) and, whenever feasible, provided in written form as well. Additional information is available to patients and family members in books and pamphlets obtainable from libraries, bookstores, and patient support groups, but, ever more commonly, information is accessible through the Internet as videos, websites, and online support groups [2, 3]. Visual aids, such as charts portraying the natural course of the treated and untreated illness or the causes and results of sleep deprivation and medication cessation, are also helpful to many [4–6]. Finally, providing the patients with self-report scales to monitor their daily progress, such as mood charts in affective disorder, not only provides invaluable clinical data, but also teaches patients and their physicians to better understand the patient's illnesses and their response to therapeutic interventions and exacerbating stressors. Family members and significant others can, and usually do, play key roles as outside sources of information which can be critically important in ensuring that the proper diagnosis is made at the outset. Patients, when they are well, also often benefit from a meeting with their family members and their doctor that focuses upon drawing up contingency plans in case their illness should recur. These meetings also provide an opportunity to shore up the support system the patient has by educating their caregivers about the nature, cause, manifestations, and treatment of their loved one's mental illness. Such meetings may also include what is to be done in the event that a psychiatric emergency arises and hospitalization is required, a discussion of early warning signs of impending psychotic or depressive episodes, methods for regularizing sleep and activity patterns, techniques to protect patients financially, and ways to manage suicidal behaviour should it occur. Suicide, globally the second leading cause of death in 15- to 29-year olds, is the major cause of premature death in severe psychiatric illnesses [7, 8], and its prevention is of first concern. Those illnesses most likely to result in suicide (mood disorders, comorbid alcohol and drug abuse, and schizophrenia) need to be treated early, aggressively, and often for an indefinite period of time [2, 10]. Lithium, which has demonstrated significant efficacy in preventing suicide, should be considered when appropriate [11]. The increasing evidence that treatment early in psychiatric illness may improve the long-term course needs to be considered in light of the reluctance of many patients to stay in treatment [10, 12, 14].

### Conclusions

The ancient proverb *medice, cura te ipsum* (physician, heal thyself) applies most pressingly to mental illness, because the rates of burnout, depression, and suicide among doctors are deeply concerning. A willingness to change the culture of medicine, so that more time, attention, and education is given to the critically important aspects of mental health, routine screening, and treatment of depression to encourage, rather than punish, seeking help.

No one who has treated or suffered from mental illness would minimize the difficulties involved in successful treatment. Modern medicine gives options that did not exist even 10 years ago, and there is every reason to expect that improvements in psychopharmacology, psychotherapy, and diagnostic techniques will continue to develop at a galloping pace. Still, the relationship between the patient and doctor will remain central to the treatment, as Morag Coate wrote more than 40 years ago in *Beyond All Reason* [13]:

'Because the doctors cared, and because one of them still believed in me when I believed in nothing, I have survived to tell the tale. It is not only the doctors who perform hazardous operations or give life-saving drugs in obvious emergencies who hold the scales at times between life and death. To sit quietly in a consulting room and talk to someone would not appear to the general public as a heroic or dramatic thing to do. In medicine there are many different ways of saving lives. This is one of them.'

#### FURTHER INFORMATION

Non-governmental mental health websites: USA  
<http://www.nami.org/>  
<http://www.dbsalliance.org/site/PageServer?pagename=home>  
 Governmental mental health websites: USA  
<http://www.nimh.nih.gov/>  
<https://www.samhsa.gov/treatment>  
 Non-governmental mental health websites: UK  
<http://www.mentalhealth.org.uk/>  
<http://www.mind.org.uk>  
 Governmental mental health websites: UK  
<https://www.nice.org.uk/guidance/conditions-and-diseases/mental-health-and-behavioural-conditions>  
<http://mentalhealthcare-uk.com>

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No one who has treated or suffered from mental illness would minimize the difficulties involved in successful treatment. Modern medicine gives options that did not exist even 10 years ago, and there is every reason to expect that improvements in psychopharmacology, psychotherapy, and diagnostic techniques will continue to develop at a galloping pace. Still, the relationship between the patient and doctor will remain central to the treatment, as Morag Coate wrote more than 40 years ago in *Beyond All Reason* [13]:

'Because the doctors cared, and because one of them still believed in me when I believed in nothing, I have survived to tell the tale. It is not only the doctors who perform hazardous operations or give life-saving drugs in obvious emergencies who hold the scales at times between life and death. To sit quietly in a consulting room and talk to someone would not appear to the general public as a heroic or dramatic thing to do. In medicine there are many different ways of saving lives. This is one of them.'

#### FURTHER INFORMATION

Non-governmental mental health websites: USA  
<http://www.nami.org/>  
<http://www.dbsalliance.org/site/PageServer?pagename=home>  
 Governmental mental health websites: USA  
<http://www.nimh.nih.gov/>  
<https://www.samhsa.gov/treatment>  
 Non-governmental mental health websites: UK  
<http://www.mentalhealth.org.uk/>  
<http://www.mind.org.uk>  
 Governmental mental health websites: UK  
<https://www.nice.org.uk/guidance/conditions-and-diseases/mental-health-and-behavioural-conditions>  
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# Public attitudes and the challenge of stigma

Nicole Votruba, Mirja Koschorke, and Graham Thornicroft

## Introduction

Stigma can be considered as an overarching term that includes challenges faced by people with mental illness related to knowledge, attitudes, and behaviour [1]. The knowledge domain includes low levels of mental health literacy, for example among the general population (ignorance); the attitudinal domain relates to almost entirely negative affect towards people with experience of mental illness (prejudice), while the behavioural aspects reflect predominantly forces for the social exclusion and diminished citizenship for people with mental illness (discrimination). This chapter considers the evidence of the implications of these elements and also summarizes the literature on what can be done to effectively reduce stigma and discrimination.

## The practical implications of stigma and discrimination

The consequences of stigma and discrimination are wide-reaching and severe, and affect people with mental disorders, their family members, mental health staff, institutions, and treatments, as well as society as a whole.

Discrimination, the behavioural consequence of stigma, adds to the disability of persons with mental illness and leads to disadvantages in many aspects of life, including personal relationships, education, and work [1, 2]. It limits the life opportunities of those affected, through loss of income, prolonged unemployment, reduced access to housing or health care, for example, and therefore reduced access to important means of recovery [3]. Commonly, people with mental disorders experience unequal treatment for physical health conditions, leading to rates of morbidity and mortality much beyond what is attributable to their primary mental disorder [4]. Discrimination because of mental illness is pervasive and universal—international studies of mental illness discrimination have shown that rates of both anticipated and experienced discrimination are consistently high across countries among people with mental disorders [5–8].

Yet another form of devaluation takes place when individuals affected by mental illness stigma accept the negative beliefs held against them and lose self-esteem, resulting in self-stigma (or ‘internalized stigma’) [9–11]. Internal consequences of stigma and

discrimination have been the subject of a number of studies and include feelings of shame, a loss of emotional well-being, poor self-efficacy, and negative recovery outcomes [12–19].

What self-stigma can mean is vividly described in a quote by Gallo [20, pp. 407–8] quoted in Angell *et al.* (2005) [21]—a statement from a person with mental illness on how stigma and discrimination have changed the way she feels about herself:

‘I perceive myself, quite accurately, unfortunately, as having a serious mental illness and therefore as having been relegated to what I called “the social garbage heap”. I tortured myself with the persistent and repetitive thought that I would encounter, even total strangers, did not like me and wished that mentally ill people like me did not exist. Thus I would do things such as standing away from others at bus stops and hiding and cringing in the far corners of subway cars. Thinking of myself as garbage, I would even leave the side walk in what I thought of as exhibiting the proper difference to those above me in social class. The latter group, of course, included all other human beings.’ [20]<sup>1</sup>

Internal consequences of stigma and discrimination can further lead to hopelessness and depression, social withdrawal, and reduced participation in treatment programmes [3] and act as a stressor that perpetuates ill health and makes recovery more difficult [22, 23]. Coping responses, such as secrecy about the condition and avoidance of others, further feed into the cycle of isolation and alienation [3].

In addition to experiences of direct discrimination from others, persons suffering from mental illness face several forms of structural discrimination, for example manifest in the lack of resources allocated to the care of mental disorders, the location and quality of some treatment facilities, and inadequate attention to the physical health needs of people with mental disorders [24, 25].

Paradoxically, stigmatizing practices and even human rights violations are found within mental health services worldwide [26–28]. Undesirable conditions in mental health institutions, as well as the shame and fear of disclosure associated with attending them, act as a barrier for help-seeking and the effective treatment of mental health

<sup>1</sup> Reproduced from *Schizophrenia Bull.*, 20(2), Gallo KM, First person account: Self-stigmatization, pp. 407–410, Copyright (1994), with permission from Oxford University Press.

conditions [29]. For example, people with mental disorders may delay seeking treatment or terminate treatment prematurely for fear of being labelled and discriminated against [3, 30].

A statement from Diana on restrained treatment by health-care professionals in a psychiatric hospital:

"There were between six and eight staff members, I am not sure, I can't remember too much. I didn't have a very clear vision. I saw people surrounding me, holding me by the hand, holding me by the legs. I don't think it was something they had to do. There was no talking. They would have helped better if they would have been more understanding and more talking... more respect. I felt really bad. While I was in hospital I tried to complain but I don't know if anybody was listening. It was a nightmare." [1, p. 87]<sup>3</sup>

Another very commonly cited source of stigma is family members. Even although many people experience great support from their families, it is family members too who often hold negative attitudes towards people with mental illness and even within their families treat them in a discriminatory way.

"There I was, the eldest son suffering a sudden deep depression, crying and unable to work. Often threatened by my confused Dad as being "weak", "a fuck-up", and a "nutter". No-one else in the family going back generations had gone "mad like that". I was told not to tell any of the neighbours what was happening – to stop the gossip. (Paul) [1, p. 2]<sup>4</sup>

In many societies where services are scarce and support systems inadequate, families feel forced to resort to chaining and other practices to restrain relatives with mental illness [28, 31].

Research has shown that mental health professionals themselves hold negative stereotypes and attitudes similar to the general population and even more pessimistic views in the domain of recovery, possibly due to their disproportionate contact with those with poorer outcomes [32]. Service users commonly report lack of empathy and interest from health professionals, diagnoses being given with negative prognosis, and lack of information and involvement in decision-making [33].

"Some of the worst experiences I have had have been in psychiatric hospitals. I recognise the need to be kept safe but often I have felt that my rights and dignity have been stripped away. Being intimately searched again and again and constantly followed whilst under "close observation" just leaves me feeling singled out and perceived as little more than a nuisance ("there's to be no trouble on my shift") [... ] I have heard many comments along the lines of "Oh, she's cut again. Why doesn't she do it properly and kill herself". (Sandra) [1], p. 94<sup>5</sup>

Stigma and discrimination do not only affect persons suffering from mental illness, but also families [34–36]. The effect of negative attitudes towards the family members of people with mental illness has been described as 'stigma by association' and may lead to

experiences of direct discrimination, as well as feelings of shame and self-blame [1]. In societies where the cohesion of family networks is strong, the impact of stigma by association may be severe and can include economic consequences, as well as impact on work or marital prospects [37].

### Contextual factors relevant to stigma and discrimination

The manifestations of stigma and discrimination are subject to the influence of a range of cultural and contextual factors [38]. Key domains through which culture shapes the manifestations of stigma include: (1) notions of 'mental illness' and explanatory models (for example, in many settings, psychiatric symptoms may not be seen as indicative of an 'illness'); (2) cultural meanings of the impairments and manifestations caused by the disorder and its stigma (for example, the impact of stigma on marital prospects may have more severe implications in cultural contexts where marriage is central); and (3) notions of self and personhood (for example, higher levels of family cohesion may offer more support but also go along with a more widespread impact of stigma across family members and generations).

Also socio-economic factors, such as poverty and access to health care, determine the context in which stigma is enacted and experienced [7, 9, 39, 40]. In low- and middle-income countries (LMICs) and other settings where most people with mental illness do not have access to social welfare benefits, the negative economic consequences of stigma, for example, through discrimination in work, may be so severe as to threaten the economic survival of entire families [41].

### Global patterns of stigma and discrimination

There are few studies comparing the frequency of experiences of stigma and discrimination in different contexts, and recent research has sought to address this gap in the literature. International surveys of experienced and anticipated discrimination among people with schizophrenia (27 countries) and among people with depression (39 countries), for example, found rates of both outcomes to be consistently high across cultures [5, 7, 8]. Significant between-country variation was found for experienced discrimination, but not for anticipated discrimination reported by people with schizophrenia [7]. A report on the qualitative data collected as part of the same study, however, found few transnational differences [6]. Another study looking at public attitudes across 16 countries identified a 'backbone' of certain prejudices that were held across all settings, even where overall stigma was relatively low [42].

On the other hand, some smaller studies suggest stark differences between high-income country (HIC) and LMIC settings, for example, studies from China [43] and India [41], with rates of experienced discrimination much lower than those commonly reported from HIC studies, and qualitative differences in the meaning and appraisal of the experiences made. At first sight, this appears to support the findings of early cross-cultural research on stigma, suggesting that the stigma of mental illness may be less marked in non-industrialized societies due to a more supportive environment with more social cohesion, and

<sup>3</sup> Reproduced from Thornicroft G, *Shunned: Discrimination against people with mental illness*, p. 87, Copyright (2006), with permission from Oxford University Press.

<sup>4</sup> Reproduced from Thornicroft G, *Shunned: Discrimination against people with mental illness*, p. 2, Copyright (2006), with permission from Oxford University Press.

<sup>5</sup> Reproduced from Thornicroft G, *Shunned: Discrimination against people with mental illness*, p. 94, Copyright (2006), with permission from Oxford University Press.

therefore less risk of prolonged rejection, isolation, segregation, and institutionalization [44, 45; 46, 47 cited in 48]. The better prognosis of schizophrenia found in international studies by the World Health Organization (WHO) [49–52] has therefore commonly been attributed to less stigmatization in LMICs [53].

Yet, in contradiction to this, there is now a considerable body of evidence documenting that in many LMIC settings, experiences of stigma, discrimination, and human rights abuses due to mental illness are common and severe [5, 11, 27, 37, 54–62]. One international study using population-wide data from 16 countries found even higher rates of reported stigma among people with mental disorders in developing (31.2%) than in developed (20%) countries [55].

In conclusion, our understanding of global patterns of stigma and discrimination is still rather limited to date, and further high-quality cross-cultural research is needed to throw light on the forces that drive intercultural differences in the manifestation of stigma. Understanding the factors that shape stigma distinctly in different contexts will serve to inform the development of context-specific anti-stigma interventions.

### How to measure stigma

Alongside the development of research into stigma, the creation and validation of instruments to measure stigma and discrimination took their beginnings in the 1960s. Early scales focused largely on the measurement of stigmatizing attitudes among the general population. Since, numerous scales have been developed, incorporating a wider range of perspectives on stigma and discrimination, notably the inclusion of the perspectives and experiences of service users and carers [63]. Nevertheless, there continues to be a distinct lack of measures developed or validated in LMIC settings and/or non-Western cultures [64]. Several methods have been put forward which seek to achieve cultural validity of measures of stigma and discrimination, including an approach by Yang *et al.* which proposes to focus on 'what matters most' in a given culture [65, 66]. A recent review concluded that future efforts in the domain of measuring stigma and discrimination should focus on: (i) procedures for achieving cultural validity of measurement tools, (ii) indicators for structural stigma and stigmatizing behaviour (underrepresented in current scales), and (iii) targeted or tailored measures for specific subgroups, all with a particular focus on LMIC countries where literature is sparse [63]. This is important as the appropriate measurement of stigma and discrimination is critical to understanding whether and how anti-stigma interventions are effective [63].

### How to tackle stigma

The critical question to tackle stigma in mental health is: what interventions work? In the past years, research on anti-stigma interventions to change knowledge, attitudes, and behaviour towards people with mental illness has increased. Most interventions aim at changing one or several of these aspects through education, social contact, or behavioural interventions.

A recent narrative review concluded with the following main findings on the evidence of anti-stigma interventions [64]:

- (1) 'at the population level there is a fairly consistent pattern of short-term benefits for positive attitude change, and some lesser evidence for knowledge improvement;
- (2) for people with mental illness, some group-level anti-stigma interventions show promise and merit further assessment;
- (3) for specific target groups, such as students, social-contact-based interventions usually achieve short-term (but less clearly long-term) attitudinal improvements, and less often produce knowledge gains;
- (4) this is a heterogeneous field of study with few strong study designs with large sample sizes;
- (5) research from low-income and middle-income countries is conspicuous by its relative absence;
- (6) caution needs to be exercised in not overgeneralising lessons from one target group to another;
- (7) there is a clear need for studies with longer-term follow-up to assess whether initial gains are sustained or attenuated, and whether booster doses of the intervention are needed to maintain progress;
- (8) few studies in any part of the world have focused on either the service user's perspective of stigma and discrimination or on the behaviour domain of behavioural change, either by people with or without mental illness in the complex processes of stigmatisation.<sup>5</sup>

It has been found that generally the effectiveness of the interventions depends much on the target group and the time frame of the intervention. However, most studies are short-term effectiveness studies looking at attitudes of the general public towards people with mental disorders in HICs. The most widely evaluated interventions are education/information and social contact [63].

Overall there remains a large knowledge gap for medium- to long-term anti-stigma interventions, and particularly for interventions in low-income countries where evidence is almost absent [63]. There is also a need for: (i) more high-quality interventions based on robust methods and validated measures, (ii) more systematic reviews on long-term effectiveness, (iii) more randomized controlled trials, and (iv) more evidence from LMICs [67].

### Social contact-based interventions

Interventions using social contact as a key element have been found to be the most effective type of interventions [68]. At the same time, social contact is also the best evidence-based intervention, particularly in short-term outcomes. Evidence from systematic reviews suggests that social contact is the most effective intervention in terms of achieving short-term improvements in knowledge and attitudes among adults.

An account by a young man who participated in the German school project 'Crazy? So what!':

'Eight years ago I became ill: I developed schizophrenia [ ... ]. I've been feeling better now for two years. But I do have to take good care of myself. But hiding because of that? These times are over. I finally want to live now! Talking to the students is exhausting but also really great [ ... ] they discover that there are a lot more commonalities than differences between us, that their images of the 'crazy ones' are

<sup>5</sup> Reproduced from *The Lancet*, 387(10023), Thornicroft G, Mehta N, Clement S, *et al.*, Evidence for effective interventions to reduce mental-health-related stigma and discrimination, pp. 1123–1132, Copyright (2015), with permission from Elsevier.

not true. It feels really good to contribute to achieving that we finally can talk openly about mental illness, and that nobody has to hide because of a mental health problem.' [69]<sup>a</sup>

Social contact is the most effective type of intervention in the short term, but it is not clear whether effectiveness is sustained in the medium to longer term [67]. While social contact has been reported to be the most effective intervention in adults, these evaluations are mostly based on intervention studies from HICs. There is a great need for more evidence from LMICs to assess whether social contact is as effective there and how to implement it to suit local requirements. In addition, more research is needed to investigate the long-term effectiveness of social contact interventions.

### Educational interventions

'The [...] practical way to stop stigma and discrimination is by better education of schoolchildren at an early age and to reinforce this message through lifelong learning. Each course or class should not only start with "household" messages about fire escapes, etc., but that bullying or discrimination will not be tolerated whilst on the course.' (Paul) [1]

(Thornicroft, 2006)

While direct social contact interventions have been found to be the most effective intervention in adults, systematic reviews have found that in students, educational interventions are more effective in reducing stigma in students' knowledge and attitudes in the short term. However, the evidence base for effectiveness in the medium to longer term is weak [64]. A meta-analysis found both social contact as well as educational interventions reduce stigma significantly and, importantly, irrespectively if these interventions are delivered face-to-face or via Internet programmes [70]. Moreover, Thornicroft *et al.* have found evidence that education and information seem to be the most effective interventions in the medium and long terms [64]. Evaluations in HICs have found that stigma and discrimination against people with mental illness can be reduced through focused, long-term information campaigns like Time to Change in the United Kingdom (UK) [71]. High-quality effectiveness evaluations for educational interventions are scarce for LMICs. Several national and regional campaigns from LMICs report qualitative changes in attitudes and behaviour; however, these effects lack high-quality evaluation for quantitative efficiency [72].

### Behavioural domain

Overall the effect of behavioural therapy and psychotherapy has not been sufficiently researched. In persons with mental illness, psychoeducational therapy, including elements of cognitive behavioural therapy (CBT), seem to be effective in reducing self-stigma

<sup>a</sup> Reproduced from *Informationsbroschuere (Information brochure), Stark, wenn sich einer traut ueber seelische Probleme zu reden! Verrueckt? Na und! Das Schulprojekt von Irrsinnig Menschlich e.V. (Cool when someone dares to speak about mental health problems! Crazy? So what! The School Project of the Association Irrsinnig Menschlich e.V., Copyright (2002), with permission from Irrsinnig Menschlich e.V.*

[73]. Yet, CBT has been found not to be effective in reducing stigma in other groups.

For medium- or long-term outcomes, systematic reviews have found there was not sufficient research to believe psychotherapy or entertainment/arts interventions can help to reduce stigma [64].

### Conclusions

From this discussion, the authors draw the following conclusions. Stigma and discrimination appear to be universal in their presence and impact, although there are clear local and regional variations in their content and manifestations. Lay stigma by the general public constitutes a powerful force for social exclusion, and in addition there is also strong evidence that stigma among health-care professionals is a powerful barrier to the mental and physical health care needed by people with mental illness. There is now increasingly strong evidence that personal and social contact methods, including filmed/virtual contact, is the most strongly evidence-based method to reduce stigma and discrimination. This evidence is now accumulating at inter-personal, organizational, and national levels. But as yet, there are few longer-term studies to know if such gains are sustainable in the long term. Nearly all the research evidence is from HICs, with a distinct evidence gap from LMICs. For the future, it is clear that service users are the central pioneers/key active ingredients in anti-stigma programmes and that interventions specifically locally and culturally adapted for use in LMICs are a pressing priority.

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