

Draft

The fight against stigma

Stigma reduction strategies and interventions

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stigma workshop to be held at
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Abstract	3
Introduction	4
The concept of stigma	5
The impact of stigma	6
Methodology	8
HIV/AIDS	9
Education	9
Contact	10
Coping skills acquisition	11
Counselling, Care and support	11
Advocacy	11
Legal and policy interventions	12
Leprosy	14
Education	14
Community Based Rehabilitation	15
Group counselling	16
Conclusion	16
Tuberculosis	17
Conclusion	18
Mental Illness	19
Protest	19
Education	20
Contact	20
Conclusion	22
Epilepsy	24
Education	24
Individual support	25
Conclusion	26
Disability	28
Conclusion	29
Discussion, differences and similarities	30
Individual level	30
Societal level	30
Structural level	32
Appendix 1 Working definitions	34
Appendix 2. An overview of the consequences of stigma and discrimination in different fields of public health.	37
Appendix 3: Overview of strategies and interventions implemented.	39
Reference List	42

Abstract

Many people with mental illnesses, leprosy, HIV/AIDS, disability, epilepsy, tuberculosis and other conditions are severely affected by health-related stigma and discrimination. This paper is one out of three background papers prepared for the international workshop on health-related stigma, 2004 and concerns stigma reduction strategies and interventions. This paper aims to give an overview of the (effective) strategies that are being implemented.

A substantial amount of work has been conducted on health-related stigma and related issues; unfortunately not much work has been done on the effectiveness of stigma reduction strategies. Within HIV/AIDS most interventions derive from education, contact, coping skills acquisition, counselling and care and support, advocacy, and legal and policy interventions. A multi-strategy however, is seen as a more promising strategy. In the leprosy field, most interventions derive from education, community based rehabilitation, and group counselling. The last two strategies are increasingly being implemented as they are regarded as promising strategies. Within TB there have been very few projects that aimed to reduce stigma. The articles that did describe attempts to reduce stigma dealt with interventions based on education. For mental illness, three strategies clearly appeared from the literature found; protest, education and contact. Evaluations of protest studies showed very limited effects; education and contact were more successful. Here also, a combination of strategies is suggested to be more effective. Stigma reduction in the epilepsy field is based on education and individual support. Here, the focus has mainly been on the patient and his experiences, whether perceived or enacted, with stigma. Finally, within the broad field of disability, interventions found were based on education and focused on the individual level.

From these findings it becomes clear that not much evidence exist for the effectiveness of many of the stigma reduction strategies found, therefore there is still a lot of work that needs to be carried out.

Stigma Reduction Strategies and Interventions

Introduction

Many people with mental illnesses, leprosy, HIV/AIDS, disability, epilepsy, tuberculosis and other conditions are severely affected by health-related stigma and discrimination. Stigma is increasingly recognised to have a major impact on public health interventions. Occasionally, this impact is positive, but usually stigma and (fear of) discrimination lead to delay in presentation to the health services, prolonged risk of transmission, poor treatment adherence and increased risk of disability and drug resistance. A substantial amount of research has been done on stigma and related issues in each of these health fields, but little effort has been made to synthesise all this work and the experiences that have been collected over the years. Great potential exists in pooling these research findings and experiences. From the 28th of November till the 2nd of December 2004 a workshop will be organised in which work done on stigma in the public health fields mentioned above, will be reviewed and in which experiences and research findings will be shared. The workshop will bring together the lessons learnt in these different fields of public health and aims to 1) develop a joint and operationally useful concept and model of health-related stigma, 2) identify crosscutting strategies and models of interventions for reducing health related stigma at different levels, and 3) develop or adapt test instruments to assess key features of stigma and discrimination. Prior to the workshop three background papers have been written, all reviewing the literature on health related stigma and discrimination. The contents of these papers are: concepts and theoretical frameworks, stigma assessment tools and stigma reduction strategies and interventions. This paper concerns the stigma reductions strategies and interventions and aims to give an overview of the (effective) strategies that are being implemented.

Before proceeding, we must clarify the difference between interventions and strategies. According to the Oxford Dictionary a 'strategy' is defined as 'a plan, or policy designed to achieve a particular goal'; an 'intervention' is defined as 'the interference to prevent something or to change the result'. Interventions derive from strategies. Several strategies for stigma reduction often re-occur in the literature.

These strategies are included in the table below. Within these strategies, numerous interventions, each with specific target groups, content and duration are being implemented. Interventions and strategies can be implemented at different levels in society: the individual (infected and affected) level, societal level and structural level (Hulscher et al. 2000). Each level has specific strategies, which can overlap. Some strategies tackle stigma directly while others create an enabling environment to do so.

Table 1: Stigma Reduction Strategies¹

Level	Individual Level	Societal Level	Structural Level
Strategies	Treatment Care and Support Empowerment Counselling Community Based Rehabilitation	Protest Education Contact Coping Skills Acquisition Advocacy	Legal and Policy Interventions Institutional Interventions Rights-based Approach

Many programs have used stigma-reduction strategies and have implemented specific interventions to reduce stigma. However, the effectiveness and impact of these strategies and interventions are rarely evaluated. This paper aims to bring together different strategies and interventions that have been used in the field of HIV/AIDS, leprosy, TB, mental health, epilepsy and disability, and tries to identify differences and similarities in the approaches used to reduce stigma.

The concept of stigma

In many health conditions stigma is receiving increasing attention. Following Goffman (1963) many authors define stigma as an undesirable or discrediting attribute reducing an individual's status in the eyes of society (Brown et al., 2001; Link & Phelan, 2001; Weiss, 2001). Several authors have tried to revise the concept. Link and Phelan proposed a definition of stigma that includes the context in which stigma originates and exists. Stigma exists when: "... elements of labelling, stereotyping,

¹ Definitions of these strategies can be found in appendix 1

separation, status loss, and discrimination occur together in a power situation that allows them” (Link & Phelan, 2001:377). Stigma is a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons. People who are stigmatised are usually considered deviant or shameful for some reason or other, and as a result are shunned, avoided, rejected, or discriminated. As such, stigma is an expression of social and cultural norms, shaping relationships among people according to those norms. Stigma must be regarded as a social process in which people out of fear of the disease want to maintain social control by contrasting those who are normal with those who are different (Parker & Aggleton, 2001). Stigma and discrimination produce thus social inequality. Stigma marks the boundaries a society creates between "normals" and "outsiders," between "us" and "them." (Link & Phelan, 2001) Stigma builds upon, and reinforces, existing prejudices (Herek & Glunt, 1988). It also plays into, and strengthens, existing social inequalities – especially those of gender, sexuality and race (Brown et al. 2001; Nyblade et al. 2003; Heijnders, 2004).

The impact of stigma

Important life areas that are commonly affected by stigma are people’s dignity, social status, employment opportunities or job security, marriage, family relationships and friendships. Stigma may be ‘enacted’, as in the case of overt discrimination or ‘perceived’. ‘Perceived’ stigma (also called ‘felt’ or self-stigma) has widespread and powerful effects. It is sometimes based on enacted stigma observed in others, but more often on past images of the disease and stereotypical thinking (de Stigter, de Geus, & Heynders, 2000; Scambler, 1998; Green, 1995; Jacoby, 1993). Self-stigmatising behaviour may even enforce enacted stigma, by creating a ‘victim’ attitude and response (Valencia, 1989). Perceived stigma is fuelled by fear and may result in the same restrictions of social participation as ‘enacted’ stigma or discrimination. Importantly, fear of stigma may also jeopardise a person’s participation in public health programmes. They may delay to present to the health services, increasing their risk of disability and continuing to be a potential source of infection in the community. Concealment is also common after diagnosis (Engelbrektsson, 1999; Heijnders, 2002). In HIV/AIDS, stigma links in with denial of risk. Since the activities that put someone at risk are perceived as “immoral and bad”, most people would deny their risk on the basis that they do not want to be considered

“bad” (WHO, 2002; Nyblade et al. 2003). However, continuation of these activities exposes them to infection and prolongs the risk of themselves and their partners. Fear of ‘being found out’ and its possible consequences may lead to discontinuation of treatment (Hyland 1993; Heijnders 2002). Similarly, stigma may lead to non-compliance with self-care routines in e.g. leprosy and diabetes, leading to worsening of impairments. In contrast, however, Heijnders (2002) found that fear of stigmatisation also strongly motivated some people to continue treatment, because they related the treatment with the prevention of visual symptoms of the disease and thus prevention of stigmatisation. The consequences of stigma and discrimination are summarised in appendix 2.

Methodology

A literature review was conducted to identify work done to date on effectiveness of stigma reduction strategies and interventions. The references were found using ScienceDirect, Pubmed and PsychInfo, with stigma, the specific health field, and interventions as main keywords. The bibliographies of relevant papers were reviewed, and an Internet search was conducted using the same keywords. Other keywords like strategies, implementation, project* and effectiveness* were used to either generate more results or to narrow down the search. Studies with no element of evaluation were not included. Reviews were given priority. If no reviews existed we included original articles. The search was limited to English and Dutch documents published in peer-reviewed journals after 1990. For the field of disability we had to include documents published before 1990.

We will first look at the different health fields and the strategies that have been used to implement stigma-reduction interventions. Where possible we will look at the effectiveness of the specific interventions. In the discussion we will present an overview of main findings and compare the differences and similarities between the health fields discussed.

HIV/AIDS

Ever since the first case of HIV/AIDS was detected and the epidemic began to spread, stigma has surrounded this disease. Twenty years later the Global Campaign 'Live and Let Live!' stated: 'Despite 20 years since the discovery of AIDS and the scientific advances gained, there is still much denial, discrimination, fear and stigma all over the world - even in countries where large numbers of people are infected' (WHO, 2002). The most devastating effect of stigma in the field of HIV/AIDS is the failure of preventive measures, causing continued transmission. An advantage of fighting stigma is that it would help reduce HIV-transmission (Brimlow et al, 2003). We will look at these strategies mainly focusing on the work of Brown et al. (2003), as this was the only review found. Where needed we have complemented their findings with some of the articles found through our literature search. Brown et al. (2003) found that multi-strategy and multi-level approaches are more effective in raising knowledge and reducing stigmatising attitudes, than single approaches, like education and contact. Below, the strategies that dominate the literature on stigma reduction strategies in the field of HIV/AIDS are discussed.

Education

The first strategy found is education. This strategy is often the first step in stigma reduction and is often combined with other strategies. Education includes interventions that aim to inform the general public and health professionals by replacing false assumptions with accurate information. Information given is mostly about the modes of transmission, treatment, etc.

Most studies gave mixed results on attitude change (Brown et al, 2003). Only four studies are described in which only educational approaches were used and these studies all had a positive effect measured as an increased tolerance of people living with HIV/AIDS (PLWHA). However, most studies gave mixed results on attitude change. For example the study by Ashworth et al. (1994) aimed at poor black women applying for certification in a Women, Infant and Children programme in the U.S. showed that their increased knowledge did not lead to long-term changes (Ashworth et al. 1994). This failure to reduce fear through education was also noted in interventions aimed at health workers. Herek et al. (2002) found mixed results for

educational interventions. He found that educational efforts were effective in improving knowledge on HIV/AIDS transmission but the efforts did not convince the general public that HIV/AIDS could not be transmitted through casual contact. Education as a strategy is often documented in the literature (e.g. Monico et al, 2001; Foreman et al, 2003; Kidd & Clay, 2003; Nyblade, 2003; Siyam’Kela, 2003; Crompton, 2004; Hikuam, 2004; Morrison & Cuadra, 2004; Morrison et al. 2004; Savariaud, 2004). Education can be regarded as an important strategy, one, however, that is not always effective. The review of Brown showed that the effectiveness of educational approaches can be best increased in combination with other approaches, like contact and skills building.

Contact

Contact, used within the field of HIV/AIDS, refers to all interactions between the public and persons affected or infected by HIV/AIDS with the specific objective to reduce stigmatising attitudes. Contact can either be direct and face-to-face, or vicariously (e.g. through the media). Interventions derived from the contact strategy can be targeted at groups, individuals and as some authors have proposed, even to an entire nation, demonstrated by the influence of the ‘coming out’ of influential, popular people like Magic Johnson (Herek et al. 2002). Contact interventions can use these types of media images, but also video-presentations and individual encounters with persons infected with HIV. According to the WHO (2002) personal contact with someone affected by or infected with HIV can help dispel myths about the disease, and generate empathy and understanding. The review by Brown et al. (2001; 2003) describes the potential positive outcomes of contact as a strategy. However, there are no results given that confirm this expectation. They argue that a more personal relationship with a person affected by HIV or hearing of a testimonial will demystify and dispel misinformation and generate empathy. They further conclude that a contact strategy in combination with an educational approach is one of the most promising approaches. In a project in the UK an artist educates schoolchildren about HIV with art. After several lessons he discloses that he has HIV himself. Through education, acceptance and their friendship with him, the children develop a bond and regard HIV-positive people as normal (Leigh, 2004).

Coping skills acquisition

Interventions derived from coping skills acquisition strategies aim to teach skills for diffusing conflicting situations at the individual or group level (Brown et al. 2003). Two studies used a combination of education and coping skills acquisition. One study aimed at primary school children in Tanzania (Klepp et al. 1997), the other study aimed at physical therapy students in New York (Held, 1992). Coping skill acquisition consisted of discussions about risk reduction and perceptions of HIV risk factors. Attitudes towards people affected by HIV/AIDS had in both studies improved.

Counselling, Care and support

The care and support strategy includes interventions aimed at the infected or affected individual or group that aim to empower. Brown et al (2003), did not mention care and support as a strategy though their counselling strategies are related. For these they found that in combination with educational interventions they generated a positive effect. Two studies found a reduction in anxiety and distress, three other studies found an increase in disclosure of one's positive status and improved community attitudes.

The care and support strategy can also aim at the community and health workers. Nyblade et al. (2003) argue that while people with HIV/AIDS do get care from their family, community volunteers, and the health care providers, this care can come with stigma. It is therefore important to educate those caring and supporting HIV affected persons about the language they use, available resources, possible care and support and to mobilize the communities to come into action (Kidd, 2003).

Advocacy

No study was found which looked into the effectiveness of advocacy approaches within HIV/AIDS. Advocacy programmes work towards provision of an enabling environment, address governments to influence them to change policies and discriminatory laws, and to better access to treatment and care for persons with HIV/AIDS. Advocacy interventions go beyond education, they try to seek support, commitment and recognition from policy and decision-makers and the general public about the problem (Hamand, 2001). The International Planned Parenthood Federation (IPPF) has published an Advocacy Guide (Hamand, 2001), in which

numerous advocacy activities and projects are described in detail. Another organisation, which is concerned with advocacy activities, is ACORD. Their projects in Uganda and Burundi recognised care and advocacy strategies as the key strategies to challenge HIV/AIDS- related stigma and discrimination (Hadjipateras, 2004).

Legal and policy interventions

Legal and policy interventions make up a strategy since they all aim to enforce the protection of rights of people suspected to be or people infected with HIV/AIDS. The WHO mentions setting policy guidelines and confidentiality, strengthening the legal framework and mandatory testing and encouraging political, community and religious leaders to provide leadership as possible interventions. According to the authors: “Policies on discrimination, access to prevention and care, confidentiality of care and individual’s rights can make a significant impact” (WHO, 2002). Though interventions on this level are widely implemented (e.g. Foreman et al, 2003; Monico et al, 2001; Mahendra & Gilborn, 2004; Samaras, 2004) there are no evaluations found.

In this regard, Parker and Aggleton (2003) aim to present a new framework to understand HIV/AIDS-related stigma and its effects, which also highlights the limitations of individualistic modes of stigma alleviation and proposes a new approach to reduce stigma in the future. According to them: “... our collective inability to more adequately confront stigmatization, discrimination and denial in relation to HIV and AIDS is linked to the relatively limited theoretical and methodological tools available to us” (Parker & Aggleton, 2003:14). They stress that stigma and discrimination take place in specific cultures and contexts and as a result generalised strategies to reduce stigma might not be effective. They especially criticise individual level interventions which: “... could never be scaled up in the manner required for an efficacious response throughout Africa, Asia, Central and Southern America” (Parker & Aggleton, 2003:21). Such interventions should be complemented with other modes of stigma reduction and the authors propose to look for interventions that address community mobilisation and social transformation.

Ultimately, together with a new emphasis on community mobilization aimed at unleashing resistance to stigmatization and discrimination, structural interventions aimed at developing a rights-based approach to reducing HIV and AIDS-related

stigmatisation and discrimination should be a high priority in order to create a transformed social climate in which stigmatisation and discrimination will no longer be tolerated (Parker & Aggleton, 2003).

Conclusion

Though a lot has been done, only a limited number of HIV/AIDS stigma reduction interventions have been evaluated. Most of the studies reviewed by Brown et al. (2003) used some form of multi-strategy design to stigma reduction. The strategy of education in combination with coping skill acquisition and contact is the most promising approach. These approaches appear effective at least in the short term and on a small scale. However, actual evidence of long-term effects is weak or lacking. One reason is a lack of appropriate tools to measure stigma. Studies to develop such tools are underway and several instruments are now available for piloting (Siyam'kela, 2003). Ideally, a multi-strategy and multi-level approach would give the best results in the fight against stigma and discrimination (Brown et al, 2003; Foreman et al 2003; Parker & Aggleton, 2003). If interventions are being implemented it is imperative that they will be evaluated. The development of clear stigma indicators should be made available for this purpose.

Leprosy

A number of articles describe interventions to reduce stigma related to leprosy. Three articles originally came out of our search on effective interventions to reduce leprosy-related stigma (Awofeso, 1992; 1996; Floyd-Richard & Gurung, 2000). A hand-search of relevant bibliographies resulted in another six articles (Gershon & Srinivasan, 1992; Raju & Kopparty, 1995; Opala & Boillot, 1996; Croft & Croft, 1999; Nash, 1999; Lynch, 2000; Arole et al. 2002).

Education

Awofeso studied ways to diminish leprosy stigma, starting with education and later adding socio-economic reintegration. His first article described the knowledge and attitudes of Nigerian nurses towards leprosy. He found that, due to a lack of knowledge, the nurses feared leprosy, resulting in stigmatising attitudes (Awofeso, 1992). To increase awareness and decrease stigma, the author proposed to include leprosy in the basic training of nurses.

Education has been considered successful in reducing leprosy-related stigma by a number of authors (Awofeso, 1992; 1996; Croft & Croft, 1999; Floyd-Richard & Gurung, 2000; Lynch, 2000; Arole et al., 2002). The effect of education has been subject of discussion. In their study on the impact of knowledge on the attitudes towards leprosy patients, Raju and Kopparty (1995) pointed out that the knowledge of the community about leprosy correlated poorly with attitudes towards people affected. Opala and Boillot (1996) discussed in detail the failure of education campaigns aimed at achieving attitude and/or behaviour change at the community level. They describe a Leprosy Control Programme among the Limba in Sierra Leone that managed to change behaviour towards treatment and people affected by leprosy, but failed to change the traditional beliefs about the disease. They emphasised the importance of taking into account the underlying world-view of the target group in messages about leprosy. Education messages should be meaningful in the context of culture: "... as long as the traditional world view persists largely unchanged, some changes in behaviour are very difficult to effect. The only way health workers can overcome those limits is by appealing to their patients within the framework of their world view – by shaping a message consistent with their traditional way of thinking" (Opala &

Boillot, 1996:17). The National Leprosy Elimination Campaign in Nepal is a good example. This campaign was initiated by the WHO but acted out by national organisations, companies, celebrities and most importantly; people affected by leprosy. The campaign created a more positive image of people affected by leprosy, more people reported voluntary at the health posts and those working in the field of leprosy felt very encouraged (Lynch; 2000). This was confirmed on a more general scale in the evaluation of learning materials by Nash (Nash, 1999). She concluded that learning materials are tools that should be well adjusted to their end-users. These observations plead for improved educational interventions or, as several authors have mentioned, an integrated approach to reduce stigma (Floyd-Richard & Gurung, 2000; Arole et al., 2002).

The second article by Awofeso (1996) addressed factors that lead to leprosy-related stigma in Nigeria and looked at several ways of minimising it. At national level, for example, policies should restructure rehabilitation programmes and legal protection should be provided to people with leprosy. At the community level, leprosy control should not only be integrated into the primary health care services, but focus on rehabilitation. Awofeso further emphasised that health education should focus on better communication between patients and health workers and that the latter should be better trained. The integrated approach to reduce leprosy-related stigma has been evaluated by Arole et al. (2002). They compared the influence of integrated versus vertical care approaches to the level of stigma faced by people with leprosy and their families in India. The results of the study indicated that an integrated approach leads to a reduction in the level of stigma and has helped the treatment of leprosy as well. People in communities where the vertical programme had been continued showed pervasive negative attitudes and a lack of knowledge as signs of high levels of stigma.

Community Based Rehabilitation

Gershon and Srinivasan (1992) studied the effect of community-based rehabilitation (CBR) in the city of Madras, India. The outcomes of their study showed that CBR had positive effects on the reactions of patients and their families towards leprosy and had an even larger effect on people's occupational and economic status. However, the study did not identify the specific factors that had particular relevance to these changes and how these changes relate to stigma reduction

Group counselling

Group counselling is another intervention that has been proposed to reduce leprosy-related stigma. Floyd-Richard and Gurung (2000) conducted a pilot study on the effect of this type of intervention. Though the outcome of such an intervention is hard to measure, this study led the authors to claim positive results. They concluded that group counselling is a time-efficient and productive method of counselling to reduce the effects of stigma on the lives of people with leprosy but that counselling alone will not eradicate stigma. Other interventions like economic rehabilitation and health education are also seen as necessary.

Conclusion

Most interventions to reduce leprosy-related stigma have been implemented on the community level and are derived from the educational strategy. Attention for individual interventions, such as counselling and empowerment, is increasing. The question of how knowledge influences behaviour was raised in the leprosy field also and deserves more attention. Future research should establish the effectiveness of education and individual support strategies. Interventions derived from other strategies should be implemented and tested. The experience of community-based rehabilitation provides new possibilities both within and outside the field of leprosy.

Tuberculosis

A number of authors have reported stigma related to TB (Farmer, 1997; Jaramillo, 1999; Ogden, 2000; Family Health International, 2001; Hoang Long et al. 2001; Demissie et al. 2003; Hoa et al. 2004). However, examples of and studies on effective interventions to reduce TB-related stigma are difficult to find. For this paper we found two articles describing specific interventions. The first article describes the effectiveness of “TB Clubs” in Ethiopia in improving compliance with TB treatment and their impact in improving societal attitudes towards people with TB (Demissie et al, 2003). The second article evaluated the impact of health education in Vietnam (Hoa et al. 2004). We include one article addressing the relation between knowledge and TB-related stigma (Jaramillo, 1999) and one report addressing a combined approach towards AIDS and TB, in which education plays an important role (Family Health International, 2001).

The TB Clubs studied by Demissie et al. focused their activities on mutual support and information exchange to enhance patient compliance and to improve societal attitudes towards TB. Mutual support consisted of encouraging and supporting fellow patients to adhere to their treatment. The educational component included sharing experiences among club members and exchanging information with the general public through public readings and the dissemination of educational materials.

Demissie et al. found that the clubs had positive effects on the attitudes of patients, health workers and community members. Patients’ reactions to the first diagnosis improved, misconceptions on the cause and treatment were reduced, social isolation of patients lessened and compliance to treatment increased. The authors recommended further large-scale studies to see whether this approach can be scaled up to the national level and to other countries.

Hoa et al. (2004) described a study on patients’ knowledge of TB, to evaluate the impact of the health education provided by the Vietnamese National Tuberculosis Programme. This programme registers newly diagnosed patients and offers them treatment and education. Health workers, who are especially trained for this task, provide the education. Materials are produced in local languages, some especially designed to reach ethnic minorities. The study showed that the level of education of the participants and the manner in which the information was provided influenced the

knowledge level of participants. Knowledge about the cause and modes of transmission was limited and the authors relate this to a higher level of social stigma. To reduce stigma, health education should not only provide basic facts on TB, it should also try to counter the false assumptions on which stigma is based. The authors recommend an ongoing health education programme designed to increase the knowledge level throughout the population. Unfortunately, the authors did not discuss the content of information or the best manner to provide this information.

Jaramillo (1999) looked at the predictors of prejudice towards people with TB, testing the hypothesis that people's beliefs about mechanisms of TB transmission are the main predictors of TB-related stigma. Verifying this hypothesis, Jaramillo also found that the respondent's age and level of fear of people with TB were of influence.

Jaramillo concluded that, if early diagnosis, and affordable treatment become available, these can, together with health education, reduce the burden of stigma as they decrease the false beliefs on TB transmission and the disease progression (Jaramillo, 1999).

The Family Health International (FHI) report on TB in high HIV prevalent areas (FHI, 2001) showed the link between HIV and TB, and the common grounds of stigma related to these diseases; lack of knowledge. It also mentioned that the stigma related to HIV increases the stigma related to TB. The report proposed to create a better understanding of both diseases that should reduce the impact of stigma and help the prevention of these diseases. Unfortunately no evaluations of such interventions by FHI are published yet.

Conclusion

Very few studies have addressed the social consequences of TB and the related stigma. The available studies on stigma reduction plead for more and better education as they have shown that improved knowledge has a positive impact on attitudes and that knowledge is an important predictor of prejudice towards people with TB. The study in Ethiopia showed that integrating education in the health system is a very effective way of disseminating information and creating a better understanding between patient and practitioner. From these studies it also becomes clear that more research is needed on how knowledge influences stigma and how information can best be provided.

Mental Illness

Within the literature on stigma and mental illness we found six relevant reviews on stigma-reduction strategies and interventions (Couture & Penn, 2003; Hayward & Bright, 1997; Corrigan & Penn, 1999; Cathoor et al., 2003; Smith, 2002). One was a meta-analytic review on contact interventions (Kolodziej & Johnson, 1996). Mainly three stigma reduction strategies are described in these reviews. These are protest, education and contact.

Protest

The first strategy to reduce stigma in the field of mental illness is protest. Corrigan and Penn state that protest as a stigma reduction strategy aims to suppress stigmatising attitudes towards mental illness. Examples of interventions within this strategy are advocacy activities, educational support groups and patients empowerment groups (Corrigan & Penn, 1999). In their review of studies conducted in Europe and the United States, Corrigan and Penn found that protest interventions can contain two messages, one addressing inaccurate representations of mental illness, the other addressing negative beliefs about mental illness. There is little research on the impact or effectiveness of this strategy. With evidence from the field of social psychological research Corrigan and Penn do show that protest interventions generated only short-term effects on attitude change (Corrigan & Penn, 1999).

Protest interventions have two important limitations. The first is that, in most protest interventions the negative stereotypes are not replaced with other attitudes or beliefs. A second limitation is the occurrence of the rebound effect. This effect is a negative consequence of suppression of prejudice, where: “suppression of targeted ideas leads to the same psychological reactions as active thought about these ideas” (Corrigan & Penn, 1999: 768). Following Wegner and Erber (1992), the authors explain that suppression has an adverse effect, making negative attitudes more persistent. Repeated instructions to suppress a stereotype could prevent this rebound effect. Protest appears to be a legitimate intervention but the actual effect on stigma-reduction seems minimal and needs further research.

Education

The second strategy is education which aims to increase knowledge about mental illness and provides facts that counter false assumptions on which stigma is based. Educational interventions can present these facts through presentations, discussions, simulations, audiotapes, and films, targeting specific populations.

Studies examining the effects of education have found mixed results. Some studies show that participation in brief courses on mental illness and treatment result in improved attitudes towards persons affected by mental illness, other studies fail to show this effect of education on attitudes (Corrigan & Penn, 1999). For example, information on acute symptoms was reported to increase stigma, while information on post treatment living arrangements and perceived dangerousness were reported to reduce stigma (Corrigan & Penn, 1999).

The interventions reviewed showed that education is limited because many stereotypes are resilient to change (Corrigan & Penn, 1999). Disconfirmation of negative stereotypes has been undermined by the consistency – confirmation effect: people recall social information consistent with pre-existing – negative – stereotypes, allowing new ideas and information to get lost. Corrigan and Penn conclude that:

These findings suggest that participants in an education program may easily recall information that confirms mental illness stigma about dangerousness and may ignore information that challenges these stigmas (Corrigan & Penn, 1999).

However, they concluded that education programmes might lead to diminished discrimination even if dramatic changes in stereotypes were not observed (Corrigan & Penn, 1999) and argue that future studies should examine the effects of educational interventions on behaviour change and the long-term impact on attitude and behaviour change.

Contact

Contact aims to challenge public attitudes about mental illness through direct interactions with persons affected. The review article by Couture and Penn (2003) only included contact interventions whereby contact involved direct, face-to-face interactions. The reviewed studies showed that contact interventions are associated with improved attitudes, the strongest association was found in the context of general undergraduate training, i.e. situations in which contact occurred on a more equal and

voluntary level (Couture et al, 1997; Hayward & Bright, 1997; Corrigan & Penn, 1999; Kolodziej & Johnson, 1996).

The effectiveness of contact to reduce stigma has been studied using retrospective and prospective reports of contact. Couture et al. (1997) suggest that the effectiveness of contact-interventions can best be studied prospectively because of the memory bias in retrospective studies. They show that prospective studies in a laboratory, classroom or presentation setting can be effective in reducing negative attitudes towards persons affected.

Kolodziej and Johnson (1996) conducted a meta-analytic review of studies dealing with contact in the United States and Canada. In these studies, contact occurred either in the context of general student training, specialized student training or mental health employee training. Specialised student training included nurses, medical students, and pharmacy students. The reason for contact ranged from informal, social activities to formal health care settings. In line with the contact hypothesis, this certainly had an effect on the outcome of the interventions. The informal, general student training, where people were less authoritative and restrictive, resulted in more positive attitude changes than the other settings. Not in line with the expected outcome was the influence of contact duration: “Although prolonged contact ideally should be associated with more positive attitudes towards persons with psychiatric disorders, our data suggest that this is not necessarily the case” (Kolodziej & Johnson, 1996).

Couture and Penn (2003) argue that studies that examined contact in a more real-world setting, like job training, did not show an increase in positive attitudes. This could have been because many of these contacts were doctor-patient interactions and therefore had no equal status between patient and practitioner. Contact in volunteering situations had a more positive effect. Several studies showed that the impact of contact interventions increased under specific conditions namely, an equal status between participants, cooperative interaction, institutional support for contact, frequent contact with individuals who mildly disconfirm the stereotype, high levels of intimacy and real-world opportunities to interact (Kolodziej & Johnson, 1996; Hayward & Bright, 1997; Corrigan & Penn, 1999; Couture & Penn, 2003).

Couture and Penn concluded that future research should pay more attention to the issue of individual and other factors that influence attitude change, looking at what factors are necessary and sufficient for contact to work and what mechanisms cause attitude and/or behavioural change.

All these reviews were limited to strategies for changing public attitudes and behaviours. Corrigan and Penn (1999) emphasised that people with mental illness are not passive agents in the stigma reduction process. People affected by stigma can use a number of methods to cope with the impact of stigma, like selective disclosure of one's mental health history, joining support groups, and consumer services. Hayward and Bright (1997) proposed, for this reason, a holistic conception of mental illness in which patients are encouraged to develop their skills and talents, to increase their self-efficacy and personal worth. Smith (2002) proposed a rights-based approach that would counter stigma and discrimination by monitoring and enforcing equal access to health care, housing, employment and justice (Smith, 2002:318). One advantage of this approach is that it does not require the general public to be familiar with mental illness. This approach allows one to insist on the enforcement of rights, and according to Smith, involves practical interventions with measurable outcomes. Creating acceptance through normalisation could be achieved by the 'medicalisation' of mental illness. Smith illustrates the influence of this process with examples of stigma reduction in the field of tuberculosis and cancer. According to Smith both TB and cancer became less stigmatised as scientific knowledge and medical treatment improved.

Conclusion

The literature on mental health and stigma focuses on three main strategies: protest, education and contact. These strategies have mainly been applied to the community level, with a high number of studies targeting specific groups like students and health workers. Protest has not been found to generate a high impact on stigmatising attitudes or behaviours. Most research that has been done, however, has looked only at the short-term impact and most authors suggest to evaluate its long-term impact, both on attitudes as well as behaviour because one important advantage of this strategy is that, especially using media campaigns, a large audience can be reached (Corrigan & Penn, 1999). Different kinds of educational interventions have shown mixed effects on stigma reduction. The type of information offered and the context, in which the intervention is carried out, have an important influence on the outcome. The positive effect of education has caused most authors to conclude that education is and can be an effective strategy to reduce stigma. Overall, contact is seen as the most effective or most promising strategy. Given the right conditions it can have

considerable positive effects. One important limitation is that reducing stigma through contact is time-consuming and may be cost-inefficient (Cathoor et al, 2003). A combination strategy of education and contact is therefore proposed (Cathoor et al, 1999; Kolodziej & Johnson, 1996). However:

Empirical research must provide us with more definite information regarding the extent to which educational and persuasive messages contribute to the effectiveness of contact interventions (Kolodziej & Johnson, 1996).

Finally, Couture and Penn (2003) concluded that a challenge lies in translating attitude change into behaviour change and in investigating which level of behaviour is conceptually linked to specific attitudes (Couture & Penn, 2003; Corrigan & Penn 1999).

Epilepsy

We found six articles (Jacoby, 1994; Jilek-Aall et al., 1997; Baker et al., 2002; Ablon, 2002; Austin et al., 2004; Snead, 2004) and one review (MacLeod & Austin, 2003) addressing interventions to reduce stigma in epilepsy. Since hardly any studies have been carried out on the effectiveness of stigma reduction interventions, most articles deal with the literature available to summarise what *is* known, to identify gaps in the literature and to suggest directions for future research (MacLeod & Austin, 2003). In the field of epilepsy it has been shown very important to distinguish perceived from enacted stigma. Several authors have indicated that few people with epilepsy can recall an actual instance of stigma while they do perceive their illness as one against which there are different forms of prejudice (Scambler & Hopkins, 1986). Jacoby points out that:

Individuals did not generally come to see their epilepsy as stigmatising because of experiencing discrimination: most often, felt stigma was the product of stigma coaching by key individuals such as parents, and *preceded* rather than resulted from episodes of enacted stigma (Jacoby, 1994, italics in original).

Education

The first study addressing education is a psychosocial study on epilepsy in Tanzania, by Jilek-Aall et al. (1997). The study was conducted in two communities in Tanzania. In one of these communities an epilepsy-clinic was based that has been providing medication and treatment for more than 36 years. In the last four years the clinic had started educating the larger community on epilepsy through public education. The other community had no such interventions. The study therefore can be used to look at the effect of the education offered by the clinic on the perspectives of individuals in that community. One limitation of this article is that the content of the educational messages was not given.

The research team conducted several selected focus group discussion with patients and controls in the two communities. The results of these discussions led the researchers to conclude that the two communities differed markedly and that the more positive attitude towards epilepsy and people with epilepsy was due to the presence of the clinic. In the 'clinic community', traditional beliefs were less influential and the attitudes and behaviours towards people with epilepsy had been changed positively.

The people from the second community still held beliefs that epilepsy was caused by evil spirits or witchcraft, resulting in unwillingness to talk about epilepsy and more specifically a loss of confidence and self-efficacy in patients and their families. From this study it becomes clear that better treatment as well as education could serve as interventions to reduce stigma and discrimination. It remains unclear which intervention, better treatment or education, had the strongest impact on reducing epilepsy-related stigma or that it was the combination of these two interventions that generated the success.

Baker et al. (2002) did not specifically describe an intervention but aimed to assess the possible contribution knowledge can have on reported levels of stigma. In a large European sample the authors tried to determine the relationship between knowledge and stigma correlating the outcomes of the Epilepsy Stigma Scale (ESS) with the Epilepsy Knowledge Questionnaire (EKQ). Of all respondents, 46% reported feeling stigmatised, with marked differences between the respondents in the different countries. Baker et al. also found that, along with seizure frequency, knowledge was an important predictor of stigma. These findings suggest that the education of patients might lead to lower levels of perceived stigma.

Austin et al. (2002) looked at education without addressing a specific intervention and tried to identify the link between knowledge and attitudes among adolescents in the general population. Their sample of 19441 high school students indicated that stigma and a lack of knowledge on epilepsy were still common features in the social environments of adolescents with epilepsy. The authors proposed that the general lack of knowledge and familiarity about epilepsy among adolescents indicates the need to teach children and adolescents with epilepsy to cope with their disease and the stigma related to it.

Individual support

Ablon (2002) proposed to offer more support to people with epilepsy to cope with their illness and the related stigma, increasing attention to individual empowerment:

Individuals with stigmatized medical conditions, including epilepsy may benefit from support groups that can help enhance their confidence. By focusing on the social and political resources and recourses available to them, such individuals can make substantial strides toward gaining their freedom from stigma (Ablon, 2002).

This individual approach can also be used with people indirectly affected by the disease, like close relatives.

The article by Snead et al. (2004) did not specifically address stigma but the quality of life of adolescents with epilepsy in general, stating that perceived stigma could play an important role in this. Snead et al. (2004) described the development and initial implementation of a 6-week structured psycho-educational group intervention for adolescents with epilepsy and their parents. They used five educational topics: (a) the medical aspects of epilepsy, (b) healthy behaviours and attitudes, (c) stress management, (d) social concerns and opportunities and, (e) dealing with family, peers, and others. In these content areas, related to the quality of life in general, ideas and concepts can be identified that relate to interventions to reduce stigma. For example, educating patient and relatives, and teaching adolescents with epilepsy to cope with the disease and to deal with the possible negative views held by their environment. The methods and interventions used in this study, or more specifically, the psycho-educational group interventions, might be very relevant for developing group interventions to reduce stigma related to epilepsy and other illnesses.

Conclusion

The above results shown that, within the field of epilepsy, especially in the US and UK, considerable attention goes to the individual patient and his/her ways to deal with the disease. Interventions to reduce stigma are therefore mostly aimed at the individual, educating the individual and teaching him or her how to cope with their disease. Next to that, attention is paid to the close environment of the patient, including health practitioners and family. The education strategy focuses on the individual, 'patient' level and their close environment and to a lesser extent on the community level. Given the limited number of articles describing effective interventions to reduce stigma, it becomes clear that research on stigma in epilepsy has just recently been implemented. In their review, MacLeod & Austin (2003) state that to develop interventions to decrease the impact of stigma, it is important to understand how people with epilepsy experience and cope with the stigma related to their disease. This is especially important for adolescents, who are in a critical period for identity formation and self-definition, and for whom it is crucial to understand how experiences with stigma influence their present and future psychosocial well-being.

According to Macleod & Austin, the few studies conducted and published have led to a lack in understanding on the concept of stigma and the social context in which stigma occurs. This could explain the lack of interventions and programs to reduce stigma, because only when: "... we understand the peer social environment, interventions and programs can be developed to help rectify misinformation about epilepsy and promote more understanding and tolerance of difference" (MacLeod & Austin, 2003). Currently, a collaborative research project on epilepsy stigma (CREST) is being implemented, that aims to fill in these gaps. The project has just started with rapid appraisal studies in Vietnam and China and anticipates that the findings from these studies will bring about a more thorough understanding of epilepsy-related stigma (CREST poster presentation, 2004).

Disability

Disability is an umbrella term encompassing many conditions, from birth defects to post-traumatic conditions (ICF, 2001). In many countries, several of the conditions discussed above, e.g. HIV/AIDS, mental illness, epilepsy and leprosy, are included as a disability category. In this paper therefore, we will restrict ourselves largely to locomotor disability. We found only few articles that discussed the effectiveness of interventions to reduce stigma explicitly in this field. This could be due to the fact that, within the field of disability the focus is on quality of life, and not on stigma. However, quality of life is a concept strongly influenced by stigma. The impact of stigma reduction at the individual level could be measured in terms of quality of life. This review is based on 5 articles, describing studies specifically on physical impairments, hearing impairments, and on disability in general. Most studies aimed to reduce stigma through coping skills and protest interventions at the individual level, followed by or alongside education at all levels.

Richardson (1971) described preference rankings of children towards other children with or without physical handicaps. From the results the author identified stigma, and proposed two interventions to reduce the effect of stigma related to various types of physical appearance and handicap. The first intervention aimed at the individual level of the 'disabled' child, teaching the child skills in interpersonal relationships and specific social techniques to overcome and break through the problem of 'presenting others with the visible cues of physical handicapping' (1971). The second aimed at the social environment surrounding the child, teaching peers how to deal with disability and handicaps. The individual level interventions were also brought forward in the articles by Becker et al. (1981), Susman (1993), and Summers et al. (2004).

Anspach (1979) described the use of political activism to elevate the self-esteem of participants. Political activism can be seen as an intervention on the individual level and an empowerment strategy, as it aims to increase a sense of belonging and to elevate self-esteem. According to the author, the political movement of the time in which the research was conducted did not seek to modify patient's own behaviour in conformance to a pre-existing normative mould, but to influence the behaviour of

others. Seen in this way, political activism could be regarded as a protest intervention, aiming to tackle false assumptions and stigmatising attitudes.

Becker (1981) focused in his article on individual coping techniques. He studied 200 deaf people over the age of 60 and found that their creation of a deaf identity and the development of a social support system influenced their management of the stigma attached to being deaf, in a positive manner. He discusses 'normalisation', as a strategy of social interaction in which the interaction with group members enhances a sense of normality, increasing people's self esteem. Susman (1993) also addressed normalisation in her article on 'disability, stigma and deviance' and showed how the concept has moved from a strategy to adjust to society to a way of interacting with others in that society. Following Davis (1961), she discussed the strategy of 'deviance disavowal'. This strategy involves the recognition, rather than the denial, of disabling conditions and can therefore also be seen as a normalising strategy. The recognition of the disabling condition, however, is done in such a way as to prevent disability from becoming central or disruptive. The strategy aims not to ignore differences, but to show that these differences can be overcome or that they are not vital to the interactions of disabled people with others.

Conclusion

Looking at these articles, most interventions to reduce disability-related stigma have been aimed at the individual and their close social environment, i.e. the family and peers or people with the same disability. Most authors have recognised the need to educate the larger community, but interventions to do so were not discussed. The effect of the interventions aimed at individuals and their close social environment was not described or even measured and work on this topic remains a recommendation for future research.

Discussion, differences and similarities

In the health fields discussed, stigma and stigma reduction have a lot in common. At the same time there are differences in the scope of work that has been done and the aspects of stigma that have been addressed. We will discuss the similarities and differences of the strategies related to the levels they were implemented in.

Individual level

Strategies to reduce stigma at the individual level have been defined differently within the health fields discussed, also its emphasis varied. In the field of HIV/AIDS, strategies implemented were counselling, care and support and empowerment, in epilepsy individual interventions focused on empowerment and within leprosy and mental illness on treatment. Other interventions encountered used terms like advocacy, coping and support or self-help groups. The effect of these types of interventions is generally positive. According to Ablon (2002), who discussed support groups, this type of intervention can help individuals with stigmatised conditions to enhance their confidence, cope with the stigma they face and make an effort to eliminate the stigma encountered. The study of Floyd-Richard et al. (2000) on the effect of group counselling of people affected by leprosy confirms this. Unfortunately no other studies on the effectiveness of these interventions were found.

Societal level

In the literature found, societal level approaches were described most. The most common discussed strategies were protest and advocacy, education and contact.

Protest and advocacy

This group of strategies aims to suppress stigmatising attitudes, to emphasise the equality of the people affected and to assert their individual or collective rights. Most interventions in this group are found in the field of HIV/AIDS, mental illness and disability. Protest interventions have been largely evaluated within mental health and it has been shown that the effect of these interventions is limited. First, the interventions do not replace the misconceptions they are trying to eradicate and

second, the effect of rebound. Several authors have proposed to use protest interventions along with other strategies and a general recommendation is to look at its effect in the long term.

Education

Education is a strategy that includes interventions aiming to supplement lacking knowledge, to replace incorrect beliefs and to modify stigmatising attitudes and behaviours. These interventions are found in every field and therefore share common ground. The differences between the health fields lie in the content of the information provided and the groups at which the messages are targeted. Especially within the field of HIV/AIDS, TB, leprosy and mental health, we have seen that information and education has been largely targeted at the wider public through mass campaigns. Though this type of education has the benefit of reaching a large audience, it has also received criticism for not reaching specific target groups and for spreading a too broad and general message. Experiences from the field of mental illness have shown that education has achieved mixed results. Some authors even found a rise in stigmatising attitudes after giving information on acute symptoms of mental illness (Corrigan & Penn, 1999). Though these results were not related to mass education campaigns, the critique can be useful. Several authors have stated that the content of educational messages should be carefully considered. In the field of leprosy, Opala and Boillot (1996) have emphasised that educational messages should be shaped consistent with people's traditional ways of thinking and Nash (1999) proposed to carefully look at the end-users of each type of educational approach. In general, the content of educational messages should be well adjusted to the context in which an individual with a stigmatised disease finds him or herself, for stigmatisation itself is a product of that particular context.

Where education has been aimed at individuals affected by a particular condition, it has often been as part of treatment and in combination with another approach as part of a larger strategy. This is especially the case in epilepsy. Two studies in this field (Baker et al. 2000; Austin et al. 2004) have illustrated this by identifying the link between knowledge and attitudes and suggesting that improved knowledge in patients might lead to lower levels of perceived stigma. Overall, education is seen as an effective strategy. To improve its effectiveness, most authors have concluded that

more research is needed on the effects of education at different levels, and the most effective ways of presenting information.

Contact

There are several interventions that derive from the contact strategy. The most important difference is whether contact has to be face-to-face or not. Within the mental health field, the contact interventions studied were face-to-face, while in the field of HIV/AIDS this was not a prerequisite. Though there have been only few evaluations of these interventions, most articles from the fields where the strategy is used, i.e. HIV/AIDS, epilepsy and mental health, indicated positive results. Especially in the field of mental health, researchers have tried to identify the most favourable condition in which contact should occur. Voluntary and high levels of confidentiality seem to influence the effect in a positive manner while contact duration did not influence the outcome of the intervention (Kolodziej and Johnson, 1996).

Contact, however, is still regarded as a promising strategy. More research should be done, especially on how to effectively scale up these kinds of interventions, in a cost and time efficient manner.

Structural level

All the above-mentioned strategies and interventions will have more effect when different legislative and policy frameworks support them. These strategies have also contributed to a decrease in stigma, especially through suppressing stigmatising attitudes and behaviours.

Legal and policy interventions

Especially in the field of HIV/AIDS, great importance is placed on legal and policy interventions that protect PLWHA and that counter stigma. Legal and policy interventions as a strategy relate closely to the rights based approach used by the disability movement. Many authors see these interventions as essential components of the societal response to stigma and discrimination (Klein et al. 2002). There has been little research on the effects of legal and policy interventions in reducing stigma. According to Haghghat (2001) it is very likely that people will hold on to their negative stigmatising attitudes and change their behaviour according to the new laws

and regulations. It will then only suppress stigmatising attitudes and behaviours and not reduce them.

Overall, we have seen that a lot of work has been carried out on stigma and stigma reduction. There still needs a lot to be done especially related to the monitoring and evaluation of interventions. It remains unclear what really works. As some authors have proposed to use an integrated, multilevel approach, e.g. a combination of education and contact in the field of HIV/AIDS and mental illness, and the integration of education in health care and treatment in the field of leprosy, more research is certainly needed.

Appendix 1 Working definitions

Stigma:

(1) A social process, which exists when elements of labelling, stereotyping, separation, status loss, and discrimination occur in a power situation that allows them (Link & Phelan).

(2) A social process or related personal experience characterised by exclusion, rejection, blame or devaluation that results from experience or reasonable anticipation of an adverse social judgement about a person or group. In health related stigma, this judgment is based on an enduring feature of identity conferred by a health problem or health related condition. (Weiss and Ramakrishna).

Stereotype: A belief that all members of a group possess the same characteristics or traits exhibited by some members of that group.

Strategy: a plan or policy designed to achieve a particular goal.

Intervention: the interference to prevent something or to change the result.

Protest: Suppressing stigmatising attitudes and behaviours.

The rights-based approach or legal and policy interventions: a strategy that counters stigma and discrimination by monitoring and enforcing equal access to health care, housing, employment and justice.

Education: aims to replace false assumptions that induce stigma with accurate information about the disorders.

Contact: all interactions between the public and persons affected or infected by a particular health condition with the specific objective to reduce stigmatising attitudes.

Community Based Rehabilitation: A strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR draws on the resources and efforts of people with disability, their families, and their communities, as well as government agencies and non-governmental organizations to improve the lives and opportunities of people with disability.

Counselling: Strategy designed to assist PLWHA to increase support and self-efficacy through the use of conflict resolution methods in dealing with family members, spouses, and communities in a safe environment.

Coping skills acquisition: A strategy that aims to teach skills for diffusing conflicting situations at the individual or group level.

Empowerment:

(1) The process by which individuals, groups and/or communities become able to take control of their circumstances and achieve their own goals thereby being able to work towards maximising the quality of their lives (Adams, 1990).

(2) Making it possible for people to have power and to have more control over their own lives (Croft and Beresford, 1993).

Advocacy:

(1) involves either an individual or a group, or their representatives, pressing their case with influential others, about situations which either affect them directly or, and more usually, trying to prevent proposed changes that will leave them worse off (Brandon and Hawkes, 1997).

(2) Is a process of communication, which is different from the mere dissemination of information and education (IEC). Advocacy goes beyond this, and first seeks support. Commitment and recognition from policy and decision makers and the general public about the problem. Advocacy provides solutions and support in tackling issues (International Planned Parenthood Federation IPPF, 2001).

Care and Support: all care provided to a person affected by a particular illness, outside regular treatment

Quality of life: The perception by individuals of their position in life, in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHO, 2001).

Appendix 2. An overview of the consequences of stigma and discrimination in different fields of public health.

	Leprosy	HIV/AIDS	TB	Mental illness	Epilepsy	Disability	Buruli ulcer	Oncho
Effect on the individual and/or community								
Emotional stress and anxiety	X	X	X	X	X	X	X	X
Problems in marriage or in getting married	X	X		X	X	X	X	X
Problems in friendships and social relationships	X	X	X	X	X	X	X	X
Problem with employment or in getting a job	X	X		X	X	X		X
Reduced educational opportunities	X	X		X	X	X		
Increased inequities between those affected and those who are not	X	X		X	X	X		
Concealment of the disease after diagnosis	X	X	X	X	X			
Poor(er) prognosis	X	X	X	X				
Other participation restrictions (e.g. economic dependency, denied access to loans and credit, etc.)	X	X		X	X	X	X	
Isolation	X	X	X	X	X	X		X
(Increased) psychological and psychiatric morbidity	X	X	X	X	X	X		X
Lack of motivation to continue treatment, or	X	X	X					
Motivation to continue treatment	X		X	X	X			
Increased	X	X	X	X				

disability								
Empowerment, e.g. positive self image and confidence developed in resistance to discrimination	X	X		X	X	X		
Effect on public health programmes and interventions								
Delay in presentation for treatment	X	X	X	X		X		
Poorer treatment prognosis; more complicated and more expensive treatment	X	X	X	X		X		
Continued transmission	X	X	X					
Failure of prevention		X						
Poor adherence and default	X	X	X	X				
Risk of drug resistance	X	X	X					
Increased burden on the health services	X	X	X			X		
Poor image of the public health programme	X	X	X	X				

Appendix 3: Overview of strategies and interventions implemented. *Not yet finished*

Country	Author Date	Target group	Strategy	Intervention	Measures	Results/Recommendations
Epilepsy						
Vietnam and China	The Collaborative Research on Epilepsy Stigma Project. 2004	General Population	Education			Not yet implemented
US	Snead et al. 2004	Adolescents with epilepsy and their parents	Counselling	Educational session on a specific topic. Group discussion Distribution of different teaching materials	A positive trend for quality of life improvement	
Tanzania	Jilek-Aall et al. 1997	Village community	Education	Public education	Focus group discussions	A significant change in notions about epilepsy, in attitudes toward and in the social status of people with epilepsy.
US	Joan Ablon 2002	Individuals with stigmatising medical conditions	Empowerment	Support groups	-	-
Country	Author Date	Target group	Strategy	Intervention	Measures	Results/Recommendations
Leprosy						
Nigeria	Awofeso 1992	Nurses				There was a general lack of knowledge on leprosy among the nurses. Taking up leprosy in the training curriculum is recommended.
India	Gershon & Srinivasan 1992	Community and individual level	Community Based rehabilitation			
Nigeria	Awofeso 1996	National and community level	Education Rehabilitation Legal and policy			

			interventions			
Bangladesh	Croft & Croft 1999	General population – Community level	Education	Information, education and communication (IEC) activities		Health education can make a large contribution to community attitudes
Nepal	Floyd-Richard & Gurung 2000	People with leprosy	Empowerment	Group counselling	Self-image	Group counselling is time efficient and productive, though it cannot reduce stigma alone. Other strategies like economic rehabilitation and health education are also needed.
Nepal	Lynch 2000	Entire nation	Education	Mass media campaign with TV/Radio spots, programmes, posters, pop/folk songs, school materials and commissioned articles.		
Country	Author Date	Target group	Strategy	Intervention	Measures	Results/Recommendations
Tuberculosis						
Bangladesh	Croft & Croft 1999	General population – Community level	Education	Information, education and communication (IEC) activities		Health education can make a large contribution to community attitudes
Ethiopia	Demissie et al. 2003	Community level	Care and Support Education	“TB-Clubs”	Compliance to treatment Societal attitudes associated with TB	The TB club approach improves patients’ compliance and builds positive attitudes and practices in the community.
Vietnam	Hoa et al. 2004	TB patients Individual level	Education			An ongoing health education programme to increase levels of knowledge in the whole population appears warranted.
Country	Author Date	Target group	Strategy	Intervention	Measures	Results/Recommendations
Disability						

US	Richardson 1971	Children				
US	Anspach 1979	Physically disabled and former mental health patients	Advocacy Empowerment	Political activism Normalisation		
US	Becker 1981	Deaf people	Coping	Normalisation Support groups		
US	Susman 1994	Disabled people				
Country	Author Date	Target group	Strategy	Intervention	Measures	Results/Recommendations
Mental Health						
US	Corrigan et al. 2001	Adults enrolled at community college in Chicago	Education Protest Contact	Presentation and discussion reviewing myths Presentation by a former patient	Pre- and post test questionnaires	Results suggested that education and contact led to attitude change, while protest yielded no improvement.

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