REVIEWS

Interventions for Stigma Reduction–Part 1: Theoretical Considerations

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ABSTRACT

The contributors to the Working Group that produced this paper are like countless others who are confronted by programme realities in developing countries, such as the pressure to respond to the challenge of stigma in environments of extreme poverty, the issues of scant resources and the requirements to adapt objectives accordingly, and the competing demands for relief and emergency aid. It is in such contexts that researchers have the responsibility of making evidence-based recommendations and yet, regarding stigma interventions, they are confronted by a domain almost devoid of reliable evidence. Without examples of comparable situations that can be reviewed, it may be possible to make progress only through recourse to theoretical concepts. Broad guidelines, based on respected theories, may prove to be a sound foundation on which intervention programmes can be designed.

In this article, the discrete components of stigma that should be targeted in stigma intervention programmes are identified. It is also recommended that since stigma affects different levels in society simultaneously, stigma programmes should be multi-targeted and designed with an intention to adjust interactions between groups at different societal levels.

This article lays the foundation for a companion article that presents a generally applicable method by which plans for stigma interventions can be assessed (Interventions for Stigma Reduction – Part 2: Practical Applications).

Key words: *Identity, status, self-esteem, components, interpersonal, intrapersonal*

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INTRODUCTION

"All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood" (Article 1, The Universal Declaration of Human Rights, 1948).

A need for field guidance to address the issue of stigma was recognised by the ILEP Technical Commission. On the advice of that body, Netherlands Leprosy Relief and the American Leprosy Missions sponsored a Stigma Research Workshop, which was held in Amsterdam in October 2010. The primary aim of the workshop was to produce scientific papers and field guidelines that could be used to target actions against health-related stigma. Participants at the workshop were assigned to groups that were requested to work towards agreed outputs on four different themes, i.e. research priorities, measurement, interventions, and counselling.

The effects of stigma can be brutal; the discrimination it may engender can be a major affront to the dignity of affected people and can seriously impede *'the right to life, liberty and security of person'* (Article 3, The Universal Declaration of Human Rights, 1948). The effects of stigma can also be subtle; the labelling, stereotyping and separation that characterise it can cause affected individuals to lose their identity, self- esteem, and sense of purpose. Such loss can have negative effects on physical and psychological health (Van Brakel, 2006). Where stigma is an effect of disease, the treatment of that disease is incomplete if stigma is not addressed. Interventions to address stigma should not be considered optional; they are essential. A fundamental problem that frustrates efforts to identify possible interventions, however, is that evidence to support them is sparse, and when found, it is weak. Brown et al (2003) in their review of AIDS-related stigma interventions concluded that not much is known about which types of mixed method interventions work best for reducing stigma. Some methods appear to work, at least on a small scale and in the short term. Heijnders and Van Der Meij (2006) reported that stigma reduction interventions have, in general, not been evaluated adequately, and called for a common set of measurements so that outcomes of stigma reduction programmes can be compared in future. In an editorial of the British Journal of Psychiatry, Thornicroft et al (2007) stated that, "most work on mental illness and stigma has been descriptive, overwhelmingly describing attitude surveys or the portrayal of mental illness by the media and that little is known about effective interventions to reduce stigma" (Thornicroft et al, 2007, p.192) . This was a significant observation because most of the work

on stigma has been developed in either the domain of mental health or in that of HIV/AIDS. Angermeyer (2002) was particularly harsh in his assessment. His impression was that interventions that had been implemented had not been based on evidence but had been "guided by personal preferences" (Angermeyer, 2002, p. 21). Sartorius (2002) also expressed dissatisfaction. In responding to a Corrigan and Watson review of mental illness stigma, Sartorius (2002) opined that, "Corrigan and Watson also list some of the broad scale interventions that were found to be useful. These interventions are probably among those that cost most and achieve least" (Sartorius, 2002, p. 26).

Heijnders and Van Der Meij (2006) conducted a systematic and thorough review of evaluated stigma interventions. The outcomes were salutary. They reported a general weakness in the evaluation of the reviewed interventions, and concluded that interventions that included cognitive therapy, counselling, home-based care, CBR, education and contact, appeared to be the most promising ones. Mak (2011) recently conducted a systematic review (in preparation) which built on the earlier review of Heijnders and Van Der Meij. Mak concluded that there was some evidence to support approaches that included various training programmes, contact and education. The same was concluded by Brown et al (2003) in their review of AIDS-related stigma interventions. They reported that some multi-method approaches seemed to work: information in combination with skill-building approaches, and information together with contact approaches. In her review, Mak stated that there are however, limitations which should be considered. Most of the studies that fitted Mak's criteria for inclusion were undertaken in countries ranked by the World Bank as 'high income economies'. The culture, resources, opportunities and levels of sophistication (technological and educational) will be different for those in countries with lower income economies. Furthermore, the interventions reviewed were condition specific; whilst some have methods that may be adapted to affect other stigmatising conditions, others do not. Some studies in the field of HIV/AIDS have shown how the same disease appears to demonstrate different mechanisms for stigmatising, relative to time and context (places and communities) (Bos et al, 2008; Nanda, 2010).

It should also be acknowledged that the measurement of stigma remains a challenge, which may explain the dearth of evidence for stigma-reducing interventions. On close examination, for example, it appears that most training and education programmes actually aim to reduce discrimination, which is an aspect of stigma, but is not stigma per se. The term 'stigma' is sometimes used

too loosely. Most of the studies Mak reviewed were of training or education programmes suggesting that stigma is simply a correlate of ignorance, and that education is therefore a panacea for stigma. In many circumstances however, stigma is not logical. Very few of the reviewed studies reported long-term outcomes, and many used Knowledge Attitude and Practice (KAP) surveys as a method for data collection. Making assumptions about long-term attitudinal or behavioural change based on KAP results, is dubious. Many of the studies were methodologically weak. Although the authors are of the view that well constructed qualitative studies can present sound evidence, randomised control trials are generally accepted to present gold standard evidence. However, of the 34 studies reviewed by Mak, there were only 7 randomised control trials, and of these, four were highly specific and the other 3 (all closely related) assumed access to technology that is not generally accessible in low, or even lower middle-income countries (Mak, in preparation).

COMPONENTS OF STIGMA: AIMS FOR INTERVENTION

Stigma is complex. For some it is a profoundly personal experience, an individual attribute, and yet it is also a dynamic process that is linked to competition for power and tied into existing social mechanisms of 'exclusion and dominance' (Link & Phelan , 2001; Heijnders & Van Der Meij , 2006). According to Link and Phelan (2001), the stigmatisation process starts with identifying and labelling human differences, following which is a process of stereotyping, in which individuals are linked to undesirable characteristics. Subsequently, those in the group who impose the labelling ('us') distinguish themselves from 'them' – the stigmatised group. The perpetrators of negative attitudes then consider these three first components as a justification for discrimination; and loss of status of the labelled individuals will result. A direct consequence of that discrimination is that the stigmatised are disadvantaged and subsequently lose self-esteem. The loss of self-esteem can increase disability, because their access to social and financial resources is reduced or curtailed. Several authors also stress that the outcome of the process is determined by the social, economic, and political power relationships that allow the process of stigmatisation to happen (Link & Phelan , 2001; Heijnders & Van Der Meij, 2006; Weiss, 2008).

Sartorius (2002) suggested a model very similar to that described by Link and Phelan (2001), except that Link and Phelan also suggest that the effects of

stigma are dependent on the environment of power in which it exists. Weiss (2008) gave a succinct description that emphasised the complexity of power relationships. He suggested that power holders may use their power with direct discriminatory effects against those who are stigmatised, but that others who do not actively participate in discriminatory actions may still endorse them. Others may disagree with the stigmatising behaviour in their society but, for complex reasons, they do not intervene to prevent it. In the "concealment cycle" Heijnders (2004) developed, she describes how people often know of the disease and talk casually about it, but initially remain silent; a preliminary 'wait and see' phase exists. People with power who have a stigmatising condition are protected from discriminative actions during this phase. However, people with little or no social status can be discriminated against from the outset. In their paper on AIDS and stigma in Brazil, Abadia-Barrero and Castro (2006) demonstrated how power plays a role in the patients' experiences of distress and discrimination. There existed an interplay between individual experiences, social inequality and power differentials, in relation to stigma.

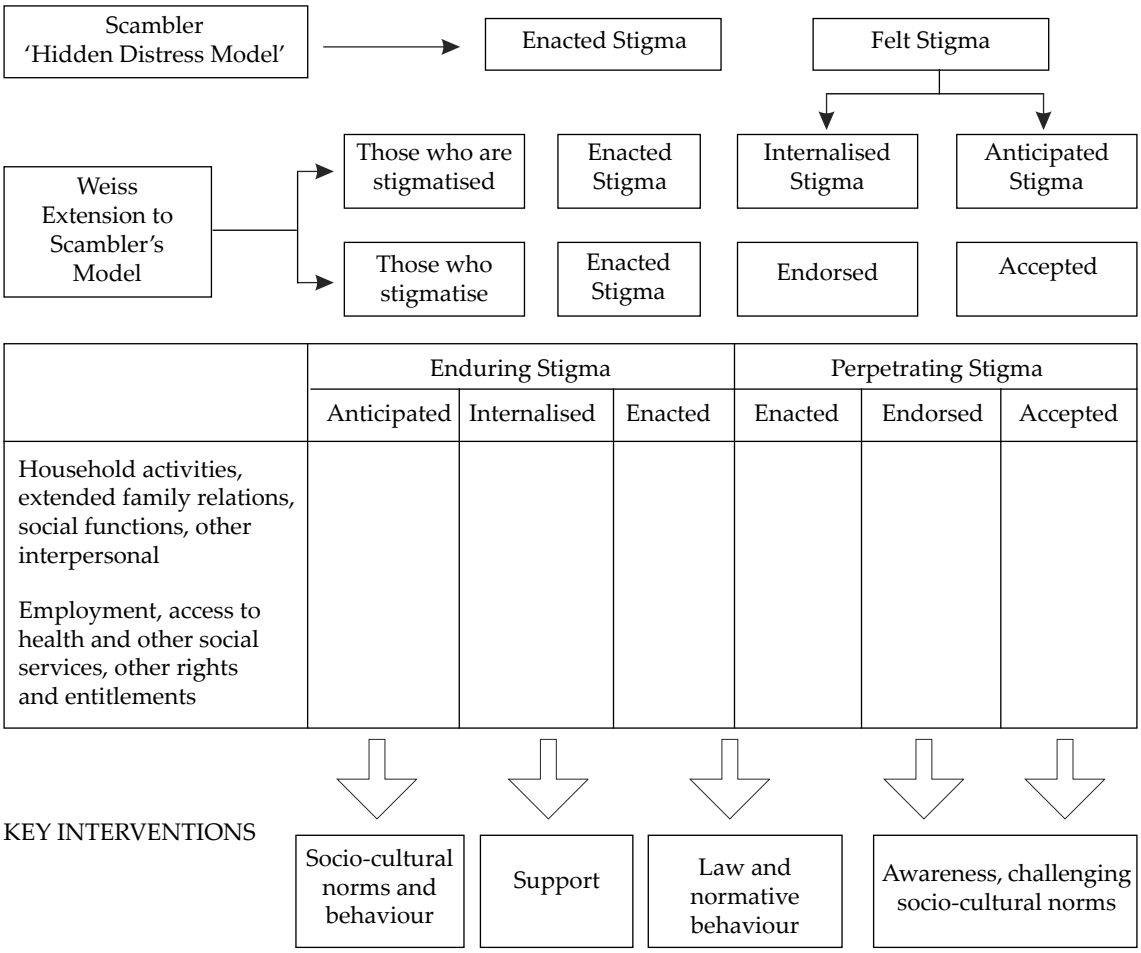
Scambler et al (2006) elaborated on the notion of stigma, by introducing a perspective on 'enacted' and 'felt' stigma. 'Enacted' stigma, they suggested, is defined by actual discrimination or unacceptability; the fear of such discrimination is the definition of 'felt' stigma. Having considered the experiences and coping strategies of people with epilepsy, Scambler et al suggested a 'hidden distress model' of stigma which is based on the distinction between the two types of stigma they defined. Scambler's 'hidden distress model' suggests that a diagnosis of epilepsy can initially generate an acute sense of felt stigma, which precedes any experience of enacted stigma. An initial consequence of that sense of felt stigma is the adoption of non-disclosure, and concealment of the condition and the label associated with it. Consequently, instances of enacted stigma are circumvented. Scambler et al suggested that living with concealment, however, means that felt stigma can prove to be a more disruptive factor than enacted stigma. Perhaps greater stress is laid on 'enacted stigma' as it has much more power to offend social conscience, but if Scambler's model applies, interventions should be more focused on addressing 'felt stigma'. Within the leprosy-related literature on stigma, this process from diagnosis concealment to disclosure and discrimination is described by Heijnders (2004), and called the 'concealment cycle'.

Weiss (2008) extended Scambler's Hidden Distress Model by categorising 'felt stigma' further into internalised and anticipated stigma. In the case of internalised

stigma, individuals accept the discriminating and exclusionary view of society, and stigmatise themselves; they internalise guilt and blame for having the disease, and tend to isolate themselves. On the other hand, anticipated stigma refers to the real or imagined fear of societal attitude because of the stigmatised condition. It has been suggested that some may even adopt anticipated stigma as a coping mechanism to protect against the possibility of enacted stigma (Brown et al, 2003) (see Figure 1).

The authors accept the general guidelines for developing interventions suggested by Weiss in his development of Scambler's model, but suggest that more precise interventions can be developed if the process of stigmatisation suggested by Link and Phelan is also considered (Link & Phelan, 2001; Scambler et al, 2006; Weiss, 2008).

Figure 1: Scambler's Hidden Distress Model as extended by Weiss (2008)



LEVELS OF STIGMA: TARGETS FOR INTERVENTION

From the components and processes of stigma described above, it would seem that the progression of stigma might be challenged through the implementation of multifaceted strategies aimed at affecting players at all levels. Link and Phelan (2001) caution that interventions which focus narrowly on only one mechanism at a time are likely to fail, because their effectiveness will be undermined by other contextual factors. The overarching aim of any response to stigma should be targeted at changing harmful stigma-related attitudes and actions. Whether or not an intervention should aim at adjusting the power relationships that dominate the context for manifestations of stigma is a moot point. Ideally, the goal should be to make people aware of the existence of power relations, and make dominant groups aware of what their attitudes and beliefs can provoke, so that each person can contribute towards reducing stigma.

Motivated by a perceived need for more effective health promotion, McLeroy et al (1988) also perceived a need for interventions that were multidimensional. They suggested a model that aimed to address the contemporary criticism that individualistic life-style interventions failed to recognise contextual factors and the influence they have on health and disease.

Building on the model proposed by McLeroy et al (1988), Heijnders and Van Der Meij (2006) grouped stigma strategies and interventions according to the social/ecological level under which each could be categorised: intrapersonal, interpersonal, organisational / institutional, community and government / structural. Strategies or interventions implemented at an 'intrapersonal' level are those that focus on addressing internalised and anticipated stigma. If interventions are designed to affect intimate groups of people: family, work and social networks, they are 'interpersonal'. Interventions or strategies implemented at organisational and institutional levels will be those that target individuals in organisations and institutions that have particular relevance to stigmatised people: e.g. health-care providers or police officers. Whereas specific community groups may be the target for interventions or strategies that intervene at community level, interventions or strategies aimed at governmental and structural levels will be those which aim to affect an entire state or organisation.

In their review of stigma interventions, Heijnders and Van Der Meij (2006) searched for commonalities between interventions in the same categories.

Concurring with McLeroy et al (1988), they also suggested that interventions should be multi-targeted, and should be designed to affect stigma at more than one level. The suggestion was based on their observation that programmes that included counselling (individual level), education and contact (both community level) appeared to be the most promising of the many interventions they had considered. They were also of the opinion that interventions should aim primarily at empowering stigmatised individuals, with the intention that those individuals might be instrumental in the design and implementation of strategies to address stigma at other social levels. Whilst their suggestion is well reasoned, the level of empirical evidence supporting it is not strong; it does, however, resonate well with the opinions of other researchers.

CONCLUSION

A Working Group for the development of interventions to address the stigma of leprosy accepted that health-related stigma is a dynamic process that differentiates and excludes people on the basis of their health condition. The extent of discrimination against stigmatised people, however, is dependent on the power relationships that prevail in the social context in which stigma is manifested. Stigma may be experienced as 'enacted' (overt exclusion and discrimination) or as 'felt' (perceived exclusion and discrimination), and people who 'feel' stigmatised may deepen their experience of stigma by either internalising the perceived effects or by living in anticipation of harmful effects (either of which will have negative consequences for health and well-being). Therefore stigma may be a crisis at an intrapersonal level, at an interpersonal level, at an organisational / institutional level, at a community / governmental level, or at multiple levels simultaneously. The Working Group also accepted that there are components in the process of differentiation: it starts with labelling, which leads to stereotyping, which in turn sanctions the separation of people from society. They suggest therefore that interventions should be multifaceted: designed to affect the components of stigma at the levels of interaction where stigma is manifested.

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