Interventions for Stigma Reduction–Part 2: Practical Applications

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ABSTRACT

This paper reports the endeavours of the Working Group assigned to develop guidelines for interventions to reduce stigma. The group was comprised of academics and experienced field personnel, all of whom had either investigated stigma, implemented actions to address stigma, and/or had experienced stigma. The group's mandate was to develop an intervention to reduce the stigma of leprosy, but while accepting that there are commonalities relating to stigma that cut across different health conditions, it was hoped that a generic intervention might be developed.

This goal proved to be unattainable in the time given: condition-specific peculiarities and the diversity of cultural contexts presented significant challenges. The group agreed, however, that a considerable body of theory and expert opinion does exist, and that general strategies might be developed from this. The Working Group discussed a systematic review of such material. It also discussed other material that was considered to be important but had not met the criteria for the systematic review. One conclusion of the group's deliberations was that a "Stigma Intervention Matrix" could be a useful guide for cross-checking the development of situation-specific stigma interventions. The Stigma Intervention Matrix is presented in this paper.

Key words: Labelling, stereotyping, status, discrimination, intrapersonal, interpersonal.

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ESSENTIAL CONSIDERATIONS: KNOWLEDGE AND BELIEFS

The effects of beliefs as determinants of stigma were suggested in the works of researchers such as Valencia and Hyland, who studied different cultural groups independently and emphasised that understanding cultural belief systems was crucial to gaining insight into stigma (Valencia, 1989; Hyland, 2000). Weiss recognised the importance of this factor in relation to leprosy too. He contended that if the stigma of leprosy is to be reduced, it is essential to understand its social history and current cultural meaning (Weiss, 2008). To support this point, he cited a seminal paper in which Gussow and Tracy (1970) stated the following: "One cannot hope to understand the adaptational problems of patients without an understanding of the 'world-view' of the people involved and their view of such concepts as health and illness".

From a health promotion perspective, Secker et al (1999) suggested that initiatives were unlikely to be successful unless people's own understandings, beliefs and concerns were taken into account. They found that young people's attitudes to mental illness could be adjusted when an intervention took into consideration their own perspectives, and when stress was laid on creating a cultural environment which would support the development of more positive attitudes. Smith (2002) made a similar statement. He said that imparting accurate information is not likely to be successful unless people's own beliefs, understanding and concerns are taken into account.

ESSENTIAL CONSIDERATIONS: REQUIREMENTS FOR PRECISION FOCUSING

In addition to the requirement for multi-dimensional considerations, stigma interventions will also require fine tuning for greater specificity. Weiss declared his opinion that there are features of stigma that are condition specific (Weiss, 2008; Weiss & Ramakrishna, 2006). There may be, for example, attributes of moral condemnation and blame that are attributes of the stigma of leprosy, but those factors are not associated with all the other health conditions that also give rise to stigma. He suggested that such specific ideas about stigma appear to be related to the experience, meaning, and behaviour associated with a disease, among both affected persons and unaffected persons in a community.

Angermeyer (2002) also drew attention to the need for specificity. With regard to mental illness (already quite specific), he suggested that there were

considerable differences with regard to stereotypes and the potential effects of stereotyping, and that there were also differences in emotional reactions and degrees of discrimination that were condition specific. There was an imperative need suggested in his paper: the variation of the stigma components between disorders should be considered so that interventions can be 'tailored more closely to the actual needs'. Bos et al (2008) in their article on AIDS-related stigma in developing countries, stated that similar (cognitive) factors determine AIDS-related stigma. However, their manifestations and relative importance may vary for each context. AIDS stigma is often associated with norm violating behaviour. In western countries, for example, this norm violating behaviour is associated with homosexuality and injection drug use. In developing countries, however, it is associated primarily with norm violating heterosexual behaviour (e.g. prostitution and adultery). Bos et al concluded that 'it is important to investigate different cultural meanings of HIV/AIDS and to examine the importance of different determinants of AIDS-related stigma for each context'.

EFFECTIVE APPROACHES FOR REDUCING STIGMA

Training and Contact

Studies have shown that education leads to improvements in knowledge about diseases and to the correction of false beliefs and myths associated with them (Watson, 2004; Lapshin, 2006; Martiniuk, 2007; Bozkaya, 2010). Thornicroft et al (2008) defined stigma as a term that is characterised by three elements: problems of knowledge (ignorance), problems of attitude (prejudice), and problems of behaviour (discrimination). They sounded a cautionary note and drew attention to observations which suggest that although education might improve knowledge, an increase in knowledge does not imply a change in attitudes. This factor was emphasised in a recent study conducted by Raju and colleagues in Uttar Pradesh (Raju et al, 2008). The authors suggest that the abandonment of certain behaviour and the adoption of an alternative are more likely to be dependent on the perceived social cost of change than on knowledge. They do accept, however, that gains in knowledge should contribute to the reduction of ignorance, identified by Thornicroft et al (2008) as one of the 'elements' of stigma.

Mak (2011) found that training programmes and the combination of education and contact were by far the most implemented and evaluated approaches to address stigma. Brown et al (2003) came to the same conclusion in a review on AIDS-related stigma reduction interventions. They opined that information in

combination with skills building is more effective than imparting information alone, and that personal contact with persons with AIDS is one of the most promising approaches to reduce the stigma associated with it. The training programmes that were reported in Mak's review were programmes that were predominantly implemented in health-care settings. This was appropriate because it has been established that health-care workers can contribute substantially to the process of stigmatisation. Mak concluded that the reported success of training programmes may be due to the fact that the programmes reported were designed for specific groups. This would have allowed for targeting to address specific issues and concerns. Mak found that the training programmes described were often actually combinations of a variety of strategies: different types of education, contact, and skills development. She also suggested that attempting to determine which parts of the programmes really reduced stigma and which components were superfluous, was problematic.

Brown et al (2003) suggested that if education programmes are to be effective as stigma reduction interventions, they should contain four key components: personal information, a direct attack on myths, promotion of empathy through simulations and opportunities for discussion. Chan et al (2007) found that a strategy that ensured that education preceded contact was more successful in changing negative attitudes and social distance, than a strategy in which contact preceded education. They also reported that the combination of education and contact was more effective than contact alone.

Some consider contact with stigmatised people to be an essential intervention for changing negative attitudes (Penn, 1994; Holmes, 1999; Uys, 2009; Bozkaya, 2010). In the pursuit of effective contact initiatives, efforts to develop an acceptance of equal status in relationships between target groups and stigmatised people appear to be important. This could indeed explain why health-care workers have been cited as initiators and perpetuators of stigmatising attitudes: the interaction between them and stigmatised people is of a hierarchical nature. Creating an environment of equality, however, should extend beyond the intimacy of contact at interpersonal levels. If stigma is to be comprehensively addressed, the much larger questions of societal values and justice need to be considered.

Rights-based Strategies

A successful rights-based approach to discrimination can result in the removal of restrictive legislation that denies stigmatised people access to health care,

housing, education, employment and justice. Enforcing equality in this way may also create an environment in which stigmatised individuals experience increased self-confidence and greater social inclusion. Protagonists of such an approach like Smith (2002), argue that an advantage of rights-based interventions is that they are founded on moral authority and are not dependent on familiarity, understanding or affection towards the stigmatised group. Smith cited a pertinent point made by Ignatieff: 'Negative tolerance is the minimum we require in a liberal society ... but we do not need to love each other, reach out to each other, or even particularly value our different cultures. A minority will practice such positive tolerance, and, as time passes, that minority will become a majority' (Ignatieff, 1999).

Weiss suggested that the court-awarded compensation to people affected by leprosy who had been incarcerated in Japan, was an example of how legal protection and codes of conduct could be used to protect people from enacted stigma. He suggested that such measures were also a statement of values that may discourage the endorsement and acceptance of stigmatisation (Weiss et al, 2006).

A Social Capital Strategy

An approach that can incorporate, but is not exclusive to elements of training, contact and advocacy, is social marketing. Social marketing, furthermore, has the potential to effect changes at community, interpersonal and intrapersonal levels of experience simultaneously. Social marketing aims to achieve the acceptability of a social idea or practice, with the ultimate goal of increased social capital.

The Elimination of Barriers Initiative has been hailed as a successful social marketing project. It was a three year project, designed and implemented by the Substance Abuse and Mental Health Services Administration's Centre for Mental Health Services (http://mentalhealth.samsha.gov/). The aim was to address stigma and discrimination associated with mental illness. Corrigan and Gelb (2006) considered this project to be an example of social marketing, because it displayed four essential characteristics of this:

- problem identification
- 2. description of targets of the marketing plan
- 3. development of technology for change
- 4. evaluation of process and outcome

The Stigma Elimination Project (STEP) also bore the characteristics of a social marketing exercise, although it was not presented as such (Cross & Choudhary, 2005a; Cross & Choudhary, 2005b). STEP methodology was developed on the basis of considerations suggested by Weinrich as being essential when planning a social marketing programme: product, price, place, promotion, publics, partnership and purse (Weinrich, 1999).

In the STEP example, the 'product' was enhanced social capital (positive acceptance and participation of people affected by leprosy in community life); 'price' included contribution to voluntary community development activities by leprosy-affected people; 'place' - local communities where people affected by leprosy were living; 'promotion' - locally specific messages through culturally sensitive media; 'publics' - the involvement of a wide constituency of stakeholders and gate keepers; and 'partnership and purse' included facilitation of access to local government provisions. The STEP intervention included training to promote personal responsibility for impairment control (self-care), skills development (adult literacy), contact between leprosy disabled people, village development officers and others. It also included advocacy and development activities. These actions and their consequences, in combination, were responsible for affecting attitudes at community, interpersonal and intrapersonal levels. The ultimate effect of the combined approaches was that the social participation of people disabled by leprosy was significantly improved (Cross & Choudhary, 2005a; Cross & Choudhary, 2005b).

DESIGNING INTERVENTIONS

It is apparent from the literature that was considered that there are various actions that could be developed and implemented. The authors feel, however, that it is important to emphasise that these are rarely effective alone. Combinations of a variety of methods should be constructed for maximum effect.

Weiss has suggested an extension to Scambler's 'Hidden Distress Model' to facilitate the design of strategic interventions (Weiss, 2008). Taking into consideration types of stigma: enacted, anticipated and/or internalised stigma, he argued that interventions could be aimed at addressing each type of stigma at the level of the perpetrator and/or the stigmatised people. The intervention model was further elaborated with the suggestion that actions could be specified for the various domains in which they might ordinarily be executed. The scheme devised by Weiss offers suggestions for the types of intervention that may be

appropriate for the level of stigma to be targeted. The authors offer a matrix that they suggest might be used for cross-checking intervention plans with greater precision. The Intervention Matrix incorporates levels of stigma as suggested by McLeroy, Heijnders and others, and the components of stigma as suggested specifically by Link, but also indirectly by Sartorius and others (McLeroy et al, 1988; Link & Phelan, 2001; Sartorius, 2002; Heijnders & Van Der Meij, 2006).

(Please see Figure 1 - Potential Tools for the planning and management of stigma interventions: A matrix for cross-checking intervention plans.)

Figure 1 - Potential Tools for the planning and management of stigma interventions: A matrix for cross-checking intervention plans.

Consider at which level of stigma the intervention is intended to have an impact at **

Consider how the intervention addresses each component of stigma at the level of stigma targeted*

Level	Components				
	Labelling	Stereotyping	Separation	Status Loss	Discrimination
Intrapersonal	How does the intervention facilitate the creation and internalisation of a new identity	How does the intervention reverse or alter internalised stereotypes	How does the intervention increase self- respect and reduce self- loathing	How does the intervention increase self-efficacy and provide opportunity for role development	How does the intervention raise self- esteem and self-assurance
Interpersonal	How does the intervention persuade others to acknowledge new identities	How will the intervention change perception from negative to positive stereotype	How will reconciliation between players be facilitated	In what ways will the intervention demonstrate the value of new role to others	What does the intervention do to promote commitment to embrace equality
Organisational/ Institutional	How does the intervention facilitate the sanctioning of changed identities	How does the intervention challenge the process of negative stereotyping	How does the intervention lead to greater participation and inclusion	How will the intervention affect power relationships to positive effect	How will the intervention ensure censure for discriminatory behaviour
Community/	Changing cultural norms:				
Government	How does the intervention discourage the acceptance and endorsement of				
	stigmatisation (community level)				
	How does the in	the intervention lead to favourable legislation (government level) and			
	commitment to rights				

CONCLUSION

This Working Group concluded that it is difficult, if not impossible, to develop generic stigma reduction interventions that would apply to all health conditions, given the specificity of these conditions and the complexity of factors related to each person's experience of stigma. However, it is possible to propose generic strategies that can be adapted to particular conditions and circumstances. As a comprehensive approach to the issue of stigma, the authors suggest that a social marketing approach will be appropriate, because it requires engagement with people in multiple domains; it is culture sensitive, adaptable and pragmatic. Social marketing demands negotiation and compromise, but the potential outcomes are perceived to be positive for all players. Training and contact, but particularly a combination of both, appear to be appropriate for targeting specific levels of stigma, but since they do not address each component of stigma at all levels of stigma, it seems unlikely that they will yield a comprehensive effect.

The complexity and multiplicity of factors that need to be considered when designing a comprehensive stigma intervention may be daunting; the authors offer, therefore, an Intervention Matrix against which plans to develop and implement an intervention could be cross-checked. Reference to the 'Intervention Matrix' should help to ensure that fundamental considerations are addressed in stigma intervention plans.

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