Strategies for Addressing HIV/AIDS-Related Stigma

Gayle Restall, O.T. Reg. (MB), Ph.D. & Miriam Gonzalez, Ph.D. (Candidate)

Department of Occupational Therapy, School of Medical Rehabilitation, Faculty of Medicine University of Manitoba
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Research Team
Tara Carnochan (Nine Circles Community Health Centre), Emily Etcheverry (University of Manitoba), Pumulo Roddy (Community Member), Kerstin Rogers (University of Manitoba), Theresa Sullivan (University of Manitoba)

Contact
Gayle Restall, O.T. Reg. (MB), Ph.D.
Associate Professor
Department of Occupational Therapy, School of Medical Rehabilitation
University of Manitoba
R106-771 McDermot Avenue
Winnipeg, MB, Canada, R3E 0T6
Phone: 204-975-7736
E-mail: gayle.restall@med.umanitoba.ca
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1. ABSTRACT

We conducted a rapid review of the literature to identify effective strategies to reduce stigma related to living with HIV/AIDS. Stigma reduction interventions are being implemented across diverse fields. These interventions can be classified into six broad domains: information-based approaches, skills-building interventions, counseling interventions, contact with stigmatized groups, structural interventions and biomedical interventions. Interventions have been implemented at various levels of the environment targeting personal, interpersonal, organizational/institutional and community/government/structural levels. There is some quality research on effective interventions to reduce stigma associated with HIV. Much of this research comes from studies that implemented multiple strategies. Although information-based approaches are the most common, the literature that is available suggests that approaches combining multiple strategies have the most promise for stigma reduction. Information-based together with skills-building, information-based together with contact with stigmatized group, information-based in combination with skills-building and contact with stigmatized groups, and information and skill-based combined with organizational policy/structural approaches have been shown promise in raising knowledge levels, reducing stigmatizing attitudes, increasing tolerance toward people living with HIV/AIDS (PLWHA), improving infection control practices, and increasing willingness of providers to treat PLWHA. Other combinations of stigma reduction strategies across the levels of the environment are also emerging as promising approaches as research on their effectiveness increases.
2. INTRODUCTION

2.1 Background

HIV/AIDS stigma is a global problem. Although the HIV/AIDS epidemic emerged in 1981 and governmental responses as well as knowledge of HIV have increased, stigma is universally experienced by those affected by the disease both at the individual and societal levels (UNAIDS, 2010). HIV/AIDS stigma refers to the devaluation of people either living or associated with HIV/AIDS (UNAIDS, 2007). Link and Phelan (2001) defined stigma as existing “when elements of labeling, stereotyping, separation, status loss and discrimination occur together in a power situation that allows them” (p. 377). Stigmatization involves cognitive (e.g., beliefs or attitudes towards the disease and those affected), emotional (e.g., fear, pity), and behavioural (e.g., behaving in unfair or discriminatory ways) responses (Bos, Schaalma, & Pryor, 2008). In addition, Link and Phelan distinguish between individual discrimination in which a person acts in a discriminatory way toward another person and institutional discrimination resulting from stigmatizing environments (physical, social, cultural and/or policy) that disadvantage and marginalize a group. Thus stigma can affect people living with HIV in many ways, both in individual contact with others and when negotiating environments in which they live day to day.

The various manifestations of stigma at the intrapersonal, societal, and cultural/national levels have made it challenging not only to measure its prevalence and impact on HIV prevention and treatment programs, but to design interventions to reduce it (Mahajan et al., 2008). However, there is a need to reduce HIV/AIDS-related stigmatization. A large body of research suggests that HIV/AIDS-related stigma is associated with poor physical and mental health outcomes (Logie & Gadalla, 2009), negatively affects work and family life (dos Santos et al., 2014), is a barrier to disclosing HIV status (Nachega et al., 2012), influences individuals’ decisions to be tested for HIV (Jürgensen, Tuba, Fylkesnes, & Blystad, 2012), impacts access to health services (dos Santos, Kruger, Mellors, Wolvaardt, & van der Ryst, 2014), and negatively affects adherence to treatment (Katz et al., 2013).

Despite the need to reduce HIV/AIDS-related stigmatization, little research attention has been given to developing and evaluating stigma reduction interventions (Brown, MacIntyre,
Greater awareness about the effectiveness of strategies to reduce HIV/AIDS stigma is urgently needed.

We held a forum in Winnipeg, Manitoba, Canada in November 2012 to develop priorities for research related to enhancing opportunities for activity and social participation for people living with HIV/AIDS (PLWHA). The diverse group of PLWHA, service providers, researchers and policymakers attending the forum identified stigma as the highest priority topic. This rapid review is a response to the identified need for current information regarding stigma reduction that can be translated into actionable strategies for individuals and organizations.

2.2 Purpose and Objectives

We conducted a rapid review of the literature to identify effective HIV/AIDS stigma reduction strategies. The purpose of the literature review was to address the following questions:

1. What are effective strategies to reduce stigma related to living with HIV/AIDS?
2. What recommendations for reducing HIV/AIDS-related stigma can be drawn from the literature?

2.3 Methodology

To identify published articles pertaining to stigma reduction strategies and interventions, a literature search was conducted using the following databases: PubMed, CINAHL, PsychINFO, EMBASE, SCOPUS, and Cochrane. The search was limited to English language documents published in peer reviewed journals between January 2000 and November 2013. The following search terms were used: (1) human immunodeficiency virus, HIV, acquired immunodeficiency syndrome, (2) stigma, prejudice, discrimination (discriminat*), and (3) systematic review, meta-analysis.

Titles of articles were scanned for significance to topic. Abstracts of articles were then reviewed and selected articles were included or excluded based on inclusion criteria. To be included in the review, articles had to: (1) be systematic reviews, randomized control trials, surveys, or narrative reviews, 2) include people living with HIV, and (3) focus exclusively on stigma reduction. This yielded 6 articles. The reference lists of these articles were then scanned for additional relevant research articles which resulted in additional articles. Because we were seeking an overview of effective strategies we focused on identifying and summarizing
published systematic reviews. The articles that were included in our review: 1) focused on reduction of stigma of a group by another group rather than self-stigma and 2) were review articles. To develop recommendations we also included reports from the grey literature that identified specific strategies for stigma reduction.

3. STRATEGIES FOR REDUCING HIV/AIDS-RELATED STIGMA

Much of what is known to date about interventions to reduce HIV/AIDS stigma comes from review articles published between 2003 and 2013. These reviews include: a review of stigma reduction strategies for various diseases or conditions including HIV/AIDS (Heijnders & Van Der Meij, 2006), a review of the HIV/AIDS stigma literature that identifies promising strategies to address stigma (Mahajan et al., 2008), a review of interventions used to reduce HIV/AIDS stigma in both developed and developing countries (Brown et al., 2003), a systematic review of HIV interventions to assess their effectiveness in reducing HIV stigma (Sengupta et al., 2011), a systematic review of HIV-related stigma reduction interventions (Stangl, Lloyd, Brady, Holland & Baral, 2013) and a handful of articles that review the HIV/AIDS stigma literature and provide suggestions for programs and interventions that address stigma (Bos et al., 2008; Skevington, Sovertkina, & Gillison 2013).

Heijnders and Van Der Meij (2006) reviewed the literature in the fields of HIV, mental health, leprosy, tuberculosis, and epilepsy to identify use of stigma reduction strategies. Although the review did not focus on HIV/AIDS specifically, it identified various levels at which stigma reduction strategies are used: intrapersonal, interpersonal, community, organizational/institutional, and governmental/structural levels. At the intrapersonal level strategies used include: treatment, counseling, cognitive behaviour therapy, empowerment, group counseling, self-help, advocacy, and support groups. At the interpersonal level, strategies used include: care and support, home care teams, and community based rehabilitation. Training programs and policies (e.g., patient-centred and integrated approaches) are strategies used at the organizational and institutional level, while contact with affected persons, education, and protest are strategies used at the community level. Finally, strategies used at the governmental/structural level include rights-based approaches as well as legal and policy interventions.

A systematic review of the HIV/AIDS stigma literature revealed that only a small number of published studies have evaluated the effectiveness of stigma reduction interventions (Mahajan
et al., 2008). The majority of these interventions were designed to: (1) reduce stigma at the community level by increasing tolerance of PLWHA, (2) increase the willingness of healthcare providers to treat PLWHA, and (3) develop the coping skills of PLWHA (Mahajan et al., 2008). The predominant strategy used in these interventions was education through the provision of information about HIV/AIDS. However, the exact relationship between this strategy and stigma reduction was not examined. Further, the authors reported that these studies were plagued with methodological problems: small sample sizes, use of convenience samples, and lack of specific stigma measures or ambiguous or unstandardized measures of stigma (Mahajan et al., 2008). Mahajan et al. (2008) also noted that the potential impact of mass-media campaigns on HIV-related attitudes, knowledge, and behaviour is understudied but has the potential to reduce stigma.

To date, three systematic reviews have examined the effectiveness of HIV/AIDS stigma interventions. Brown et al. (2003) focused specifically on interventions with stigma reduction components. Their systematic review included 22 studies that tested interventions to decrease AIDS-related stigma in developed (United States, Canada, England, Scotland) and developing countries (e.g., Tanzania, Nigeria, Thailand, Uganda). The studies aimed to increase tolerance of PLWHA among the general population (14 studies), increase willingness to treat PLWHA (5 studies), and improve coping strategies for dealing with AIDS stigma among PLWHA or at risk groups (3 studies). A variety of interventions were tested and these were classified by Brown et al. (2003) into the following four categories based on the studies reviewed and the AIDS stigma literature.

(1) Information-based approaches consist of fact-based information conveyed through written or verbal communication. Examples include videos, written information such as pamphlets, media advertisements, peer education, and classroom-type factual presentations.

(2) Skills-building interventions aim to teach people in the general population and PLWHA coping skills for resolving conflicting situations such as dealing with being excluded (for PLWHA) or coming into contact with a PLWHA (for the general population). Examples include learning coping behaviours through role-play, reframing, relaxing techniques, and group desensitization. In group desensitization, relaxation techniques are taught and then the person or group is progressively exposed to situations where there is exposure to the conflicting situation (e.g., exposure to PLWHA).
(3) Counseling interventions include providing information about HIV/AIDS, discussing concerns, teaching coping skills and providing support for behaviour change or positive behaviour. An example of this type of intervention is a support group for PLWHA.

(4) Contact with stigmatized groups consists of interactions that are direct (e.g., PLWHA speaking to a person or group) or indirect (e.g., recorded testimonial). Contact with an affected person may dispel misconceptions, generate empathy, and reduce stigma (Brown et al., 2003).

Most of the studies reviewed by Brown et al. (2003) tested interventions that consisted of various strategies. Few tested one strategy such as providing information alone. Brown et al. (2003) concluded that most of the studies showed that: (1) information together with skills building is more effective in raising knowledge levels and reducing stigmatizing attitudes than information alone, (2) information together with contact with affected groups and skills building was effective in improving infection control practices, knowledge about HIV/AIDS, and willingness to treat PLWHA, and (3) information in combination with contact with an affected group was also effective in increasing tolerance toward PLWHA and reducing stigmatizing attitudes.

Similarly, Sengupta et al. (2011) examined the effectiveness of HIV-related interventions that measured stigma before and after intervention. Nineteen articles published in the last 20 years were included in the systematic review. All articles focused on perceived stigma or assessing respondents’ attitudes toward people living with HIV/AIDS. They reported that of the 19 articles reviewed, 3 evaluated interventions to reduce stigma but only 2 were methodologically sound. Further, only one of these studies was effective in reducing stigma. The interventions evaluated in these studies included a combination of the following strategies as per the Brown et al. (2003) classification: (1) provision of information (2) skills building, (3) counseling, and (4) testimonials by people affected by HIV/AIDS. However, the exact impact of each of these strategies on stigma reduction was not examined. The authors noted that the poor quality of the studies reviewed (e.g., use of unstandardized measures, lack of internal validity) suggests more attention should be given to assessing the effectiveness of interventions and specific strategies targeting HIV/AIDS stigma through well-designed studies (Sengupta et al., 2011).

The remaining studies included in Sengupta et al. (2011) review involved eight studies evaluating interventions that did not focus on HIV/AIDS stigma reduction as well as eight
evaluations of interventions with one or more components targeting stigma reduction. Although seven of these studies were effective in reducing HIV/AIDS stigma, only one study was considered methodologically sound. The intervention used in this study involved a combination of information and skills-building strategies. All other studies were considered by the reviewers to be of poor quality, lacking methodological rigour.

In addition to reviews that have focused on evaluating the effectiveness of HIV/AIDS stigma reduction strategies or interventions, other studies have reviewed the HIV/AIDS literature to highlight promising stigma reduction strategies and provide suggestions for programs and interventions that address stigma. In their review of theory and evidence-based strategies to reduce AIDS-related stigma in developing countries, Bos et al. (2008) came to similar conclusions as Brown et al. (2003) regarding the effectiveness of stigma reduction strategies. Bos et al. (2008) noted that interventions that provide information about the disease and promote skills building are more effective than those that provide information only. Interventions that combine provision of information and personal contact with the stigmatized group are effective as well (Brown et al., 2003). Bos et al. (2008) proposed that effective stigma-reducing interventions include (1) thorough context-specific needs assessments, (2) theory and evidence-based strategies, and (3) collaborative planning between PLWHA, communities, stakeholders, and key decision-makers. Further, Bos et al. (2008) noted that research has suggested stigma reduction interventions should (1) create awareness of stigma and discrimination, (2) provide information about HIV/AIDS, (3) create a safe environment to discuss stigma-related values and beliefs, (4) use language appropriate for target population, and (5) ensure PLWHA are involved at all levels of intervention (Bos et al., 2008; Nyblade et al., 2003).

There is also evidence about the effectiveness of an HIV/AIDS community prevention program in reducing stigma about HIV. Skevington et al. (2013) conducted a quantitative systematic review of evidence on the effectiveness of the Stepping Stones HIV/AIDS community prevention program. The program is a community training program designed for HIV vulnerable communities living in low income countries. The review included 8 articles about 7 studies evaluating the effectiveness of the program. Only two of the studies assessed the impact of the program on reducing stigma towards PLWHA. Both studies show Stepping Stones reduces stigma about HIV. Compared to participants in the control group, a higher proportion of Stepping Stones participants reported: (1) they would provide home care for a relative with HIV,
(2) that HIV infected children should be allowed to attend local schools, (3) people living with HIV/AIDS should not be blamed for their status, (4) people living with HIV/AIDS have community rights equal to others, and (5) PLWHA should be allowed to stay in the community and be involved in community life. Although the studies showed that the program reduces stigma, the impact of each of the components of the programs on stigma reduction was not examined.

More recently, Stangl et al. (2013) conducted a systematic review of interventions to reduce HIV-related stigma. They included literature spanning the time frame of 2002 to 2013 to include articles published since the Brown et al. (2003) review. Their review included 40 peer reviewed articles, 6 grey literature reports and 2 dissertations across a wide geographic area. Unlike other reviews they reported that most of the articles reviewed were assessed to be of high-quality. Similar to Brown et al. they found that most interventions reported in the studies implemented more than one stigma reduction strategy. Information was the most common strategy category followed by skills-building, contact, and counseling/support. In addition to these four categories, Stangl et al. identified two additional categories: structural approaches and biomedical approaches. Structural approaches target structures in society that can influence stigmatization such as criminalization related to disclosure. Biomedical approaches are biomedical HIV prevention strategies that aim to de-stigmatize counseling and testing. Stangl et al. also found that most interventions were implemented at the individual level followed by community, organizational, interpersonal and public policy. A few studies implemented strategies at more than one level, most commonly individual and organizational. They noted limitations in stigma reduction research including lack of standardized measures of stigma, limited research on the impact of stigma reduction strategies on health and well-being, difficulties in determining whether a strategy caused a reduction in structural stigma and lack of studies comparing strategies.
Main Findings: Strategy Types

- Little research attention has been given to evaluating the effectiveness of strategies used to reduce HIV/AIDS-related stigma. Most of the literature in this area has focused on identifying promising (as opposed to effective) strategies and providing suggestions for programs and interventions that address stigma.

- To date, what is known about effective stigma reduction strategies comes from two systematic review of HIV/AIDS interventions with stigma reduction components (Brown et al., 2003; Stangl et al., 2013) and a review of the effectiveness of HIV-related interventions (Sengupta et al., 2011).

- Interventions that have been implemented to reduce HIV/AIDS stigma can be classified into 6 categories:
  
  - **Information-based approaches**: fact-based information conveyed through written or verbal communication (e.g., videos, written information such as pamphlets, media advertisements, peer education, and classroom-type factual presentations (Brown et al., 2003).
  
  - **Skills-building interventions**: these aim to teach people in the general population and PLWHA coping skills for resolving conflicting situations such as dealing with being excluded (for PLWHA) or coming into contact with a PLWHA (for the general population). Examples include learning coping behaviours through role-play, reframing, and relaxing techniques (Brown et al., 2003).
  
  - **Counseling interventions**: these include providing support for behaviour change or positive behaviours (e.g., support group for PLWHA), providing information about HIV/AIDS, discussing concerns, and teaching coping skills (Brown et al., 2003).
  
  - **Contact with stigmatized groups**: interaction can be direct such as PLWHA speaking to a person or group or indirect such as using recorded testimonials (Brown et al., 2003).
  
  - **Structural interventions**: these remove or change structural factors that influence stigmatization (e.g., criminalization, workplace policies of mandatory testing, lack of supplies to implement universal precautions) (Stangl et al., 2013).
  
  - **Biomedical interventions**: biomedical prevention strategies that impact on stigma either positively (by normalizing HIV infection) or negatively (by precipitating unwanted disclosure). An example is community-wide availability of home-based counseling and testing (Stangl et al., 2013).
Main Findings: Strategies Directed Across Environments

- Across different health fields, stigma reduction strategies are being implemented at the personal, micro, meso, and macro levels of the socio-ecological environments. Although there is some inconsistency in how strategies are categorized in the literature, we provide this framework of levels of strategies modeled after and adapted from Heijnders and Van Der Meij (2007)

  o **Personal Level Strategies**: treatment, counseling, cognitive behaviour therapy, empowerment, group counseling, self-help, advocacy, support groups.

  o **Micro (Interpersonal) Level Strategies**: approaches to reducing stigma in care and support providers and home care teams.

  o **Meso (Organizational/Institutional) Level Strategies**: training programs and policies within organizations.

  o **Macro (Community/Governmental/Structural) Level Strategies**: community development and rights-based approaches as well as legal and public policy interventions.

Suggested Strategies:

- **Information-based together with skills-building** has been shown to be more effective than information alone in raising knowledge levels and reducing stigmatizing attitudes (Brown et al., 2003).

- **Information-based together with contact with affected groups and skills building** can be effective in improving infection control practices, knowledge about HIV/AIDS, and willingness to treat PLWHA (Brown et al., 2003).

- **Information-based in combination with contact with affected group** can be effective in increasing tolerance toward PLWHA & reducing stigmatizing attitudes (Brown et al., 2003).

- **Other combinations** of strategies such as information-based and skills-building approaches combined with organizational policy change have also shown promise in reducing health care-related stigma (Stangl et al., 2013).
4. LIMITATIONS
A number of limitations can be identified. First, little research attention has been given to developing and evaluating stigma reducing interventions. Therefore, little is known about the effectiveness of strategies that aim to reduce HIV/AIDS related stigma. Effective strategies highlighted in this report pertain to those reported in the two systematic reviews that were found on this topic. Second, the search strategy was limited to articles published between the years 2000 and 2013. Grey literature was examined only for suggested strategies rather than evaluations of programs to reduce stigma. Third, a lot of the studies included in the systematic reviews were not methodologically rigorous. That is, these studies used small sample sizes, convenience samples, or ambiguous or unstandardized measures of stigma. Further, most of the studies evaluated the effectiveness of interventions that consisted of various strategies. Few tested the effectiveness of a given strategy. This limited the ability to determine which of the multiple strategies may have contributed to stigma reduction.

5. LIMITATIONS
The intent of this overview was to do a rapid review of what is currently known about HIV/AIDS-related stigma reduction strategies. Thus we limited our search to reviews of the literature between the years 2000 and 2013. Relatively little research attention has been given to developing and evaluating stigma reducing interventions. The results reported here are gathered primarily from three reviews. Thus, more detailed information on approaches and outcomes would be found in the primary studies. Overall, the three reviews reported variable levels of methodological quality of the research on which they reported. For example, some used small sample sizes, convenience samples, ambiguous or non-standardized measures of stigma, or study

Designing Effective Stigma-Reducing Interventions

- Research in developing countries has identified guidelines for the development of AIDS stigma interventions (Bos et al., 2008).

- Interventions should:
  - Create awareness of stigma and discrimination (Bos et al., 2008; Nyblade et al., 2003).
  - Provide information about HIV/AIDS discrimination (Bos et al., 2008; Nyblade et al., 2003).
  - Create a safe environment to discuss stigma-related values and beliefs (Bos et al., 2008; Nyblade et al., 2003).
  - Use language appropriate for the target population (Bos et al., 2008; Nyblade et al., 2003).
  - Make sure PLWHA are involved at all levels of intervention (Bos et al., 2008; Nyblade et al., 2003).

- Interventions should also include:
  - Thorough context specific needs assessments (Bos et al., 2008).
  - Theory and evidence-based strategies (Bos et al., 2008).
  - Collaborative planning between PLWHA, communities, stakeholders, and key decision-makers (Bos et al., 2008).
designs that made it difficult to determine the validity of the findings. Further, most of the studies evaluated the effectiveness of interventions that consisted of various strategies. Few tested the effectiveness of a given strategy or compared strategies to determine the most effective approaches.

6. CONCLUSIONS
There is an urgent need to develop interventions to address HIV/AIDS-related stigma. While there is a relatively large body of literature on the impacts of stigma on the lives of PLWHA, there is only scant information on effective interventions to reduce stigma. What the existing literature suggests, however, is that multiple strategies that intervene at personal and environmental levels may be most effective in addressing both individual and structural stigma. There is also a need for the use of an anti-stigma lens during the development and evaluation of all programs and policies that affect PLWHA. This lens encourages examination of key questions about the potentially unintentional impact of each program and policy on perpetuating, increasing or reducing HIV/AIDS-related stigma. Implementation and evaluation of stigma reducing strategies need to be done at multiple levels of the environment and in strong partnership with people living with HIV/AIDS.
6. REFERENCES


