Interventions for reduction of stigma in people with HIV/AIDS (Protocol)

by Windy Wariki 5

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[Intervention Protocol]

Interventions for reduction of stigma in people with HIV/AIDS

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ABSTRACT

This is the protocol for a review and there is no abstract. The objectives are as follows:

1. To assess the effectiveness of interventions to reduce stigma towards people living with HIV/AIDS, improve coping strategies and increase tolerance, compared with a control group.

2. To assess the most effective form of interventions to reduce stigma towards people living with HIV/AIDS, improve coping strategies and increase tolerance, compared with a control group.

BACKGROUND

Description of the condition

First observed in 1981 in the United States, HIV/AIDS has transformed into a global epidemic (UNAIDS 2011). In 2011 alone, an estimated 34.2 million people worldwide were living with HIV/AIDS (UNAIDS 2011). Stigma related to HIV/AIDS was first addressed in a statement at an informal briefing on AIDS to the 42nd Session of the United Nations General Assembly in 1987 (Mann 1988), and there have been a wide range of discussions about effective responses to HIV/AIDS stigma. Despite widespread recognition of the consequences of HIV/AIDS stigma over the first 30 years of the epidemic (Mahajan 2008; Parker 2003; UNAIDS 2011), stigma continues to be an obstacle to HIV prevention efforts (de Bruyn 2004; Rahmati-Najarkolaei 2010; Thi 2008).

Conceptualization of stigma according to Goffman's theory is described as a "dynamic process of devaluation that significantly discredits" an individual from a whole and ordinary person to one tainted (Goffman 1963). On the basis of this traditional perspective, recognition of stigma has increased through various research characterizing it as a social process, including negative social attitudes (perceived stigma) as well as social inequality and discrimination (enacted stigma) towards particular individuals (Corrigan 1999; Pryor 2004). HIV/AIDS-related stigma has been conceptually defined as "a mark of disgrace, which invokes discrimination, prejudice, discounting, discrediting, and negative attitudes, beliefs and behaviours directed at people with or perceived to have HIV/AIDS infection, their families and communities with which they are associated" (Alonzo 1995; Herek 1993; Herek 2007; Parker 2003; Steward 2008). The lack of a comprehensive framework for HIV/AIDS-related stigma precludes meaningful appraisal and

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comparisons of interventions that target stigma, and limits the ability to design effective programs and interventions.

In the era of the HIV/AIDS epidemic, recent research to better understand the types of HIV/AIDS-related stigma (e.g., enacted, vicarious, felt normative and internalized) has raised awareness of this complex problem (Corrigan 2004).

Discrimination is a type of stigma towards people living with HIV/AIDS, which can be defined as experiences of stigma (enacted stigma), or prejudicial attitudes and behavior based on their HIV status, such as isolation, exclusion, rejection or harm by other people in the community. Discriminatory behavior, such as loss of jobs, exclusion from community activities, loss of social support, problems in accessing health care or even physical violence (i.e., enacted stigma) and threats to personal well-being because of their serostatus (Gostin 1999; Varas-Diaz 2005; Zierler 2000) may impact people living with HIV. Exposure to reported stories of discriminatory behavior (vicarious stigma), awareness of people's perceptions of stigma (felt normative stigma) as well as self-stigma or believing the stigma surrounding one's own condition (internalized stigma) are also experienced by people living with HIV/AIDS (Steward 2008).

Globally, stigma may arise through a combined interplay of social interaction practices, structural inequality, cultural differences and relation of power (Castro 2005; de Bruyn 2004; Herek 2002; Letamo 2003; Link 2001; Parker 2003; Unnikrishnan 2010). Stigmatization of people living with HIV/AIDS is positively associated with misconceptions about modes of transmission of the disease, lack of HIV knowledge and accurate information, HIV/AIDS serostatus, fears related to its incurability, poorer mental health, as well as discrimination and prejudice towards risky behavior, though it is manifested differently across settings, groups and individuals (Dias 2006; Kalichman 2005; Mahajan 2008; Sengupta 2011). Therefore, identifying risk factors for HIV/AIDS-related stigma is important in confronting perceptions that promote stigmatizing behaviours towards people living with HIV/AIDS (Earnshaw 2009; Nyblade 2009).

People who are HIV-positive or who are perceived to have an HIV infection are affected by stigma (Earnshaw 2009), including children and young adults (Boyes 2012; Reyland 2002). In Brazil, children and young people living with or affected by HIV/AIDS can be denied the right to education and job opportunities (Abadia-Barrero 2006). Experiences of stigma and discrimination are also common in pregnant women, and have been reported as a potential barrier to pregnant women's acceptance of HIV testing in antenatal care (Kilewo 2001; Turan 2011), as well as their initial participation in and adherence to a preventing mother-to-child transmission program (Awiti Ujiji 2011; Bwirire 2008; Mepham 2011; Winter 2005). HIV/AIDS-related stigma is common towards men who have sex with men or gay populations, e.g. in India, the United States and Scotland (Chakrapani 2011; Courtenay-Quirck 2006; Diaz 2001; Flowers 2000; Logie 2012). HIV-positive lesbians, bisexuals and transgender women, e.g. in Canada and India (Chakrapani 2011; Logie 2012a), are also affected by stigma. Researchers have highlighted the urgent need to consider the potential effect of stigma amongst sex workers and the implementation of interventions to reduce stigma (Baral 2012; Biradavolu 2012). Necessary HIV preventive interventions related to negative emotion and its association with drug cravings have also been suggested to address HIV/AIDS-related stigma amongst injecting drug users (Mimiaga 2010; Rudolph 2012).

Stigma related to HIV/AIDS is associated with negative health outcomes, such as lack of access to HIV-related prevention (Mahajan 2008; Piot 2006; Rahmati-Najarkolaei 2010; Sengupta 2011), reduced HIV care-seeking behavior (Sayles 2007), fewer treatment efforts (Bogart 2008) and lack of quality services in many settings (Chakrapani 2011; Fox 2010; Li 2012; Ma 2007; Sayles 2007; UNAIDS 2011; Young 2010).

HIV/AIDS-related stigma can be measured effectively using validated survey instruments (Earnshaw 2009). A number of scales have been developed and tested in multiple settings to measure how the social processes of HIV/AIDS-related stigma affect people living with HIV/AIDS. In Thailand and Zimbabwe, a comprehensive 50-item scale was tested measuring three factors associated with HIV/AIDS stigma including shame, blame and social isolation; discrimination; and equity towards people living with HIV/AIDS (Genberg 2008). Although the scale showed good construct validity and high internal consistency, reporting bias due to self-reported HIV stigma could not be avoided (Genberg 2008). In India, Steward and colleagues developed an HIV stigma scale measuring four components of stigma (i.e., enacted, vicarious, felt normative and internalized) and reported an association between HIV/AIDS-related stigma and disclosure, with disclosure avoidance and depression (psychological distress) found among people living with HIV/AIDS (Steward 2008). In South Africa, Swaziland and the United States, the Internalized AIDS-Related Stigma Scale has been used, with results indicating a significant association between internalized stigma, and depression and social support (Kalichman 2009). This scale was also adopted in Uganda and was found to have high internal validity for measuring the outcomes of HIV/AIDS-related stigma (Tsai 2013). In South Africa, the HIV Stigma-by-Association Scale for Adolescents was adapted to measure stigma and symptoms of depression and anxiety (Boyes 2012). This scale assesses associations between stigma-by-association, bullying, peer problems, depression and anxiety symptoms (Boyes 2012).

Description of the intervention

A variety of specific and general intervention campaigns involving individuals living with HIV have been conducted to reduce HIV/AIDS-related stigma, and several underlying factors that may produce stigma have been addressed (Bellingham 1993; Brown 2003). These interventions have reportedly been effective in improving quality of life among people living with HIV/AIDS and

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contributing to better health outcomes amongst all populations. In this review, we will focus only on individual interventions that address actionable causes of stigma and discrimination, including behavioral, educational and social interventions in creating awareness of what stigma is, how it manifests, and the resulting negative consequences. It is also interesting to assess the effect of interventions in addressing fears and attitudes of the individual, and their advantages in reducing stigma.

Behavioral intervention efforts have shifted to people living with HIV/AIDS (Earnshaw 2009). "Popular opinion leaders" or peer educators were effective in reducing stigma by improving the attitude and behavior of healthcare providers towards individuals living with HIV in China by focusing on self-protection and occupational safety (Kelly 1991; Li 2013). Education-based interventions, to date, have commonly focused on education workshops, curriculum-based psychosocial support including knowledge of HIV/AIDS transmission and risk behaviours (such as sex outside marriage, having multiple sex partners, substance use, sex work and homosexuality), a preventative vaccine for HIV/AIDS and cultural norms of silence regarding sexuality and sexual practices (de Bruyn 1992; de Bruyn 2004; Liu 2006; Luoma 2012; Parker 2003; Rendina 2012). Interventions that solely target perceptions of and attitudes towards people living with HIV (Abadia-Barrero 2006), provide sensitivity training related to those living with HIV/AIDS or promote tolerance through individual contact with HIV/AIDS-diagnosed individuals (Brown 2003; Herek 2002) are still limited. For example, an AIDS education program developed in a high school in a socioeconomically disadvantaged urban area in South Africa addressed the whole school community and aimed to raise awareness about HIV/AIDS using a variety of educational methods (Kuhn 1994). Community and home-based care interventions using capacity building, care and support, resource mobilization and income generation were effective in increasing better social and environmental relations of people living with HIV/AIDS in Ethiopia (Okello 2012). Skilled birth attendance is one evidence-based intervention amongst pregnant women with HIV/AIDS aimed at improving maternal and infant health. Women who give birth with the assistance of a healthcare professional are more likely to receive information relating to HIV-related healthcare, which can reduce the fear of HIV/AIDS-related stigma that often presents an added challenge for pregnant women (Gabrysch 2009).

How the intervention might work

By decreasing HIV/AIDS stigma, a challenging impediment to public health programs will be overcome, leading to a reduction in further HIV infections, the provision of adequate health care and support as well as mitigating the impact of HIV/AIDS (Brown 2003).

Interventions that aim to reduce HIV/AIDS-related stigma have been measured (e.g. in randomized controlled trials, pre- and post-test studies with a non-randomized control group, or pre- and post-test studies with one-group designs) and HIV/AIDS stigma is one of the assessed outcomes (Sengupta 2011). Statistics that demonstrate pre- and post-intervention changes in HIV/AIDS stigma outcomes have been used to assess the availability of effective interventions to reduce stigma. The extent to which stigma reduction interventions reduce barriers to an array of positive behaviours including HIV testing, harm reduction, treatment adherence support and prevention of mother-to-child transmission have also been determined (Doherty 2006; Kalichman 2003).

Why it is important to do this review

HIV-AIDS stigma continues to be a significant hurdle to effective treatment. The variability of efforts to reduce stigma in cultural and local settings has led to complexity in assessing the extent of HIV/AIDS-related stigma and its impact on the effectiveness of HIV prevention and treatment programs, as well as the effectiveness of interventions to reduce stigma (Wu 2008). These challenges hamper local, national and global efforts to address HIV/AIDS-related stigma (UNAIDS 2011).

Therefore, it is important to conduct a systematic review to quantitatively document the current state of research, with an emphasis on summarizing the established knowledge of effective interventions, including defining, measuring and assessing the impact of HIV-related stigma. This review will act as a valuable resource to translate evidence into practice in the global response to the HIV/AIDS epidemic.

OBJECTIVES

1. To assess the effectiveness of interventions to reduce stigma towards people living with HIV/AIDS, improve coping strategies and increase tolerance, compared with a control group.

2. To assess the most effective form of interventions to reduce stigma towards people living with HIV/AIDS, improve coping strategies and increase tolerance, compared with a control group.

METHODS

Criteria for considering studies for this review

Types of studies

All identified published, unpublished and ongoing randomized controlled trials (RCTs) to reduce stigma towards people living with HIV/AIDS that compare two different interventions, including individual specific or general intervention campaigns, or one

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type of intervention strategy with a control, will be included. The unit of randomization will be individual or cluster level. Quasi-RCTs will be excluded.

Types of participants

The general population living with HIV/AIDS, as well as specific target groups living with the disease, including sex workers, drug users (drug users who inject drugs as well as other drug-using populations), men who have sex with men, bisexual people, pregnant women and adolescents.

Types of interventions

Specific or general intervention campaigns (particularly behavioral-, educational- and social-based interventions) targeted at a population level or at specific target groups, including at an individual level, that aim to reduce stigma. These interventions include lectures, group discussions, individual education, radio, television, print (newspapers, magazines, booklets, leaflets, posters, pamphlets), films, documentaries, billboards, folk media (such as street dramas), or a combination of these aimed at achieving behavior change.

The comparison will be other interventions for reduction of HIV/AIDS-related stigma or no intervention.

Types of outcome measures

Primary outcomes

1. Experiences of stigma: prejudicial attitudes and behaviours towards people living with HIV/AIDS, including refusal to provide health care, segregation in healthcare settings, threats of violence, being fired from a job, being refused a job offer, abandonment by family, physical assault, social avoidance, self/social isolation, secrecy, non-disclosure and sexual abuse-related stigma.
2. Anger symptoms: easy to anger, existential anger.
3. Depressive symptoms: hopelessness about the future, fear, anxiety, frustration, feeling sad, crying easily.

Secondary outcomes

1. Increase in tolerance towards people living with HIV/AIDS in the general population, healthcare providers or any other target groups.
2. Improvement in coping strategies for dealing with HIV/AIDS stigma among people living with HIV/AIDS.

Search methods for identification of studies

The Cochrane HIV/AIDS Group search strategy will be followed.

1. Electronic searches

An exhaustive search strategy in collaboration with the trial search coordinator of the Cochrane HIV Review Group will be formulated to identify all relevant trials regardless of language or publication status (published, unpublished, in press and in progress). The following electronic databases will be searched: Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE, EMBASE, LILAC, NLM Gateway, CINAHL, AIDSearch, PsycINFO, Sociological abstracts, and Communication studies. The reference lists of related reviews and all articles obtained will also be reviewed for additional citations. Other relevant websites of international agencies especially those concerned with the prevention of HIV/AIDS (Joint United Nations Programme on HIV/AIDS (UNAIDS), World Health Organization (WHO), United Nations Population Fund (UNFPA), World Bank, and Centers for Disease Control and Prevention) will also be searched.

2. Hand searching

A hand search of key HIV/AIDS research journals will be conducted. The reference list of all studies identified by the above methods and bibliographies of any systematic reviews, meta-analyses, or current guidelines we identify during the search strategy process will be checked.

3. Personal communication

Authors of significant papers and relevant policymakers based in organizations working on HIV/AIDS intervention programs, including UNAIDS and WHO, will be contacted to find other relevant published and unpublished studies.

4. Conference proceedings

Conference proceedings will be searched for relevant abstracts. Conferences include the Conference on Retroviruses and Opportunistic Infections (CROI), 1999-2012; International AIDS Conference (IAC), 1985-2012; and International AIDS Society Conference on HIV Pathogenesis, Treatment and Prevention (IAS), 2001-2012.

5. Cross-references

Bibliographies of studies identified by the procedures described above will be scrutinized to locate additional studies. The search strategy is iterative in that bibliographies of the included studies will be searched for additional references.

Data collection and analysis

The methodology for data collection and analysis will be based on guidance from the Cochrane Handbook for Systematic Reviews of Interventions (Higgins 2009).

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Selection of studies

The selection of potentially relevant studies will be performed in collaboration with the Cochrane HIV/AIDS Group. All identified citations will be appraised independently and critically by two review authors (EO, WW) to determine the potentially eligible studies for inclusion. The titles, abstracts, and descriptor terms of the remaining references will be scanned, and the inclusion criteria will be applied. Irrelevant reports will be discarded, and the full article or abstract obtained for all potentially relevant or uncertain reports will be reviewed for relevance based on study design, types of participants, interventions and outcome measures. No language restrictions will be applied. All disagreements will be resolved by discussion with the third author (RM). Reasons to exclude the potentially relevant trials will be described in an excluded studies table. Reference management software will be used to remove duplicate references.

Data extraction and management

A dedicated pre-designed data extraction sheet for each selected study will be completed by two review authors (EO and WW) independently, after initial search and article screening. The extracted data will include the following information:

- Study details: Study design; type, duration and completeness of follow-up; country and location of the study.
- Participant details: Sociocultural and economic characteristics, inclusion and exclusion criteria including diagnostic criteria for HIV-related stigma.
- Intervention details: Social, behavioral and educational interventions.
- Outcome details: Increase in tolerance towards persons living with HIV/AIDS and improvement in coping strategies for dealing with HIV/AIDS stigma.

Discrepancies will be resolved through discussion or by consulting with the other review author (RM). Data will be entered into the Review Manager software and the accuracy will be checked. When information regarding any of the above is unclear, contact with authors of the original articles will be attempted to elicit further details.

Assessment of risk of bias in included studies

The risk of bias within the included studies against key criteria described below will be assessed independently by two review authors in accordance with methods recommended by the Cochrane Effective Practice and Organization of Care (EPOC) Group and the Cochrane Handbook for Systematic Reviews of Interventions (Higgins 2009). The following judgments will be used: low risk of bias, high risk of bias or unclear risk of bias (either because of lack of information or uncertainty over the potential for bias). Disagreements will be resolved by consensus or reconciled with the third reviewer, or an arbitrator will be involved when necessary.

The components of each included study related to risk of bias will be assessed using a standardized form. This will include information on the sequence generation, allocation concealment, blinding (participants, personnel and outcome assessor), incomplete outcome data, selective outcome reporting and other sources of bias. Methodological components of the studies will be assessed and classified as adequate, inadequate or unclear as explained in the Cochrane Handbook for Systematic Reviews of Interventions and as detailed below:

1. Sequence generation (checking for possible selection bias)

For each included study, the method used to generate the allocation sequence will be described in sufficient detail to allow an assessment to be made of whether it would have produced comparable groups.

Low risk: authors described a random component in the sequence generation process, such as the use of random number tables, tossing coins , or shuffling cards or envelopes.

High risk: authors described a non-random component in the sequence generation process, such as the use of odd or even birth dates or an algorithm based on the day/date of birth, hospital or clinic record number.

Unclear: insufficient information to permit judgment of the sequence generation process.

2. Allocation concealment (checking for possible selection bias)

For each included study, the method used to conceal the allocation sequence will be described and a judgment made as to whether the intervention allocation could have been foreseen in advance of or during recruitment, or changed after assignment.

Low risk: participants and the investigators enrolling participants could not foresee assignment.

High risk: participants or investigators enrolling participants could foresee assignment.

Unclear: insufficient information to permit judgment of allocation concealment or the method not described.

3. Blinding (checking for possible performance bias)

A description will be provided of the methods used, if any, to blind study participants and personnel from knowing which intervention a participant received.

Low risk: blinding of the participants, key study personnel or outcome assessor; no blinding in the situation where non-blinding is unlikely to introduce bias.

High risk: no blinding or incomplete blinding, whereby the outcome is likely to be influenced by lack of blinding.

Unclear: insufficient information to permit judgment of adequacy or otherwise of the blinding.

4. Incomplete outcome data (checking for possible attrition bias through withdrawals, dropouts, protocol deviations)

For each included study and for each outcome or class of outcome, completeness of the data will be assessed including checking attrition, noting exclusions, checking the numbers included in the analysis at each stage (compared with the total number of randomized participants) as well as reasons for attrition or exclu-

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sions where reported, and whether missing data is balanced across groups or is related to outcomes. Where sufficient information is reported, or will be supplied by the trial authors, missing data will be included in the analyses.

Low risk: no missing outcome data, reasons for missing outcome data unlikely to be related to true outcome, or missing outcome data will be balanced in numbers across groups.

High risk: reason for missing outcome data likely to be related to true outcome, with either imbalance in numbers across groups or reasons for missing data.

Unclear: insufficient reporting of attrition/exclusions.

5. Selective reporting bias

For each included study, the possibility of selective outcome reporting bias will be investigated and a conclusion reported.

6. Other sources of bias

For each included study, all other possible sources of bias, including study design and early trial cessation because of data-dependent processes or extreme baseline imbalance, will be reported.

7. Overall risk of bias

Explicit judgements will be made about whether studies are at a high risk of bias according to the criteria given in the handbook (Higgins 2009). With reference to (1) to (6) above, the likely magnitude and direction of the bias and its likely impact on the findings will be assessed and reported.

Measures of treatment effect

1. Dichotomous data

For dichotomous data, results will be presented as summary risk ratios (RR) with a 95% confidence interval (CI).

2. Continuous data

For continuous data, the mean difference (MD) will be used if outcomes are measured in the same way for all trials. Standardized mean differences will be used to combine trials that measured the same outcome with different methods.

Unit of analysis issues

All RCTs including cluster-RCTs will be identified.

Dealing with missing data

For included trials, attrition levels will be noted, and the impact of including trials with high levels of missing data in the overall assessment of the treatment effect will be checked using a sensitivity analysis. For all trials, outcomes analyses will be conducted on an intention-to-treat basis. The denominator for each outcome in each trial will be the randomized number minus any participants whose outcomes are known to be missing.

Assessment of heterogeneity

Given that we anticipate heterogeneity between studies, random effects models will be used to generate pooled effects. Statistical heterogeneity amongst trials will be assessed and quantified using an I^2 statistics for heterogeneity (p value<0.1). If there is sufficient data, statistical heterogeneity will be explored by looking at the outcomes of various studies. A narrative form will be provided in the case where we are not able to combine the outcomes of various studies.

Assessment of reporting biases

When reporting bias is suspected, attempts will be made to contact study authors to ask them to provide missing data. If this is not possible and the missing data are thought to introduce serious bias, the impact of including such studies in the overall assessment of results will be explored through sensitivity analysis.

Data synthesis

The analysis will be performed using the latest version of Review Manager software (RevMan 5). Two authors (EO, WW) will enter the data independently to minimize potential errors leading to heterogeneity.

For each included trial, we will calculate the relative risk, with 95% CI for dichotomous outcomes. For continuous outcomes, weighted mean differences will be used. If studies are considered clinically and methodologically suitable to be combined, a meta-analysis will be conducted. If there are no studies with identical interventions and combinable outcomes, a narrative review will be undertaken.

For the meta-analysis, outcome measures for dichotomous data will be reported as a relative risk with 95% CI. Continuous data will be analysed using the weighted mean difference and standard deviations. If different psychometric scales are used between trials, we will calculate the standardized mean difference (SMD). Survival analysis data (if provided) for time to resolution of symptoms will be analysed using a hazard ratio.

A meta-analysis will be conducted using Review Manager software. Fixed-effect inverse variance meta-analysis will be used for combining data when trials examine the same intervention and their populations and methods are judged sufficiently similar. When heterogeneity between treatment trials is suspected, random-effect meta-analysis will be used. The criteria of the Grading of Recommendations Assessment, Development and Evaluation (GRADE) to evaluate the quality of the evidence by outcome will be performed (Guyatt 2008).

Subgroup analysis and investigation of heterogeneity

Subgroup analysis will be conducted for the primary outcomes of:

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1. Increase in tolerance towards people living with HIV/AIDS by the general population, healthcare providers or any other target groups.

2. Improvement in coping strategies for dealing with HIV/AIDS stigma and discrimination among key groups or people living with HIV/AIDS .

For the fixed-effect meta-analysis, a planned subgroup analysis of age, gender, groups, settings or type of care will be conducted, classifying whole trials by interaction tests as previously described (Deeks 2001).

Sensitivity analysis

A sensitivity analysis will be performed to evaluate bias introduced by variability in allocation concealment in the included studies. We will also perform a sensitivity analysis, excluding the smaller studies, if their results are systematically different from the larger studies. Where available, the frequency and severity of adverse events will be compared between groups.

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WHAT'S NEW

Date	Event	Description
24 August 2012	New citation required and major changes	New author team taking forward this review

HISTORY

Protocol first published: Issue 3, 2007

Date	Event	Description
11 November 2008	Amended	Converted to RevMan 5, and re-published without new citation

CONTRIBUTIONS OF AUTHORS

WW, SN and EO designed, developed and drafted the protocol. RM and KS provided technical support and commented on the draft versions of the protocol. All authors approved the final version to be published.

DECLARATIONS OF INTEREST

We declare that there are no conflicts of interest to report.

SOURCES OF SUPPORT

Internal sources

- No sources of support supplied

External sources

- Ministry of Health, Labour and Welfare, Japan.

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