A method for the quantitative analysis of the layering of HIV-related stigma

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Abstract

HIV-related stigma is regarded as one of the major barriers in the development of effective prevention and care programs; but the stigma associated with HIV stigma is not a singular entity. The stigma of the infection is layered with other stigmas, such as those associated with the routes of transmission (e.g., sex work and injecting drug use) and personal characteristics (e.g., race, religion, ethnicity and gender). In developing programs and policies to overcome HIV-related stigma, cognisance needs to be taken of all the sources of stigma, and how they may interact. A novel method is described for examining the layers of HIV/AIDS-related stigma, and secondary data are adapted to illustrate this. The importance of understanding the layering of stigma for the development of effective interventions is also discussed.

Introduction

Stigmatization is the process of marking individuals and groups judged to be unworthy of social investment (Reidpath et al., forthcoming). In the HIV area, stigma is considered to be one of the greatest barriers to preventing further infections, and to the provision of care and support for people living with HIV/AIDS (PLWHA) (Aggleton, 2002; Parker & Aggleton, 2003); and it is argued that reducing HIV stigma is an integral component of a comprehensive approach to the control of the epidemic (Klein et al., 2002, p. 44). HIV-related stigma, however, is not a singular entity. PLWHA are stigmatized by virtue of their serostatus, risk factors associated with the routes of transmission (e.g., injecting drug use and sex work) and other personal characteristics (e.g., ethnicity, religion, gender and disability) (Bishop et al., 1991; Capitanio & Herek, 1999; Demleitner, 2001; Fassin, 2001; Herek, 1999; Stevens, 1998; Stryker, 1989).

This co-occurrence of multiple stigmatizing attributes is referred to in terms of double stigma (Grossman, 1991) or layers of stigma (Herek, 1999; Scheper-Hughes & Lock, 1991). It has been investigated in a number of ways; however, two of the most common approaches have been through qualitative studies of the experiences of PLWHA (e.g., Barroso & Powell-Cope, 2000; Surlis & Hyde, 2001) and quantitative studies of attitudes towards PLWHA (e.g., Powell et al., 1998; St Lawrence et al., 1990). The second approach generally measures...
levels of stigmatizing attitudes towards people with HIV and other possibly co-stigmatized characteristics through the presentation of vignettes in either experimental or survey designs. It is with this approach that the current paper is principally concerned.

For example, if one were interested in the layering of stigma associated with homosexuality and HIV, then participants would be presented with vignettes describing various combinations of the characteristics in (some variation of) a 2 × 2 factorial design. This was essentially the approach taken by Kelly et al. (1987a) in their experimental study of medical students’ attitudes towards a hypothetical patient, who was either admitted with HIV or leukaemia, and who was either in a heterosexual or a homosexual relationship.

Stigma was measured as a function of social distance (Angermeyer & Matschinger, 2003; Bogardus, 1925) and the results showed that medical students held highly stigmatizing attitudes about patients with HIV and about patients who were in homosexual relationships. Surprisingly, however, given later studies (e.g., McBride, 1998), there was no significant interaction effect between sexuality and disease. Kelly et al. (1987b) conducted a parallel study of physicians, using a related analytic approach, which reported similar results.

Herek and Capitanio (1999) conducted a large population-based survey in the US on attitudes toward PLWHA in which respondents were presented with a random description of a PLWHA. The survey extended the factors examined by Kelly et al. by including race, routes of transmission and gender, but also reduced the factors insofar as every person described was HIV-positive (p. 1135). The advantage of this approach was that (a) it provided population-based estimates, and (b) a range of other (possibly) stigmatized characteristics could be examined. The limitation, of course, was that the independent effects of the co-stigmas in the absence of HIV could not be studied. The authors report a complex pattern of results according to the demographics of the respondents; however, the general finding was, as expected, of more negative attitudes towards PLWHA who were gay.

McBride (1998), like Kelly et al., used an experimental study to look at the attitudes of undergraduate psychology students, but like Herek and Capitanio (1999), the results related specifically to attitudes held towards a person who was HIV-positive. McBride contrasted two factors, sexual preference (heterosexual and bisexual) and the mode of viral transmission (blood transfusion, unsafe sex and injecting drug use) and reported differences between the levels on the two factors and a significant interaction effect. Again, the results indicated a considerable level of stigma associated with HIV and with sexual preference. However, where an HIV infection was associated with ‘innocent’ or ‘blameless’ transmission such as a blood transfusion, the stigma associated with it was significantly less.

Generally ignored in these quantitative studies, the layering of HIV stigma has significant consequences for HIV stigma interventions. Consider, for instance, the implications of an HIV stigma intervention in an environment where injecting drug use (IDU) is stigmatized and a significant route of transmission. Further, imagine that a study was conducted to measure the stigmatizing attitudes towards people who were HIV-positive and/or IDUs. Table I shows the cell means from the ‘study’.

Table I. The mean stigma scores from a hypothetical study of the layering of HIV- and IDU-related stigma.

<table>
<thead>
<tr>
<th>IDU</th>
<th>HIV negative</th>
<th>HIV positive</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>0</td>
<td>30</td>
</tr>
<tr>
<td>Yes</td>
<td>30</td>
<td>X</td>
</tr>
</tbody>
</table>
The average level of stigma associated with a person who is HIV-positive and not an IDU is ‘30’. This is identical to the level of stigma associated with being an IDU and HIV-negative. If a person is both HIV-positive and an IDU, the value of the cell mean (marked as \( x \) in Table I) will depend on whether the stigma of HIV is independent of the stigma of IDU. If the stigmas are independent, then the total level of stigma is simply the sum of the two, and \( x = 60 \). Under these circumstances, a successful program to deal with HIV stigma will remove that stigma in its entirety; and the stigma associated with a person who was an IDU and HIV-positive would be reduced from 60 to 30. If, however, the stigmas were not independent, then (in general) the total level of stigma would lie somewhere between 30 and 60, and under these circumstances some of the stigma associated with HIV will remain even after the successful implementation of the stigma campaign (Figure 1).

Figure 1 uses the cell means from Table I (assuming \( x = 40 \)) to illustrate the layering of the stigmas of IDU and HIV. The unique stigma of HIV is shown as the lower block. The unique stigma of IDU is shown as the upper block. The stigma that is shared is shown as the middle block. In this situation, a stigma intervention that addresses only HIV stigma will remove only the lower block of unique HIV stigma, leaving the shared and IDU stigma intact.

The potential program implications of this are significant in an environment where IDU is common. A blisteringly effective campaign to address HIV-related stigma that fails to address IDU-related stigma would have little impact on the overall level of stigma. An HIV-positive IDU would continue to avoid treatment and support services, and would avoid harm reduction strategies that had the potential to identify him or her as a member of that highly stigmatized class of people who engage in injecting drug use. Disentangling the layered nature of HIV stigma thus becomes crucial because it is only through understanding the complexity of it that comprehensively effective policies and interventions can be developed.

Unfortunately, the kinds of quantitative studies that have demonstrated the existence of HIV layering, such as those of Herek (Capitanio & Herek, 1999; Herek, 1999; Herek & Capitanio, 1999) and McBride (1998), have not identified the extent to which the stigmas are layered, the extent to which they are independent or the extent to which they are decomposable.
In this paper, a method is proposed for analyzing data to do just that. The method is illustrated with data loosely derived from McBride's (1998) study. The exposition is then extended to a more general consideration of how stigma may theoretically be layered. Although Kelly et al. (1987a,b) described what might be characterized as a more ideal study, because HIV status was itself a factor included in their vignettes, they unfortunately did not describe the results in sufficient detail to reconstruct the data.

Inferential statistics and hypothesis testing are not discussed in this exposition because they divert attention away from the methodological thrust of the paper. The approach, however, neither precludes nor protects researchers from testing hypotheses and in a ‘real world’ application it would be critical to know whether the observed difference between groups were a chance phenomenon.

**Methods**

In the original study of McBride (1998), ‘… 181 heterosexual undergraduate students …’ were each shown short, three-line, vignettes describing HIV-positive males (p. 597). In each of the vignettes the male was either heterosexual or bisexual, and his HIV infection was attributable either to a blood transfusion, unsafe sex or injecting drug use. For each vignette, participants completed a seven-item measure of social distance. Social distance was used there, as elsewhere, as a proxy of stigma (Kelly et al., 1987a,b).

Conventionally these data would be analyzed as a 2 x 3 repeated-measures factorial design. In this context, however, the analysis is not intended to say anything specific about the original study, which is used here simply to provide a backdrop and as ‘plausible’ data.

For the purpose of simplifying the illustration of the method, but without loss of generality, the analysis focuses on blood transfusion and IDU as the modes of HIV transmission (i.e., a 2 x 2 design). The data that are used are the cell means published by McBride (1998), p. 600).

The mean scores associated with each of the four cells (heterosexual/transfusion, bisexual/transfusion, heterosexual/IDU and bisexual/IDU) could theoretically lie between 7 and 49 inclusive, where 7 represents the lowest possible level of stigma and 49 represents the highest. The disadvantage of this scaling is that it does not have ratio properties. The raw cell mean scores were, therefore, converted to a percentage of the stigma scale maximum (%SM) using the formula:

\[
\%SM = \frac{\text{score} - \text{scale}_{\text{min}}}{\text{scale}_{\text{max}} - \text{scale}_{\text{min}}} \times 100,
\]

such that the level of stigma would now lie in the interval 0 and 100 (Cummins, 1995). An additional advantage of this approach is that it becomes possible to write of the percentage of the stigma score attributable to one source of stigma and the percentage attributable to another.

**Results**

The%SM means and raw score means derived from the original data are shown in Table II. The HIV-positive, heterosexual male who acquired his infection from a blood transfusion may be considered to have a baseline or ‘pure’ measure of HIV-related stigma. This hypothetical person engaged in no high-risk behaviours or acts that could be judged immoral or illegal; and his sexuality conforms to the hetero-normative behaviour of his
community. The notion of a ‘pure’ stigma, however, is an artifice and necessarily oversimplifies things. Embodied within the heterosexual male is a confluence of other risk factors. It is, nonetheless, in the nature of the vignette design that other unseen risk factors are treated as controlled—because they should be equally present in the other cells. This assumption may be unreasonable, but rather than detracting from the analysis, it simply reinforces the need to unpack the layers of stigma further. Even under these circumstances, the mean%SM stigma score is 28.6.

The HIV-positive, bisexual male who acquired his infection from a blood transfusion layers any stigma associated with being HIV-positive on the stigma of being bisexual. He has a mean%SM stigma score of 38.5; which is to say, he is stigmatized on average 1.35 times more than his heterosexual counterpart simply by virtue of his sexual preference. Figure 2 illustrates the complexity associated with the layering of HIV stigma. The bar labeled ‘HIV’ shows the ‘pure’ stigma associated with being HIV-positive; that is, the stigma of being a heterosexual who acquired HIV through a blood transfusion (%SM, 28.6). The three bars to the right show the possible interpretations attached to the layering of HIV stigma and bisexual stigma. In disentangling the layering of stigma, the question is, how much of the stigma could be explained by the HIV status alone, how much could be explained by the bisexuality alone and how much could be explained equally well by either.

![Figure 2](image-url)
The bar labeled ‘HIV/Sex (1)’ portrays the most conservative interpretation of the layering of stigma. It shows the stigma associated with being HIV-positive and the stigma associated with being bisexual as strictly additive. That is, the stigma score of being HIV-positive and being bisexual (38.5) is additively composed of the stigma score of being HIV-positive (28.6) and the stigma score of being bisexual (i.e., 38.5 – 28.6 = 9.9). In effect, this model ‘privileges’ the stigma of HIV by assuming that it makes a larger unique contribution to the overall stigma.

If this model were correct and an effective intervention were developed to deal with the HIV stigma, the heterosexual male would no longer experience any stigma and the bisexual male would now experience only a relatively small amount of residual stigma (i.e., %SM of 9.9).

The bar labeled ‘HIV/Sex (2)’ portrays the least conservative interpretation of the layering of stigma. It shows the stigma associated with being HIV-positive and the stigma associated with being bisexual as completely layered, with much of the stigma being shared. If this model were correct, and an effective intervention were developed to deal with the stigma of the disease, the heterosexual male would no longer experience any stigma, but the bisexual male would continue to experience exactly the same levels of stigma as before (i.e., %SM of 38.6). However, the stigma would be solely attributable to his sexual preference.

The final bar labeled ‘HIV/Sex (3)’ portrays the position that lies between the two extreme interpretations. It shows that the stigma associated with being HIV-positive and the stigma associated with being bisexual is comprised of: (a) some stigma uniquely associated with being HIV-positive, (b) some stigma uniquely associated with being bisexual, and (c) some stigma that reflects a sharing of the stigma between being HIV-positive and being bisexual. If this model were correct, and an effective intervention were developed to deal with HIV stigma, the heterosexual male would no longer experience any stigma. The stigma experienced by the bisexual, however, would only be reduced by the amount that was uniquely associated with being HIV-positive. The stigma he would continue to experience lies between the extremes of the most conservative (%SM = 9.9) and least conservative (%SM = 38.6) possibilities.

The bars showing ‘HIV/Sex (1)’ and ‘HIV/Sex (2)’ represent, in effect, the boundary conditions—the two possible extreme interpretations of either completely independent and unique stigmatizing effects of HIV status and sexual preference (HIV/SEX (1)) or a complete layering of stigma (HIV/SEX (2)). The absolutes of boundary conditions are generally rare and the reality is likely to be found in some combination of the two explanations (i.e., that shown in HIV/Sex (3)).

If one considers the full results shown in Table II, it quickly becomes apparent that the complexity of layering is actually greater than that shown in Figure 2. For instance, the marginal difference between the level of stigma associated with being a heterosexual versus bisexual, HIV-positive injecting drug user is small (48.9 versus 53). This suggests that in these adapted data, the stigma of being an IDU is much greater than the stigma of bisexuality. More importantly, it indicates that, in this instance, the stigma is not strictly additive. An intervention that addresses the stigma of bisexuality will, on average, have little impact on the stigma experienced by those who are both bisexual and IDUs.

Moving away from the specifics of the data in Table II, there are other possible ways in which the layering of stigma could be revealed by this kind of analysis. Figure 3 shows the generalized situation of four possible sources of stigma given two co-occurring stigmatizing
characteristics. There are the two unique sources of stigma associated with a stigmatized characteristic, such as IDU and bisexuality. Then there is the shared stigma, which is the degree to which the stigmas of the two characteristics overlap. Finally, there is what is referred to here as ‘synergistic stigma’. This would occur if, for example, being both bisexual and IDU was worse than the simple addition of the stigma associated with each characteristic in isolation. Thus, the controlling of one unique source of stigma would remove the stigma associated with the synergy of the co-occurring characteristics, but leave the shared stigma and the unique stigma associated with the other characteristic.

Discussion

The people living with HIV/AIDS who inject drugs, work in the sex industry or engage in homosexual sex will not necessarily have a less stigmatized experience just because a campaign that addresses HIV stigma is successful. If stigma is a significant barrier to the successful implementation of campaigns to reduce the transmission of HIV and to the improvement in the quality and length of the lives of PLWHA, then it is not enough to focus on single sources of stigma. Rather, there needs to be an understanding of the layering of the stigma so that informed policies and interventions can be developed that will address the entire experience of stigma.

These results are pertinent to many HIV stigma interventions, but they are, perhaps, most obviously important for the setting in which the marginalized groups that embody the risk factors for the transmission of HIV are particularly stigmatized.

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References


