



The value of reducing HIV stigma



Robert J. Brent

Department of Economics, Fordham University, 441 East Fordham Road, Bronx, NY 10458, USA

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ABSTRACT

HIV-stigma is a major reason why HIV continues to be a global epidemic. Interventions targeting HIV-stigma are therefore necessary. To find an intervention that is worthwhile, a Cost-Benefit Analysis is needed which compares costs and benefits. There are many documented costs of HIV-stigma. What is missing is a valuation of the benefits of reducing HIV-stigma. The purpose of this paper is to present a general method that can be used to value the benefits of stigma reduction programs. The method involves estimating the marginal rate of substitution (MRS) between stigma and income in the utility function of older people with HIV. To illustrate how our framework can be used, we applied it to a sample of just over 900 people coming from the 2005–06 ROAH study (Research on Older Adults with HIV) in New York City.

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1. Introduction

By the end of 2010 there were 1.2 million people in the US living with HIV/AIDS. Between 2006 and 2009, the average number of new infections in the US was between 48,600 and 56,000, see [UNAIDS \(2011\)](#). UNAIDS call stigma a “social enabler”. UN Secretary General, Ban Ki-Moon ([2008](#)) states that stigma is a chief reason why the AIDS epidemic continues to devastate societies worldwide. He argues that because of stigma people do not get tested and, if tested and found positive, do not seek treatment. [Dieffenbach and Fauci \(2009\)](#) report that treatment is now considered a major way that HIV can be prevented. So by hindering treatment, HIV transmission increases greatly because of the existence of stigma. The adverse effect of stigma is clearest in the context of South Africa where stigma leads many in affected areas to fail to accept that HIV is the cause of increased deaths, see [Taylor and Kvalsvig \(2008\)](#).

Because HIV infection is an invisible health condition, HIV stigma is directly linked to disclosure. If stigma is internalized, it may make disclosure difficult, or even impossible. Once being HIV positive is disclosed, it exposes the person to the risk of experiencing various negative stereotypes, prejudices and forms of discrimination. In contrast to various other stigmatized health conditions, HIV infection was believed in the 1990s in the US to be acquired exclusively by stigmatized - and even criminalized - forms of behavior. Historically, these were homosexual relationships of men, the sharing of needles by illegal drug users, and men visiting

commercial sex workers. It is only relatively recently, since 2000, that the general public became aware of the possibility of HIV infection also by means of non-stigmatized forms of behavior, such as heterosexual relations or transmission from mother to child. The association of HIV infection with stigmatized forms of behavior, however, still constitutes an integral part of the stigma related to HIV, see [Herek et al. \(2002\)](#).

Michael Sidibe, the UNAIDS executive director, argues in his introduction to [UNAIDS \(2012a\)](#) that stigma is undermining the HIV response across the world and that this will continue until we make major investments in programs that reduce such stigma. To judge whether any investment would be worthwhile it is necessary to carry out a Cost-Benefit Analysis (CBA) of stigma interventions. Many effective interventions have been identified and [UNAIDS \(2012b\)](#) has developed a tool for estimating the costs. But, we need also to estimate the benefits to be able to fully evaluate the potential programs. The purpose of this paper is to present a general method that can be used to value the benefits of stigma reduction programs in order that CBAs can be undertaken in the future (to see how CBA is applied in the health care field refer to [Brent, 2015](#)).

Although we will be focusing on HIV stigma, it is important to recognize that stigma is a widespread phenomenon that prevents access to services in many branches of the health care field. We give five examples without claiming that we are in any way being exhaustive. (i) [Porter et al. \(2009\)](#) report that stigma presents a barrier to managing chronic illness by preventing people from being tested, especially for TB. (ii) [McSween \(2002\)](#) shows that

E-mail address: brent@fordham.edu.

preferences for government expenditures on mental health are determined by stigmatizing attitudes, as mental health is one aspect of general health, yet it receives less support for government spending increases than does non-mental health care; (iii) [Tsiou and Liu \(2006\)](#) explain how stigma leads to non-obese (judged by their BMI) educated females engaging in weight loss practices because they consider themselves to be obese. These practices expose the women to unnecessary health risks. (iv) [Thomas and Nair \(2011\)](#) cite numerous studies throughout the world where physicians react to the stigma of epilepsy by failing to give family members full information. Lastly, (v) [Zeldenryk et al. \(2011\)](#) state that a fear of being identified as a Lymphatic Filariasis (LF) patient, which is one of the leading causes of disability in the world and should therefore be well understood, prevents many accessing LF services. Many only sought assistance once symptoms significantly affected work activities. The method for valuing HIV/AIDS stigma reductions that is presented in this paper also could be used in all these other situations where stigma acts as a barrier preventing access to health care.

The method that we explain in this paper to estimate the value of HIV stigma prevention, although new in this context, is very basic to economics. We estimate a utility function with stigma and income as arguments and obtain the marginal rate of substitution (MRS) between the two. Three formulations of the MRS will be presented. In the more general versions, a recursive estimation framework is used whereby stigma first determines income and then the income-influenced stigma determines utility. To illustrate how our framework can be used, we applied it to a sample of older people living in NYC with HIV.

The remainder of the paper is organized as follows. The next section is devoted to a brief literature review which serves to define stigma and how it can be measured and identifies the types of stigma reduction programs that have been found to be effective. Section 3 explains the MRS method and covers cases where income is, and is not, a function of stigma. Section 4 describes the data that will be used and section 5 gives the empirical results. Section 6 concludes.

2. Literature background

We first summarize what the literature has to say about stigma, and HIV/AIDS stigma in particular, and then explain how our measure that we will be using to value HIV/AIDS stigma fits in with these concepts.

[Goffman \(1963\)](#) uses the term stigma to refer to both a trait, an attribute that is viewed negatively by society, and the outcome of being known to possess that trait, whereby the negative social meaning attached to the discrediting attribute gets linked to the individual with the attribute. Discrimination against individuals then occurs as a consequence of the stigma they possess. Such discrimination may affect income, education, housing status, medical treatment and health. The three reasons why society has these negative views of people living with HIV has been attributed by [UNAIDS \(2012a\)](#) to be ignorance about the harm of stigma, continuing irrational fears of infection and moral judgment.

Since Goffman's pioneering work on stigma, there have been more recent attempts to broaden the definition. For example, [Link and Phelan \(2001\)](#) suggest that stigma include five interrelated components: First, people distinguish and label human differences. Second, dominant cultural beliefs label persons with undesirable characteristics which, third, leads to a separation of "us" from "them". Fourth, labeled persons suffer status loss and discrimination. Fifth, stigmatization occurs because there exists social, economic and political power that allows the first four components to operate. That is, people identify differences, construct negative

stereotypes and separate labeled persons into categories, culminating in disapproval, rejection exclusion and discrimination. This broader definition of stigma led [Parker and Aggleton \(2003\)](#) to reinterpret Goffman's work to suggest that stigmatization devalues relationships rather than just being a fixed attribute assigned to a person.

Apart from defining stigma, the literature also, for example [Brown et al. \(2001\)](#), divides stigma into felt or perceived stigma and enacted stigma. Perceived stigma relates to real or imagined fears of social attitudes towards discrimination. Thus a person may not disclose their HIV status because of the fear of negative reactions by society and suffer because of this by not seeking treatment. Enacted stigma on the other hand refers to the real experience of discrimination, whereby a person suffers the consequences of stigma by, for example, losing their job. This job loss is separate from the fact that those with HIV may lose their jobs due to ill health. There is widespread evidence that losing one's job, or not getting a job in the first place, due to HIV stigma is universal and extensive. For example, in a study of nine countries in four regions of the world, in all countries except Mexico, HIV-related discrimination, and HIV-related discrimination combined with poor health, was a more frequent cause of loss of employment/income than poor health alone. In Poland, 100% of job losses were due to stigma alone and not due to poor health, so HIV discrimination played a part in all cases. The evidence on being refused employment in the last 12 months because of HIV positive status was also extensive. The country percentages ranged from a high of 27% for Nigeria to a low of 5% for Mexico, see [GNP + ILO \(2012\)](#).

To measure HIV/AIDS stigma we will use the Berger scale (see [Berger et al., 2001](#)). This was constructed with the Goffman definition in mind, but is wide enough to accommodate some of the more recent extensions. In particular it includes both perceived and enacted stigma. Most importantly, the scale reflects stigma as experienced by the receivers and not what researchers think the receivers are experiencing. Link and Phelan argue that research on stigma is largely based on theories that are uninformed by the lived experience of the people they study. The Berger scale is a measure that comes entirely from the responses of those living with HIV/AIDS experiencing the stigma. The details of the Berger scale are given in full in section 4.

In the context of the US population, perceived HIV stigma is extensive. A 1999 national telephone survey of 1,135 persons aged 18 and over (56% female and 82% non-Hispanic white) found that: 86% believed that people living with AIDS (PWA) faced "some" or a "great deal" of unfair persecution in the past and that 77% believed that PWA still experience unfair persecution; 68% believed that they would be "very concerned" or "somewhat concerned" about stigma if tested positive; and of those concerned, 33% believed that such concern would have a "great deal" or "some" effect on their decision to be tested, see [Table 1](#) based on [Table 1](#) of [Herek et al. \(2003\)](#). For subsets of the HIV/AIDS population where the number of infections is particularly large, stigma can have an even greater negative impact. In a 2008 data set related to 21 cities across the US, the [CDC \(2008\)](#) estimated that, the prevalence rate among Black men having sex with men was 28%. For this group, [Bogart et al. \(2013\)](#) found that 45% experienced discrimination due to HIV-status. This is just the enacted form of stigma that we will be analyzing.

To capture many of the ways that stigma reduces the quality of life of an HIV infected person, this paper uses a quantitative measure for stigma that includes both perceived and enacted stigma and then estimates the impact of this stigma index on a person's life satisfaction. As we report, changes in income will be a determinant of utility in its own right and, in addition a mechanism by which stigma manifests itself indirectly working through its effect on

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