Towards a Sustainable Theory of Health-Related Stigma: Lessons from the HIV/AIDS Literature

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ABSTRACT

Stigma has been identified as a major barrier to health care and quality of life in illness management. But unfortunately there is no common theoretical perspective on stigma. We need a sustainable theory of health-related stigma. This would start with a coherent definition of stigma that brings together both individual and social dimensions of this complex phenomenon. It would reassess the existence of ‘types’ of stigma and explain how stigma relates to disadvantage. A sustainable theory would help researchers to move from theory into practice: to develop a comprehensive measurement tool for stigma and related disadvantage, and inform design, monitoring and evaluation of anti-stigma interventions. This paper draws on two recent literature reviews on HIV/AIDS stigma to introduce several key issues in developing a sustainable theory of stigma. We suggest limiting the definition of stigma to the process of othering, blaming and shaming (often called symbolic stigma). We argue that there is value in analytically separating stigma from discrimination in order to better understand the relationship between them. We also suggest the need to understand discrimination caused by stigma as only one element of stigma-related disadvantage. Copyright © 2006 John Wiley & Sons, Ltd.

Key words: HIV/AIDS; stigma; discrimination

INTRODUCTION

Researchers have found it difficult to develop a common theoretical perspective on stigma (Link & Phelan, 2001). It is crucial to have a sustainable theory of stigma, which would begin with a coherent model of the process of stigmatisation that can help us to understand both its origins and its effects, and provide a way of bridging the divide between research models, evidence and interventions. In dealing effectively with a complex social problem, Dorner (1989) suggests that we need to know both how the individual components of a system fit into a hierarchy of broad and narrow concepts (e.g. stigma, discrimination, disadvantage) and how these individual components of a system relate to...
each other, so we can hypothesise interactions between them. We also need to know what factors might reduce stigma.

Theories provide frameworks or models within which researchers can develop better research and intervention strategies. They should be constantly revisited and reassessed in a dialogue with evidence from research. This paper is a call to look critically at the theory of stigma in order to try and understand the various components of the system in which stigma and discrimination have their negative effects. In it we offer some thoughts on the development of a sustainable theory of health-related stigma, drawing from more detailed discussions in two wide-ranging recent literature reviews on HIV/AIDS-related stigma in adults and children (Deacon, Stephney, & Prosalendis, 2005; Deacon & Stephney, 2006).

HIV/AIDS provides a good case study for reviewing our theoretical understanding of health-related stigma because it provides evidence of the complex relationship between stigma and existing forms of prejudice and disadvantage, discrimination and the variety of different responses to stigma and discrimination by people living with HIV and AIDS. This evidence emerges from the vast body of literature that has been written on HIV/AIDS-related stigma in the last decade or so. One of the problems with the size of this body of literature is that most studies cannot review the broader stigma literature outside of HIV/AIDS, or reflect on the broader debates (notable exceptions being the work of Link & Phelan, 2006; Parker & Aggleton, 2003). In our own literature reviews, we therefore specifically sought insights from other areas of work, and different disciplinary approaches to the problem.

We suggest that the concept of stigma has suffered from ‘conceptual inflation’ and a consequent lack of analytical clarity—the same problem that was identified in the 1980s with theories of racism that encompassed discrimination (Miles, 1989). As one paper says:

Stigma . . . is creaking under the burden of explaining a series of disparate, complex and unrelated processes to such an extent that use of the term is in danger of obscuring as much as it enlightens (Prior, Wood, Lewis, & Pill, 2003, p. 2192).

There is confusion as to how various ‘types’ of stigma (instrumental, symbolic and resource stigma) should be defined and how they relate to each other. Because of space constraints, however, this will be debated elsewhere. In this paper we focus on how theories of stigma address the relationship between stigma, discrimination and disadvantage. Defining stigma in terms of discrimination stretches the concept of stigma to accommodate both stigmatising beliefs themselves (unjustified negative things people believe about others that involve a moral judgement) and the effects of some stigmatisation processes—discrimination (what people do to disadvantage others).

We suggest that we need to revisit our theories of stigma and discrimination by:

1. Developing a definition of stigma that allows for both psychological and social dimensions of the stigmatising process, without confusing stigma with discrimination.
2. Explaining how stigma and discrimination relate to other forms of disadvantage, and
3. Distinguishing between different sources of disadvantage related to stigma.

A sustainable, coherent theory of stigma can improve HIV/AIDS-related stigma research and intervention planning because how we define stigma structures our understanding of how to measure it, and how to design and evaluate interventions. Researchers need to measure stigma across the full range of domains (e.g. knowledge, attitudes, discriminatory behaviours, perceived stigma, experiences of stigma), and to establish why people are thinking and behaving in certain ways (Nyblade, 2006). A deeper
theoretical understanding of stigma and disadvantage will help us understand how these
domains relate to each other, and research on the social environment of stigma can be
integrated better with research on personal attitudes and experiences.

Given the current lack of coherent theory in the field, and the complexity of the problem
of stigma, most researchers advocate a mixed bag of anti-stigma interventions for HIV/
AIDS. Brown, Trujillo, and Macintyre (2001) suggest that education should be combined
with counselling, coping skills acquisition and contact with PLWHA. Others suggest
encouraging community involvement in anti-stigma programmes, and empowering
PLWHA through social advocacy, legal rights protection, and general poverty relief
(Visser, Mundell, & Gcabo, 2004; Parker & Aggleton, 2003). But unless we have a better
understanding of stigma and discrimination, and more evaluations are actually done of
interventions (Brown et al., 2001), it is difficult to choose what kinds of interventions
should go into the mixed bag.

STIGMA AS A SOCIAL PROCESS

As we discussed in the introduction to this special edition, various authors have challenged
the tendency in traditional stigma research to see HIV/AIDS stigma (or indeed, any health-
related stigma) in individual psychological terms. Herek has been criticised for
individualising stigma, but he does see stigma as a social construct. For example, he
defines stigma as ‘an individual’s negative attitude towards a social group, which matches
the negative evaluations of society towards the attributes held by that group’. He
distinguishes it from discrimination, which he defines as ‘behaviour or actions that are
differentiated according to membership of a specific group, which only becomes a
manifestation (an effect?) of stigma when society defends or encourages it’ (Herek,

It is an understanding of social power relationships that has rightly been seen as crucial
in developing a more holistic theory of stigma, both in sociological analyses (e.g. Parker &
Aggleton, 2003), and in cognitive and psychoanalytic theories from social psychology
(Link & Phelan, 2001; Joffe, 1999). While we support the broad trend towards a social
psychological analysis of stigma that addresses relationships of power, it is neither
necessary nor desirable to achieve this by defining stigma as something that has to result
in discrimination, as some researchers have done. For example, Link and Phelan (2001,
p. 367) argue that:

Stigmatization is entirely contingent on access to social, economic and political power that allows
the identification of differentness, the construction of stereotypes, the separation of labeled
persons into distinct categories and the full execution of disapproval, rejection, exclusion and
discrimination. Thus we apply the term stigma when elements of labeling, stereotyping,
separation, status loss and discrimination co-occur in a power situation that allows them to unfold.

As we outlined in the introduction, Joffe (1999), has also defined stigma as a social
process, drawing on existing forms of social representation that are rooted in social power
relations, emerging from an individual psychological blaming and othering response, a
cognitive justification for an emotional reaction of fear. Stigmatizing discourse allows
people to distance themselves and their self-defined in-groups from the risk of infection by
blaming contraction of the illness on characteristics normally associated with out-groups,
who are classified as deviant and ‘other’. In different contexts, for example, various
different groups have been defined as particularly at risk for (and somehow responsible for) contracting HIV/AIDS, including ‘promiscuous’ people, gay men, commercial sex workers and women, in general.

Building on Joffe’s work, we argue that in understanding stigma as a social process we do not need to define it in terms of discrimination to appreciate the importance of social power relations. We can define stigma as a social process in which:

1. Illness is constructed as preventable or controllable;
2. ‘Immoral’ behaviours causing the illness are identified;
3. These behaviours are associated with ‘carriers’ of the illness in other groups, drawing on existing social constructions of the ‘other’;
4. Certain people are thus blamed for their own infection; and
5. Status loss is projected onto the ‘other’, which may (or may not) result in disadvantage to them.

Defining stigma in this way helps us to understand both the individual and the social dimensions of stigma. Stigmatising views exist as social discourse and draw on existing forms of social prejudice and power, but they are enacted by individuals to reduce perceptions of personal risk. It is not possible or desirable to separate ideology completely from practice, from the expression of ideology in words, and the consequences that might result from this activity. But it is possible to link stigma to its necessary consequences (status loss in the view of the stigmatiser) without defining it specifically in terms of discrimination.

**STIGMA AND DISCRIMINATION**

Why do we wish to separate stigma from discrimination? Doing so allows us to think more clearly about negative consequences of stigma, including unjustified beliefs in immunity against disease, discrimination and disadvantage of other kinds, such as that caused by responses to stigma and discrimination (e.g. internalisation) in stigmatised people. It also allows us to conceptualise possible positive responses to stigmatisation such as resistance and activism.

Defining stigma as something that results in discrimination reduces analytical clarity about the relationship between stigma and its effects. There are several reasons for this.

Firstly, anyone can stigmatisate, no matter what their social position. Poorer and more marginal groups can stigmatisate wealthier and more powerful groups, both within and between societies (Joffe, 1999). The process of stigmatisation can therefore continue to happen because there is a psychological pay-off for the stigmatiser, whether or not it can be enacted as discrimination in the current social context. Even so, stigma can remain a problem because it may result in people feeling protected from the risk of contracting a specific illness through membership of their in-group, and thus not practicing preventive measures (e.g. condom use in the case of HIV/AIDS).

Secondly, even in the absence of any active discrimination, stigma may have a negative impact on the self-concept and actions of stigmatised people. Expecting to be stigmatised or discriminated against may change people’s behaviour, causing social withdrawal and consequent disadvantage. Mills (2004) shows how fear of HIV/AIDS-related stigma affects people’s ability to accept and access services from clinics and home-based carers in South Africa. In her work on disability-related stigma, Sayce (2003, p. 628) complains
about the confusion caused by Link and Phelan’s use of one term, ‘stigma’, ‘to describe both the act of discrimination and the personal experience of being labelled’. We need a better understanding of how health-related stigma leads to disadvantage, not just through discrimination. Internalisation of stigma can lead to self-doubt, lower self-esteem, depression, immuno-suppression and even premature death (Berger, Ferrans, & Lashley, 2001; Fife & Wright, 2000; Santana & Dancy, 2000).

Thirdly, stigmatisation does not always lead to disadvantage for the stigmatised, and can be challenged. The activism of groups like South Africa’s Treatment Action Campaign (TAC), with its ‘HIV-Positive’ slogan, directly challenges the stigma associated with having HIV and consequent lack of attention to treatment issues. In certain contexts, people may gain status if they ‘come out’ about a stigmatised characteristic and they become legitimate spokespeople for minority or marginalised groups in the process. Stigmatised status forms the basis for many minority group identities and establishes their legitimacy in lobbying for state recognition (Berbrier, 2002).

Understanding the relationship between stigma and social power can best be achieved by trying to understand stigmatisation as a process with psychological functionality for individuals, drawing on patterns of social representation that are embedded in social power relationships. Defining stigma in terms of discrimination narrows our understanding of the range of effects stigma can have, and presupposes an over-simplistic relationship between stigma and consequent or existing disadvantage. We have thus made the case for separating stigma analytically from discrimination, following Miles (1989), who proposed a similar solution in theorising racism.

STIGMA AND EXISTING FORMS OF DISADVANTAGE

Separating stigma analytically from discrimination does not imply that one should understand stigmatisation and its effects in isolation from broader power relations, just that existing forms of discrimination or disadvantage for marginalised groups should not be mapped directly onto stigma.

In the introduction we introduced the concept of ‘layered stigma’ which has been used to describe the relationship between stigma and existing forms of negative social representation and disadvantage, borrowing from the notion of double or triple oppression used in the women’s rights field. People already in positions of social power and authority tend to be heard more and can act on stigmatising beliefs more readily (Link & Phelan, 2001). Structural constraints based on historical disadvantage can prevent people from acting on information or resisting new forms of discrimination, thus entrenching marginalisation. Stigma and discrimination often follow the fault-lines of existing social marginalisation or social exclusion:

Categories of blame often reflect deep social-class biases. Illness is frequently associated with poverty and becomes a justification for social inequities. ... disease is frequently associated with the ‘other’, be it the other race, the other class, the other ethnic group. Inevitably the locus of blame is also tied to specific ideological, political and social concerns. (Nelkin & Gilman, 1988, pp. 362–363).

At a global level, for example, HIV/AIDS stigma has been stronger and discrimination has been more intense against already marginalised groups like gay men, sex workers and
drug users. In Africa, women (especially sex workers and HIV-positive mothers) have been blamed for transmitting HIV to others.

Stigma is embedded in unequal, gendered, racist societies, but it is not simply an agent of disadvantage wielded by the powerful on the already marginal. Sayce (2003, p. 627) argues that ‘social exclusion . . . is a useful term to draw common cause with other groups facing inter-locking processes leading to joblessness, lack of hope and so forth. However, ‘social exclusion’ does not capture the key process of identifying particular types of human ‘difference’ . . . and attributing to them all kinds of undesirable attributes’.

Perhaps researchers need to distinguish between layering of stigma and negative social representations (which is relatively easy to track) and layering of stigma and social disadvantage (which is more difficult to track). It is not easy to determine how stigma specifically contributes to the intensification and reproduction of social inequalities, because even without stigmatisation, some groups of people would be more likely to contract HIV and thus the HIV/AIDS pandemic would exacerbate existing inequalities (Heywood, 2002). If already immune compromised through malnutrition, for example, poor people are more vulnerable to contracting HIV and developing symptoms of AIDS more quickly.

As Miles (1989) points out in respect to racism, not all disadvantage for stigmatised groups can be ascribed to stigma. Stigma is just one possible cause of disadvantage. Castro and Farmer (2005) for example, argue that logistical and economic barriers to health service access in Haiti are more critical than AIDS-related stigma for people living with HIV/AIDS. Poor families usually suffer more from the effects of chronic illness in a household than do wealthy families, quite apart from stigma. If we are serious about addressing disadvantage experienced by specific stigmatised groups, we have to understand disadvantage in holistic terms, and in the case of stigma, show the specific link between specific kinds of disadvantage and the kind of stigma being researched.

Although experiencing multiple forms of stigma usually increases the burden of disadvantage for the already marginalised, it is worth noting that stigma also has effects on high-status members of a society, who are disadvantaged only through contracting a specific stigmatised illness. Members of high status groups often expend considerable personal and financial resources to conceal stigmatised conditions because they fear status loss. In Zambia, Bond et al. (2003) found that more blame is sometimes directed at high status members by communities if they contract a stigmatised illness because they ‘should have known better’.

Both gender and economic inequality help to create a material and discursive environment in which HIV/AIDS and related stigma can flourish and gain new layers of meaning, and in which discrimination can become socially acceptable. However it is crucial to recognise that HIV/AIDS-related stigma does not only affect the marginal (e.g. women or poor people), and that it has negative effects within poor households, between women and among high status groups. Stigmatisation is closely related to, and draws on, other forms of stigmatisation and social disadvantage, but is not determined by them: it is not just a replication of existing power relations—it is a new source of social power, with its own specific characteristics. It is only by understanding these characteristics better that we can develop ways of addressing it, exploiting the fault-lines between stigma and existing forms of social power.

CONCLUSION

In this paper we argue that for research and interventions against health-related stigma to improve, we need to develop a more coherent, sustainable theory of stigma. In order to do
this, we need a better understanding of stigma and its relation to discrimination and disadvantage. We also need a better understanding of the relationship between stigma, ignorance and existing forms of social marginalisation. In this paper we introduce some ideas from the existing literature on HIV/AIDS-related stigma that can begin the process of doing this.

We argue that stigma is conceptually inflated, and should not be defined in terms of discrimination. We propose a model of health-related stigma as a social process. Blaming certain groups of people for having an illness provides stigmatisers with an opportunity to distance themselves and their in-groups from risk of infection. This represents the fundamental cause and mechanism of stigma—the main reason it is reproduced in society. Ignorance of transmission methods, poverty or gender inequality create social contexts in which stigma is formulated and enacted, but do not create different types of stigma. If ignorance is not associated with othering, blaming and shaming, it is simply ignorance, not stigma.

Stigma always results in blaming, shaming and status loss for the stigmatised person or group, at least in the eyes of the stigmatiser; but it does not always have to result in discrimination to have a negative effect. Negative effects of stigma include status loss, discrimination, internalisation and failure to take advantage of social, economic and healthcare opportunities because of expected stigma and discrimination. Indirect effects of stigma such as internalisation and fear of stigmatisation are extremely important in reducing PLWHA access to key health services and a better quality of life.

REFERENCES


