

The Theoretical Basis of Stigma as Applied to Genital Herpes

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KEY WORDS

■ STIGMA ■ GENITAL HERPES ■ THEORY

SUMMARY

This paper defines stigma and its characteristics, outlines strategies and consequences of stigma management, describes the theoretical basis of stigma, and offers methodological considerations for those applying stigma theory to the domain of genital herpes. Stigma is an interactional process, defined within societies, in which particular social identities are collectively devalued. The subjective experience of stigma may vary due to features associated with the stigmatizing condition (e.g. concealability, course, strain, aesthetic qualities, cause and peril). The interpersonal management of stigma may include secrecy, withdrawal, covering, informing or disclosing. Future research addressing herpes-associated stigma should benefit from theoretical frameworks including attribution theory, social-cognitive theory, preoccupation model of secrecy and the illness intrusiveness framework, although the difficulty in identifying and recruiting stigmatized individuals and the lack of domain-specific measures of herpes-related stigma remain barriers to progress.

Introduction

THE AIMS OF this paper are to: define stigma and its characteristics; outline strategies and consequences of stigma management; describe the theoretical basis of stigma (including contributions from social and cognitive psychology); and offer methodological considerations for researchers applying stigma theory to the domain of genital herpes.

Defining Stigma

The ancient Greeks used the term 'stigmata' to describe a physical mark, often burned or cut into the body, that signified shame and designated the bearer as morally defective and to be avoided.^{1,2} In his influential book, Erving Goffman described stigmatized individuals as 'reduced in our minds from a whole and usual person to a tainted, discounted one' (page 3), and 'not quite human' (page 5).¹ Goffman's construction of stigma theory essentially dichotomized society into 'normals' and those possessing a discrediting attribute (a stigma). Contemporary definitions of stigma reflect Goffman's sociological perspective, while emphasizing the psychological experience of the stigmatized individual. Psychologists have therefore defined stigma as: a characteristic that individuals possess (or are believed to possess) that conveys a social identity that is devalued;³ a personal characteristic that is contrary to a norm (shared belief about behaviour) of a social unit;⁴ a 'mark' (attribute) that links a person to undesirable characteristics (stereotypes);⁵ and a label that allows the components of stigma to unfold.⁶ Stigma is an interactional process that exists within a social or cultural context and is perpetuated by 'the acceptance of the stigma by the stigmatized'.²

Stigma has traditionally been applied to people with acquired medical conditions, such as obesity or sexually transmitted infections (STIs); there is a perception that the person bears some degree of

personal responsibility for acquiring the condition. Absence of personal responsibility for other stigmatizing conditions, such as epilepsy,⁷ physical disfigurement^{8,9} and mental illness,¹⁰ suggests that perceived responsibility (i.e. 'assigning blame') is neither essential nor helpful in understanding stigma.

'Perceived stigma' describes how an individual conveys their own experience of being stigmatized, and may reflect the intensity and nature of the experience – for example, how embarrassed they feel, or whether they feel isolated or avoided because of the stigmatizing condition.

Dimensions of Stigma

The social consequences of stigma (e.g. rejection, isolation) may be similar across a variety of stigmatizing conditions. The subjective experience of possessing a stigma, however, may differ depending on the nature of the condition. Goffman¹ attempted to categorize stigmas by their features. He described 'abominations of the body' or uninherited physical characteristics, 'blemishes of individual character' related to personality or behaviour, and 'tribal stigma' (that refers to familial membership in devalued groups). Jones¹¹ described six dimensions on which stigma can vary:

- *Concealability* – the degree to which the condition can be hidden or is invisible to others;
- *Course* – how much the stigmatizing condition changes over time;
- *Strain* – the extent to which the stigma strains interpersonal relationships;
- *Aesthetic qualities* – how much a person's appearance is affected by the condition;
- *Cause* – whether the stigmatizing condition is congenital or acquired;
- *Peril* – the danger to others that is associated with the condition.

Stigma is intensified when the condition is believed to be the responsibility of the individual possessing it. Intensity is also increased when the stigma is contagious to others, the consequence of the illness is serious degeneration or death, or manifestations of the stigma are perceived as ugly, repellent or upsetting.¹²

Others have collapsed the six dimensions into two general features of stigma: visibility and controllability.³ Visibility reflects concealability. According to Goffman, individuals with visible stigmas are 'discredited' as they know that others can use the stigma as a basis for judging them.¹ In contrast, individuals possessing a concealable or invisible stigma are 'discreditable'. The ability to conceal the stigma affords the individual the option to 'pass for normal', while adding the stressor of potentially 'being caught in a lie' (to use Goffman's terms).¹ For these reasons and others, people with concealable stigmas report lower self-esteem and more negative affect (i.e. negative emotions, such as depression or anxiety) compared with people with visible stigmas.¹³ Controllability, like the dimension of cause, addresses an individual's responsibility for possessing and eliminating the stigma.¹⁴

People with genital herpes may be particularly vulnerable to the social consequences of stigma. They must attempt to understand their experience of stigma, manage the stigma across varied social situations, and overcome the psychological and physical consequences of genital herpes.

Stigma Management

In this paper I address the management of stigma from an individual level, rather than a societal level, which is beyond the scope of the current literature. There is little information regarding how to reduce stigma at the societal level, as stigma itself is a social construction – to understand how to reduce it requires an understanding of how stigma is created, which Dr Fortenberry's paper alludes to with regard to societal taboos and values (see pages 8–11, this issue).¹⁵ Some suggest that stigma can be reduced by efforts to provide familiarity with the stigmatizing condition, through education (intellectual familiarity) and contact via direct interaction with people who have the stigmatized condition (personal familiarity). A third strategy that has been discussed is protest, or promoting moral indignation for those who hold negative attitudes toward the condition. These three approaches have been outlined by Corrigan,¹⁶ and reductions in stigma surrounding cancer may have occurred, in part, through adopting such strategies. Efforts to reduce stigma at the societal level may not yield results for decades, however, and the measurement of success requires longitudinal research efforts.

Individuals can manage stigma by secrecy, withdrawal, covering, informing or disclosing; Joachim and Acorn¹⁷ provide an excellent presentation of these various strategies in the context of chronic illness. Fundamental dimensions of the stigma determine, in part, available options for management, i.e. whether the stigmatizing condition is visible or concealable and whether it is perilous to others.

Those possessing a concealable stigma can keep it secret. Secrecy is believed to carry a high cognitive cost¹⁸ and may ultimately lead to stress^{17,19} as the individual manages the constant threat of being discredited.

The withdrawal strategy involves removing oneself from social situations in which the stigma (concealable or visible) can become apparent. For individuals with genital herpes this may involve withdrawing from situations in which physical intimacy is anticipated.²⁰

Covering is a strategy whereby the stigmatized individual attempts to deflect the stigma and enable others to be more comfortable with the condition. Such attempts may consist of jokes or open acknowledgement of an obvious condition, such as obesity, blindness or physical disfigurement. This approach may 'give permission' to others to acknowledge the stigma and move it to the background of the social interaction.¹⁷

The strategy of informing involves wide dissemination of the stigma, often in a perfunctory manner. Individuals who anticipate the stigma becoming obvious over time (if not already) may consider this approach. For example, a person diagnosed with cancer may inform all members of their work group who will notice their absence when treatment begins.

Finally, managing a stigma can occur through disclosure, which may be protective, spontaneous or preventive. Protective disclosure is usually planned: the individual controls who, when, where and how they reveal the stigma. In contrast, spontaneous disclosure is sometimes characterized as an 'emotional outburst' in which the stigma is revealed, but this approach can lead to regret. Preventive disclosure occurs when a discreditable individual perceives that he/she is at risk of being discredited. Rather than risk

being exposed, the individual elects to disclose the stigma under the belief that by doing so they can change the negative perceptions of themselves.²⁰

Applying stigma theory to genital herpes can improve patient management by offering care providers a clearer understanding of the underlying social framework of the disease, and of the individual's psychological experience as a stigmatized member of society. From diagnosis onwards, the person with herpes is transformed with regard to self-perception (how they view themselves in their own eyes) and self-presentation (how they present themselves in society). Medical personnel can use their understanding of the psychological and social consequences of stigma to expand the scope of treatment beyond disease management, to encompass managing and caring for the entire individual who presents with herpes.

Theoretical Considerations for Research

Several theoretical approaches have been applied to examine stigma in the context of illness, including: attribution theory, social-cognitive theory, the preoccupation model of secrecy, and the illness intrusiveness framework.

ATTRIBUTION AND SOCIAL-COGNITIVE THEORIES
The frameworks of the attribution and social-cognitive theories consider how information is used to explain certain events or behaviours. For example, Weiner's attribution–emotion model of stigmatization²¹ explains stigma by attributions of personal responsibility for the condition, and the emotional responses of anger and pity. According to this model, the belief that an individual with a stigma is personally responsible for his/her plight can invoke anger in the person attributing responsibility. Anger, in turn, may result in hostility and social rejection that is directed towards the person with the stigma. Individuals not believed to be personally responsible for their condition invoke a pity response from others. This can result in pro-social (e.g. helping) behaviour.

Weiner's framework has been extended to explore other determinants of stigmatizing reactions, such as severity²² and the perceived dangerousness of the condition (i.e. risk to others).¹⁶ Anxiety²² and fear¹⁶ are other mediating emotional responses that have been explored. Exploring the attribution–emotion framework within the context of genital herpes may provide valuable insight into a patient's experience of stigma, and may further develop the theoretical framework.

PREOCCUPATION MODEL OF SECRECY

People with a concealable stigma can manage the stigma by keeping it a secret. The preoccupation model of secrecy^{23,24} provides a framework to explain the cognitive consequences of a secrecy management strategy. In a series of studies using eating disorder characteristics as the stigma, Smart and Wegner¹⁸ demonstrate that attempts to conceal the stigma can result in increased secrecy, thought suppression and intrusion. This study did not support the hypothesis that secrecy would impact negatively on social interaction (e.g. increased awkwardness, decreased social skills), but its findings suggest that individuals can become highly skilled at maintaining both the secret and social interaction.

ILLNESS INTRUSIVENESS

The illness intrusiveness framework addresses the extent to which illness, or its treatment, interferes with the ability to participate in valued activities and interests.²⁵ This framework was used to examine the relationship between illness features (including symptom severity, perceived stigma, illness intrusiveness and quality of life) among men and women with irritable bowel syndrome (IBS).²⁶ This paper provides an exceptionally good

explanation of how a stigmatizing condition impacts on quality of life for people with a chronic and deeply personal illness, and illustrates how the experience of stigma can vary as a function of gender.²⁶ Stigma among IBS patients is thought to arise because IBS is diagnosed by excluding other conditions, and/or has socially undesirable symptoms.^{27,28} Perceived stigma negatively impacts on quality of life through its association with (greater) illness intrusiveness.²⁶ Moreover, although the level of perceived stigma did not differ between men and women with IBS in this study, the negative influence of perceived stigma on quality of life was greater among men than women. This investigation demonstrated how important it is to examine factors that may mediate the relationship between perceptions of stigma and psychological outcomes. The study also identified gender differences in the impact of perceived stigma on psychological and behavioural outcomes.

Methodological Considerations for Research

There are several important methodological considerations for conducting research relating stigma theory to genital herpes. These issues concern sampling of stigmatized persons, testing moderators and mediators, identifying appropriate comparison groups, selecting study outcomes, measuring stigma and effective use of theoretical frameworks.

SAMPLING

Access to particular stigmatized groups may be difficult because the stigma is concealable and individuals cannot be readily identified. Alternatively, access may be restricted to those who have joined support groups, become affiliated with local or national organizations, or sought specialized care in identifiable centres (e.g. STD clinics). These individuals may experience stigma in qualitatively different ways than those who do not publicly identify with the stigmatized group. People who have acknowledged and sought help for their condition, such as patients with IBS who join support groups,²⁶ may display fewer stigmatization effects.

Additional challenges arise in sampling individuals from different cultural and socio-economic backgrounds. For example, attitudes surrounding sex and sexual behaviour differ between cultures; findings of studies involving European individuals may not be generalizable to experiences reported by individuals from the US. Moreover, how the scope, severity and social consequences of stigma are measured may differ when considered from international perspectives. Cross-cultural perspectives are necessary, at the most basic levels, to explore how and whether the word and meaning of stigma maintains its translation across people, nations and languages.

As an alternative to recruiting study participants from an identifiable group, Frable *et al.*¹³ used 'anonymous' self-identification via a Yes/No questionnaire to sample students from various social groups of interest. These groups included obese, bulimic, African-American, physically attractive, affluent and athletic people. This sampling method allowed individuals to report their membership in a broad spectrum of social groups, without focusing specifically on groups that are stigmatized within American culture.

Owing to the sensitive nature of stigma research, it is important to consider experimental methods that avoid exposing vulnerable persons. Experimental paradigms that include role-playing or use of vignettes may effectively allow stigmatized persons to be studied in a less threatening manner. These methods may invite criticism regarding external validity, but have been widely used in psychological studies.

MODERATORS AND MEDIATORS

The complexity of stigma research requires that investigators measure and formally test multivariate models, including effect modifiers (moderators) and mediators. Fortenberry *et al.*²⁹ demonstrated, within a multivariate framework, that low levels of perceived stigma were associated with receiving screening for gonorrhoea and HIV. This was after accounting for the influence of other important screening-related factors, such as age and gender. Demographic factors such as gender, race/ethnicity and age can serve as covariates in multivariate models and also as effect modifiers. With the latter, the effect of the stigma on social, psychological or behavioural outcomes may differ across demographic groups. Gender, for example, moderated the relationship between perceived stigma and illness intrusiveness among individuals with IBS,²⁶ and between perceived stigma, disclosure and care-seeking among individuals with STIs.³⁰ Other investigations have revealed contextual moderators between perceived stigma and psychological outcomes such as anxiety and depression. Specifically, increased negative affect (e.g. anxiety or depression) was observed among stigmatized individuals in situations involving non-stigmatized people, compared with situations when stigmatized individuals were in the presence of 'similar others'.¹³

Mediators can be tested as explanatory mechanisms through which perceived stigma may influence study outcomes. For example, illness intrusiveness mediated the relationship between perceived stigma and quality of life among people diagnosed with IBS. This suggests that perceived stigma impacted indirectly (through illness intrusiveness) on quality of life, rather than directly.²⁶ Carefully identifying and testing mediators in the context of genital herpes research may explain the mechanisms through which perceived stigma impacts on important outcomes (such as partner notification, care-seeking and preventive behaviours related to reducing transmission).

IDENTIFYING APPROPRIATE COMPARISON GROUPS

To identify appropriate comparison groups in stigma research, one must consider the characteristics of the stigma. Frable *et al.*¹³ studied concealable stigmas and the influence of similar others. They divided subjects into five groups: concealable and stigmatized (bisexual, gay, lesbian, bulimic, lower-income); conspicuous and stigmatized (African-American, overweight, those with stutter); concealable and valued (Olympic trial qualifiers, affluent); conspicuous and valued (physically attractive); and a control group (non-members of above groups). Examining genital herpes from a stigma framework requires that the investigator consider the characteristics of the infection as they relate to stigma theory, before considering appropriate comparison groups for the research.

SELECTION OF STUDY OUTCOMES

Unsurprisingly, stigma research has primarily focused on negative social and psychological sequelae. High perceived stigma has been associated with anxiety and depression,¹³ low self-esteem¹³ and, among individuals diagnosed with STIs, delays in care-seeking³⁰⁻³³ and negative sexual self-images.^{34,35} Recognized membership in a stigmatized group may be associated with positive psychological sequelae; adaptive coping strategies and psychological benefits may ensue as individuals develop a sense of group advocacy and experience the positive effects of being in the company of similar others.¹³ Investigations that include multiple study outcomes of negative and positive valence will expand the field of stigma research, and enrich our understanding of the social and psychological impact of stigma.

MEASURING STIGMA

Several methodologies can be used to measure stigma. Experience sampling methodology can measure perceived stigma across multiple measurement points and contexts within a single study.¹³ Topic-specific, multi-dimensional measures have been developed to assess levels of perceived stigma for STIs,³⁰ HIV,³⁶ cancer^{37,38} and obesity.³⁹ To date, however, no genital herpes-specific measure of perceived stigma has been published.

APPLICATION OF THEORY

The application of stigma theory to the study of genital herpes must be rigorously tested and constructs from other well-developed theoretical frameworks in health and social psychology explored within existing stigma frameworks. Lee and Craft²⁰ applied identity theory to understand the experience of stigma among 20 people in a herpes self-help group. This investigation revealed conflict between stigma disclosure as a management strategy and preserving one's ability to maintain social relationships. Developing new theoretical models is an important component of helping people manage the stigma attached to a lifelong infection of genital herpes.

Conclusion

Stigma surrounding genital herpes has changed through the decades and will continue to change through the influence of the media^{40,41} and new options for medically managing the disease.⁴² Many factors make research into the stigma associated with genital herpes an exciting prospect. These include the paucity of stigma research in this area, the richness of the framework of stigma theory and the inherent methodological challenges. Researchers have the potential to impact theory development and application within the context of genital herpes.

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