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Structural forces and the production of TB-related stigma among Haitians in two contexts

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ABSTRACT

In recent years renewed interest in health-related stigma has underscored the importance of better understanding the structural underpinnings of stigma processes. This study investigated the influence of sociocultural context on perceived components of tuberculosis-related stigma in non-affected persons by comparing Haitians living in South Florida, USA, with Haitians residing in Léogane Commune, Haiti. Using the methods of cultural epidemiology, a two-phase study based on fieldwork between 2004 and 2007 collected ethnographic data on the cultural context and components of tuberculosis (TB) stigma, and administered a stigma scale developed specifically for these populations. Thematic analysis of stigma components expressed in interviews, focus groups and observation revealed commonalities as well as distinctive emphases of TB stigma in the two comparison groups. Factor analyses of stigma scale scores confirmed the thematic differences revealed in ethnographic findings and highlight the influence of political and economic factors in shaping the meaning and experience of illness. Perceived components of TB stigma among Haitians in South Florida incorporated aspects of Haitian identity as a negatively stereotyped minority community within the larger society, while in Haiti, stigma was associated primarily with poverty, malnutrition, and HIV co-infection. Discussion of findings focuses on the social production of perceived and anticipated stigma as it is influenced by structural forces including the influences of politics, economics, institutional policies, and health service delivery structures. The findings also demonstrate the value of a transnational framework encompassing both sending and receiving countries for understanding TB-related stigma in immigrant communities.

Introduction

Greater attention in recent years to health-related stigma has highlighted the need for better understanding of the structural influences on stigma processes (Pescosolido, Martin, Lang, & Olafsdottir, 2008; Phelan, Link, & Dovidio, 2008; Scambler, 2006; Somma & Bond, 2006). Social relations of power, prejudice, discrimination and other structural dynamics in the production of stigma have gained currency in scholarly discourse (Link, Castille, & Stuber, 2008; Link & Phelan, 2001; Weiss, 2008). However, few empirical studies have been conducted on the influence of social structure on health-related stigma.

We investigated the influence of structural forces in the production of TB-related stigma among Haitians living in two very different sociopolitical contexts, the United States and Haiti. These contexts include political and economic forces that shape the meaning of illness experience, as well as institutional policies and practices that reinforce negative stereotypes or lead to discrimination (Corrigan, Markowitz, & Watson, 2004; Link & Phelan, 2001). Social context also affects cognitive components or attributions of meaning about stigma, including "anticipated stigma" (Weiss, 2008), based on the intersection of social structure and the social identity of stigma targets. Expectations and experience of stigma in one domain, such as illness, may be closely associated with other stigmatized identities and statuses (Stuber, Meyer, & Link, 2008). For example, health-related stigma may intersect with gender, ethnicity, social class and sexuality (Allotey & Gyapong, 2008; Collins, von Unger, & Armbgrister, 2008). In the case of Haitians,

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whose national identity itself has been the focus of prejudice and negative stereotypes in the global media, and particularly within American society (Farmer, 1992; Granich et al., 1998; Nachman, 1993), the potential for TB-related stigma to reflect larger social forces is noteworthy.

This report analyzes findings from a cross-national study that investigated the influence of sociocultural context on tuberculosis-related stigma by comparing the components of perceived and anticipated stigma in an immigrant population with those found in the country of origin. The comparison groups were Haitians residing in South Florida and Haitians living in Haiti. The sociocultural context in this study is comprised of both the larger society and the local communities in which people live. In the U.S. it includes national and local media stories and images of immigrant groups, as well as government, health, education, and religious institutions, among many others, that interact with and shape public perceptions of ethnic minority populations. In Haiti, the sociocultural context differs dramatically from that of the U.S. There, the concepts of immigrant or ethnic minority status have little meaning, and the context is profoundly shaped by extreme economic, environmental and political conditions.

The social history of tuberculosis also differs considerably in the two settings. In Haiti tuberculosis has remained a leading cause of death since colonial times, and is associated with poverty, misery and HIV infection. In the U.S., tuberculosis declined markedly in the 20th century, then experienced a resurgence with the AIDS epidemic. In recent years TB became associated with immigration from endemic countries such as Haiti, and thus is viewed as a problem of "foreign-born" populations (Cain, Benoit, Winston, & MacKenzie, 2008), and the condition tends to be "blamed" on the immigrant groups themselves. Additionally, as Haitian Americans are an ethnic minority within a larger industrialized society, the pressure to assimilate to the host culture impacts both identity and social interactions in a way not found in home country settings. These circumstances allow us to investigate the influence of structural factors on perceived stigma.

The transnational framework of the study is significant not only for understanding social determinants of stigma, but also from the standpoint of current perspectives on immigration experience, ethnic minority identity, and the epidemiology of tuberculosis in the United States. The image of Haiti and its people in the American imagination, shaped by enduring stereotypes, selective media coverage, discriminatory U.S. immigration policies and global disease history, profoundly influences the situation of Haitians living in the United States (Farmer, 1992; Stepick, 1998). Furthermore, in areas such as South Florida, where Haitians number significantly within immigrant groups, public concern about tuberculosis has been disproportionately associated with Haitian immigration (Coreil, Lauzardo, & Heurtelou, 2004; Granich et al., 1998; Nachman, 1993; Stepick, 1992).

The organization of TB services itself reflects the convergence of disease concerns and immigration. In Florida, public health programs related to tuberculosis and immigrant groups are jointly served by the Bureau of Tuberculosis and Immigrant Health. On World TB Day 2004 (March 24), the Bureau sent out a press release announcing the increase in TB cases state-wide from the previous year. The statement noted that a large number of the new cases were diagnosed among "foreign-born" persons. A follow-up interview by a media source revealed that Haitians made up more than half of the TB cases in the foreign-born group. The following day, a National Public Radio broadcast reported that tuberculosis rates were on the rise in Florida because of Haitian immigration to the state. The media have been an important force in perpetuating negative stereotypes of Haitians in the United States.

Stigma and tuberculosis

The study of tuberculosis provides a powerful lens through which to view the impact of structural forces on the production of stigma (Farmer, 1999; Macq, Solis, & Martinez, 2006), including perceived stigma. Throughout the ages, societal attitudes and behavior toward this disease have been infused with shame, rejection, discrimination and neglect. In the 20th century, improved living conditions in urban areas and the availability of antibiotic drugs dramatically reduced TB prevalence as well as the social stigma associated with it. However, as the 20th century came to a close, erosion of public health funding and infrastructure worldwide, along with the reemergence of TB as a co-infection with HIV/AIDS, led to restigmatization of TB (Coreil, 2010).

In developing countries, where tuberculosis has remained a leading cause of mortality for centuries, the disease continues to be stigmatized because of its association with poverty, discrimination and contagion. Although the availability of effective antibiotic therapy undoubtedly lowered the degree of TB stigma associated with disease communicability, exaggerated notions of transmissibility and fear of the disease continue to produce stigmatizing effects (Long, Johansson, Diwan, & Winkvist, 2001; Weiss, Auer, et al., 2006).

The situation has improved somewhat today, yet the disease continues to be stigmatized because of its enduring association with marginalized and disenfranchised groups, and particularly with HIV co-infection. Research conducted in HIV/AIDS endemic areas has shown that even HIV-negative TB patients are suspected of having AIDS, and this may cause delays in seeking TB care and treatment non-adherence (Møller & Erstad, 2007; Ngamvithayapong, Winkvist, & Diwan, 2000).

Farmer (1997, 1999) has criticized both biomedical and social science research for overemphasizing the influence of cultural beliefs and social stigma on treatment outcomes such as patient compliance, calling for greater attention to structural barriers to health care. Similarly, Das (2001) documents how state institutions in India obstruct the reintegration of TB patients with society even after their disease has been cured. Furthermore, the role of racism in the production of disease-related stigma must be taken into account. The early unfounded labeling of Haitians as a "risk group" for AIDS in the United States reflected both racial bias and the tendency to attribute blame for contagion to foreign immigrants (Farmer, 1992). Moreover, tuberculosis has long been linked with people of African origin in the United States (Wailoo, 2001). Our study design allowed us to expose dimensions of stigma that might be influenced by racial prejudice.

Study aims and oversight

The aims of the study were twofold: first, to identify the components of stigma perceived as important within non-affected community samples in the two study populations; and second, to understand the contextual influences on these stigma components across sites. Ethical oversight of the study was provided by Institutional Review Boards of the University of South Florida, the Florida Department of Health and Hôpital Ste. Croix in Haiti.

Methods

Our study used a mixed method approach that combined qualitative and quantitative techniques. Fieldwork was conducted between 2004 and 2007. The study design is based on the methodology of cultural epidemiology which integrates multi-phased data collection with interactive quantitative-qualitative survey instruments (Weiss, 2001). The basic instrument in cultural epidemiology is the Explanatory Model Interview Catalog (EMIC), which is developed