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Reducing Stigma-Driven Health Disparities in People Living with HIV (PLWH): A Literature Review

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Mentors: Dr. Constance Hill, Dr. William Armaline, Dr. Maria Cruz

Biography

Stephanie Dizon is a Nursing major with minors in Human Rights and Justice Studies. She wants to become a Public Health nurse, and advocate for marginalized and disadvantaged communities. Her research interests are health disparities and health equity, social and cultural determinants of health, and sociocultural factors as barriers to health. Stephanie's other interests include traveling, outdoor adventures, playing with her dog, and reading good books.

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Abstract

Introduction: Research has found that HIV-related stigma has numerous negative impacts on the lives of people living with HIV (PLWH). Although there are more resources than ever dedicated to HIV/AIDS efforts, stigma continues to be a major factor challenging the prevention and treatment of HIV today. Understanding the impacts of stigma on health outcomes and quality of life in PLWH is essential to address the global HIV epidemic and reduce health disparities.

Search Strategy: We conducted a secondary meta-analysis of existing research that discussed and evaluated the impacts of HIV-related stigma and discrimination on PLWH. We searched the following databases for peer-reviewed articles: EBSCO Host, Cumulative Index of Nursing and Allied Health Literature (CINAHL), and PubMed. We also obtained reports from Centers for Disease Control (CDC), Food and Drug Administration (FDA), Office of the High Commissioner for Human Rights (OHCHR), World Health Organization (WHO), and the Joint United Nations Programme on HIV/AIDS (UNAIDS).

Results: Our review of the literature revealed that HIV-related stigma is a socially constructed global phenomenon that reflects social and cultural tradition. Most current stigma-reduction interventions are designed to address individual-level stigma (symbolic stigma). While this has contributed to improvements in individual attitudes towards PLWH, interventions at the individual level alone do not address the macro-level attitudes and societal norms that influence individual ideals and behaviors.

Conclusion: Findings in the literature review suggest that because of the pervasiveness of HIV-related stigma globally, addressing stigma is imperative to the HIV response. It also suggests that interventions that

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address stigma at the structural level and target multiple domains might have a more profound impact on HIV-related health outcomes.

Keywords: HIV stigma, health disparities, social determinants of health, stigma reduction

Background

In the United States, more than 1.2 million people are living with HIV. Among those at risk, men who have sex with men (MSM), African-Americans, Hispanics, and those who are economically disadvantaged bear a disproportionate burden of HIV (CDC, 2016). Despite the availability of more resources than ever before dedicated to HIV/AIDS efforts, stigma, discrimination, blame, and denial are still several key factors that continue to challenge the prevention and treatment of HIV in 2016. Former head of the World Health Organization's Global Program on AIDS, Jonathan Mann, labeled stigma as the "third epidemic" related to the HIV/AIDS outbreak (Pulerwitz, Michaelis,Weiss, Brown, & Mahendra, 2010). Although it is widely acknowledged that stigma poses a major barrier to effective HIV prevention and treatment, efforts to reduce stigma are still relegated to the bottom of HIV/AIDS program priorities (Mahajan et al., 2008). Current evidence and growing bodies of literature might contribute to shifting HIV intervention priorities as they reveal the impacts of stigma reduction on overall health outcomes in people living with HIV (PLWH).

HIV-related stigma builds upon preexisting prejudices that work to reinforce existing social inequalities that maintain the relationships of power and control (Maluwa, Aggleton, & Parker, 2002). The intersection of discrimination and stigma in these different facets work simultaneously to perpetuate inequality and support a power hierarchy that disadvantages individuals based on gender, minority status, socioeconomic standing, occupation, HIV status, and more (Maluwa, Aggleton, & Parker, 2002; Melton, 2011). Under General Comment No. 14, the United Nations Committee on Economic, Social, and Cultural Rights, states that the right to health is "closely related to and dependent upon the realization of other human rights," including human dignity, education, non-discrimination, and equality (Committee on Economic, Social, and Cultural Rights CESCR,

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2000). Although some of these aspects are beyond the scope of this research, they underscore the role that underlying determinants such as discrimination and stigma play on the quality and implementation of health care. The Centers for Disease Control acknowledges that a significant health disparity exists among populations in which HIV is rampant, and successful HIV prevention is dependent upon addressing these disparities and achieving health equity (2015).

Search Strategy

The search strategy and criteria included terms such as "HIV-related stigma," "HIV," "stigma" and "HIV stigma and health." Databases accessed for peer-reviewed articles included EBSCO Host, Cumulative Index of Nursing and Allied Health Literature (CINAHL), and PubMed. Grey literature such as program reports, evaluation reports, and policy documents were obtained from the California Department of Health Care Services, Centers for Disease Control (CDC), Food and Drug Administration (FDA), Office of the High Commissioner for Human Rights (OHCHR), World Health Organization (WHO), Google, and the Joint United Nations Programme on HIV/AIDS (UNAIDS). Inclusion criteria included publications in English and studies of any design from any country that contained stigma and/or discrimination related to HIV. Studies discussing stigma and discrimination outside of the HIV context were excluded.

Drivers of Stigma

HIV-related stigma is a global phenomenon that is highly reflective of social and cultural mores, tradition, and values (Chambers et al., 2015; Gagnon, 2015). It is deeply embedded in social processes and manifests in varying forms on interpersonal, institutional, community, and legislative levels (Pulerwitz et al., 2010). HIV-related stigma is often compounded with other stigmatizing determinants such as homelessness, history of drug use, occupation (e.g., sex work), poverty, race, and sexual orientation (Maluwa, Aggleton, & Parker, 2002; Pulerwitz et al., 2010). It is overtly displayed through interpersonal interactions manifesting as symbolic stigma, or nuanced under laws, policies, and general practices as structural stigma.

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Symbolic Stigma

Symbolic stigma within the healthcare context is experienced through interactions with healthcare providers who have negative perceptions of PLWH (Gagnon, 2015). It is evident in the way that PLWH are treated and perceived in healthcare settings. Examples of symbolic stigma are negative stereotypes associated with particular groups (e.g., MSM, drug users, sex workers), mode of transmission (e.g., drug use, unprotected sex), and categorization (e.g., labeling as infectious, dangerous, deviant, guilty) (Gagnon, 2015). Symbolic stigma in healthcare settings can have pervasive repercussions on patients' overall health. Some impacts of HIV-related stigma include incorrect knowledge about HIV transmission, decreased effectiveness of prevention efforts with refusal of HIV testing, reduced adherence to biomedical treatment, refusal to participate in health promotion behaviors (e.g., regular clinic visits, condom use), nondisclosure to partners, and lack of social support (Pulerwitz et al., 2010; Stangl, Lloyd, Brady, Holland, & Baral, 2013; Wagner, McShane, Hart, & Margolese, 2016).

Structural Stigma

Structural stigma includes stigma that is manifested in policies, structures, and discourse that inadvertently result in stigmatizing or discriminatory practices towards PLWH (Gagnon, 2015). This type of policy is exemplified in the U.S. Federal Drug Administration's recommendations for blood donation of MSM. In 1985, the FDA issued a recommendation prohibiting any male who has ever had sex with another man from donating blood as a measure to reduce risk of HIV transmission by blood and blood products. Almost three decades later, studies evaluating this deferral policy indicated that the recommendations for indefinite deferral of MSM were suboptimal. This ultimately led to changes in recommendations for blood donation. Under current guidelines, the deferral policy for MSM is 12 months from the most recent sexual contact with another man (U.S. Department of Health and Human Services, Food and Drug Administration, 2015). However, according to the FDA, "establishments may voluntarily elect more stringent donor deferral criteria than those required or recommended by the FDA" (U.S. Department of Health and Human Services, Food and Drug Administration, 2015, para. 4).

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Allowing establishments to individually determine who may or may not be eligible to donate blood despite current recommendations will continue to reinforce institutionalized stigma by form of exclusion. In addition, these policies do not reflect best current scientifically based evidence. Other manifestations of structural stigma are presented in systematic risk management and fear management across health care settings.

Risk Management

Through the language of risk, PLWH are subject to structural stigma. Structural stigma varies from symbolic stigma in that it is often embedded in institutions and is felt beyond individual interactions. An example of this is in risk management and organizational policies. Risk management procedures and organizational policies such as precautionary segregation of PLWH, although initially intended to protect patients, such as from opportunistic infections, could stigmatize them through demarcation and separation from the general public (Chambers et al., 2015; Gagnon, 2015). Additional issues related to risk management within the clinical setting include confidentiality violations such as public display of infection control markings, use of scheduling policies (e.g., scheduling HIV-positive patients last in the day to reduce potential of risk exposure to other clients), and disclosure of patient HIV status among healthcare workers outside of a need to know (Gagnon, 2015). This may pose a problem in multiple ways. Not only can it create an environment that fosters stigmatizing attitudes, it also compromises the protection and confidential handling of patient protected health information required under the Health Insurance Portability and Accountability Act of 1996 (California Department of Health Care Services, 2015).

Fear Management

Although the lack of education or misperceptions regarding the mode of transmission of the HIV virus has been frequently attributed to HIV-related stigma within healthcare settings, research findings indicate that affective dimensions (i.e., emotions) can be a strong driver of HIV-related stigma in the context of healthcare (Chambers et al., 2015). For example, even practitioners knowledgeable of HIV transmission risks report fear of casual contact with HIV-positive patients not because of a

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cognitive knowledge gap relating to modes of transmission of the virus, but because of existing prejudices that influence the affective dimensions that overpower rational decision-making (Chambers et al., 2015). This finding further reinforces the social and cultural influences that contribute to HIV-related stigma.

Stigma Reduction

In a systematic review of 48 studies involving stigma-reduction interventions, Stangl et al. (2013) found that the most common types of interventions were targeted at a single socioecological level (n = 41) (Table 1), the most common being at the individual level (n = 27). Less common types of interventions were community level interventions (n = 7), organizational (n = 3), interpersonal (n = 2), and public policy level interventions (n = 2). Only seven studies intervened at multiple socioecological levels (Stangl et al., 2013). Of all studies reviewed, Stangl et al. (2013) found that 79 percent of studies reported statistically significant reductions in stigma.

Table 1
Socio-ecological levels targeted in 48 studies (Stangl et al., 2013)

Individual	27
Community	7
Organizational	3
Interpersonal	2
Public Policy	2
Multiple targeted levels	7

Overall, the reviewed studies reveal the overwhelming complexity and multidimensional nature of HIV-related stigma. The findings indicate the significance of addressing both symbolic and structural stigma, and thus, suggest the need for interventions to reduce both interpersonal and structural forms of HIV-related stigma.

Results

Findings suggest that HIV-related stigma is a socially constructed phenomenon that is representative of social and cultural traditions and

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norms. It is often compounded with other stigmatized conditions such as racial and ethnic minority status, socioeconomic standing, and sexual minority status (Maluwa, Aggleton, & Parker, 2002; Pulerwitz et al., 2010; Chambers et al., 2015; Gagnon, 2015). This reveals that determinants such as racial and ethnic background, income, and class play a role in stigma that many PLWH encounter. Problematic stereotypes about people of color, the poor, LGBTQ, drug users, sex workers, etc. contribute to negative perceptions about PLWH. Therefore, such determinants must be taken into account when examining appropriate responses and interventions for addressing HIV, particularly in those who fall into these categories. Because HIV-related stigma permeates social structures and reflects dominant culture ideology, it remains salient today and continues to present a challenge in the HIV/AIDS response.

Current research indicates that there has been considerable progress in reducing stigma and negative attitudes toward PLWH as a result of stigma-reduction interventions (Stangl et al., 2013; Clair, Daniel, & Lamont, 2016). A majority of research surrounding HIV-related stigma examines the impacts of stigma on an interpersonal level, with a focus on individual attitudes and behaviors towards PLWH. Moreover, most current stigma-reduction interventions have targeted individual-level stigma, which has contributed to improved individual attitudes towards PLWH. However, interventions that address structural level stigma that target macro-level attitudes such as those toward minority groups, the poor, and those who participate in perceived socially deviant behaviors, cultural norms, and tradition remain relatively understudied.

Analysis

In order to gain a greater understanding of the impacts of stigma on PLWH, it may be helpful to think about HIV-related stigma as a systemic problem. Stigma can be real, perceived, overtly expressed, or subtly conveyed. Regardless of the mode of delivery, it affects all who are faced with stigmatizing experiences.

In 1943, Abraham Maslow described a hierarchy of human needs that falls into five stages: physiological needs (e.g. air, food, drink, shelter, warmth, etc.), safety and security needs (e.g., protection from elements, security, order, law, stability, etc.), love and belonging needs

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(e.g., friendship, intimacy, affection and love), self-esteem needs (e.g., achievement, mastery, independence, status, dominance, prestige, self-respect, respect from others), and self-actualization needs (e.g., realizing personal potential, self-fulfillment, seeking personal growth and peak experiences. He argued that the basic physiological needs must first be satisfied before any higher level needs can be met, followed respectively by safety and security, love and belonging, self-esteem, and self-actualization. Thinking about HIV stigma in relation to Maslow's hierarchy of needs, one can argue that Western societal values relegate stigma into the realm of higher level needs (i.e., self-esteem). Using Maslow's hierarchy as a framework might explain why HIV-related stigma remains at the bottom of HIV/AIDS priorities. While it can be argued that stigma appropriately falls into the category of self-esteem needs, it can also be said that stigma impacts certain aspects of physiological and safety needs through allocation of resources and lack of access to essential components in these categories. Our findings indicate that HIV-related stigma can contribute to or detract from fundamental human physiological and safety and security needs; thus, we argue that stigma remains a pertinent barrier to addressing the HIV epidemic and remains a pressing aspect in the HIV response.

Discussion

While there have been significant improvements in reducing individual stigmatizing attitudes and behaviors toward PLWH, existing stigma-reduction interventions rarely address structural stigmas. Emerging themes in the literature emphasize the need for collective efforts and a multidimensional approach that involves social and cultural paradigm shifts (see Table 2). Clair et. al (2016) suggest that social actors play a significant role in shaping cultural constructions surrounding stigmatized groups, and these constructions must be changed using the influence of these social actors. Others suggest the importance of increasing awareness through education, support, and legislation (Thapa, Hannes, Cargo, Buve, & Mathei, 2015; Clair et. al, 2016).

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Table 2

Comparison of proposed stigma-reduction intervention strategies

Clair, Daniel & Lamont, 2016	Thapa et al., 2015	Chambers et al., 2015
Change cultural constructions surrounding stigmatized groups by using social actors (i.e., public health and medical experts, legal experts, social science and policy experts, media and journalists, social movement activists, firms and workplaces) to remove blame and create equivalencies in PLWH and the general public.	Create awareness using HIV-specific information-based written or verbal communication and education.	A multidimensional approach involving healthcare settings, and also address discrimination within institutional culture as well as factors that foster HIV-related stigma at the individual, environmental, and societal levels.
	Provide psychosocial, clinical, socio-economic, and family and community support to people living with or at risk for HIV/AIDS. Implement interventions that incorporate HIV-specific legislation that protects and respects the human rights of people living with HIV, and develop normative behavior by increasing community organizing and actions.	

Conclusions

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Findings in this research suggest that 1) stigma must be a priority in the HIV response, and 2) both individual-level and structural-level stigma must be addressed in order to decrease overall HIV-related stigma. While interventions addressing symbolic stigma have shown considerable progress, there remain significant gaps and challenges in understanding and encompassing stigma on a larger scale. Due to the complexity and multi-faceted nature of HIV-related stigma, it is imperative to also address the structural factors that foster public stigmatizing attitudes and behaviors such as negative perceptions of minority groups including people of color, LGBTQ, and people of lower socioeconomic status. Further, it is crucial to examine the impacts of factors and conditions that compound these stigmas. Findings suggest that incorporating both symbolic and structural stigma and understanding the compounding effects of other stigmas (i.e., occupation, poverty, homelessness, race, sexual orientation, etc.) and structural determinants could have a more drastic impact by addressing the root of HIV-related stigma. To fully understand the scope of the problem, it may be helpful to gain a better understanding of stigma from the perspectives and experiences of PLWH. Future research evaluating the impacts of stigma that juxtapose the perceptions of stigma from PLWH who belong to minority groups (i.e., racial/ethnic minorities, LGBTQ) and PLWH from majority groups (i.e., non-racial minorities, heterosexual) could relay invaluable information that may guide potential stigma-reduction interventions and ultimately contribute to addressing stigma-driven health disparities in PLWH.

References

California Department of Health Care Services (2015). Health Insurance Portability and Accountability Act. Retrieved October 22, 2016, from http://www.dhcs.ca.gov/formsandpubs/laws/hipaa/Pages/1.00What isHIPAA.aspx

Centers For Disease Control and Prevention (2016). HIV/AIDS. Retrieved from http://www.cdc.gov/hiv

Chambers, L., Rueda, S., Baker, D. N., Wilson, M., Deutsch, R., Raeifar, E., Rourke, S., & The Stigma Review Team. (2015). Stigma, HIV,

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and health: A qualitative synthesis. *BMC Public Health*, 15 (848), 1-17. doi: 10.1186/s12889-015-2197-0

Clair, M., Daniel, C., & Lamont, M. (2016). Destigmatization and health: Cultural constructions and the long-term reduction of stigma. *Social Science and Medicine*, (165), 223-232. doi:10.1016/j.socscimed.2016.03.021

Committee on Economic, Social, and Cultural Rights CESCR (2000). The right to the highest attainable standard of health. Retrieved from http://www.nesri.org/sites/default/files/Right_to_health_Comment _14.pdf

Gagnon, M. (2015). Re-thinking HIV-related stigma in health care settings: A qualitative study. *Journal of the Association of Nurses in AIDS Care*, 26(6), 703-719.

Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Ortiz, D., Szekeres, G., & Coates, T. J. (2008). Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. *AIDS* (London, England), 22, S67–S79. http://doi.org/10.1097/01.aids.0000327438.13291.62

Maluwa, M., Aggleton, P., & Parker, R. (2002). HIV- and AIDS-related stigma, discrimination, and human rights: A critical overview. *Health and Human Rights,* 6(1), 1-18. doi:10.2307/4065311

Maslow, A. (1943). A theory of human motivation. *Psychological Review, 50*(4), 370-396. doi:http://dx.doi.org/10.1037/h0054346

Melton, M. L. (2011). Sex, lies, and stereotypes: HIV positive black women's perspectives on HIV stigma and the need for public policy as HIV/AIDS prevention intervention. *Race, Gender & Class*, *18*(1), 295-313. Retrieved from http://www.jstor.org/stable/23884880

Pulerwitz, J., Michaelis, A., Weiss, E., Brown, L., & Mahendra, V. (2010). Reducing HIV-related stigma: lessons learned from horizons research and programs. *Public Health Reports, 125*(2), 272-281.

Stangl, A., Lloyd, J., Brady, L., Holland, C., & Baral, S. (2013). A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: How far have we come? *Journal of the International AIDS Society, 16* (3). doi:10.7448/ias.16.3.18734

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Thapa, S., Hannes, K., Cargo, M., Buve, A., & Mathei, C. (2015). Effect of stigma reduction intervention strategies on HIV test uptake in low- and middle-income countries: A realist review protocol. *Systematic Reviews, 4*, 142.http://doi.org/10.1186/s13643-015-0130-3

U.S. Department of Health and Human Services, Food and Drug Administration (2015). Revised Recommendations for Reducing the Risk of Human Immunodeficiency Virus Transmission by Blood and Blood Products. Retrieved October 22, 2016, from http://www.fda.gov/downloads/BiologicsBloodVaccines/Guidance ComplianceRegulatoryInformation/Guidances/Blood/UCM446580 .pdf

Wagner, A. C., McShane, K. E., Hart, T. A., & Margolese, S. (2016). A focus group qualitative study of HIV stigma in the Canadian healthcare system. *Canadian Journal of Human Sexuality, 25*(1), 61-71. doi:10.3138/cjhs.251-A6

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