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Addressing Disease-Related Stigma During Infectious Disease Outbreaks

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Abstract

Outbreaks of emerging infectious disease are a constant threat. In the last 10 years, there have been outbreaks of 2009 influenza A (H1N1), Ebola virus disease, and Zika virus. Stigma associated with infectious disease can be a barrier to adopting healthy behaviors, leading to more severe health problems, ongoing disease transmission, and difficulty controlling infectious disease outbreaks. Much has been learned about infectious disease and stigma in the context of nearly 4 decades of the human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome pandemic. In this paper, we define stigma, discuss its relevance to infectious disease outbreaks, including how individuals and communities can be affected. Adapting lessons learned from the rich literature on HIV-related stigma, we propose a strategy for reducing stigma during infectious disease outbreaks such as Ebola virus disease and Zika virus. The implementation of brief, practical strategies such as the ones proposed here might help reduce stigma and facilitate more effective control of emerging infectious diseases.

Keywords

Human societies have a long history of singling out, shunning, or avoiding groups of people with a particular attribute or characteristic that is viewed as undesirable or threatening to others. Symptoms of disease or the perception that an individual may be a carrier or simply

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exposed to those with a serious illness can be stigmatizing. In the past, outbreaks of plague, cholera, and yellow fever led communities to marginalize people who were infected or thought to be infected.[1,2] Historically, health inspectors were instructed to monitor the movements and inspect the homes of persons with tuberculosis (TB), resulting in sharp declines in TB during the 1920s and 1930s. However, this was also accompanied by increased prejudice against persons with TB or "lungers" as they were known.[3] Recent examples of outbreaks with disease-related stigma include the human immunodeficiency virus (HIV) infection and acquired immunodeficiency syndrome (AIDS), TB, severe acute respiratory syndrome (SARS), Ebola virus disease, and Zika virus.[4–7] Although some authors point out that fear of people with infectious disease facilitates disease avoidance and improved personal hygiene (eg, hand washing) early on,[8] diseaseassociated stigmatization and discrimination of individuals can also become barriers to accessing health care and adopting healthy behaviors. These barriers could potentially contribute to more severe health problems, ongoing transmission, and difficulties controlling infectious diseases during an infectious disease outbreak. To effectively control public health emergencies, communities must adopt science-based measures to protect themselves and stop the spread of disease.

Nearly 4 decades of experience with stigma from HIV/ AIDS provide a wealth of information about how stigmatization affects a population exposed to the risk of an infectious disease and what public health can do to address it. Although HIV/AIDs is a long-standing pandemic, lessons from it and the recent 2014–2015 Ebola response can inform responses to infectious disease outbreaks. To inform a public health audience, including individuals employed by community-based organizations, and local and state government, on ways to address disease-related stigma in emergency responses, we searched PubMed for articles published from 1995–2017 using the following keywords: AIDS/ HIV, *infection/ infectious, disease, stigma, public health, and intervention*. We examined the reference lists of literature identified through PubMed and consulted Centers for Disease Control and Prevention (CDC) articles and documents on stigma reduction with a focus on lessons learned from HIV/AIDS and Ebola. We address the following questions: (1) What is disease-related stigma? (2) How does disease-related stigma impact individuals and communities during an infectious disease outbreak? and (3) What steps can be taken to reduce disease-related stigma during future outbreaks and emergency response efforts to facilitate more effective control of emerging infectious diseases?

WHAT IS DISEASE-RELATED STIGMA AND WHY IS IT RELEVANT TO INFECTIOUS DISEASE OUTBREAKS?

For this paper, we consider disease-related experienced stigma broadly as "the co-occurrence of labeling, stereotyping, separation, status loss, and discrimination in a context in which power is exercised."[9] In this definition, labeling refers to the social selection of a tag or designation that is "affixed" to a person or group. Labels that associate people with undesirable characteristics can develop into stereotypes that can lead to status loss and discrimination.[9] Stigma can affect a diverse range of people, such as those with disease, caregivers, family and friends of affected persons, and their communities. The effects of stigma are tied to whether an individual is known or perceived to possess a disease, disease

characteristic, or related attribute devalued by society. People may hold prejudices and perpetuate discriminatory behavior based on such stigma, as illustrated in the following:

> Being Haitian is not itself a risk factor. However, Haitian Americans have already begun to pay the price for the stigma given them by the media. 'Boat people' have been housed in makeshift prisons, and Haitians who have immigrated legally are housed in a different 'prison' in our ghettos. Some have already lost desperately needed jobs and others are beginning to experience the prejudice of their neighbours who see them not only as black and poor and different but, now, also as contaminated by disease of which they are, rightfully, frightened.[10]

Stigma may be internalized by people who currently have a disease or who have survived a disease. Stigmatized individuals may see themselves as inferior to others and worthy of self-hate due to their disease status.[11,12]

HOW DOES STIGMA IMPACT INDIVIDUALS AND COMMUNITIES DURING AN OUTBREAK?

During an infectious disease outbreak, people in affected areas often need to comply with specific guidelines to prevent further disease transmission or to stay healthy if uninfected. Public health officials may recommend that people be tested for infection, adopt certain behaviors to prevent disease transmission, and take medications for prevention or treatment. For example, when persons who are HIV positive get tested and become aware that they are infected, they can take measures to prevent passing on the virus to others. During an Ebola outbreak, those who have come into contact with the body fluids of an Ebola-infected individual would need to be identified so they can be monitored for the development of fever or other symptoms. In an anthrax incident, exposed persons would need to make themselves known to health officials in order to be given a course of antibiotics. Stigma can deter these behaviors. HIV-related stigma was shown in a meta-analysis of 21 studies to have an inverse association with HIV disclosure.[13] Health-related stigma and the perception that one might be HIV-infected were also associated with never receiving an HIV test among black/ African American and Hispanic/Latino young adults,[14] lower medication adherence,[15] and higher levels of depression, anxiety, excessive worry, avoidant coping strategies, and suicidal ideation.[16–19] HIV stigma has been associated with substance abuse and sexual risk-taking,[20–21] although perhaps in nuanced ways for subgroups.[22] Similar to HIV, stigma has recently been associated with lower levels of TB testing and treatment seeking, as well as difficulties with TB contact tracing in outbreak investigations.[23–27]

These findings demonstrate that stigma represents a common and substantial obstacle to the control of infectious disease outbreaks. If people feel stigmatized, whether externally or internally, their compliance with public health measures may be significantly reduced compared with non-stigmatized groups, which could impede outbreak control efforts.

A STRATEGY TO REDUCE DISEASE-RELATED STIGMA DURING INFECTIOUS DISEASE OUTBREAKS AND PUBLIC HEALTH EMERGENCY RESPONSES

Brief, practical strategies to reduce disease-related stigma during a public health emergency may facilitate more effective control of emerging infectious diseases, as outlined below.

1. Anticipate Stigma and Be on the Watch for It

Stigma is common and has been documented in outbreaks of Ebola and other infectious diseases such as TB and SARS.[4–7] A recent review of the US Ebola response illustrates:

> Shunning of individuals who were thought (often incorrectly) to have been potentially exposed to Ebola virus was widespread, especially early in the response. Stigmatized populations included individuals from affected countries, international travelers, and health care workers from affected facilities. Stigmatization occurred among coworkers at affected hospitals and extended to health-care workers' family members in settings like schools and daycare centers.[28]

Anticipating disease-related stigma during infectious disease outbreaks enables those planning and coordinating emergency response efforts to address it, and thereby potentially counteract its negative effects.

2. Assess What People Know and Don't Know About the Disease to Help Identify Stigmatization

Misinformation and myths are key contributors to stigma. At the outset of a response, it is vital to find out what people affected or potentially affected by an epidemic know and don't know, what they believe and don't believe, what they are hearing and not hearing, and what they are saying and not saying about the disease. Rapid, low-resource means of assessment could include obtaining input from partner organizations and having discussions with community leaders and clinicians as they have important roles early in an emergency response. Other approaches are to analyze news media messaging, examine e-mails and phone calls to public health departments, and obtain information about which pages are being read the most on a public health department website. Responders can also conduct searches of publicly available social media posts and messages, although this may require significant expertise and staff time. These approaches would provide information about where people might lack knowledge, which, in turn could help determine where stigma might arise. Additionally, telephone polling, community meetings, and focus groups could provide direct information about barriers, opportunities, and potentially conflicting messages from other sources. Keeping open lines of communication between public health officials and the public is critical in any public health emergency. Whatever the method and focus of assessing current knowledge and beliefs, a systematic approach is needed to gather a valid and reliable basis of information from which to move forward.

3. Partner with Community Leaders and Groups to Address Stigma

Respected community groups and leaders can provide valuable insight about stigmatization and stigmatized groups, add legitimacy to public health efforts, and serve as a critical conduit to disseminate information to individuals and groups who might mistrust the government or other sources. For example, in 2014, when a Liberian man was diagnosed with Ebola in Dallas, Texas, a CDC representative met with community leaders and groups to educate them about Ebola symptoms, how it is transmitted, and about how stigma sometimes is associated with the virus. Afterward, Dallas City Council member Jennifer Staubach Gates emphasized to constituents, "The residents are being unfairly targeted by those who don't understand they are not at risk of passing on the Ebola virus."[29] Similarly, local pastor Brent Barry told his congregation, "The scientists are doing their very best job. Let's show our very best selves – [by] not buying into fear, the anxiety, the rumors."[30] As de facto cultural translators, community leaders can help determine which methods and messages may reduce stigma and help organize community events designed to reduce stigma.

4. Develop and Conduct Public Messaging and Community Campaigns to Fight Stigma

Developing informative public messages that do not convey or perpetuate stigma, and directly counter stigmatization of groups or individuals, is a critical step in addressing disease-related stigma. Disease responders can develop and disseminate messages through public outreach and social-marketing campaigns with trusted community leaders and subject matter experts.[28] Working with community leaders or peer role models for messaging also can be helpful (see Box 1). It is important to tailor health messages and interventions for specific populations because the experience of disease-related stigma can vary across groups.[31]

Health-care workers are another important target group, though often overlooked, for messaging to decrease disease-related stigma. During the US Ebola response, stigmatization occurred among coworkers at affected hospitals and extended to health-care workers' family members. A local physician described, "family members freaking out about you caring for a patient with Ebola, daycare facilities concerned about your child having the virus, other hospitals not wanting a health-care worker who cares for Ebola patients to work/moonlight at their facility."[32] Studies indicate that messaging and education aimed at stigma among public health and health-care workers can have an impact on their attitudes.[33–35]

5. Implement Practical Interventions, Skills-Building Training, and Other Educational Programs to Reduce Stigma

Information campaigns and public outreach by trusted community leaders and experts are necessary but may not be sufficient alone to counter stigma. In certain situations, education that is more intensive may be needed. For example, as more information became available about HIV transmission risk over time, HIV-infected individuals and their partners benefitted from extended education about updated prevention information. In the HIV/AIDS literature, the most common target populations for intervention were students, teachers, community members, and people with infection.[36–39]

Preferably, interventions should be relatively brief, as time is critical during an emerging disease response. They might be integrated into counseling staff and volunteers about fears. In the HIV/AIDS literature, intervention duration varied widely from a single, 50-minute lecture for nursing students in Hong Kong, to a 90-minute session on stigma issues during a 2-day HIV and sexual and reproductive health and rights training for 300 health-care providers.[33] More in-depth training included a 4-day workshop to become community mobilizers and to present workshops and lead a support group.[38] In some cases, more extensive and nuanced training is required for optimal benefit in addressing disease stigma.

Creating opportunities for affected groups to interact with unaffected groups has been shown to be a promising approach to reduce stigma, particularly when combined with information-based interventions.[37] Examples of contact-based interventions include engaging in 1-on-1 conversation or listening to a testimonial from an affected individual.[40–42]

Interventions that use skills building can focus on role-play exercises, strategies for resolving negative attitudes, and coping behavior[37] such as engaging with and providing social support for stigmatized groups and refusing to exclude people who pose no risk of transmitting illness.

6. Evaluate Stigma-Reducing Efforts

Interventions designed to reduce stigma during public health emergency response efforts should be evaluated to assure that they are effective and to improve their effectiveness. Detailed evaluation methods are out of scope here, but we provide a few key points that would be relevant for an evaluation embedded within an emergency response. From the outset, members of the evaluation team should have a clear understanding of the program goals and evaluation objectives related to the stigma-reducing efforts being assessed. Evaluators should obtain feedback from those who delivered and from those who received stigma-reducing interventions to assess not only whether the interventions worked, but also whether they reached the target groups. Further, public health agencies can monitor public reactions to information to identify barriers, provide evidence of success, and determine a need for additional resources, and adjust messages accordingly.

CONCLUSION

During a disease outbreak, stigmatization can prevent the adoption of healthy behaviors and social adaptation, potentially contributing to more severe physical health problems, as well as mental health difficulties, ongoing transmission, and challenges controlling infectious diseases. The information contained herein may serve as a guide for developing an approach to reduce stigma during emergency responses. However, staffing and other resource constraints may limit the ability to design and implement extensive stigma-reducing interventions as described. In these situations, some basic activities can still be done. CDC provides a checklist to help identify and address stigmatization before, during, and after infectious disease outbreaks (see Box 2). Brief, practical steps may reduce disease-related stigma during public health emergency response efforts. Effective responses to infectious disease outbreaks require mitigating fear and implementing rational, science-based protective measures for the benefit of all.

Acknowledgments

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BOX 1

Case Study of a Role Model Approach

Dallas County Judge Clay Jenkins oversaw the first US Ebola emergency response. Jenkins repeatedly demonstrated that Ebola isn't contagious unless a person is showing symptoms of the disease. Without protective clothing or gear, he made a point of visiting the apartment where an Ebola patient had been staying, clearing the apartment of contaminated linens and driving the quarantined family to a new location.

He sent a message by modeling how it was important "to go into their apartment and see them as human beings and explain to them the situation." Jenkins told the press, "I'm wearing the same shirt I was when I was in the car for 45 minutes today with that family. If there was any risk, I wouldn't expose myself or my family."

Source: Time.com. This Texas judge is fighting fear and Ebola in Dallas. Published October 2015. http://time.com/3474650/ebola-dallas-judge-jenkins/. Accessed December 29, 2017.

BOX 2

Checklist for Inhibiting and Countering Stigmatization

Before an Outbreak

- Remember: products, animals, places, and people can be stigmatized.

- Avoid geographic mentions of past infectious disease outbreaks; instead, substitute dates (eg, Toronto SARS outbreak versus the 2003 SARS outbreak; the Spanish influenza pandemic versus the 1918 influenza pandemic).

- Avoid constant use of visuals that portray only 1 ethnic group in briefing and education/outreach materials (media reports are different and set in time).

- Avoid typefaces and symbols that evoke a specific ethnic group (subconsciously you may think it's relevant, although it's not). For example, sᴛɪɢᴍᴀ.

- Ask staff members who share the ethnic background of persons experiencing the earliest outbreaks whether the proposed materials are offensive. If no staff members share the ethnic background, reach out to trusted partners.

- If a particular parasite, virus, bacteria, or toxin evokes an instant association with a particular ethnic/racial/age/gender group – stigmatization is already occurring (eg, When you read the next words "head lice," stop! Now who/ what comes to mind?).

- Teach response officials and communication staff as broadly as possible about the harm that results from stigmatization – people may literally hide their illness to avoid the stigma, which could hamper containment measures.

- Share with media the concern about stigmatization, and work together to create visuals that tell the story without targeting 1 group.

- Address the issue in preplanning community checklists and guides. The more people who are aware that this could occur, the more people who can help guard against it.

- Have a mechanism in place that allows people to seek the help of public health experts in determining real risks versus imaginary or theoretical risks.

- Have a mechanism in place to allow people who are feeling stigmatized to express their concern and ask for help.

During an Outbreak

- All of the above continue to apply.

- Ensure that the environmental scanning process being used is able to discern and alert communication staff to stigmatizing visuals, statements, or behaviors.

- Monitor misperceptions in the community regarding real risks versus imagined or theoretical risks in relation to products, animals, places, and people.

- When stigmatization occurs in the community, counter it immediately with emotional appeals for fairness, justice, and sound scientific facts. For example, when nail salon, Vietnamese owners appealed for help from the health department during the SARS outbreak because women feared they would get SARS at the salons, the health department was able to allay public concern about increased risks and shorten the negative emotional and fiscal impact of the stigmatization.

- Engage respected political and civic leaders in countering stigmatization (eg, the governor of Hawaii visited Honolulu's Chinatown during the SARS outbreak).

After an Outbreak

- Continue to do all of the activities above.

- Ensure that historical accounts of the event do not unfairly show any 1 ethnic group. The potential is high for historical accounts that cover the early part of the outbreak to unintentionally perpetuate the stigmatization.

- If stigmatization does occur in the community, reach out to the stigmatized community to learn (believe me, they will know) when it started, what led to it, how it manifested, and how they coped or countered it themselves. Learn the lessons and engage them in the future for help.

Adapted with permission from:

Department of Health and Human Services. Centers for Disease Control and Prevention. Checklist: inhibiting and countering stigmatization in crisis and emergency risk communication: pandemic influenza. Last revised October 2007. https://emergency.cdc.gov/cerc/cerconline/pandemic/pandemic/transcripts/checklist3.pdf. Accessed April 23, 2019.