

Disease and Stigma: A Review of Literature

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Abstract

This article presents a review of literature pertaining to disease and stigma. Specifically, a definition of stigma is provided along with an historical overview of disease and stigma and research trends related to three public health perils—AIDS, mental illness, and obesity.

Introduction

Throughout history, humans have encountered and confronted stigma. Stigma can be defined as “a mark of shame” (“Stigma,” 2007) or “an attribute that is deeply discrediting within a particular social interaction” (Goffman, 1963, p. 3). While stigma represents a global phenomenon (Keusch, Wilentz, & Kleinman, 2006), race/ethnicity, gender, socioeconomic status, disability, and sexual orientation signify sources of stigmatization among Americans (Valdiserri, 2002). Sources of stigmatization precipitate health disparities, crime, hatred, and other forms of inequity (U.S. Department of Health and Human Services, 2000). As indicated by Link and Phelan (2006), “Stigma processes have a dramatic and probably under-recognized effect on the distribution of life chances such as employment opportunities, housing, and access to medical care” (p. 528). The purpose of this paper is to delineate the connection between disease and stigma through a comprehensive review of literature relative to three public health perils—AIDS, mental illness, and obesity. The aforementioned public health perils were selected because of their growing prevalence and impact on health policy in America.

Historical Roots of Disease and Stigma

To better understand sources of stigma and disease in America, a closer look at the history of the concepts is necessary. The presence of disease-causing stigma arguably predates the Pre-Modern era. Nonetheless, perhaps the most notorious historical figure to bear the blight of stigma was Mary Mallon (a.k.a., Typhoid Mary). During the early 1900s, Mary Mallon was shunned and captured by local authorities for her role in spreading typhoid. Mary represented a healthy carrier of typhoid and unknowingly spread the disease to people for whom she prepared meals. Mary underwent a great deal of trauma and hardship as a

result of her unfavorable condition and her permanent label (i.e., Typhoid Mary) signifies the stigma she endured (Merrill & Timmreck, 2006).

During the era of Typhoid Mary and prior to the social activism of the 1960s and 1970s, African-Americans were the target of stigma. As noted by Wailoo (2006), “In an era when infectious disease predominated, African-Americans were often portrayed as a key disease vector, capable of infecting other parts of the American population” (p. 531). The Tuskegee Syphilis Study that spanned four decades is symbolic of the injustice and stigma directed toward African-American males during the middle part of the 20th century (Centers for Disease Control and Prevention, 2007).

In addition to pervasive and erroneous beliefs about race, varying beliefs about the etiology of disease existed during the latter half of the 19th century and the early part of the 20th century. For example, many diseases were considered taboo and were thought to have evolved from bad vapors (Butler, 2001), sinfulness, and evil spirits among other improbable determinants (Fitzgerald, 2000). Historically, beliefs about etiology and practices employed to control diseases (e.g., quarantine, etc.) evoked stigma. In fact, practices such as quarantine can be traced back to Biblical times when individuals with leprosy were deemed as social outcasts (Gussow, 1989).

While early attempts to explain the etiology of disease were based on factors beyond the control of individuals, recent historical trends have highlighted the linkage between controllable behaviors and disease. Butler (2001) described the period between the late 1970s and the present as the Health Promotion Phase. According to Butler, the Health Promotion Phase has placed continued emphasis on the importance of lifestyle behaviors in thwarting the occurrence of disease. While the recent thrust on individual behaviors lends support for health promotion and prevention efforts, it arguably opens the door for stigmatization among individuals afflicted with selected diseases.

Essentially, the mere term, “disease” induces a sense of stigma. Stigma manifests in the presence of diseases such as gonorrhea (Fortenberry et al., 2002), herpes (Newton & McCabe, 2005), human papilloma virus (HPV) (Newton & McCabe), hepatitis (Beeching, 2004; Zickmund, Ho, Masuda, Ippolito, & LaBrecque, 2003), Alzheimer’s disease (Holston, 2005), severe acute respiratory syndrome (SARS) (Person, Sy, Holton, Govert, & Liang, 2004), irritable bowel syndrome (Dancey, Hutton-Young, Moye, & Devins, 2002), autism (Gray, 2002), psoriasis (Vardy et al., 2002), attention deficit hyperactivity disorder (Kendall & Hatton, 2002), epilepsy (Meisler, 2001), and schizophrenia (Stuart & Arboleda-Florez, 2001). Perhaps one of the most stigmatizing diseases in American history is acquired immunodeficiency syndrome (AIDS).

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AIDS

During the initial stages of the AIDS outbreak in America, the public was overcome with fear, unrest, and confusion. At the time, AIDS represented a mysterious and misunderstood disease that supposedly was attributable to behaviors of homosexual men (Herek, Widaman, & Capitanio, 2005). In his 1987 bestseller, *And the Band Played On*, Shilts provided an early chronological account of AIDS in America. According to Shilts, advocacy groups continually confronted state governors for shortchanging funds for AIDS-related research. In the midst of political opposition for AIDS funding, Rock Hudson acknowledged his disease status and sexual orientation.

While Hudson's proclamation failed to nullify the public's misconceptions about AIDS, several key events assisted in debunking myths surrounding the epidemic. Most notably, Ryan White, a young boy who contracted AIDS through a blood transfusion, emerged to share his story with the world (Health Resources and Services Administration HIV/AIDS Bureau, n.d.). Similarly, the film *Philadelphia* played a salient role in dispelling myths about the spread of AIDS and its victims. *Philadelphia* depicted the story of a gay lawyer who was wrongfully fired from his position with a prestigious law firm when his disease status was discovered. The film illustrated the harsh reality of experiencing "social death" prior to physical death (Demme, 1993).

Perhaps one of the most recent historical events that changed the face of AIDS in America was Magic Johnson's announcement of his HIV-positive status in 1991. In essence, Magic Johnson, former NBA basketball star and champion for underprivileged youth, is considered the poster boy for HIV/AIDS (Brown, Baranowski, Kulig, Stephenson, & Perry, 1996). While sexual biases and misconceptions about HIV/AIDS transmission persist today (Herek et al., 2005), stigma associated with HIV/AIDS has lessened over the past decade due to Magic's advocacy and experience with the virus (Herek & Capitanio, 1997), increased awareness about the manner in which the virus/disease is transmitted (Dias, Matos, & Goncalves, 2006), and advancements in managing the virus/disease (Rajabiun et al., 2007).

Despite progress that has transpired through advocates like Magic Johnson, stigma continues to plague the lives of AIDS victims and their families (Xiaobin, Sullivan, Jie, & Zunyou, 2006). As indicated by Xiaobin et al., "Stigma is associated with the disease as well as the behaviors that lead to the infection" (p. 518). Consequently, AIDS victims are subject to blame (Herek, Capitanio, & Widaman, 2002) and have an intense fear of disclosing their disease symptoms.

Through in-depth interviews, Goggin et al. (2001) discovered that women, particularly mothers, living with HIV held deep reservations about disclosing their statuses to their children, close friends, and family members. The women also expressed concerns about experiencing social rejection.

In a similar study, Ermet (2006) examined the relationship between stigma and disclosure of disease status among older and younger adults afflicted with HIV. Results from his

study indicated that younger adults were hesitant to reveal their disease statuses to employers, while older adults were fearful of disclosing their conditions to family members, significant others, mental health professionals, neighbors, and church affiliates.

The consequences of disease stigma and disclosure are marked and substantial. Most notably, HIV/AIDS stigma has resulted in lack of treatment and adherence to therapies. Rintamaki, Davis, Skripkauskas, Bennett, and Wolf (2006) conducted a study among HIV-infected adults and found that those affected by stigma were less inclined to follow recommended treatments due to fear of disclosure.

Not only is HIV/AIDS-related stigma acknowledged by adults, but it also is recognized by youth (Dias et al., 2006). Rao, Kekwaletswe, Hosek, Martinez, and Rodriguez (2007) facilitated focus groups to explore barriers to treatment adherence among HIV-infected youth. HIV-related stigma inhibited half of participants from taking prescribed medications. HIV-related stigma also precluded many participants from revealing their maladies to friends, family members, and health care providers.

Perhaps one of the most disturbing repercussions of HIV/AIDS stigma is that it thwarts prevention and treatment efforts among vulnerable groups. According to Brooks, Etzel, Hinojos, Henry, and Perez (2005), "The pervasive negative attitudes toward HIV and homosexuality found in communities of color have contributed to a lack of participation in HIV prevention services by gay, bisexual, and heterosexual men of color" (p. 738).

Screenings represent one of the most powerful lines of defense in the battle against HIV/AIDS. Alas, HIV/AIDS-related stigma inhibits many individuals from undergoing screenings. Fortenberry et al. (2002) surveyed a sample of individuals between the ages of 14 and 59 to uncover predictors of gonorrhea and HIV screenings. Gender differences revealed that females were more receptive to gonorrhea and HIV testing than males. Furthermore, both gonorrhea and HIV testing were more common among individuals with minimal STD-related stigma.

A myriad of interventions have been instituted to counteract negative attitudes toward people living with HIV/AIDS. Brown, Macintyre, and Trujillo (2003) evaluated interventions designed to curb HIV/AIDS stigma among infected individuals, the general population, and the health care workforce. While many of the interventions showed promising results, they concluded that further testing is needed to confirm effectiveness within selected settings and populations.

Mental Illness

AIDS sufferers are not alone in their struggles with stigma. Stigma is considerably pronounced among individuals who suffer from mental illness. As noted by Beam (2001), "From the high culture of literary memoirs to the low culture of talk shows, tales of life in the 'bin' or the 'zoo' are part of the cultural landscape" (p. 83). Perhaps one of the most

eminent films portraying the stigma and misuse of mental hospitals was *One Flew over the Cuckoos Nest*. Directed by Forman (1975), *One Flew over the Cuckoos Nest* depicted the story of a man who inappropriately was institutionalized for not conforming to society's expectations and failing to maintain a job. Before being killed by a fellow patient, the man, played by Jack Nicholson, succumbed to the throes of mental illness.

Throughout history, mental hospitals have been inhabited by individuals from all walks of life. In his book *Gracefully Insane*, Beam (2001) provided an historical account of Massachusetts's famous mental hospital, McLean. During the latter half of the 19th century and greater part of the 20th century, McLean was considered to be one of America's most prestigious mental hospitals and was frequented by highly acclaimed literary figures and musical artists including Sylvia Plath, James Taylor, Ray Charles, and others. Noteworthy political figures also roamed the grounds of McLean Hospital and attempted to conceal family histories of mental illness.

Beam (2001) discussed the allure of McLean Hospital which resembled a resort for the mentally ill and accommodated patients for months, and sometimes years, at a time. He also explored the changing face of mental health care. Sleep therapy, teeth pulling, removal of large intestines, fever inducement, hypothermia, hydrotherapy, insulin coma, and metrazol shock represented a few of the early practices employed to treat sufferers of mental illness. According to Beam, "Today's psychiatrists must stabilize, diagnose, treat—usually with a prescription drug—and release a disturbed man or woman in less than a week" (p. 235).

Unfortunately, stigma inhibits many individuals with mental illness from receiving much needed treatment. As purported by Wittwer (2006), "stigma tops the list" in terms of barriers to mental health care. Secondary to stigma are issues regarding access to care and mental health parity. According to Wittwer, "The issue of nonparity between general medical care and mental health care perpetuates the stigma" (p. S22).

Stigma, access to care, and mental health parity ultimately interfere with patients' use of medication and quality of life (Wittwer, 2006). While medication assists many individuals with managing their symptoms, side effects often are noticeable and adverse. As indicated by Leal (2005), "Some psychiatric medications can have severe and long-lasting side effects that can evoke more stigma than the illness that they are used to treat" (p. 1028).

Failure to seek treatment for mental illness is perhaps most recognized among minorities who, by virtue of their disadvantaged social status, succumb to the perils of elevated stigma including pervasive misdiagnosis (Bolden & Wicks, 2005; Gray, 2005). Using data from the Nationwide Inpatient Sample (NIS), Bolden and Wicks discovered that African-Americans reported significantly longer hospital stays and greater frequencies of emergency room visits than other demographic groups. They concluded that these outcomes were a result of delayed treatment-seeking behaviors among

African-Americans suffering from mental illness.

In a similar investigation, Leal (2005) analyzed data from the NIS to explore diagnoses and treatment variables among Hispanic youth. She found that a substantial proportion of Hispanic youth sought treatment for mental illness through emergency rooms. According to Leal, "When Hispanic patients present for care, whether as a routine admission or via the emergency department, they are at risk for being stigmatized by health care providers, family members, and other members of society" (p. 1029).

Perhaps the greatest source of stigma surrounding mental illness in America emanates from society's views about causal factors. Goldstein and Rosselli (2003) surveyed a group of college students to discern their perceptions regarding underlying causes of mental illness. They found that students who support the biological model of mental illness are less prone to stigmatizing perceptions. On the contrary, students who embrace the psychological model of mental illness are more attuned to stigmatizing stereotypes.

Corrigan, Watson, Byrne, and Davis (2005) presented the notion of viewing mental illness through the lens of social justice. According to Corrigan et al., "Framing mental illness stigma as a social justice issue reminds us that people with mental illness are just that—people" (p. 363).

Despite facing stigma in recent years, Americans appear to be more vocal about mental illness. As articulated by Beam (2001), "In our own time, it is not so unusual for men and women to discuss their stays in mental hospitals" (p. 83). Mike Wallace, Kitty Dukakis, and William Styron represent a few renowned figures who publicly have described their devastating bouts with depression (Cronkite, 1994).

Like celebrities, public health professionals diligently strive to raise awareness on depression and other forms of mental illness. The recent integration of an optional mental illness and stigma module to the Behavioral Risk Factor Surveillance System (BRFSS) signifies the increasing presence and impact of stigma as a barrier to public health goals (Texas Department of State Health Services, 2006).

National attention toward mental illness and stigma has been complemented with local interventions among selected populations including youth. Youth as young as 8 years old are cognizant of the stigma that accompanies mental illness (Pitre, Stewart, Adams, Bedard, & Landry, 2007). In light of their awareness, Pitre et al. designed an experimental intervention to counteract negative perceptions toward mental illness. Specifically, they administered pre- and post-tests consisting of items from the Opinions about Mental Illness Scale to students in grades 3-6. Students in the experimental group were introduced to a series of plays performed by puppets. The entertaining and non-stigmatizing plays depicted scenes related to schizophrenia, depression/anxiety, and dementia. Students who witnessed the plays reported less stigmatization, stereotyping, and pessimism toward sufferers of mental illness. Moreover, students exposed to the plays exuded greater sensitivity, kindness, and social acceptance toward individuals plagued by mental illness.

Obesity

Like AIDS and mental illness, obesity increasingly continues to plague Americans. As estimated by the Centers for Disease Control and Prevention (2006), "In 2005, only 4 states had obesity prevalence rates less than 20 percent." Like sufferers of AIDS and mental illness, obese individuals are often targets for stigma. Rogge, Greenwald, and Golden (2004) interviewed 13 obese women to uncover their experiences with stigma. They framed participants' responses around the concept of civilized oppression. In accordance with the concept of civilized oppression, many of the women reported being devalued, socially isolated, and ostracized. Moreover, many of the women experienced a lack of self-worth that was perpetuated by their families, health care providers, and coworkers.

The stigma attached to being overweight and/or obese can have long lasting effects, especially among youth (Harper, 2006). Children affected by the stigma of obesity increasingly are at risk for low self-esteem (Strauss, 2000) and unfavorable academic outcomes such as absenteeism and substandard test performance (Datar & Sturm, 2006).

Strauss (2000) analyzed data from the National Longitudinal Survey of Youth to study changes in self-esteem among obese youth over the course of a 4-year timeframe. Findings from his investigation revealed that, regardless of gender or race, obese youth experienced reductions in self-esteem from the ages of 9-10 to the ages of 13-14. Decreases in self-esteem were most pronounced among Hispanic and White females marked by obesity. Of particular importance was the fact that obese youth characterized by low self-esteem were more prone to alcohol and tobacco use than their respective peers.

Using data from the National Longitudinal Survey of Adolescent Health, Strauss and Pollack (2003) employed a complex social network analysis to identify differences between the breadth of friendships experienced by overweight and normal weight adolescents. Results from their analysis showed that overweight adolescents had fewer close and extended friends and consequently, were considered less popular.

In light of obesity-related stigma among youth, body mass index (BMI) screenings in schools represent one of the most recently debated health policies. Arkansas legislators' decision to mandate BMI screenings in schools consistently has generated controversy and debate. Ikeda, Crawford, and Woodward-Lopez (2006) summarized literature pertaining to BMI screenings among youth. "Increased stigmatization" was cited as a concern for youth undergoing BMI screenings. Labels attached to being overweight and/or obese potentially are demoralizing and degrading among youth who continually seek to balance peer pressure with social acceptance. As noted by Ikeda et al., "The reason children are so fearful of becoming fat has little, if anything, to do with the health risks associated with obesity. Instead, it is based on early awareness that having a fat body is socially unacceptable in our culture" (p. 766).

Unfortunately, obesity-related stigma manifests at a young age. In a landmark study, Staffieri (1967) examined stigmatizing attributes among 6-10-year-olds and revealed that they consistently applied unfavorable adjectives (e.g., "lazy," "dirty," "stupid," "ugly," "sloppy," etc.) to describe overweight individuals. Similarly, Cramer and Steinwert (1998) presented a group of 3- and 5-year-old preschool children with a series of stories and pictures depicting "thin" and "chubby" characters. Findings from their study indicated that the children, irrespective of age and gender, expressed biases toward the "chubby" character.

In a more recent study, Latner and Stunkard (2003) presented 5th and 6th grade students with sketches illustrating children afflicted with and without obesity and disability. Findings from their study revealed that the students favored the healthy child above the children marked by obesity and disability. Moreover, the students reportedly disliked the obese child more than the healthy and disabled children. Gender differences indicated that female students were more critical of the obese child than the male students. When compared to results from a study conducted by Richardson, Goodman, Hastorf, and Dornbusch (1961), a significantly increased level of stigmatization was uncovered, thus signifying the rising prevalence of stigma in contemporary society.

Ironically, health professionals often share the same stigmatizing views as children and the general population. Schwartz, Chambliss, Brownell, Blair, and Billington (2003) administered the Implicit Attitudes Test (IAT) to a group of health professionals with interests in obesity and found that they harbored implicit biases toward obese individuals. Specifically, the group implicitly acknowledged obese individuals as being "lazy," "stupid," and "worthless."

The lack of sensitivity afforded by health professionals responsible for treating obese individuals is noteworthy and alarming. That said, the omnipresent stigmatization faced by obese individuals has sparked a culture of extreme measures consisting of dieting, exercise, support groups, medication, and surgery (Spence-Jones, 2003).

NBC weatherman and newscaster Al Roker and singer Carnie Wilson underwent gastric bypass surgery after lifelong battles with weight. Their stories arguably challenged many Americans to consider bearing the risks of obesity surgery. Bishop (2005) analyzed messages from selected television, magazine, and newspaper excerpts to explore Roker and Wilson's personal motives for undergoing gastric bypass surgery and societal reactions to their decisions. According to Bishop's analysis, Roker's decision to undergo surgery was deemed "heroic" because he was motivated by his family and a desire to actively participate in his children's lives. Roker was portrayed as a man who took an active role in bettering his health and family life. On the contrary, Wilson was construed by the media as a passive patient whose impetus for surgery evolved from a desire to enhance her appearance. Despite Wilson's divulgence of an unfavorable childhood and advocacy for gastric bypass surgery, the media and general public were more supportive and forgiving of Roker's plight with obesity and surgery. As stated by Bishop, "It is

impossible for women to gain approval of their improved bodies, even when they have made use of a procedure that is now culturally condoned” (p. 137).

The recent surge in obesity surgery, a procedure marked by potential complications and discomfort, is indicative of the lengths to which obese individuals will go to overcome the throes of stigma. While the benefits of obesity surgery purportedly exceed the barriers, the procedure is serious and potentially can leave individuals with chronic and severe symptoms (American Obesity Association, 2002).

The effects of stigma extend beyond social and emotional anguish and encompass physical implications. Puhl and Brownell (2006) surveyed two samples of obese individuals including a group of female participants and a group representative of both genders. Participants were assessed on sources and frequency of stigmatization, coping, and other related variables. Puhl and Brownell found a positive relationship between BMI and stigma in the sample consisting of obese females. Similarly, they found a positive correlation between childhood weight and stigma among females in the sample that included representation from both genders. In relation to stigmatizing situations, participants in both samples reported being negatively affected by weight-related assumptions purported by others and comments voiced by children. Family members, physicians, and classmates represented the most common sources of stigma among obese individuals in both samples. Furthermore, participants in both samples exercised positive self-talk, sought social support, and attempted to disregard biased comments as mechanisms for coping with weight-related stigma.

In another study conducted among obese women, Puhl, Moss-Racusin, and Schwartz (2007) analyzed responses to stigmatizing stereotypes and weight bias. Among other findings, they discovered that women who internalized stigmatizing stereotypes and accepted them as valid were more apt to engage in unhealthy coping strategies, namely binge eating. Women who legitimized such stereotypes also were more likely to resist dieting as an approach to weight loss.

Conclusion

Stigma represents a powerful and dehumanizing phenomenon. As new diseases emerge, old diseases re-emerge, and existing diseases remain steady, stigma inevitably will occur. Like disease, stigma is not confined to specific demographic groups. While individuals can be immunized against specific diseases, they cannot be immunized against stigma. Health educators are faced with many challenges as they strive to minimize health disparities. AIDS, mental illness, obesity, and other public health perils present many challenges insofar as addressing health disparities. Exacerbating these challenges are funding limitations, resistance from policymakers, health care access, and social norms perpetuated by the media. As illustrated by this literature review, the connection between disease and stigma

is considerably extensive. In light of this connection, health educators must strive to prevent stigma that accompanies selected diseases and potentially hinders individuals from seeking treatment and counsel. As health educators seek to change the face of disease-causing stigma in America, they should be mindful of three strategies—awareness, advocacy, and action. Awareness of the presence and implications of stigma, advocacy for increased health care access and funding, and action in the form of educational delivery and social marketing are needed to address the barrier of stigma in the prevention and control of disease.

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