

# STAND UP TO STIGMA



How We Reject  
Fear and Shame

**PERNESSA C. SEELE**

CEO and Founder of The Balm in Gilead, Inc.

# SERVANT LEADERSHIP ONLINE TRAINING SUMMIT

**If you enjoy this excerpt...**

consider becoming a member of the reader community on our website!

[Click here for sign-up form.](#) Members automatically get 10% off print, 30% off digital books.

Berrett-Koehler Publishers

# **STAND UP TO STIGMA**

**How We Reject Fear and Shame**

**PERNESSA C. SEELE**



Berrett-Koehler Publishers, Inc.  
*a BK Currents book*

Copyright © 2017 by Pernessa C. Seele

All rights reserved. No part of this publication may be reproduced, distributed, or transmitted in any form or by any means, including photocopying, recording, or other electronic or mechanical methods, without the prior written permission of the publisher, except in the case of brief quotations embodied in critical reviews and certain other noncommercial uses permitted by copyright law. For permission requests, write to the publisher, addressed "Attention: Permissions Coordinator," at the address below.

BERRETT-KOEHLER PUBLISHERS, INC.

1333 Broadway, Suite 1000, Oakland, CA 94612-1921

Tel: (510) 817-2277 Fax: (510) 817-2278 [www.bkconnection.com](http://www.bkconnection.com)

#### ORDERING INFORMATION

**QUANTITY SALES.** Special discounts are available on quantity purchases by corporations, associations, and others. For details, contact the "Special Sales Department" at the Berrett-Koehler address above.

**INDIVIDUAL SALES.** Berrett-Koehler publications are available through most bookstores. They can also be ordered directly from Berrett-Koehler:

Tel: (800) 929-2929; Fax: (802) 864-7626; [www.bkconnection.com](http://www.bkconnection.com)

**ORDERS FOR COLLEGE TEXTBOOK/COURSE ADOPTION USE.** Please contact Berrett-Koehler: Tel: (800) 929-2929; Fax: (802) 864-7626.

**ORDERS BY U.S. TRADE BOOKSTORES AND WHOLESALERS.** Please contact Ingram Publisher Services, Tel: (800) 509-4887; Fax: (800) 838-1149; E-mail: [customer.service@ingrampublisherservices.com](mailto:customer.service@ingrampublisherservices.com); or visit [www.ingrampublisherservices.com/Ordering](http://www.ingrampublisherservices.com/Ordering) for details about electronic ordering.

Berrett-Koehler and the BK logo are registered trademarks of Berrett-Koehler Publishers, Inc.

#### PRINTED IN THE UNITED STATES OF AMERICA

Berrett-Koehler books are printed on long-lasting acid-free paper. When it is available, we choose paper that has been manufactured by environmentally responsible processes. These may include using trees grown in sustainable forests, incorporating recycled paper, minimizing chlorine in bleaching, or recycling the energy produced at the paper mill.

#### LIBRARY OF CONGRESS CATALOGING-IN-PUBLICATION DATA

Cataloging-in-Publication Data is available at the Library of Congress.

ISBN: 978-1-62656-937-9

#### FIRST EDITION

22 21 20 19 18 17      10 9 8 7 6 5 4 3 2 1

Cover design: Paula Goldstein.

Book interior production and design: VJB/Scribe.

Copyediting: John Pierce. Proofreader: Nancy Bell. Index: Theresa Duran.

## CONTENTS

*Preface*      xi

**Introduction**      1

1. **The Venom of Stigma**      7
2. **The Audacity of Stigma**      21
3. **The Process of Stigmatization**      35
4. **The Outcome of Stigma:  
Stereotypes and Prejudices**      45
5. **Stigma and Health**      61
6. **Levels of Intervention**      85
7. **Changing How We Think  
about Stigmatized Diseases**      101
8. **Practical Stigma Management**      113

*Notes*      123

*Index*      133

*About the Author*      145

## Stigma and Health

**Stigma can have a** detrimental effect on both the physical and psychological health of individuals. Problems in school, at home, at work — as well as with making payments and purchases — can wreak havoc on one's emotional state, which can easily transmute into a wide variety of health problems. There is so much information on this particular topic that I have dedicated an entire chapter to it. Further, nowhere has the impact of generational stigma been so vividly displayed as throughout the health-care system and on the psychological and sociological health of populations of people.

As we saw in the previous chapter, stigma can cause various problems in the areas of education, job performance, home life, and the economy. The end result of all these problems is that stress and even psychological distress are produced in people affected by stigma, which can eventually lead to a deterioration of their mental and physical health. As people who are continuously stigmatized fall into ill health, their quality of living can erode even further as mental and physical conditions compound individuals' ability to earn money, get satisfactory housing, acquire health care and insurance, maintain solid relationships, interact socially, and perform other normal, healthy activities.

Perhaps it might be helpful to consider the impact of institutional biases, including racism, sexism, gender identity, and socioeconomics, on our personal journeys through life.

## Mental-Health Stigma

Our mental and emotional states play key roles in our overall health and our ability to live a productive and happy life. When those elements are agitated and thrown out of balance, we can experience a range of problems. Of course, not all people develop mental issues when dealing with the everyday annoyances of life. However, those who do often-times struggle with the added pressures of stigma on top of their mental-health issues.

Experts recognize two forms of stigma that affect those with mental disorders. The first type is *social stigma*, which consists of attitudes and behavior that are both prejudiced and discriminatory against those with mental-health issues. Stigmatization is commonly placed on the mentally ill who have serious mental issues such as substance addictions, schizophrenia, post-traumatic stress disorder (PTSD), or obsessive-compulsive disorder (OCD).

Society, however, also discriminates against those with lesser-known ailments or illnesses deemed less serious — conditions considered to be self-inflicted, such as eating disorders and substance abuse. In certain cases this is true, and at other times it is simply perceived to be true. Regardless, the outcome leads to the second type, known as *self-stigma* or *perceived stigma*, which is the internalization of shame and guilt that is the result of an individual's perceptions of

the applied stigma or discrimination. This can lead people to experience deeper degrees of mental illness or reduce the effectiveness of treatment programs.

People suffering from severe forms of mental illness who are eighteen and older account for only around 6 percent of the US population. However, the issue of mental disorders is much more widespread, both in the United States and internationally. The percentage of American adults diagnosed with some type of mental disorder in any given year is approximately 26.2 percent, or 57.7 million people, based on the 2004 census.<sup>1</sup> That equates to roughly one in four adults with known mental-health issues — and that number easily rises when undiagnosed people are considered. Anxiety disorders, panic disorders, mood disorders, social phobias, and other mental diagnoses — although less known or recognized — still cause millions of people pain and suffering that often go undiagnosed and untreated.

According to the Centers for Disease Control and Prevention, more than one out of twenty Americans who are twelve years of age or older reported current depression (moderate or severe depressive symptoms in the past two weeks) in 2009–12. Mental disorders are a major epidemic in the United States. With the daily cycles of negative cable news spewing forth immediate images of killings, devastations, and other horrors, mental disorders have become a silent health challenge in our country. Seeking proper diagnosis at any age and then getting professional help for mental disorders is vital to recovery, especially when assistance is received in the early stages. People diagnosed with mental disorders may be provided corrective medications,

counseling, information, support groups, and other valuable resources that help them gain control of out-of-control mental stresses, anxieties, and other issues. Those who pursue and receive mental-health services often fully recover and return to living normal, productive lives. Unfortunately, many adults diagnosed with a mental-health condition do not receive services. According to a 2014 survey, only 41 percent of persons with a mental-health condition received help, and of those with serious mental illness, only 62.9 percent received assistance.<sup>2</sup>

Stigma plays a major role in hindering the recovery process for millions of persons with mental-health illnesses. First of all, because mental illness is so radically stigmatized in our society, many people refuse to seek professional help for fear of being tagged with labels such as “crazy” or “insane.” They choose to go through life haunted by their problems rather than face being ridiculed and judged as outcasts. Needless to say, this leads to deeper degradation of their mental state and, as we shall soon see, endangers their physical well-being as well. As a person declines into a worsening mental condition, she or he find it increasingly difficult to function at home, school, and work or within social circles.

Second, a person who seeks professional help and is diagnosed with a mental disorder has to deal not only with the reality of their problem, but also with the burden of discrimination and stigma with which they may now be labeled. It is much more difficult for persons with diagnosed mental disorders to find work; receive good housing; hold long-term, meaningful relationships; or gain acceptance in

mainstream society. This is mainly because of the ignorance of the majority that automatically deems anyone with any type of mental disorder to be unstable and dangerous — to themselves or others. The media tends to feed this stereotype by portraying the mentally disturbed as violent criminals, villains, or horribly unstable citizens who are unable to carry out normal existences.

Thus, stigma creates a lose-lose situation for so many persons experiencing mental-health issues — they are affected either by the fear of being stigmatized or they must actually face the stigma placed on them by society after seeking help. Stereotyping only works to magnify the problem and drive individuals with mental illness into worsening states of mental torment.

### **How Stigma Affects Physical Health**

Our physical health is tightly knit into the fabric of our mental well-being. As our mental state is agitated for long periods of time and becomes weak and unstable, it is often mirrored in some physical ailment. One simple example that I often experience regarding how the mind and emotions are connected to the physical body is when I give a speech in front of a large audience. The stress and anxiety experienced by the mere thought of giving the presentation produces an influx of gastric acid, upsetting my stomach and resulting in what we call “butterflies.” If, however, you are a member of the club of persons involved in a constant flow of situations where stress and anxiety levels are elevated over a long-term period — such as being stigmatized

at school, work, when shopping for groceries, or as you walk down the street on a daily basis — the overproduction of stomach acid and the feeling of butterflies can turn into heartburn, gastroesophageal reflux disease (GERD), peptic ulcers, or other health problems.

On the other hand, stress plays a beneficial role in human survival under normal conditions, triggering us to move into a flight-or-fight stance. When stress occurs, the body is flooded with hormones that cause the heart to accelerate, which raises blood pressure and provides a rapid burst of energy that is quite beneficial for fending off wild animals or fierce adversaries. In today's world, we seldom have to deal with such extreme dangers unless we're attacked by someone with a weapon or our personhood is thrust into violence. However, we continue to utilize stress to acquire the motivation to perform everyday tasks well, like landing job interviews, handling irate clients, confronting poorly performing employees, or waiting in traffic jams.

Unfortunately, sudden surges of high-level stress or prolonged stress that becomes chronic are well-documented sources of numerous types of sicknesses, ailments, and diseases. Sudden bursts of emotional stress brought on by accidents, terrorism, severe weather, and similar events can trigger such incidents as panic attacks, respiratory failure, heart attacks, or other forms of arrhythmia (erratic electrical impulses), which can lead to unconsciousness and even death. Chronic stress caused by prolonged illness, job loss, divorce, and the like can lead to sleep disorders, eating disorders, heart disease, ulcers and digestive problems, chronic pain, depression (which can lead to suicide),

and other ailments.<sup>3</sup> One of the hormones released under stress is cortisol, which has numerous important functions, such as reducing inflammation. However, when someone is under chronic stressful conditions, the body is bombarded with a steady stream of cortisol, which desensitizes cells and produces increased inflammation. Chronic inflammation, in turn, causes damage to blood vessels and brain cells, which results in insulin resistance and possible diabetes, as well as painful joint conditions.<sup>4</sup>

#### **STIGMA AND THE IMMUNE SYSTEM**

Stress and psychological disorders that are often caused or intensified by stigma adversely affect the immune system. Chronic stress causes a deficiency of the immune system, resulting in the body's inability to effectively fight germs, viruses, and disease. Thus, those plagued by chronic stress find that they take longer to heal from wounds, surgeries, colds, and diseases such as cancer. A weakened immune system can also drastically affect a person's mood, leading to major changes in behavior and even schizophrenia. Depression is one of the most common responses, and it creates behavior changes such as poor eating habits, drug abuse, and sleep disorders that work to reduce white blood cell counts used to fight invading elements.<sup>5</sup>

#### **STIGMA AND OBESITY**

Stigma concerning the obese is another plague on society that causes additional mental and physical stress to those who are overweight. Having struggled with obesity since my childhood, I know too well that stigma is applied to

individuals in a variety of ways, including name calling, ridiculing, and displaying overtly aggressive actions. Living as an obese person provides a constant target for stigma and discrimination at home, in the workplace, in church, during school, and in all public and private settings. Unlike other diseases that may be hidden under the skin, obesity is who you are and can be seen by all. Thus, employment, social events, travel, and all activities are opportunities for stigma, discrimination, and hate crimes.

As with all forms of stigma, stigma against the obese tends to magnify existing issues and create new ones. It is a myth that all overweight (or underweight) persons are always suffering from barrages of health challenges. For some, obesity is not compounded by other health issues. However, we know that obesity will eventually culminate in other significant ailments and complications if not properly addressed. In addition to stigma and discrimination directed at them by others, persons who are overweight tend to live a life of self-stigmatization. The destructive attacks of stigma and discrimination from persons on the outside, as well as those from within their own minds, can be devastating for obese persons. For some, it causes indulgence in unhealthy habits other than overeating, or it produces mental disorders such as the “nobody likes me” syndrome. Persons who are obese tend to experience greater degrees of anxiety, stress, depression, isolation, and low self-esteem.<sup>6</sup>

## STIGMA AND HIV

Stigma associated with HIV patients presents a significant problem in the United States as well as globally. HIV-related stigma places additional burdens on those living with the disease and can produce interference with the processes of prevention and treatment, research, and caring for and supporting HIV patients. Discrimination of persons living with HIV places additional suffering and hardship on individuals affected by the virus, but it also affects family members, friends, and caregivers.<sup>7</sup>

Since the beginning of the AIDS epidemic in the 1980s, the fear, shame, and religious dogma that promoted an austere response to people with the disease resulted in the globalization of the AIDS stigma as a social norm. This justified the displacement of human beings living with an incurable disease from their families, places of worship, and communities. Some were beaten privately or in the public square, many were denied care and compassion, scores died alone and were denied a proper burial upon death. Unfortunately, this response to persons living with HIV remains in effect in too many families, places of worship, and cultures around the world, including in the United States. The Obama administration in 2010 lifted a twenty-two-year travel ban that prohibited persons living with HIV from entering the United States. The travel ban, imposed in 1987, restricted all immigrants living with HIV from obtaining a US tourist visa or permanent residence status unless granted a special waiver. The reality of this ban denied physicians, researchers, global HIV advocates,

friends, and family members entry into the United States for more than two decades. Dr. Tom Coates, director of the UCLA Center for World Health, during an interview reiterated that the ban fueled a sense of “false security” and misunderstanding that public health and prevention programs were the primary efforts for stopping the spread of the disease.<sup>8</sup> The facts: acquired immunodeficiency syndrome (AIDS) is caused by the human immunodeficiency virus (HIV). The virus is spread to another person only when that person comes in contact with the body fluids of someone who has the virus — for example, blood, semen (cum), preseminal fluid (pre-cum), rectal fluids, vaginal fluids, and breast milk.

In 1981, the Centers for Disease Control published their “Morbidity and Mortality Weekly Report” and described a rare lung infection, *Pneumocystis carinii pneumonia*, discovered in five young, previously healthy gay men in Los Angeles. The world is now approaching forty years of fighting the global pandemic of AIDS. The medical advancements that have been made in understanding the virus that causes this disease are extraordinary. However, there is still *no cure*. Until there is a cure, we are rowing a boat with holes in it.

Today, we have volumes and volumes of science-based lessons regarding effective, preventive measures for AIDS. Yet, religious, political, and ideological rhetoric continues to drive stigma and discrimination toward specific groups of people: men who have sex with men, people who inject drugs, sex workers, and everyone living with HIV, including heterosexual women. Actively working in the trenches of HIV in the United States, Africa, and the Caribbean for

most of those forty years, I attest that there have been several debacles of the highest order by both public-health officials and congressional and religious leaders. I will not prolong this chapter by stating all the gross acts of negligence from my viewpoint. However, there is one that bears review. Federal funding for needle-exchange programs, a scientifically proven HIV prevention strategy, had been denied for years, until December 16, 2009, when President Obama signed into law an end to this longstanding ban. The lifting of this ban allowed federal funding for needle-exchange programs, which provided more opportunities to stop the spread of HIV among injecting drug users (IDUs). How many lives might have been saved or transmissions of the virus halted if science, rather than ignorance, fear, and hate, had been embraced by legislators?

The dual stigma of drug addiction and HIV has been propelled by laws that banned access needed to prevent the disease among persons who are viewed as unfit to live. One could argue that there are those who still believe that gay men, lesbians, transgender, and queer human beings are unfit to live as well. Seventy-five countries in 2015 listed homosexuality as a crime.<sup>9</sup> Certainly, there are many conservatives and liberals that would add the United States to this list. Today, twelve states still uphold antisodomy laws on their books, even after the Supreme Court ruled against it in 2003.<sup>10</sup>

Black women and men who have sex with men have the highest rates of HIV and AIDS in the world. Sadly, the fact that one in every nineteen African American women and one in two (50 percent) of African American gay man

live with HIV is a loud silence in our nation. As previously stated, the burden of stigma on all persons with HIV in the United States and around the world continues to be at an all-time high. However, the burden of stigma on men who have sex with men and live with HIV is a double-edged sword. According to the Centers for Disease Control and Prevention, gay and bisexual men age thirteen to twenty-four accounted for an estimated 92 percent of new HIV diagnoses among all men in their age group and 27 percent of new diagnoses among all gay and bisexual men in 2014. All men who have sex with men do not have the HIV virus, although they are often perceived that way.

Stigma and discrimination toward persons living with HIV have been horrific since the beginning of this global pandemic. The spiritual, emotional, and physical suffering of women and gay and bisexual men, especially those in their formative years (thirteen to twenty-nine), cannot be ignored. Behaviors of sexual violence, sexual promiscuity, homophobia, and HIV stigma are sustained through silence within the population at large. This indifference quietly supports violence and bullying against women and gay men of all ages, and the relief they often seek is through suicide and other self-destructive behaviors. Certainly, stigma has supported the spread of HIV over the past decades. Fear of being stigmatized forces people into isolation or prevents them from disclosing their HIV status to friends, loved ones, and sexual partners. As we have witnessed throughout the AIDS epidemic thus far, stigma can also prevent persons from getting employment, housing, insurance, or other benefits, as well as result in them being ostracized by family, friends,

and other social circles. According to research by the International Centre for Research on Women (ICRW), the possible consequences of HIV-related stigma are loss of income and livelihood, loss of marriage and childbearing options, poor care within the health sector, withdrawal of caregiving in the home, loss of hope coupled with feelings of worthlessness, and loss of reputation.<sup>11</sup>

An estimated thirty-five million human beings have died of AIDS-related illnesses since the beginning of this horrendous pandemic, which is still unfolding. According to the Centers for Disease Control, there “were approximately 36.7 million people worldwide living with HIV/AIDS at the end of 2015. Of these, 1.8 million were children.”<sup>12</sup> In the United States, one in four persons between thirteen and twenty-four are living with HIV. Today, regardless of all of this death and sickness, too many faith-based institutions across the United States — and the world, for that matter — refuse to even utter the word *sex*. They continue to condemn the use of condoms, another scientifically proven preventative measure. Stigma has proved to be more deadly than the HIV virus. Yet it is widely promoted and accepted.

## **Stigma and Public Health**

“Of all the forms of inequality, injustice in health is the most shocking and the most inhumane.” This powerful truth was spoken in 1965 by Martin Luther King at the end of the Selma to Montgomery March in Alabama.

Stigmatism is not confined to the ignorant masses of society. For centuries, the medical community has been and

is still guilty of applying stigma to patients of certain ethnicities, socioeconomic brackets, or gender, resulting in denial of service, refusal to provide quality treatment, or stigmatizing entire families. I am often asked to assist in various ways to encourage African Americans to participate in clinical studies or health-related programs. Most times those making the request are research or academic professionals who are somewhat unfamiliar with African American culture but have received funding to conduct comparative studies on those who have been historically missing from research studies of various types. So often, those making the requests have a multitude of misconceptions inherited from their ancestors that suggest that black people are just too ignorant to understand the value of participating in a clinical study, being in a health program, or seeking quality health care. Surely, it is clear to those who often make the requests, although unspoken, that if they (blacks) really understood how bad their disease state was and the burden of their diseases on our society, they would happily engage in their clinical studies and out-reach programs. Needless to say, these clinical studies and programs are oftentimes run by members of the majority population, with no representation of those they desire to reach on staff. As in education, the field of public health, including physicians, nurses, researchers, technicians, and educators, is filled with kind-hearted, well-intentioned health professionals who truly care about people and the field of public health, like I do.

Strikingly, Harriet Washington, in her groundbreaking best seller *Medical Apartheid*, shared a situation she

encountered that leaped off the page and connected to my realities of working in public health since I was a graduate student in the 1970s. A professor at a US medical school requested a meeting to have Dr. Washington tell her about the book she was writing. After hearing about it, the professor angrily attacked the premise of the book, stating, “It’s a terrible thing that you are doing. You are going to make African Americans afraid of medical research and physicians! You cannot write this book!”<sup>13</sup> Thank God Dr. Washington moved forward with this brilliant account of the medical apartheid endured for centuries by African Americans.

A few quotes from Dr. Washington’s book unveil the demise of consciousness when acknowledging black people as human beings. These scientists inherited this explicit hate, and it continues to be passed on from generation to generation.

“[It was] cheaper to use Niggers than cats because they were everywhere and cheap experimental animals” — from a speech delivered by neurosurgeon Harry Baily, MD, while at Tulane Medical School (1960).

“The future of the Negro lies more in the research laboratory than in the schools. When diseased, he should be registered and forced to take treatment before he offers his diseased mind and body on the altar of academic and professional education” — Public health physician Thomas Murrell (1940).

“These persons don’t have any money and they’re

black and they're poorly washed" — Radiation scientist Clarence Lushbaugh, MD, explaining why he chose "slum" patients as radiation subjects (1995).

"Celia's child, about four months old, died last Saturday the 12th. This is two negroes and three horses I have lost this year" — David Gavin (1855).

Dr. J. Marion Sims is recognized worldwide as the father of gynecology. As such, he was the world's leading authority on female reproductive health. In the 1840s he bought slaves in Alabama and sharpened his surgical skills by performing painful operations on the genitals of female slaves in his backyard surgical hospital. It is recorded that Sims operated on one young slave woman thirty-four times without anesthesia.<sup>14</sup>

The impact of this extreme hatred upon a population of people has been devastating for centuries for both the descendants of slaves and those of their masters. All have suffered and all must heal. The descendants of slave masters and others must continue to "wash clean" their inherited beliefs and erroneous thinking that black, brown, and poor people do not deserve quality health care and are, in fact, too ignorant to understand their health-care needs.

The impact of the well-known Tuskegee Syphilis Study has been and continues to be devastating for America. The study concretely established an already widespread distrust of the health and medical industries among African Americans of all backgrounds and socioeconomic statuses. For this reason, medical advancements that require the

participation of large numbers of black men, women, and children seem to progress more slowly.

In 1932, the US Public Health Service began a study involving 600 black men: 399 with syphilis and 201 without.<sup>15</sup> The purpose of the study was to record the natural progression of the disease and to “justify” a treatment program for blacks. Researchers, employed by the US government, did not inform the men about the real purpose of the study. They also did not get their informed consent. In fact, according to the records of the US Public Health Service, the researchers told these black men they were being treated for having “bad blood.”<sup>16</sup> Their compensation for participating in the Tuskegee study was free medical exams, free meals, and burial insurance. Forty of the men’s wives became infected, and fourteen children were born with the disease.<sup>17</sup> In 1947, when penicillin became available for the treatment of syphilis, the researchers did not offer this cure to the men participating in the study. In October 1972, the assistant secretary of health and scientific affairs announced the end of the Tuskegee study, forty years after it began.<sup>18</sup> The last study participant died in January 2004. The appointed Ad Hoc Advisory Panel, upon reviewing the forty-year study, found the knowledge gained from the study was very limited compared with the overwhelming, life-threatening risks the study posed to the men and their families.<sup>19</sup> Unknown is the daily impact and legacy of the Tuskegee study on African Americans. The loss of lives because of fear, shame, and distrust of the health-care system will echo for decades, perhaps for centuries.

Moreover, medical research has undoubtedly been hindered by the lack of participation of specific populations of human beings, so clearly needed in many areas of biomedical research.

It is a mystical phenomenon that under our diverse skin colors, all human beings are made up of a miraculous system of cells, tissues, and organs that function in the same way. However, our individual genetic makeup, that which makes us different, just might be the one thing that changes everything and makes the world better.

This brings us to yet another horrific medical injustice, one that, consequently, resulted in *the* most extraordinary medical breakthrough in modern history. Henrietta Lacks was a black woman, born in Roanoke, Virginia, who later moved to Tuner Station (now a part of Dundalk), Maryland. Henrietta developed a knot in her womb and went to the medical center at Johns Hopkins University in January 1951, which at the time was the only facility in her area that provided treatment for black patients. At first she was misdiagnosed with malignant epidermoid carcinoma of the cervix, which is a type of skin cancer, but in 1970 she was correctly diagnosed with adenocarcinoma, a cancerous tumor.

Henrietta's doctors admitted her to Johns Hopkins and began treatment. However, they removed two cell samples from her cervix for testing without her knowledge or the knowledge of her family. One of the tissue samples was healthy and the other turned out to be cancerous. Both samples were passed along to the hospital's cancer research lab, where Dr. George Otto Gey examined them. He found that Henrietta's cells were extremely durable, outliving the

normal cell lifespan of only a few days. In his research lab and without consent, Dr. Gey multiplied the unusual cell and produced a cell line that became known as HeLa, an abbreviation of the source, Henrietta Lacks.

The HeLa line of cells began being mass produced in 1955 and became revolutionary for medical research and treatments for people of all races and ethnicities worldwide. Over time, the strain was used for polio vaccine development, which triggered movements in disease research and product development. HeLa cells have been used in cancer and AIDS research, gene mapping, toxic substance and radiation effects and treatment, and many other scientific purposes.<sup>20</sup> Since the beginning of HeLa cell research in the 1950s, more than twenty tons have been grown for scientific and medical purposes, with more than eleven thousand patents being produced.<sup>21</sup>

Henrietta Lacks died at thirty-one on October 4, 1951, while at Johns Hopkins, but her family didn't find out about HeLa cells and Dr. Gey's research until the early 1970s, after a scientist tried to gain more genetic material from family members. Once the collection of her cells was discovered, a lengthy legal battle over the ownership of genetic materials and the ethics surrounding genetic harvesting ensued without any real recognition for the Lacks family. Finally, in August of 2013, the National Institutes of Health announced that an agreement had been reached with the family giving them limited control over the HeLa DNA code (genome) that was published by German researchers in March of the same year (again without consent). Under the agreement, the Lacks family is also to receive acknowledgment in scientific

papers concerning HeLa cells. The family was not/has not been awarded any financial contributions in spite of the trillions of dollars continuing to be made by health, medical, and pharmaceutical industries. The world has finally been introduced to this global hero, Henrietta Lacks. Oprah Winfrey secured the movie rights to Henrietta Lacks's story and will star as Deborah Lacks, Henrietta's youngest daughter. The HBO movie is based on the experience of Rebecca Skloot, a science writer, and Deborah Lacks, who worked for more than a decade to uncover Henrietta Lacks's story.

"To forgive is not just to be altruistic, it is the best form of self-interest." This statement was made by Archbishop Desmond Tutu, Noble Peace Prize winner and chairman of South Africa's Truth and Reconciliation Commission (TRC), created by Nelson Mandela's Government of National Unity in 1995. The continuous, inexcusable practices that provoke black people's mistrust in the health-care industry not only prevent them from seeking out health care but prove dangerous for all mankind.

It is important that we recognize some changes and some of the good that have occurred over the years. To ensure that a Tuskegee-type study does not happen again, institutional review boards (IRBs) were formed as independent ethics committees used by both the Food and Drug Administration and the Health and Human Services Administration to assure that steps are taken to protect the rights and welfare of those who agree to participate as research subjects. On July 30, 2008, the American Medical Association issued an apology for racism. Then-AMA president Dr. John C. Nelson stated, "On behalf of the American Medical

Association, I unequivocally apologize for our past behavior, including barring black physicians from our ranks for decades. We pledge to do everything in our power to right the wrongs that were done by our organization for decades to African American physicians and their families and their patients.”<sup>22</sup> (Policies of the AMA discriminated against black doctors and patients well into the 1980s.)

These apologies are notable. However, so much more is needed to address the “right-now/real-time” discrimination against human beings that is occurring in hospitals, medical clinics and offices, hospices, and other medical facilities. The Tuskegee Syphilis Study, Henrietta Lacks’s story, and many, many other accounts of blatant stigma, racism, and discrimination in health care must be confronted. What is needed in public health is truth-and-reconciliation discussions, to speak truthfully and openly about the medical atrocities done to black and brown people, including Native Americans, in the name of science. Instead of continuing to label the excluded nonparticipants as ignorant and misguided, we need national forums and discussions at the federal, state, and local community levels to understand the legacy of pain and the reasons why minorities do not participate in clinical studies. Included in these discussions at the local level should be corporations such as CVS, Walmart, and Walgreens, which provide convenient clinical services within neighborhoods. All have a role to play in these truth-and-reconciliation discussions.

The Food and Drug Administration (FDA) declared 2016 “the year of diversity in clinical trials.”<sup>23</sup> This authorization attempts to address the underrepresented participation of

racial/ethnic minorities and women in clinical studies. The FDA has acknowledged the truth that the majority of participants in clinical studies are men, which results in FDA-approved drugs that are not necessarily the most effective for women and minorities. As an example, men make up more than two-thirds of the participants in clinical tests of cardiovascular devices.

According to the FDA, African Americans make up approximately 5 percent of clinical-trial participants, while Latina and Latino Americans make up 1 percent. The participation of women of all races is also lacking in clinical studies. There is now a revelation among researchers that doing business (research) as usual is perhaps not good enough. Scientific data has revealed that all groups of people do not respond the same to different therapies. One drug is not a good drug for all populations of people. One example shows that two different classes of blood-pressure drugs work less well in African American patients, and at the same time, a drug for heart failure worked very well for African Americans but not as well in white patients. Thus, the pattern of clinical studies excluding minorities, including women and the elderly, is harmful and must stop.

The future success of breakthroughs in Alzheimer's and other diseases, cancer, and vaccines demands that we increase participation of minorities and women. It is critical to the survival of humankind that we all seek to tear down the barriers that support further distrust of individuals about entering clinical studies. The promise of a cure for cancer, Alzheimer's, HIV, and so many, many medical unknowns will be revealed when patients of all races,

genders, and ages are involved in research. When science succeeds, all people benefit. Sheila L. Thorne, president and CEO of Multicultural Healthcare Marketing Group and associate clinical professor at Stony Brook University School of Social Welfare, states it very plainly and simply: “Quality, Affordable, Accessible, Culturally-Respectful, Evidence-Based Healthcare is NOT a Privilege. It’s a Civil Right!”

# SERVANT LEADERSHIP ONLINE TRAINING SUMMIT

**If you enjoy this excerpt...**

consider becoming a member of the reader community on our website!

[Click here for sign-up form.](#) Members automatically get 10% off print, 30% off digital books.

Berrett-Koehler Publishers