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Study guide

Stepping up to stop stigma

ELCA World Hunger projects accompany those living with HIV and AIDS

By Robert C. Blezard

In the three-and-a-half decades that our nation has been grappling with HIV and AIDS, we have much to celebrate. Health education and prevention have reduced the incidence of infection dramatically in the United States. New medications and treatments mean that patients can live fuller, longer, more productive lives. Yet in some parts of the world there is still much fear and misunderstanding about HIV and AIDS that results in suspicion and stigmatization of patients. Our church is hard at work domestically and abroad to help care for patients and to reduce the stigma.

Exercise 1: AIDS scare

AIDS first appeared in the 1980s, and initially doctors were baffled by the symptoms that were breaking out widely in certain populations, such as hemophiliacs, gay men, Haitians and intravenous drug users. Public anxiety and confusion soared during the years it took researchers to identify the causes and isolate the virus that was to blame. Public anxiety remained high for years until effective and reliable treatments were developed. Many people in our congregations may remember those days. Discuss and share:

- How old were you when you first heard about HIV and AIDS? How did you learn? What did you think? Describe how you felt.
- How did the country react to the news when it first broke—and to the fact that scientists were stumped on its cause, much less its treatment? Is “panic” too strong a word? How about “hysteria”? How did you react? Your family? Your congregation and community?
- In what ways did the AIDS epidemic impact your life, especially when doctors were still a long way from figuring out even basic information about the disease? Can you share a specific story?
- Because the gay male community was among the hardest hit initially, do you think HIV and AIDS led to increased prejudice, fear and harassment of gay men? Can you relate any specific incidents or experiences?
- In those early days, how did our nation generally view patients who



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were suffering from HIV and AIDS? Were they regarded as sympathetically as, say, cancer patients? Explain.

- By contrast, how would you describe our country's attitudes today toward HIV and AIDS and the patients who live with them? When did our nation's attitudes change? Why?

Exercise 2: Lingerin stigma

People kept their distance from HIV and AIDS patients in the early days because doctors hadn't determined how it spread, how contagious it was or how to treat it. Medical staff were cautious in caring for patients. Now we know that—unlike, say colds or flu—the virus can't be contracted just by being in the same room as a patient or through casual conduct. And yet the stigma remains. Discuss:

- How have public education and scientific research into HIV and AIDS evolved over the 80s, 90s and 2000s? How did those two factors help shape public opinion, and in what direction?
- Even knowing that HIV and AIDS can't be contracted through casual contact, would you feel comfortable shaking hands with someone you knew was a patient? Why or why not?
- Even though there is no risk for infection, would you feel comfortable if someone with the virus served you food in a restaurant or styled your hair?
- How would you characterize the stigma that still accompanies HIV and AIDS patients today? Is it as acute as in years past? Why does it persist?
- If sexual transmission were not a major factor in the spread of the disease, would the stigma be as strong? Why or why not?
- If intravenous drug use and sharing needles were not major factors in the spread of HIV and AIDS, would the stigma be as strong? Why or why not?
- If the disease were not so strongly associated with the gay community back in the 1980s, would the stigma today be as strong?
- Now that HIV and AIDS is no longer an urgent medical problem in our country and seems to be under control, do we receive enough information about it? Have we taken it for granted?

For action: Brainstorm ways that our congregations can take the lead in dispelling the stigma against HIV and AIDS. Education and healing services might help.

Exercise 3: Jesus and the lepers

The Gospels tell of several occasions when Jesus cured people of leprosy.



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In the Jewish culture of which Jesus was a part, there was a strong stigma against lepers. Considered “unclean,” lepers were banished from the community. Healthy people would avoid them because touching a leper would render them “unclean” too. But Jesus interacted with lepers and healed them. Read Luke 5:12-13 and discuss:

- In Jesus’ day, lepers were seen as “unclean” and to be avoided. In what ways might patients with HIV and AIDS be considered today’s lepers?
- How much of the stigma against lepers stemmed from ignorance of the cause and effects, as well as the contagiousness of diseases? Could the same thing be said of our stigmatization of HIV and AIDS patients?
- How does Jesus respond to the leper? In going against his culture’s prejudice against lepers, what does Jesus reveal about the heart of God?
- Jesus not only talks to the leper, but he also touches him. What are the implications of this?
- If Jesus responds with compassion and love to an “unclean” leper, how do you think he would ask us to respond to people with serious medical conditions, such as HIV and AIDS?
- Jesus asks us to “love our neighbors as ourselves.” How would this apply to how we view and interact with people and families struggling with HIV and AIDS?

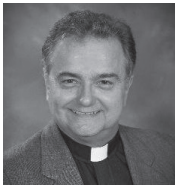
Exercise 4: Global shift

Thanks to education, prevention and treatment, HIV and AIDS is no longer an urgent medical concern in the United States, and patients no longer face the same level of prejudice, discrimination and scorn simply for suffering from a disease. But discrimination and stigma still face many people in some parts of Indonesia, Africa and other areas in the world that are battling the disease.

- Attitudes toward HIV and AIDS changed in our country due to education, prevention, proactive advocacy and caring for patients with both effective treatment and love. Would those methods help to relieve the stigma in other countries too?
- Why is it important that the ELCA and other North American churches continue to support HIV and AIDS education and treatment in parts of the world where it is an urgent problem?
- When Jesus taught “love your neighbor as yourself,” do you think he meant only our neighbors who live in our country, speak our language and share our faith?



About the study guide author:



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For action

- Get hold of the ELCA's 47-page "Strategy on HIV and AIDS" (available at elca.org). Study its observations and conclusions. Research how the world AIDS crisis might have shifted since 2009, when the strategy was written. Explore what you and your congregation can do to help.
- Educate yourselves and others about HIV and AIDS in our country and abroad. As a study group, write a newsletter article, conduct a temple talk or hold a study session on the disease and how it affects the lives of millions of people worldwide. What are other ways you could help?
- Invite a speaker to talk at your congregation who has some familiarity with HIV and AIDS. Perhaps it is a person living with the virus, or someone who has lost a loved one to the disease, or maybe a community health worker or an advocate for HIV and AIDS programs domestically or internationally.

Stepping up to stop stigma

ELCA World Hunger projects accompany those living with HIV and AIDS

By Stephanie N. Grimoldby

Dec. 1 is World AIDS Day, a time to raise awareness of HIV (human immunodeficiency virus), which often culminates in AIDS, (acquired immune deficiency syndrome). On this day, the ELCA encourages congregations to have open and affirming conversations about the health epidemic.

“It’s a general time that people have recognized for years now as a day of remembrance [for those we’ve lost], a day of commitment to action,” said Megan Neubauer, program associate for the ELCA strategy on HIV and AIDS and coordinator of domestic hunger initiative pilot projects.

There are 36.7 million people living with HIV and AIDS, according to UNAIDS (2016). In the U.S. that number is little over a million, the Centers for Disease Control and Prevention states. “[The epidemic has] fallen out of the conversation, out of the focus, but it’s something that’s still around, it’s still affecting people and it’s something we know we can prevent and treat,” she added.

This church’s strategy is administered by ELCA World Hunger (elca.org/hunger) because a connection exists between poverty and HIV/AIDS, the ELCA Strategy on HIV and AIDS says. Grants and other funding methods support prevention care and treatment, as well as programs to help eradicate the stigma associated with HIV and AIDS.

Sister Nurhayati Silalahi of the Huria Kristen Batak Protestan (HKBP) sits with Siti (last name withheld), one of the HIV-positive children at the House of Love in Nainggolan, Samosir, North Sumatra in Indonesia.



Addressing housing in San Francisco

Although the U.S. has a relatively low prevalence compared to some countries—in Swaziland, Botswana and Lesotho, the CIA World Factbook reports that more than 20 percent of the population has the disease, while the U.S. is at less than 1 percent—it's still an epidemic to be concerned with, said Nancy Nielsen, deputy director of Lutheran Social Services of Northern California (LSSNC).

“San Francisco was kind of ground zero when the epidemic began,” Nielsen said. “The health department embraced this epidemic and put services in place, and it has evolved over 30 years now.”

Many of the agency's clients receive disability benefits, funds from Veterans Affairs and/or income from a job. Many also have a high incidence of mental health or substance abuse issues that complicate their ability to manage their money and thereby maintain housing, said John Paul Soto, LSSNC program manager.

That's why the agency provides three programs to aid those affected by HIV and AIDS: money management, forensic housing and stabilization housing, which combined serve nearly 700 San Franciscans every year.

The money management program helps clients prioritize their bills by first making sure they pay their rent on time, then paying other bills and managing the rest of their income, he said.

“We have always supported the idea that housing is health care,” Soto said. “Having a roof over your head is such a big change and sense of satisfaction for folks that it allows them to focus on other aspects of their life, whether it's medical, mental or some other issue that they have going on.”

The forensic housing program has a similar focus. It provides housing and support services for HIV-positive homeless people who have recently been released from prison or have a history of incarceration, Soto said.

The stabilization housing program, meanwhile, is an emergency intervention effort that temporarily places HIV-positive clients in an apartment to get them off the streets and in reach of needed services, Nielsen said.

The ELCA has reached out with a World Hunger grant to help the LSSNC fund on-site nutrition counseling for those in the two housing programs, Soto said. Interns from the University of San Francisco host weekly nutrition classes to teach clients how to eat healthy, even if they have a small budget and only a microwave for cooking.

“When you have better health outcomes, the observable stigma [surrounding HIV and AIDS] is a lot less when someone is a lot more stable because it does make them feel better about themselves if they're not as vulnerable,” Soto said.

Combating stigma in Indonesia

A three-year World Hunger grant is benefiting the AIDS Ministry of Huria Kristen Batak Protestan (HKBP) in Indonesia.

Five full-time staff members support the ministry, which was established in 2003 and continually works to inform its 4.5 million church members about the concerns of HIV and AIDS while also reducing the stigma that plagues those living with the disease.

“We are ready to serve people,” said Nurhayati Silalahi, an HKBP deaconess. “We are ready to be neighbors.”

GET INVOLVED

Worship resources are available for congregations that wish to observe World AIDS Day on Dec. 1 or the weekend following, including:

- **Prayers** that recognize the different social factors that play a role in who is disproportionately affected by HIV and AIDS.
- **Hymns** that might be helpful for congregants to sing as they remember those who are living with or who have died from HIV-related complications.
- **Sermon ideas** for leaders on how to broach the topic of HIV and AIDS in their faith communities.

The ELCA also partners with the Ecumenical Advocacy Alliance, an initiative of the World Council of Churches, which has an ongoing “Lead by Example: Religious Leaders and HIV Testing” social media campaign.

Learn more at elca.org/hiv.



Eli (last name withheld) says he has experienced discrimination because he has HIV. Through the HKBP's AIDS ministry, he feels “received as a friend and accepted.”

Several projects are ongoing:


- For years the AIDS Ministry has worked to create a relationship with the H. Adam Malik Hospital in North Sumatra to provide antiretroviral medicine to patients. In 2009 the government allowed this hospital to give medical treatment directly to HIV and AIDS patients.
- A peer educator program at schools recruits and trains students to become vocal leaders and share information about HIV and AIDS with their classmates. Schools have shown a positive response to the program, and new students are trained every year, Silalahi said.
- The AIDS Ministry hosts a radio talk show to communicate, inform and educate listeners about the disease.

Despite this work, discrimination continues to fall upon those with HIV and AIDS, Silalahi said. One theology seminar within HKBP requires registrants to be tested and cleared of the virus before they can attend. And one local company stipulates that no employee can be HIV-positive.

The stigma doesn't exclude children either, Silalahi said. In 2015 the ministry opened "House of Love" for HIV-positive children whose parents had

already died from the disease and whose relatives had turned a blind eye because of their diagnosis, she added.

The reality of these stigmas has created a greater push for advocacy and training programs, Silalahi said, although there has been some relief. Local and central governments recently created a budget for AIDS prevention, and the ministry is becoming known for its positive work.

"I think one of the things we really hope [is that] as a church we realize we're in a position to speak against stigma," Neubauer said. "We hope that HIV and AIDS is something that comes up in conversation in a way that is more positive [and] affirming." 

A longer version of this story is available at livinglutheran.org. Download a study guide by clicking on the "Spiritual practices & resources" tab on this website.



Stephanie Grimoldby is a freelance writer living in Salem, Wis.

On Nov. 11, 1984, 18-year-old Andrew, engulfed in a dark tunnel of confusion, ended his life. For Herb Chilstrom, his wife Corinne, Andrew's siblings and friends, the world collapsed.

In ***When a Father Loses a Son***, Chilstrom opens his heart, gathers together the essence of his journey and offers it to others. Though his aim is to help fathers—especially with the loss of a child—parents, siblings or friends will find this book helpful.

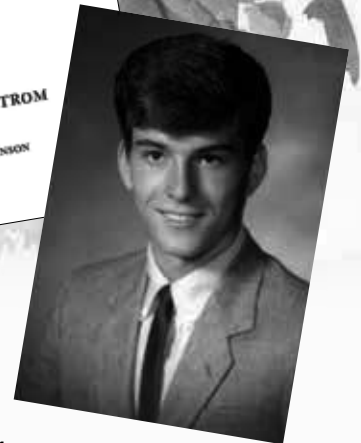
The book of Job is one of the profoundest meditations on "the hidden God" and a work that has inspired much great literature. When a Father Loses a Son is a wonderful addition to that body of literature. Several times in reading this book, tears were my only response. This book is a wonderful contribution to the life of the church and, especially, to the deepening insight of anyone who reads the book, whether believer or just plain thinker.

—William K. Friert, professor of classics, emeritus,
Gustavus Adolphus College

WHEN A FATHER LOSES A SON

HERBERT W. CHILSTROM

FOREWORD BY DENNIS J. JOHNSON



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