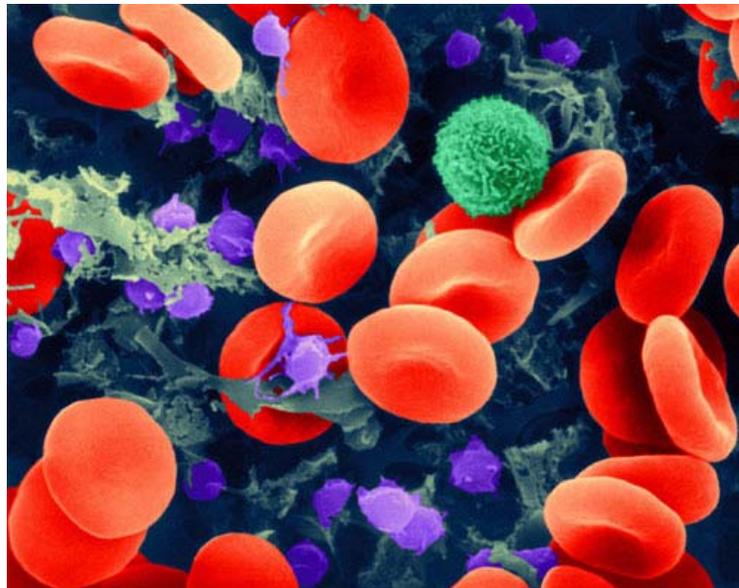


UNIT 4

Stigma and Infectious Diseases

Instructor's Background Text



PKIDs' Infectious Disease Workshop

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Table of Contents

Introduction	4
Stigma and Disease	5
What Is Stigma?.....	5
Disease-Related Stigma	6
Stigma is Personal.....	6
Stigma Doesn't Work	7
Overcoming Stigma	8
Letters from Families	10
When a Child has Hepatitis B	10
What Is It Like to Have AIDS?.....	11
The Loneliness of a Teen with Hepatitis C.....	12
Life as a 12-Year-Old with Hepatitis C	13
Living with Stigma	14
Bibliography	17

For educational activities and resources, please visit www.pkids.org/idw.

This publication contains the opinions and ideas of its authors. It is intended to provide helpful and informative material on the subject matter covered. Any information obtained from this workshop is not to be construed as medical or legal advice. If the reader requires personal assistance or advice, a competent professional should be consulted.

The authors specifically disclaim any responsibility for any liability, loss, or risk, personal or otherwise, which is incurred as a consequence, directly or indirectly, of the use and application of any of the contents of this workshop.

Introduction

PKIDs (Parents of Kids with Infectious Diseases) is a national nonprofit agency whose mission is to educate the public about infectious diseases, the methods of prevention and transmission, and the latest advances in medicine; to eliminate the social stigma borne by the infected; and to assist the families of the children living with hepatitis, HIV/AIDS, or other chronic, viral infectious diseases with emotional, financial and informational support.

Remaining true to our mission, we have designed the *Infectious Disease Workshop (IDW)*, an educational tool for people of all ages and with all levels of understanding about infectious diseases. In this workshop, you will learn about bacteria and viruses, how to prevent infections, and how to eliminate the social stigma that too often accompanies diseases such as HIV or hepatitis C.

We hope that both instructors and participants come away from this workshop feeling comfortable with their new level of education on infectious diseases.

The IDW is designed to “train-the-trainer,” providing instructors not only with background materials but also with age-appropriate activities for the participants. Instructors do not need to be professional educators to use these materials. They were designed with both educators and laypersons in mind.

The IDW is comprised of a master Instructor’s Background Text, which is divided into six units: Introduction to Infectious Diseases, Disease Prevention, Sports and Infectious Disease, Stigma and Infectious Disease, Civil Rights and Infectious Disease, and Bioterrorism and Infectious Disease.

For each unit, instructors will find fun and helpful activities for participants in five age groups: 2 to 6 years of age, 6 to 9 years of age, 9 to 12 years of age, 13 to 18 years of age and adults.

We welcome any questions, comments, or feedback you may have about the IDW or any other issue relating to infectious diseases in children.

PKIDs
P.O. Box 5666
Vancouver, WA 98668
voice: (360) 695-0293 or toll-free 877-557-5437
fax: (360) 695-6941
email: pkids@pkids.org
website: www.pkids.org

PKIDS' INFECTIOUS DISEASE WORKSHOP

Stigma and Infectious Diseases

It is an unfortunate fact of life that, too often, stigma and infectious disease go hand-in-hand. As we all become more sophisticated in our understanding of how disease does—and does not—spread, this fact will likely change. It is hoped that this unit may provide additional perspective to stigma, and those who live with it.

The Joint United Nations Program on HIV/AIDS, UNAIDS, asserts that, “freedom from discrimination is a fundamental human right founded on principles of natural justice that are universal and perpetual. The basic characteristics of human rights are that they inhere in individuals because they are human, and that they apply to people everywhere.” As a society, we readily accept the paramount importance of human rights. However, our daily actions often do not reflect our dedication to upholding the laws of natural justice.

What is Stigma?

According to some members of the University of California at Davis psychology department, stigma refers to a pattern of prejudice, discounting, discrediting, and discrimination directed at infected people, their close associates, and their communities.

Disease-related stigma is expressed around the world in a variety of ways. It can be as dramatic as physical violence or as subtle as avoidance.

For example, a parent whose son is chronically infected with the hepatitis B virus testified at a public hearing in the U.S. House of Representatives. While testifying to the emotional trauma that comes with an infectious disease, she noted that one evening, while attending a school meeting, she learned that other parents had heard there was a hepatitis B positive child in the district and requested the superintendent reveal the identity of the child with hepatitis B. They wanted to publicly identify the child so they could all feel safe.

AIDS Action reports that, in the late 1990s, Girl Scout troops in New York refused an 8-year-old girl admission because she was HIV positive. And, Kai Wright, fellow in the Pew International Journalism Program, revealed that on World AIDS Day in 1998, a South African girl, Gugu Dlamini, “came out” as part of a campaign to reduce stigma. Two weeks later her boyfriend found her body beaten and left to die.



While these responses vary in degrees of intolerance, they are all examples of stigma.

Disease-Related Stigma

Stigma is often associated with specific diseases. Jeanine Cogan and Gregory Herek assert in the *Encyclopedia of AIDS* that diseases that predominantly afflict marginalized groups of people, diseases whose causes are perceived to be the bearers' responsibility, and diseases that are unalterable or degenerative suffer the greatest stigma.

Historically, in the United States, the class, race, or ethnic background of infected people and the manner in which the disease is contracted have impacted society and the medical community's response. Breast cancer in women, sickle cell anemia predominately in African-Americans, and hepatitis B predominately in Asian-Americans, are examples of diseases that were ignored for many years by the medical research and treatment community in the United States, because those stricken were marginalized.

Likewise, those who have illnesses associated with sexual activity, such as syphilis and gonorrhea, have not received the same medical research dollars or quality of care as those with mainstream illnesses such as heart disease. They have also been discriminated against in their communities.

This phenomenon is nothing new. For centuries, fear of disease made communities banish those who were ill. In medieval Europe, leprosy was thought to be extremely contagious (it is not). Infected people were considered to be on the margins of society.

When in public, persons infected with leprosy announced themselves by sounding clappers and rattles to warn people away and pointed to their choices with staffs in the marketplace. A person suspected of having leprosy was forbidden to touch anything and anyone, except for his/her spouse. Thousands were sent to colonies called "leprosaria," which were operated by religious and municipal authorities. Centuries later, the stigma those infected endured is not dissimilar to what people with AIDS faced in the United States and around the world at the beginning of the pandemic.

Stigma is Personal

Every child remembers the sting of taunts that other children throw. Children with glasses are not infrequently called "four-eyes" and teenagers with braces often hear "metal mouth" instead of their names. While name-calling may be an unfortunate part of the childhood experience, many children endure worse. When teasing extends beyond the playground into perceptions widely accepted, it becomes stigma.



According to UNAIDS, the "undesirable differences" that stigma causes "do not naturally exist, they are created by individuals and by communities. Stigmatization describes this process of devaluation."

Those who have encountered stigma know that, while it is a societal problem, its effects are intensely personal. Stigma becomes an intimate enemy when it is yourself, your friend, your family member, or your child who is stigmatized by society.

Ryan White brought the cruelty of stigma to the forefront of the nation’s consciousness in the mid-1980s. He contracted HIV from tainted blood products and later developed AIDS. He faced extraordinary discrimination in his hometown of Kokomo, Indiana. Classmates’ families and school officials tried to prevent him from attending school and, after lengthy legal battles, Ryan and his mother settled with the school, but school officials insisted on having a separate restroom for him and disposable silverware in the cafeteria.

Upon his return, students vandalized his locker with the word “fag.” The community-at-large reacted with equal callousness; a restaurant threw his dishes away after he left, he was banned from public swimming pools, people at church would not shake hands with him, garbage was thrown onto his lawn, and someone fired a bullet into his home. Ryan died on April 8, 1990 at age 18.

Heroic as his efforts were, Ryan was not able to “cure” stigma. Children are still cruelly isolated and physically and emotionally attacked because of their diseases.



During the fall of 2002, one mother relayed to PKIDs that her hepatitis B positive daughter’s school told her that she would have to home school her daughter because of the health risk her child posed for other children. This was after the state health department had (probably illegally), upon hearing of her child’s disease, forced the mother to quarantine her daughter for three months.

All too often it is found that, those who are supposed to know the facts about disease are the worst perpetrators of action based on ignorance.

Stigma Doesn’t Work

As a responsible and compassionate people, we recognize that infectious diseases are not simple—they come with a complexity of issues.

Those not educated in methods of disease transmission and prevention truly fear the unknown, and those living with infectious diseases are deeply wounded by the harm brought on by such ignorance and fear.

We stigmatize people and push them away from us in order to make ourselves feel safer. However, stigmatizing infected individuals does not protect us from infectious diseases. HIV, hepatitis B, and hepatitis C cannot be transmitted casually. We cannot become infected with

HIV or hepatitis B or C by hugging, sharing a meal with, or sitting beside an infected person. HIV and hepatitis B and C are bloodborne viruses. They are transmitted through contact with blood and other body fluids.

We stigmatize people in order to distance ourselves both mentally and physically from the disease. Recently, the CDC reported that 19 percent of Americans believe that people who have been infected with HIV through sex or illegal drug use have gotten what they deserve. The arguments that can be made for and against making moral judgments are legion and not what we are trying to address in this discussion.



However, it is a fact that we are all at risk. Although sexual contact and intravenous drug use are significant modes of transmission for certain infectious diseases, many people do not know where, when, or how they became infected.

All types of people are infected, and many become infected although they have no known risk factors. Babies, children, young people and adults—
infectious diseases don't respect age or social position or monogamy or cleanliness. A large percentage of people living with hepatitis B or C have no idea how they became infected.

Overcoming Stigma

Education is key to preventing the spread of disease *and* the spread of discrimination and stigma against people with infectious diseases. The threat of stigma deters many who may be infected with these diseases from getting tested and treated. It also contributes to denial and, consequently, the spread of infection when proper precautions are not taken. To truly reduce infection, society as a whole must confront both the diseases and the stigma surrounding them.

At an international level, UNAIDS suggests a strategy for overcoming HIV-related stigma. This strategy, if expanded to include hepatitis B and C and other infectious diseases, will directly challenge disease-related stigma that impairs the lives of many Americans.

UNAIDS suggests five points for immediate action:

- Leaders at all levels, from politicians to religious leaders to local heroes, need to visibly challenge HIV-discrimination, spearhead public campaigns, and speak out against the multiple discriminations that poor people, women, ethnic minorities and gay men face in relation to HIV/AIDS.
- Document HIV-related violations of human rights and conduct public inquiries into them.
- Support groups of people living with HIV and ensure that they have access to mechanisms to redress discrimination and that they are fully involved in the response to the epidemic.
- Ensure that a supportive legislative environment exists so that discrimination can be tackled, in relation both to the impact and spread of the epidemic.
- Ensure that both prevention and care services are accessible to all parts of the population, making particular efforts to overcome the barriers of racial, gender and other discrimination.

At the community level, social workers in Scotland studied children suffering from AIDS-related stigma. Researchers found that children often lacked opportunities to talk about their illness. From this study, researchers made several recommendations. They include:

- Children and young people should be consulted both individually and collectively in the planning and provision of services for affected children.
- Children's workers (social workers, teachers and youth workers) should be given training in HIV, while adult agencies (including health boards and social work departments providing services for infected people) should look more closely at their own responses to children affected by parental HIV.
- Schools should designate a teacher to play a lead role in HIV
- education and children and young people affected by HIV should have a designated person (teacher or other person) to whom they can turn.

From these formal reports, we learn what compassion and common sense has already told us: creating a community intolerant to stigma and an environment that provides support to infected individuals is our moral responsibility. By arming ourselves and our children with accurate information about not only HIV/AIDS, but also hepatitis B and C and other infectious diseases, and providing them with a safe haven in which they can openly discuss their concerns, we directly combat stigma.



Letters From Families

A Parent's Perspective When a Child Has Hepatitis B

By an Anonymous Parent

Life was so much easier when Kris, my second-grade son who has chronic hepatitis B, was younger. For one thing, he now spends almost six hours a day at school. That means I'm not Johnny-on-the-spot to make sure that standard precautions are used when he falls and hurts himself. Now, I have to rely on the good sense of others, and that worries me sick.

One day on the playground he knocked a wart off his knee, and it bled all over the place. I don't know how the school handled the blood—I didn't want to grill Kris about it because I didn't want him to think that it was any big deal—but I still get nightmares thinking about it.

When he was younger I had so much more control over his life, over what he knew and what he didn't know. When I took him to the doctor, he wasn't happy about it, but he probably thought everybody else went through the same thing. It wasn't until he got to school and started comparing notes with his new friends that he realized he was treated differently.

His friends almost never left school for doctor appointments. We were evangelistic about standard precautions. His friends, and his teachers for that matter, didn't seem to think that blood should be treated any differently than spilled paint. I had to ask Kris to be responsible for his own boo-boos, and that seems so unfair for someone his age.

I also had to teach him to be very careful about what he says to other people at school. It is so hard on him! He worships his teachers and wants to share things about his life. Still, I don't want him talking about lots of doctor visits or his treatment. I'm afraid his teachers will figure out that something is wrong and either start treating him differently—or pump him for information. I could just see a teacher innocently asking Kris about missing school and him telling her in gory detail everything that the doctor did.

He's such a trusting, open child. I don't want to make him feel different from everybody else, but I also don't want him asking for trouble. It's such a fine line.

I could just see Kris talking to his friends on the playground and them, in turn, passing his comments on to their parents. How do I convince him that it's not a good idea to share certain things with his friends and teachers even if there's no reason to be ashamed of them? I'm not ready yet to tell him about the hepatitis but I still have to deal with all of these related issues. It's just tearing me apart.

What Is It Like To Have AIDS?

By Alex

Hi, my name is Alex. Life isn't very easy. Why? Because I have AIDS (acquired immune deficiency syndrome). HIV (Human immunodeficiency virus) causes AIDS. You think it's easy, try again.

How did I get it?

When I was being born, my mom was bleeding very badly. She needed some blood fast! I was already out, I assume, because I didn't have it at the time after it happened. When I was born the doctor said to breast-feed and that's how I got HIV. They found out I had it when I was two years old. For several years, once a month they would hook me up to an IV for four hours to give me medicine.

First day of school

The first day of school was OK, but forget about that. Let's talk second grade. That's when I found out I had AIDS. When I found out I had AIDS I told everyone at the bus stop and they were all frightened. A lot of people still don't know much about AIDS. It took me awhile to find some friends to understand that AIDS is only transported through blood. Soon the story spread. I got some friends as time passed, but mostly bullies bothered me or lots of people wouldn't play with me at recess. As I got older I was able to explain about me (If they didn't run away), and I got more friends.

By: Alex, age 12



A Parent's Perspective The Loneliness of a Teen with Hepatitis C

By Dorothy S.

It is hard to tell people your son is infected with the hepatitis C virus. They look at you like you're a leper. The only people I share that information with are the doctors.

My son is 17 years old. If he tells girls, they all of a sudden do not want to go out with him. The only people at his school who know are the counselors at his college. We are simply too scared to tell anyone else.

It is hard enough just dealing with hepatitis C, let alone having no friends who want to be around you. Teens need friends and people to talk to. We have no support group in our area for him to go to. All the groups are adults, there's no one in his age group.

The few people who know just say "do not worry, it will go away." The doctor my son sees does not want to do any treatments. My insurance will not let me change doctors. So every day I wonder how much longer do I have him before the disease takes over.

It seems people do not care or do not want to be bothered. This is the loneliest I have ever felt in my life. I try very hard to look up positive things to tell my son about hepatitis C, but I cannot answer his questions as to why the doctor refuses treatment.

My wish is for people to understand and be willing to listen to our fears, and maybe offer a shoulder to cry on.



A Child's Perspective
Life as a 12 year-old with Hepatitis C

By Billy M.

I am 12 years old and I have hepatitis C and cirrhosis. I think hepatitis and all of the shots stink. Having something that other kids around me don't have makes me feel special in a bad way and a good way at the same time.

I don't like telling people that I have it. I used to think I should keep it a secret but now I don't. Last year when I was on shots and missed a lot of school, some kids teased me and called me names. One time I couldn't play a sport because the coach thought I might hurt the other kids. That hurt me really bad.



Living With Stigma

By an Anonymous Parent

While I was waiting to become a mother, I dreamed almost every night of what my daughter would be like—and how her life would unfold.

Annie would be compassionate, intelligent, loving, funny, beautiful and headstrong. All of the kids at school would want to be her friend, and she would always be the president of her clubs and every student government. After a stellar career of her choice, she would take on a national role, providing leadership of the wisest kind.

Wherever my dreams led me during those nights, one thing remained constant—Annie would be loved. She would be loved by her family and friends and even those who only knew of her. She would belong.

For a few golden days after Annie was put into my arms, I felt that I had won the lottery—the baby lottery, the life lottery. Everything was perfect.



Then her pediatrician called and said she had news. Annie had hepatitis B. I didn't even know what that was.

Less than a week after I'd been told of her disease, while I was still trying to do practical things like find out what it meant for her physically to have a hepatitis B infection, the stigma and discrimination started.

At first, I told relatives and friends about Annie's disease, even though the doctors told me not to. They warned me of the stigma she would face. I thought they were exaggerating and out of touch. I needed my friends and family to help ease my pain and thought those I cared about would do so, somehow.

What astonished me about my friends and family was not that they knew nothing about hepatitis B, but that they absolutely refused to believe anything I told them. More often than not, people acted as if there was an infectious cloud around Annie and anyone too close would become infected.

Because I had very little time off, Annie had to go to daycare when she was just a few months old. I told the provider, who was also a friend of mine, about Annie's disease, and she said she didn't have a problem with it.

When I picked Annie up at the end of the first day, I mentioned to the provider that I needed her to keep Annie's medical information confidential. She said she had told the other children in her daycare, the parents of those children, some of her neighbors and several of her relatives.

And furthermore, she would continue to tell everyone who might come into contact with Annie, or who might come into contact with someone who had been around Annie.

I was flabbergasted. Nothing I said changed her mind, so of course Annie did not return to that daycare for a second day. As it turned out, for the next couple of years I could not find anyone willing to watch Annie without stigmatizing her. So, Annie went to work with me until she was almost three.

Because I could not find anyone willing to care for Annie, business trips became exceedingly complicated. When I had to travel for business, I flew Annie to my mother's home in another state, left her there, and then flew to wherever in the country my meeting was being held.

My brother and his wife reacted like Annie's daycare provider. They insisted that if I brought Annie to their home, they would tell anyone else visiting at the same time about her disease. I gave them the phone numbers of pediatric specialists, hoping that, if they wouldn't listen to me, they would listen to the experts. They wouldn't even make the call.

Ultimately, I had no choice but to break off contact with them. Obviously, I couldn't let them treat my daughter this way, and since they refused to change, I didn't know what else to do.



It was so hard for me to stop seeing them. Before I became a mother, my niece and nephews would frequently stay with me on weekends. I did and do love them and imagined we would have wonderful family gatherings when I became a mother. So far, we have had none.

In the early days, when I was still telling friends of Annie's disease, we quickly lost all but one playmate. Many mothers get their young babies or toddlers together for playdates, but no one would play with Annie. The one willing mother lived 20 miles away, so those visits were infrequent.

Within six months, my relationship with my brother was completely broken, my daughter had no playmates, and the friends I'd had when I became a mother were no longer part of my life. People either wanted nothing to do with us or were willing to be around us and have us in their homes only as long as they could tell everyone else who came to their homes that Annie had hepatitis B.

We had gone from being deliriously happy to having not one but two bombs explode in our faces—one was a scary and life-threatening disease and the other was an immense amount of fear and ignorance that poured upon us and that, to this day, no words and no facts have been able to stem.

When something life-altering happens to your child, you mourn the loss, as you do when

someone you love dies. You mourn the loss of a normal childhood. Your emotions are off the scale—you feel despair, rage, fear, sorrow, frustration—and it takes a long time before the altered life that is thrust upon your child—and you—comes full circle and is no longer considered “altered,” but just life.

While this is true for the physical aspects of the disease, it is not true for the social death that accompanies some diseases. I have accepted the fact that Annie faces an uncertain future. However, when I see the stigma and discrimination that dog my daughter’s days, I am filled with unimaginable rage.

After discovering the overwhelming presence of these diseases in our society, I realized it was not practical to try and protect the world from Annie. While my family and friends were extremely careful around this one little girl, they were not as careful around everyone else. They didn’t, and don’t, realize that so many of the people living with infectious diseases are undiagnosed.

I don’t want anyone else to face the physical challenges or social death that we live with. So instead of telling people about my daughter’s disease, I tell them about standard precautions and why we all have to use them. Some people think I’m a germ freak, but I don’t care. Maybe they’ll remember what I’ve said the next time they’re reaching to clean up a scraped knee or borrow a friend’s razor.

Maybe, if they do listen, they won’t have to lie to their crying daughter who wants to know why her best friend won’t play with her anymore or why she never gets to see her cousins.

Last night, Annie asked me if hearts really can break. I said I thought they could, a little bit.



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