

Lessons from the other side

Paul Sacamano MPH, ANP-BC, older PLWH

Objectives

1. Understand one person's lived experience of being older with HIV
2. Move beyond the disease model of health – see your patient as a person
3. Recognize that empathy and open communication are as important as clinical skills

"First of all," he said, "if you can learn a simple trick, Scout, you'll get along a lot better with all kinds of folks. You never really understand a person until you consider things from his point of view-"

"Sir?"

"-until you climb into his skin and walk around in it."

-by Harper Lee, To Kill a Mockingbird, p. 30

LIVED EXPERIENCE

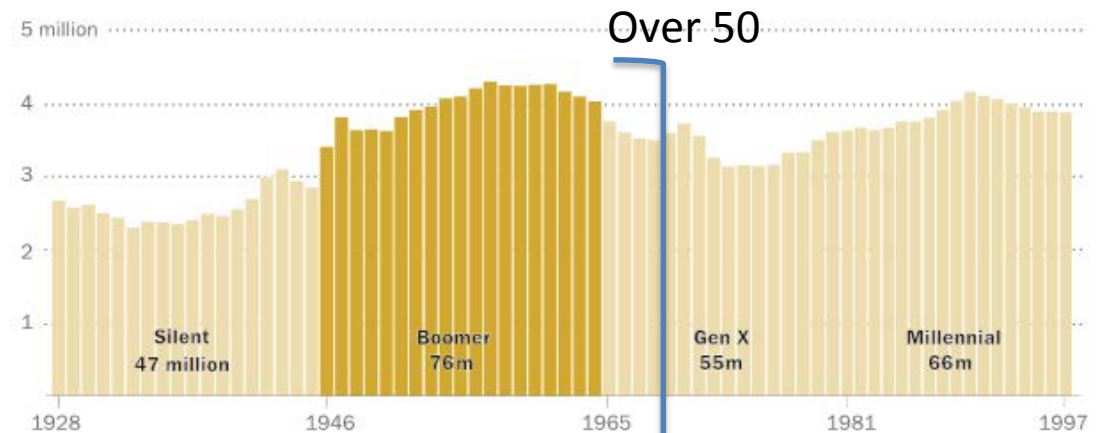
Older and living with HIV

Life-course Perspective

- Age cohort differences influence health needs and vulnerabilities
- Framework for understanding HIV-related life events and transitions as people age

Births Underlying Each Generation

Number of U.S. births by year and generation



Source: U.S. Dept. of Health and Human Services National Center for Health Statistics

PEW RESEARCH CENTER

Varied lived-experience

- Context
 - Family, friends
 - Politics, media
 - Culture, society
 - Intersectionality (racism, gender and sexual orientation biases, ageism, poverty, etc.)
- Life-stage at diagnosis
 - youth
 - middle-age
 - older adult

Getting diagnosed: 80s-90s

- Very little reason for hope
- Greater levels of stigma, prejudice and fear than today

THE NEW YORK TIMES,
FRIDAY, JULY 3, 1981

A20 L

RARE CANCER SEEN IN 41 HOMOSEXUALS

Outbreak Occurs Among Men
in New York and California
— 8 Died Inside 2 Years



The early face of AIDS



A father comforts his son, David Kirby, on his deathbed in Ohio. Widely considered the photo that changed the face of AIDS.

1985: 13-year-old AIDS patient Ryan White began “attending” classes at Western Middle School in Kokomo, Indiana, via a telephone hook-up at his home after school officials had barred Ryan from participating in person.

School bars door to youth with AIDS

By Christopher M. MacNeil
Tribune staff writer

RUSSIAVILLE, Ind. — The mother of a local 13-year-old AIDS patient who has been barred from attending classes at Western Middle School today accused the school administration of “running around a problem they thought they wouldn’t have to deal with.”

Jeanne E. White, whose son, Ryan, was diagnosed with the usually fatal virus in December, said she thinks Western administrators “hoped Ryan would be sicker than he is now so that they wouldn’t have to deal with him at school.”

Tuesday, Western Superintendent James O. Smith announced that Ryan, an incoming seventh-grader, would not be allowed in school because he has acquired immune deficiency syndrome, the lethal virus that renders the body’s disease-fighting ability powerless.

However, an interim set of guidelines released Tuesday by the state Board of Health recommended that school-age AIDS patients who feel well enough should be in school.

“But any person with AIDS is going to be sick an awful lot and there will be plenty of times when it might become a rather difficult administrative problem,” said Dr. James Barrett, director of the state board’s communicable disease division.

Meanwhile, the public nurse for the Howard County Board of Health this morning did not confirm nor deny a reported claim by Smith that his decision to ban Ryan from the classroom is backed by the health department.

“We did not receive the (state’s) guidelines until yesterday (Tuesday). They’re under advisement by us, and as such we can’t make any further comment,” said Nancy Mickelson.

She did say, however, that courses of action taken by corporations in dealing with AIDS children are “school decisions.”

It was Ryan’s case that prompted the state to prescribe the guidelines, according to a state health official.

Of the 45 confirmed AIDS patients statewide — three in Howard County — Ryan is believed to be the only one of school age.

Two other Howard County residents are among the 29 AIDS deaths in Indiana.

Ryan said this morning he feels “real fine” physically and stressed he is still passing his Kokomo Tribune paper route. He stressed even more he is “upset” with Smith’s decision not to allow him in school.

“I want to go back,” Ryan said.

Smith did not return any calls to the Tribune today. But he said in a published report that he based his decision on the “unknowns and uncertainties (about AIDS)” and “the inherent fear that would generate among classmates.”

“We are obligated to provide an education for the child,” Smith added, explaining Ryan “will have to receive instruction at home.”

“But we are also in the habit of keeping kids out who have communicable diseases,” he said.

AIDS researchers say the disease is spread by sexual contact — mainly among homosexual and bisexual men — and by intravenous drugs users and through blood transfusions.

Ryan suffers from hemophilia, a condition that prevents blood from clotting normally, and is suspected of acquiring AIDS through a tainted blood product.

The virus has been fatal in almost half of the near 12,000 confirmed cases nationwide.

White did not discount Smith’s suggestion that Ryan receive at-home education but said, “I think he needs to be with children his own age. I think they’re (school administrators) robbing him” by not allowing Ryan in school.

White added she tries “to be sympathetic” with the school corporation. But the administration’s decision is another in several personal, financial and legal problems that White said she has encountered since Ryan was diagnosed.

Asked if she might explore possible legal action against the school system, White said, “Legal action? I



Jeanne White and son, Ryan, unhappy with Western
(Tribune file photo)

don’t know. We’ve been through so much already ... that I think I’ll let it set awhile.”

Disclosure

- Most older Americans rely on family members during times of illness
- Fear of anticipated HIV stigma and anti-gay bias leads to “Protective Silence”
- Many older PLWH are disconnected from traditional informal support networks

Schrimshaw EW, Siegel K. Perceived barriers to social support from family and friends among older adults with HIV/AIDS. *J Health Psychol.* 2003 Nov;8(6):738-52. PubMed PMID: 14670207.

Singh, D. A. (2010). *Effective management of long-term care facilities*. Sudbury, Mass: Jones and Bartlett Publishers.

Growing Older with the epidemic: HIV and aging. GMHC. http://www.gmhc.org/files/editor/file/a_pa_aging10_emb2.pdf

Just like any chronic disease?

There's nothing for you to worry about, we have great medications now and HIV is just like any other chronic condition, yay!

I can't talk to anyoneI'll be rejected and judged...I feel guilty...this is my burden alone...he doesn't want to hear this, I need to smile and be quiet....



- Retention in care
- Treatment adherence

KEY POINT



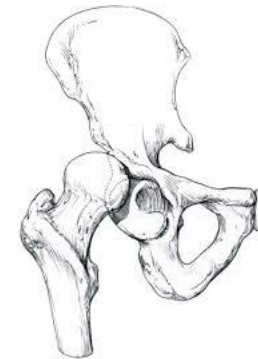
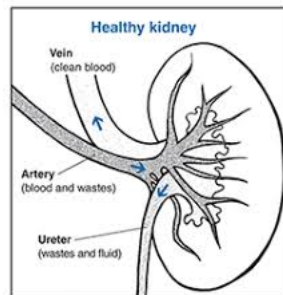
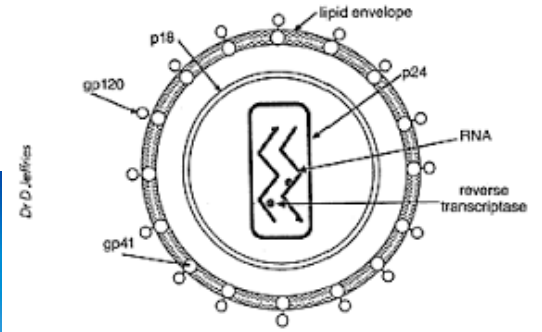
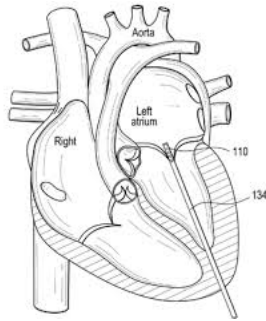
While HIV can be managed medically like any other chronic disease, people living with HIV can still face stigma, isolation and discrimination and experience feelings of guilt, shame, depression and anxiety...

don't deny their lived experience.

BEING SEEN AS A PERSON

Don't over-medicalize your patients

Person-centered vs disease-focused care



“If being ill has taught me anything about being a doctor it is the importance of seeing a patient as a person and not merely a condition or disease...”

Granger K. Painting the picture. Dr Kate Granger blog. 4 Aug 2013

“Although my schedule was busy, taking an extra moment to offer her caring and comfort wouldn't have affected my other patients much--and it would have made a world of difference to her.”

A patient called me callous. She was right – Andrea Eisenberg, MD

Ask and listen

- There is a normal natural instinct to want to please people
- It gets in the way of providers and patients really saying what is wrong
- They think providers unconsciously don't really want to hear about problems



What I needed as a patient was different than what as a physician I would have thought I needed.

I was truly focused on ... trying to treat people and bring them back to health as fast as possible, not staying in emotional spaces.

As a patient, I realized that someone could treat me but if I didn't feel they really saw me, that somehow I didn't feel healed.

Take home

1. Take a minute, sit on your hands, don't look at the computer, ask an open ended question and listen...
2. Understand that older PLWH may have varied lived-experiences that impact how they see and approach their health
3. Communication skills are as important as clinical skills

Thank you!

Paul Sacamano

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- Lessons from “the other side”: teaching and learning from doctors’ illness narratives
<http://careers.bmj.com/careers/advice/view-article.html?id=20017843#ref5>
- Brush With Death Leads Doctor To Focus On Patient Perspective <https://www.npr.org/sections/health-shots/2018/01/03/574701108/brush-with-death-leads-doctor-to-focus-on-patient-perspective>
- A View from the Edge — Creating a Culture of Caring
Rana L.A. Awdish, M.D.
<http://www.nejm.org/doi/full/10.1056/NEJMp1614078#t=article>
- When Doctors Become Patients
<http://php.nhs.uk/doctors-become-patients/>