HIV and Long Term Disability

Minnesota AIDS Project

The Minnesota AIDS Project envisions a world free of AIDS. Our mission is to lead Minnesota’s fight to stop HIV through advocacy, education, and service.

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HIV Basics
### WHAT'S THE DIFFERENCE?

**HIV**
- Virus that causes AIDS

**AIDS**
- Later stage of HIV disease

### WHEN DOES HIV TURN INTO AIDS?

<table>
<thead>
<tr>
<th>T-CELL COUNT BELOW 200</th>
<th>OPPORTUNISTIC INFECTION</th>
</tr>
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<tbody>
<tr>
<td>• Number of T-Cells or CD4 cells per ml of blood</td>
<td>• Takes advantage of weakened immune system</td>
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<tr>
<td>• Healthy immune system has 800-1200</td>
<td>• 33 AIDS defining O.I.s</td>
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### OPPORTUNISTIC INFECTIONS

- Illnesses that occur when someone's immune system isn't working properly
- Infections that a healthy immune system would resist
- A person doesn't die from HIV or AIDS, but from an illness/infection that they can't fight off due to their immune system not working properly.
- Caused by
  - Fungi
  - Parasites
  - Viruses
  - Bacteria

### T-Cells and Viral Load

**T-Cells (CD4 Cells)**
- These are the cells that HIV infects and destroys.
- CD4 cell counts are monitored to help determine the progression of HIV. This count may range from 0 to 1800.
- Goal of treatment is to get and maintain a high T-Cell count

**Viral Load**
- Number that tells how much HIV is in a milliliter of blood (can range from undetectable to millions)
- Goal of HIV treatment is to get a low viral load
- Undetectable viral load does not mean cured
T CELLS and VIRAL LOAD

HIV Epidemiological Data

United States Perspective

- The Center for Disease Control estimates 1.1 million people in the U.S. are living with HIV
  - 1 in 6 (15.8%) of those people are unaware of their infection
- Over 50,000 Americans become infected with HIV each year
- Nearly 636,000 people with AIDS have died in the U.S. since the epidemic began
Rates of Diagnoses of HIV Infection among Adults and Adolescents, 2014—United States and 6 Dependent Areas

N = 44,609  Total Rate = 16.6

Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. All displayed data have been statistically adjusted to account for reporting delays, but not for incomplete reporting.

Rates of Stage 3 (AIDS) Classifications among Persons with HIV Infection, 2014—United States and 6 Dependent Areas

N = 21,318  Total Rate = 6.6

Note. All displayed data have been statistically adjusted to account for reporting delays, but not for incomplete reporting.
Canada

- At the end of 2014, the estimated number of persons living with HIV in Canada was between 63,400 and 87,600.
- It is estimated that 1 in every 5 Canadians infected with HIV has not been diagnosed.

Cases of AIDS in Canada By Year
How HIV has evolved

Early HIV Timeline

• First known AIDS-related death in North America 1981
• HIV identified as cause of AIDS in 1984
• 1985-United States begins screening the blood supply for HIV
• 1987-First drug, known as AZT, approved for treating AIDS

HIV Today

• HIV is still a chronic, but treatable and manageable medical condition.
• There are a number of antiretroviral treatments available to help people with HIV live long, healthy lives.
• HIV is not a death sentence anymore, but people do need to be tested and receive treatment in order to manage the virus.
HIV Today

- We understand how people can become infected with HIV, and that there really isn’t a risk of infecting others in the workplace.
  - There used to be the belief that coming into the vicinity of a person living with HIV posed a risk for infection.
  - Many people believe there is a concern for healthcare providers, but they should not be doing anything that puts their clients at risk of infection.
- HIV stigma still exists, but it is recognized as a disability by the ADA, which protects them from discrimination in the workplace.

Living With HIV

- Medication adherence is crucial to healthy living
  - People need to take their medication at least 95% of the time to get to viral suppression
  - Viral suppression is when the virus does not seem to be replicating any longer in the body and will not show up on a viral load test (not a considered a cure)
  - Not taking medication at least 95% of the time can lead to the development of treatment-resistant strains of HIV, which limits medication regime options

Mental Health: Living with HIV

People living with HIV experience....

- Acute emotional stress
- Depression
  - 2X greater population
  - Characterized by low mood, apathy, fatigue, weight loss, inability to concentrate, loss of pleasure in activities, changes in appetite, trouble sleeping, low self-worth and possibly thoughts of suicide
- Anxiety
  - A feeling of panic or apprehension, often accompanied by physical symptoms of sweating, shortness of breath, rapid heart beat, agitation, nervousness, headaches and panic.
Mental Health: Living with HIV

- HIV can directly impact the brain causing impairment and memory issues
  - HIV Associated Minor Cognitive Motor Disorder
  - HIV Associated Dementia

- Some mental health side effects

Medications side effects

- Anemia (abnormality in red blood cells)
- Diarrhea
- Dizziness
- Fatigue
- Headaches
- Nausea and vomiting
- Pain and nerve problems
- Rash

Long Term Side Effects of Medication

- Fat redistribution: known as lipodystrophy
- Chronic diarrhea/gastrointestinal issues
- Chronic fatigue: can range in severity
- Increases in cholesterol or triglycerides. This can increase the risk for problems such as heart disease.
- Decreases in bone density
Medication Resistant HIV

- Not adhering to HIV antiretroviral medication can lead to medication resistant strains of HIV
- People can be infected with more than one strain of HIV
- Being infected or developing a medication resistant strain greatly limits the amount of treatment options
- People with medication resistant strains tend to have to take medications with more severe side effects

Long Term Effects of HIV

- Chronic diarrhea
  - Can be caused by medication, bacteria, or by HIV itself
- Persistent, long term fatigue
  - Can be caused by medications, particularly if someone took earlier medications, or by having a weakened immune system
- Difficultly fighting off illnesses and infections depending on how much damage has been done to the immune system.
  - Living long term with infections that can’t be treated/eradicated

HIV Today and Long Term Disability

- Why are insurers seeing less cases of people with HIV going on long term disability today?
  - Currently, we have tests that can test accurately after 3 months, along with a new test that tests accurately after 1 month
  - These new tests are making early detection possible and common, leading to people receiving treatment before the virus has done substantial damage to their body
  - Newer medications are much less toxic currently than the early AZT medications, and have less side effects
  - People have to take less medications today than before (an average of 3 pills a day vs dozens of pills a day), helping with adherence and overall health.
Case Studies

MAP’s Philosophy

• The Minnesota AIDS Project has a benefits team and legal department to help people living with HIV access the benefits they are eligible for.
• Our benefits team helps clients assess what benefits they are eligible for and helps determine how they can access those benefits.
• Our goal is to help people living with HIV.

Considerations...

• There might be cases where it seems like a client with HIV is receiving long term disability benefits when they could return to work.
• It is important to know what kind of information to look for beyond what’s on a medication chart when assessing eligibility for benefits.
• It’s best for both you and the client to consider the day to day realities of the situation.
Case Study #1

- George is a 44 year old man who was diagnosed with HIV in 2001, and is currently receiving long term disability benefits. He has been seen out at a number of community events recently, including his local Pride Fest.

- What his medical file says: George was diagnosed with HIV fairly quickly after he was infected. He had a t-cell count around 190 after he was diagnosed, and has never had an OI. The strain of HIV he is infected with is resistant to a number of medication classifications, but he is still able to receive treatment, and his T-Cell count has been around 400 for years. His doctor noted that George's medication causes him fatigue and stomach issues.

Case Study #1

- RELEVANT INFO: George would have received an AIDS diagnosis, even though he never was infected with an OI. The medication resistant strain of HIV he is infected with causes him to be extremely limited in the medications he can take to help treat his HIV, and the medication he can take causes severe fatigue and regular diarrhea. He volunteers with a local HIV organization to help do education and outreach in HIV prevention as he doesn’t want anyone to have to live with HIV if it can be avoided, but he only volunteers for short shifts since his fatigue makes it difficult for him to be able to work very long.

Important Take Aways

- Ask the client what sort of day-to-day struggles they may face as a result of their HIV
- Check-in with the client's doctor to see what issues the client is facing that could impair their ability to work beyond what is recorded in their medical charts
- Don't assume that someone who is receiving effective treatment isn't dealing with any side effects from that treatment
- If you do find the client is engaging with the community, explore what they are doing.
  - Be non-confrontational, because that volunteering may lead to a client potentially exploring how to return to work.
Case Study #2

- Henry is a 62 year old man who has been living with HIV since 1986. He had a t-cell count that was below 100 for a number of years and dealt with a number of OI's. He has recently been seen going back to school at the local community college.

- **What his medical file says:** Henry has had a t-cell count that has been in the 500 range for the past decade. He hasn't had any OI's since the early 90's. He was diagnosed with Herpes in 1992.

Case Study #2

- **RELEVANT INFO:** Henry has been living with HIV for a long time. The virus and OI's did significant long term damage to his overall health, along with the toxicity of the early AZT medications. Henry's health has been improving over the past few years, and he is looking into pursuing a career that he never thought he could have had due to his HIV. He thought he was going to die from HIV, and was having so many complications that he was never able to pursue his dream career. He can only go to school part-time at the moment.

Important Take Aways

- If someone is taking steps to potentially not have to depend on disability, explore ways that you can help them.
  - Get vocational rehabilitation specialist involved.
  - Biopsychosocial analysis
- Understand how HIV has evolved, particularly for people who have been infected for some time.
- Look at the long term affects of early AZT medications and the damage having a compromised immune system can do long term.
Sources and Citations

Sources

- [http://www.fda.gov/ForPatients/Ilness/HIVAIDS/History/ucm151074.htm](http://www.fda.gov/ForPatients/Ilness/HIVAIDS/History/ucm151074.htm)

Sources

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