

Reporting Back on the Episodic Disability Framework Study

More and more HIV is considered a chronic illness for those with access to antiretroviral drugs. People living with HIV (PHAs) may experience the long-term health-related challenges of HIV and possible side effects of treatment. Many call these health-related challenges 'disability'.

Many PHAs feel that the periods of wellness and illness with HIV come and go in **episodes**. For this reason, we used the term **episodic disability** to describe the fluctuating health-related challenges experienced by the people who took part in this study.

What was the Purpose of this Study?

The purpose of our study was to develop a "framework" or way of looking at disability from the point of view of adults living with HIV.

Why is this study important?

Like many PHAs, you may not see yourself as disabled. The term disabled often refers to something permanent. However, you may have times when you feel less able to carry out the day to day activities that you want to do.

This framework is a way to help you describe what you are going through. You may find it useful in helping you get access to services through a health care team or an AIDS service organization (ASO) to make your life easier and allow you to do more of what you want to do during episodes of disability.

What were the methods?

We (the researchers) carried out a series of focus groups and interviews with men and women living with HIV who had gone through at least 1 health-related challenge due to their HIV status. We asked individuals to tell us about their health-related challenges, how the health challenges affected their physical, social and psychological lives, and how this impacted their overall health. All discussions were audiotaped and later typed out word for word. We analyzed the words using coding techniques. This research was approved by the St. Michael's Hospital and University of Toronto Research Ethics Boards.

Who took part in this study?

Twenty-one men, 16 women and one transgendered individual with HIV took part in one of four focus groups and 15 face-to-face individual interviews at the AIDS Committee of Toronto and Voices of Positive Women in 2004-2005. Seven participants (4 women, 3 men) returned for a second focus group where we shared preliminary findings and asked for feedback on ways to refine the disability framework.

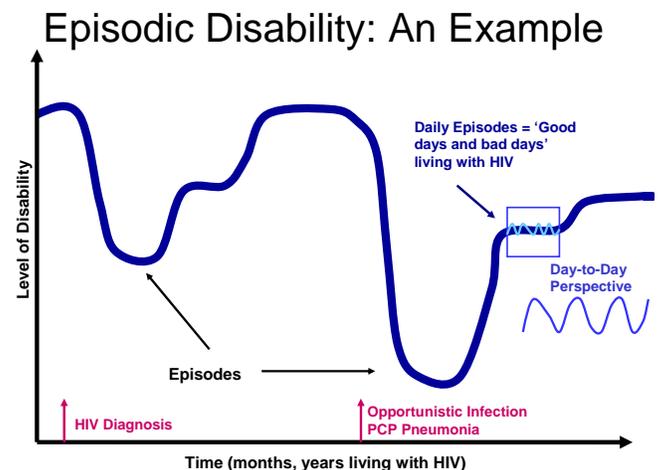
On average, participants were 41 years old (range 37-58 years), 17 participants (45%) were diagnosed before 1996, and 15 (66%) were taking antiretrovirals. Most participants rated their health as good (42%) or very good (39%).

What were the Results?

Participants described their disability as **multi-dimensional** and **episodic** in nature.

- "HIV is a little more difficult because you do go up and down..."
- "I would definitely classify HIV as ...an every now and again illness, it comes and goes...."
- "It's been a psychological roller coaster for a number of years now..."

This picture shows what one person's experience might be like, living with episodic disability:



Episodes can be major, triggered by a life event (pink) and also occur on a daily basis, known as good days and bad days.

Health Related Challenges Living with HIV

Episodic Disability Framework Study

What does 'Episodic' and 'Disability' Mean?

Many who took part in this study felt that the word "disability" sounded too permanent, but they said they accepted this label when they needed access to services.

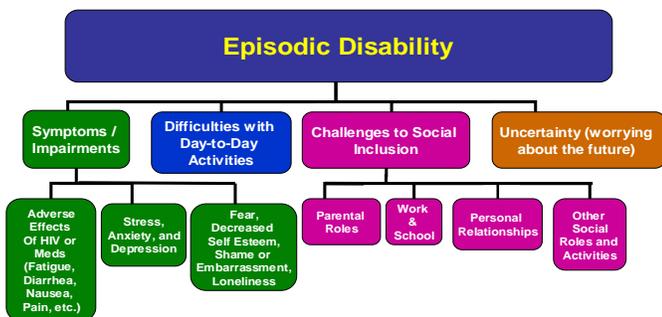
One participant in this study said she felt "part-time disabled": *"it's a reality sometimes you have to accept. But I'm not totally ready to accept that right now, because there's days when I don't feel disabled, and I accomplish as much as anybody else does on certain days. Not all days, but certain days, and those are the days that I consider myself not disabled. I accept it once in a while ...I'm part-time disabled once in a while..."*

The Episodic Disability Framework

In the next three charts, we describe parts of the episodic disability framework.

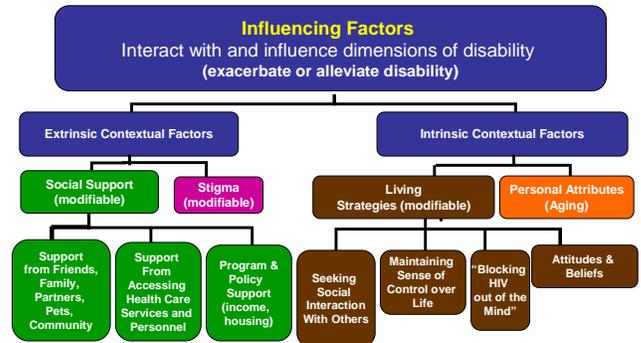
- 1) The first chart shows the dimensions, or scope, of episodic disability.
- 2) The second chart describes influencing factors - aspects of life that can either worsen (exacerbate) episodes of disability or alleviate them (make them easier to get through). The chart shows two kinds of influencing factors. Extrinsic factors are those that affect you from outside, such as the attitudes of family and friends. Intrinsic factors are about you - your own attitudes and beliefs, for instance.
- 3) The third chart gives some examples of triggers - events that could set off a major episode of disability.

1. Dimensions of Episodic Disability



For More Information: For more information on HIV disability and rehabilitation see the Canadian Working Group on HIV and Rehabilitation (CWGHR) website at www.hivandrehab.ca.

2. Influencing Factors



3. Triggers



How can we use the Episodic Disability Framework?

- **People living with HIV:** can use it to help them better understand their own condition and talk about their health challenges with health and service providers, and other PHAs.
- **AIDS Service Organizations & Health and Social Service Providers:** can use it to ask questions about the health challenges their patients are facing. Also, the influencing factors in Chart #2 suggest ways to intervene and help to prevent or reduce disability.
- **Policy Makers (public and private):** can use it to help guide new employment and disability income support programs and policies that will better meet the episodic needs of PHAs.

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