

How do adults living with HIV in Ireland experience disability? A qualitative study

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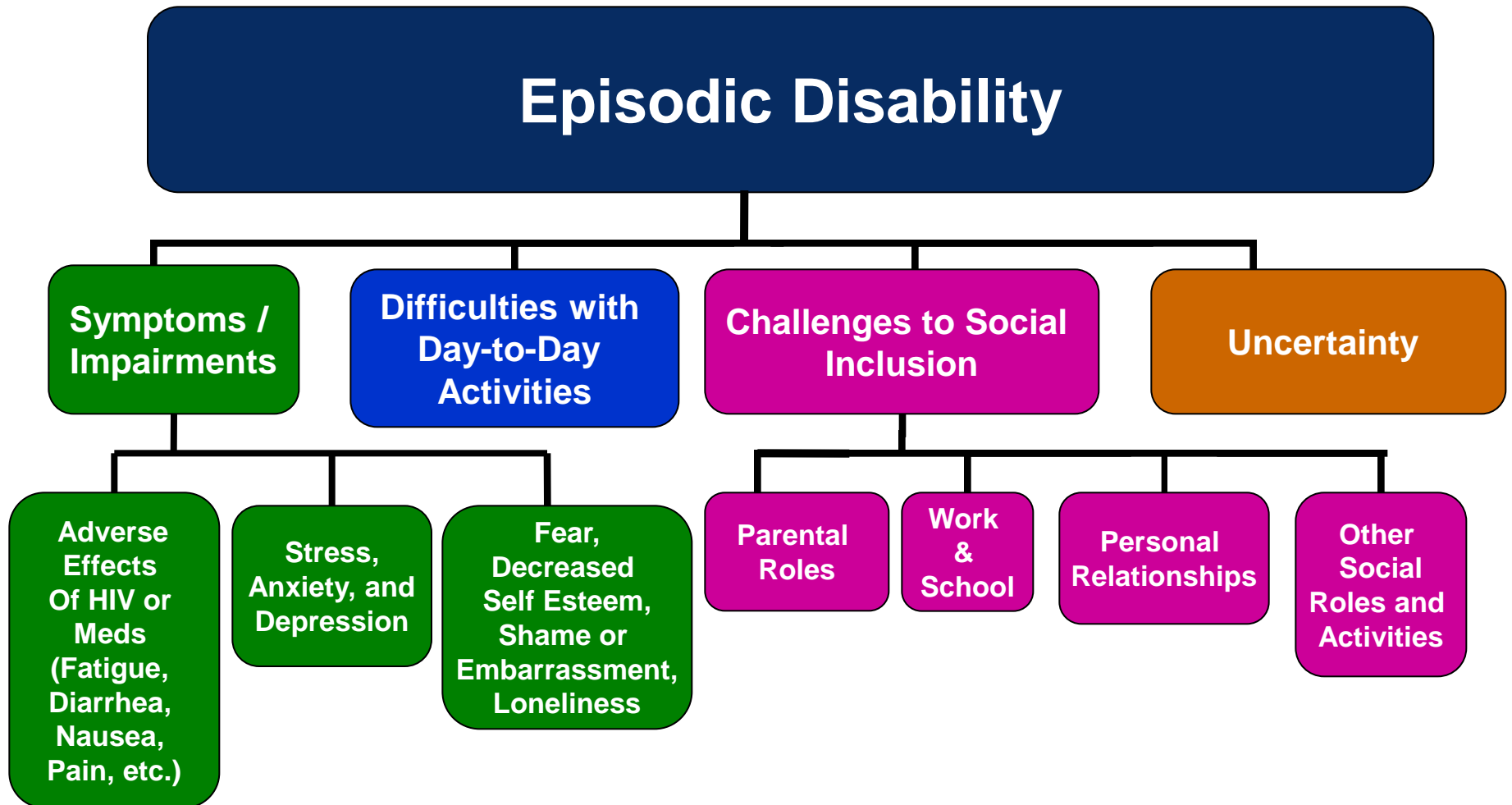
Encouraging and facilitating links between scholars in Ireland and Canada



Purpose

To explore the experience of disability from the perspective of adults living with HIV in Ireland in relation to the *Episodic Disability Framework*.

1. Dimensions of Episodic Disability



2. Contextual Factors

Contextual Factors

Interact with and influence dimensions of disability
(exacerbate or alleviate disability from the participant perspective)

Extrinsic Contextual Factors

Social Support

Stigma

Support from Friends, Family, Partners, Pets, Community

Support From Accessing Health Care Services and Personnel

Program & Policy Support (income, housing)

Intrinsic Contextual Factors

Living Strategies

Personal Attributes (Aging)

Seeking Social Interaction With Others

Maintaining Sense of Control over Life

“Blocking HIV out of the Mind”

Attitudes & Beliefs

3. Triggers

Triggers that can mark major or momentous episodes of disability (Examples include)

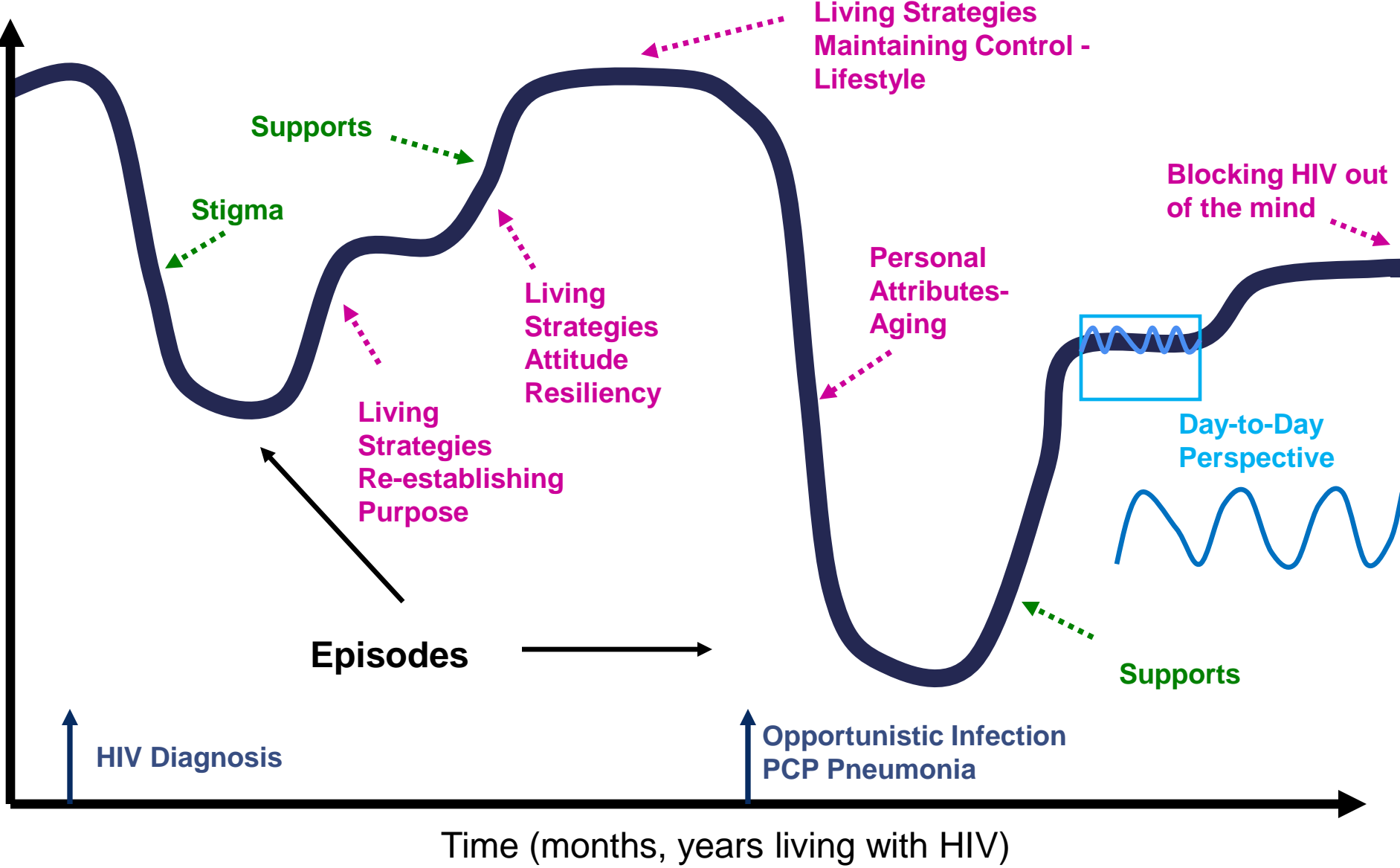
**HIV
Diagnosis**

**Antiretroviral
Medications
(e.g. starting meds,
changing meds)**

**Experiencing a
Serious Illness
(including
opportunistic
infections)**

**Suffering a
Loss of Others
(friends, family, partners)**

Episodic Disability Framework: An Example



Methods

- Recruited adults with HIV from GUIDE Clinic and Open Heart House
- Face-to-face interviews
 - Describe your health-related challenges
 - Extent to which these challenges are episodic in nature
 - Impact on overall health
- Interviews recorded and transcribed verbatim
- Transcripts reviewed for accuracy
- Analysis
 - Content analytical techniques

Participants (n=12)

Demographics	Number (%)
Gender	
Men	9 (75%)
Women	3 (25%)
Median Age (range)	45 years (36-71)
# taking antiretrovirals	11 (92%)
Median year of diagnosis (range)	2000 (1990-2012)
Median time since diagnosis	12 years
# undetectable viral load	10 (91%)
Median # of comorbidities (range)	3 (0-10)
Employment status	
Full-time	4 (33%)
Part-time	2 (17%)
Volunteering	3 (25%)
Other (retired, unemployed)	2 (16%)
Self-reported health	
Fair or Good	2 (17%)
Very Good or Excellent	10 (83%)

HIV and Disability Experienced as Chronic and Episodic

Disability Experienced as Episodic

- **Rolling Health**

“...rolling down the hill now, that’s just the way it is, right down to the bottom so... I mean, that’s the fear when you do get sick, that ... you’re not going to recover. Even if it’s just a chest infection, you get over that but just say it’s something bigger... people think oh what’s next? And... am I on a roll down hill, that kind of thing...people do worry about that deep down it affects people. ...”(INT-5)

- **It’s Up and Down**

“... it’s up and down....some days... some days I feel okay but some days I feel really down.” (INT-5)

Dimensions of Disability

Physical Symptoms and Impairments

Attributed to HIV, side effects of medications, comorbidities – difficult to ascertain the source; **episodic – fluctuates daily and within the day**

- Body composition changes (could lead to residual disclosure)
- Headaches
- Dizziness
- Muscle cramps
- Aches and pains (legs, etc)
- Shortness of breath
- Fatigue
- Diarrhea
- Numbness and tingling
- Back pain
- Nausea

Cognitive Symptoms and Impairments

- **Memory**

- “I used to have an extremely sharp memory but now I don’t...I’m 43 so I don’t know if that’s going with age or HIV as well.” (INT-5)

- **Concentration**

- “[feels] like a mild hangover in the morning....I just felt that I had to try that extra bit hard...to concentrate a bit harder”(INT-6)
- As Episodic - “I would say it’s now very mild but it’s constant but it’s so mild that I maybe don’t notice it now. You might get the odd time where it does fluctuate maybe once a week where it just gets a little bit...tougher then it comes back down again.” (INT-6)

Mental and Emotional Symptoms and Impairments - 1

■ **Stress**

- Related to HIV, work, legal challenges, residency status
- Chronic longstanding stress
 - “I worry about with the stress that I’m going through, because it’s chronic. I worry that might have an impact on my body. I’ve already asked so much of my body, you know, to accommodate me and to ... and I’ve been so thankful ... that it’s doing it’s job and it’s working properly and the cells are replicating properly. I worry that this immense continuous stress...” (INT-12)

■ **Depression – Episodic in nature**

- Related to HIV status-“if I was not HIV positive, I wouldn’t be depressed” (INT-2)
- Anxiety, depression, trauma, addictions
- “.....fluctuations on bad days.” (INT-11)

■ **Fear**

- Starting a new relationship (disclosure)
- Ending up in a bad relationship
- Disclosure
- Transmitting HIV
 - “I really want to meet someone and get along with my life but at the same time or with my situation I’m afraid.” (INT-2)

Mental and Emotional Symptoms and Impairments - 2

- **Loneliness – loss of friendships, family relationships**
 - “... I would feel down a lot of the time which might be a feeling of loneliness sometimes. If I don't have other people, that I can talk to you....I miss my parents for talking to. And, my sister is very busy with her family.... she has her own things and she doesn't have time ...But usually I snap out of it....I might go for a walk or something like that or I go down to the shops and maybe just meet people there or something and I think a lot of it is just about sometimes being on my own. And it's when I'm on my own or when I'm in bed that that's when it happens really....” (INT-8)
- **Loneliness due to inability to disclose**
 - **Fear of disclosure in social circle ...”feeling as if you can be in the crowd and on your own” (INT-11)**

Challenges to Social Inclusion

- **Challenges with personal relationships due to disclosure**
 - “meeting someone and you know...afraid of.... if I meet someone in my life that person might be negative and the fact that I’m HIV positive, how do I tell him you know, I’m HIV positive? That’s my main worry”(INT-2)
 - “I tend not to tell.... (INT-5)
 - Some chose not to pursue any personal relationships whereas others are now ready to start a relationship to build a social network
 - “I think on a relationship perspective I would like to develop maybe a long term friendship or relationship because I moved back down to my home in the countryside so I’m looking at five years, ten years time... fifteen years time to have a social structure built around me; I have family and I have neighbours and all that. So I’m looking to develop something more around that. (INT-9)

Challenges to Social Inclusion

- **Loss of relationships with aging parents**

- “I don’t have a partner, you know and my father and I are very close. Well we were very close but with the dementia, he just can’t concentrate now and it’s... that’s been very sad for me because I used to discuss everything with him.” (INT-10)

- **Challenge of starting a family**

- “I’m now 41 years old and...I really want to start a family and just... just establish my life. I want to have a kid, but at the same time ... I don’t know how I’ll be able to do that. I might meet the right guy but he might be negative and I’m HIV positive, you see? How do I tell him that? (INT-2)

Uncertainty -Worrying about future

■ **Source of Symptoms**

- “I mean I get aches and pains in my joints at times, but is that from getting older? Or is that from not exercising regularly, you know, is that normal to any normal average person? Who knows. (INT-10)
- “I don’t know whether that’s part of the HIV or not” (INT-2)

■ **Medications**

- Worried the “drugs will eventually not work” (INT-1)
- Worry about forgetting to take medications (INT-4)

■ **The Numbers**

- Worried about the numbers – CD4 counts

Uncertainty - Worrying about Future

■ **Uncertainty related to aging, living long term with HIV, and comorbidities**

- “As I get older....you always worry when you come to clinic...whether they might be something else they discover....something you haven't had before...and even though you haven't been feeling ill they discover something and send you for more checks...well it's all about getting older...” (INT-8)
- “I don't worry about HIV anymore....I worry in a small way about arthritis....cancer....Alzheimer's.’ – uncertainty not just about HIV but co morbidities associated with getting older (INT-1)

Uncertainty with Aging

- **Medical uncertainty with aging**

- “I worry if these drugs are going to affect me in different ways because I don’t think they know yet.... I mean I don’tsee people that are much older than me in here...And I’d say probably I’m one of the oldest people or maybe I’m not. Maybe there are older people but, I don’t think there are that many and maybe we’re going to be *guinea pigs for this aging process ...*” (INT-8)
- “With the medication being so advanced.....the question is getting very hazy as to how and when and why and if it will be ever HIV related or something else, old age or whatever. (INT-10)

Contextual Factors Extrinsic and Intrinsic

Extrinsic Factors - Stigma

Stigma due to HIV status, sexual orientation, gender, ageism

- **Fear of stigma related to residual disclosure**
 - “I worry maybe when I go this place...will people find out about it and how they’ll treat me I don’t tell very many people. I just tell very select few....I just wonder...will people notice? ...Will they notice things about me? Will they notice that I’m different?...that sometimes does worry me...” (INT-8)
 - “you have to kind of keep your hands very close to your chest all the time...even if ... people come in...maybe somebody can come in to the clinic here ... so I have to go in with my head down.” (INT-11)
- **Stigma among friends**
 - “even when talking to my friends... they don’t know that I’m HIV positive....their attitude against HIV is so frightening...I can’t even explain to them that, even if you have HIV, as long as take the medication you can live with it. I can’t even say that. I’m feeling that they might suspect me. (INT-2)
- **Stigma and old age**
 - “the stigma doesn’t go away, you know? I suppose the only thing with me is that I’m older and people don’t really ... wouldn’t suspect me to have it with my age.” (INT-11)

Extrinsic Factors - Stigma

- **Weighing disclosure in relationships**
 - “the most hardest I suppose would be the **stigma** and would be when you meet somebody, you’ve got like all these set questions in your mind and you have to...what am I going to tell the person? How will they react? When should I tell them? Is the best thing to tell them before sex, after sex? Should I bother telling them if I protect him?.... I have to always constantly when I meet somebody have a set of questions in my head and I also have to calculate conversations with the person unbeknownst to them that I’m calculating the conversation around their education on HIV and how do I disclose and does this person... is this person educated enough ...to disclose to....so, it’s more psychological for me.... “
(INT-10)

Intrinsic Factors - Personal Attributes - Aging

- **Aging exacerbates disability**

- “Regardless of HIV, aging is an issue we all have to deal with so...I try to keep active as much as I can and aging is a natural process so ... Trying to predict aging and HIV, what that’s going to be... *I don’t really know at this stage* and but I try to keep as fit... fit and active as I can now and that hopefully will have benefits down the road....” (INT-6)

Intrinsic Factors - Living Strategies

- **Outlook on Life**
 - **Managing stress**
 - “I try not to get too stressed about anything if I can. So I try and take things one day at a time” (INT-6)
 - **Keeping a positive outlook**
 - “I’ve proven to myself ...how positive thinking, and a positive way of living has helped me ... to be alive today. (INT-9)
- **Living Life for Today**
 - “I approach life very differently now because it’s like I almost get a second chance...thinking about taking care of today and that is what made me realize that today is the most important day of any day of the week.” (INT-10)
- **Balance...feeling grateful....**
 - “At the end of the day...I’m very happy to be alive. I’m very grateful for every breath of air that I breathe...” (INT-12)

Intrinsic Factors - Living Strategies

- **Resiliency – “Just get on with it you know?”**
 - “I take HIV like I take everything in my life as just another knock in the belt and I just find ways of coping and getting over it.” (INT-10)
 - Having the energy to do what I do at the moment, get up and go to work everyday and live a normal life, sort of gives me some kind of encouragement, ...to just prove to people that I can do everything that everybody does. (INT-3)
 - **Episodes** - “they are annoying...they don’t hamper me in any way...don’t let it get me down.....you’ve got to sort of just live with them.....and you forget about them as well...” (INT-4)

Intrinsic Factors - Living Strategies

- **Resiliency with Experience– Long Term Survivorship**
 - “I’ve had them for so long [symptoms and fluctuations]...I presume I just accept them...I don’t think about them...’ ‘I’ve just accepted everything as it comes...I never really got myself too worried about any of the things that have happened except for things like major illnesses...”(INT-4)
- **Resiliency to Reduce Uncertainty and Worrying about future**
 - “It’s not worth sitting there worrying myself...I don’t unnecessarily worry anymore than I think a normal person does with HIV would obsessively worry. I don’t see the point. It’s a waste of energy. So... but then again, I’m ... as I say I’m 12 years in right? So, I have a totally different attitude than the poor unfortunate who’s been told last week.” (INT-5)

HIV as a Chronic Episodic Illness - Resiliency

- **HIV as a Chronic Illness**

- “.... In the early years I used to worry much more. And I think I have just grown...it's like now we living with a chronic illness ... that's the way I try and look on it now. Like Diabetes or something like that and you know,.... It's amazing and that's why, I sort of look ... it's a chronic illness which can be managed.” (INT-8)
- “just because your body has been diagnosed with HIV does not mean it's a death sentence...it's quite possible to live happily... with HIV in your body and realize it's not you that has it, it's your body. You know? Anything could always be worse and it could always be better. (INT-12)

HIV as a Chronic Episodic Illness - Resiliency

- **Resiliency - Good days and Bad Days with HIV**
 - “...I suppose a bad day is where you actually feel sick and maybe you do get sick. That’s a bad day where you actually vomit and you do feel very unwell...that’s a bad day, so a good day is when even if you do wake up in the morning and your routine is where you have a little bit of pain in your ankles due to ... your arthritis or whatever, that’s standard routine, you’re used to it, it doesn’t bother you...you get used to it. I think you become more tolerant.” (INT-5)
- **Resiliency with Long Term Survivorship - Getting used to the Episodes over time**
 - “for a while you might be at a one or whatever, then the next day you’re fine and you’re back up to ten....does the bad day ruin your whole month and make your health any worse? No. I don’t think so. Personally. I think you get used to it....I think it’s hard for people who are newly diagnosed and nearly every dayBut I think... the longer you live with HIV... you get more better days than you do bad days.” (INT-5)

Conclusions

- Disability experienced by adults with HIV in this study aligned with components in the Episodic Disability Framework.
- Resiliency and positive outlook helped to minimize perceived health challenges experienced by adults with HIV.
- These dimensions of disability and contextual factors may be considered by health providers in HIV clinical practice.