



Stories of life with HIV

Living with uncertainty

Stories move in circles. They don't move in straight lines. There are stories inside stories and stories between stories, And finding your way through them is as easy and as hard as finding your way home. And part of the finding is getting lost. And when you're lost, you start to look around and to listen.

Corey Fischer, Albert Greenberg
& Naomi Newman (1992)




Living with uncertainty: Storying life within life-threatening illness

Many people with life-threatening illness live longer and healthier lives with the support of medical advances and technologies. However, the outcomes of treatment are not certain and the possibility of the disease recurring or progressing is very real. What is it like to live with the uncertainty of life-threatening illness?

This booklet has come about from a research project where people living with life-threatening illness (cancer, chronic kidney disease or CKD and HIV) were invited to share their stories of living with illness. The research was carried out from 2007-2012, with thirty-two participants sharing their stories in multiple interviews. Growing out of that research, this booklet includes the major findings of the study related to HIV and the stories of participants in their own words.

*"It's been an interesting – a long haul – interesting haul.
But... who knew we would still all be here to tell you these things?"*
Oliver

Please note: Quotes featuring quotation marks are from the participants themselves. Names provided with these quotes are aliases to help protect the privacy of those who so generously shared their stories.



"Everything that you expect is not what's going to happen ... I think that we create a set of expectations and sometimes they're negative and it isn't necessarily what has to happen, and if we can get our mind out of that expectation and spend a lot more time just trying to be where we are in the moment and then work our way through that, I think we do a lot better."

Christie

Living with uncertainties

Negotiating losses

"I talk about the early days with AIDS being ground zero, you know, neighbors died, people I worked with died, friends died. I stopped making a list when it got to be five pages." Fredrick

Losses are complex. With HIV drug therapies, life was often extended but this meant adjusting life around fatigue and other chronic health symptoms. For those diagnosed the longest, they also had lost many people they knew to AIDS.

Realizing the condition may not be a "death sentence"


"I'm healthy in every other way. I have no viral load or no discernible viral load and my CD4 count is good. . . . I finally had to say that to myself, you're in good health so you better get a life!" Kevin

People faced the social understanding of HIV as lethal, which lingered even after treatment was available. Living with uncertainties often meant a transition from fear of death, to hope for life, to finding new ways to live.

Tension of being private or public about diagnosis

"A community agency profiled me because it's difficult to find people who will – that are willing to be the 'face' of HIV." Sal

People struggled with how open they should be with others. HIV/AIDS carries a stigma that could be a problem in daily life, such as, with personal relationships of all kinds. Telling others raised questions of how one came to have the condition and this was highly personal. Some people chose to tell by becoming advocates, assisting other people with HIV.



"My illness comes up as an aside every now and then, and so life seems normal and then you start thinking, 'oh well I can live with HIV – just normally.'"

Morgan

Seeking normal

Navigating stigma in the day to day

"But I can't say to people, I can't go to anybody and say, especially my clients, 'I've got HIV and Hep C'. They'd recoil in horror." Jesse

Finding a new sense of normal is complicated when living with a disease that is heavily stigmatized and misunderstood. Participants experienced a diverse array of discrimination from loved ones, work colleagues, and society in general. Feelings of social isolation were common.

Isolation and advocacy

"Well I started volunteering because I wanted to find out more about the disease I was living with. I thought I was alone." Fay

Some people speak out about their own experience, but also speak on behalf of others who are isolated. Connecting with others was a practical way to deal with feelings of aloneness.

Living in your body

"It's just something I have, like somebody has diabetes. It's ... no more, no less. It's a disease that you're living with and managing as best as you can." Tyler

Being ill is an embodied experience - it is felt in the whole body. Becoming comfortable in one's own body again meant finding peace with what they had physically been through with illness. Life-threatening illness was something people needed to come to terms with in mind and in body.

"I'm aware of the risk of death. I don't think about, I don't obsess about it. But I'm aware of it. I allow it to help inform decisions."

Kurt



Facing dying and death

Legacy of a "death sentence"

"I'm going to die, you know, it's just that whole thing, that was all that I knew about AIDS ... was that I was going to die. I just went on and realized in a week I wasn't dead and in a month I wasn't dead."

Devyn

Diagnosis was less of a traumatic shock for people diagnosed with HIV after 1996, (when more effective drug treatments became available), yet still involved sorting out the meaning of the diagnosis for their life.

Impact of medicine on life course


"They're still learning from us ... I'm still a guinea pig." Hal

Everyday life with HIV was punctuated by new drug therapies. People made adjustments accordingly, with hopes for improved quality of life. However, with new treatments came new side effects, and reminders of mortality.

Living with chronic disease in the shadow of death

"Once the meds were out I went 'oh, I'm not going to die right away' and you kinda get used to the thought that you don't know when the end of life is coming again." Jonny

Today, HIV has come to be understood as a chronic disease that can be treated. People discussed their understanding that life expectancy depended on how long the medications continued to work, something no one could know for sure.



"I don't measure success in life anymore by the same yardsticks I used to – which had to do with success, money, merchandise, you know, just the things that you accumulate in life. I find all of that to be artificial now."

Blake

Exploring life questions

Blame and guilt

"I thought I was the only one and you know, get the shame, the blame you know, go through all that depression..." Jill

HIV has been associated with drug use and sexual activity, so there is often shame, blame, and guilt with getting it. In terms of serious illness this is a distinct aspect of living with HIV.

Reflections on beliefs and meanings

"... things happen for a reason. We don't know at the time why it happens but you're on a path that you'll realize it when the time is right." Emily

Facing illness, people openly talked about their values and their spiritual and religious beliefs. What was important, was having a personal system of values that guided daily life. Many expressed that there was purpose in life, things happening for a reason.

Beyond words

"There comes a time when you can no longer pretend. You have to admit something is wrong. It will germinate within you and grow and it'll define you eventually, it's the secret you were trying to hold back."
Riley

A number of aspects of living with a life-threatening illness were beyond words or unsayable; that is people were unwilling or unable to discuss them. There were experiences laden with emotion, memories, spirituality or even physical sensations of illness.



What

study participants would like healthcare professionals to know

In telling their stories, a number of people had messages they would like to share with health care professionals.

Give me a sense of the plan ahead:

"Umbrella support from somebody... here's how it is going to work, you know... nothing more terrifying than going into something like this not knowing." Carey

Relate to me as a human being not as an object or a disease:

"I had to know everything that was happening... for healthcare professionals to share what they were doing"... get down to the patient's level instead of standing over the patient's bed." Kelly

Choose your words thoughtfully as they have great impact and will stay with me:


"I'll never forget when he said..."

Be aware of and sensitive to the metaphors you use, as not all of us believe our illness is a battle to be fought:

"I don't like the word 'survivor' cause I don't like that, but no, I have a chronic illness that is in remission." Barbara

Overall, it's the human connection that matters, for example take time to sit with me, honor my vulnerabilities, and put kindness first.

"You feel very vulnerable and you feel you're only a number – I was 14-8-64 – that's all you are at the Institute because it's so busy." And, "Dr. C. was the doctor that really worked with me through the process. And she spent hours, oh yeah, hours educating me. Like I have a PhD in the disease." Louise



*Now I've learned, the hard way,
that some poems don't rhyme,
and some stories don't have a
clear beginning, middle, and
end. Life is about not knowing,
having to change, taking the
moment and making the best
of it, without knowing what's
going to happen next.*

Gilda Radner (2000)

Telling your story

Every person is unique. Every story is unique. There is no one "right" way to live, yet you are not alone. Other people have lived through these experiences. Facing life-threat is a part of the human condition and evokes "what is life about?" The following are such stories...

"You don't make sense of it. You go into this horrible... self-destructive... self medicating, new world of liquor, drugs, gambling, shopping, eating, anything to forget that you have HIV. You don't admit to it. You take the medications and think that you can just live your life the same way that you used to. But you can't. It has to become an integral part of your life. You have to integrate that into who you are but it doesn't have to own you. It doesn't have to be your major characteristic in life." Geoffrey

"Actually I'm seeing someone who is also HIV positive but I never think about it and yet sometimes I think oh I guess I should worry about that a little bit – but I don't – for some reason. I don't know why. I kind of like that he's HIV positive... in a funny kind of way. Because it's our given. We never talk about it – ever. I think we've mentioned it once or maybe twice and only in one sentence and then carried on because you don't have to agonize over it. And of course I don't have to pull him kicking and screaming into the disease – he already has it. And as with my straight friends or even gay friends who are not HIV positive you know that worried face that they get – worrying about you – it's stressful." Cameron



This booklet is dedicated to all people living with life-threatening illness and their families.

We want to extend special acknowledgment to the 32 people who participated in this research and their loved ones.

Notes:

Horizontal lines for taking notes on page 14.

Horizontal lines for taking notes on page 15.

“Dignity. Dying with dignity I think is important with all of us. Living with dignity is even more important.”

Sidney



This narrative research study was lead by a team of researchers at the University of Victoria and the University of Alberta. We began this research with the desire to listen to the stories of people living with life-threatening illness, with the intent being to improve understanding. Like most people, each of us has been touched personally and professionally by serious illness. Through sharing these stories we hope to improve the lives of people living with life-threatening illness.

Re-stor(y)ing life within life-threatening illness research project



Research team

Back row: Drs. Anita Molzahn; Laurene Sheilds (team leader); Anne Bruce & Kelli Stajduhar

Front row: Rosanne Beuthin, PhD Candidate; Dr. Kara Schick Makaroff & Sheryl Shermak, PhD Student



Funded by:



To learn more about the study and listen to the stories of people living with life-threatening illness please visit:

uvic.ca/illnessnarratives



Sharing stories to
improve the lives
of people with
life-threatening
illness.

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