

# BEYOND the DATA



A community arts-based pilot led by the CHIWOS Knowledge/Translation and Exchange (KTE) Champion Project and women living with HIV and AIDS.



# ACKNOWLEDGEMENTS

We thank all the hardworking contributors and all the wonderful human beings who showed their support for this pilot project.

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# TESTIMONIALS

*Beyond the Data testifies to the power of storytelling arts - be it photos, poetry, personal narratives, photovoice, and other visual and narrative arts -- in mobilizing knowledge that stats cannot convey. I thank the artists who honoured us with their work and wisdom. I look forward to the next volume.*

- Lori A. Chambers, Ph.D.

*Wow. This anthology is so moving and reminds me of the importance of storytelling. As the principal investigator of CHIWOS, I can say that I am truly humbled by this piece of work; reading the stories, poems and words and looking at the photos brought me to tears. I can see our research brought into action by women living with HIV who participated in the study and who were the frontline research assistants. While at the same time, I can see myself in the stories and acknowledge my own vulnerability. Thank you.*

- Dr. Mona Loutfy, MD, FRCPC, MPH, CHIWOS Principal Investigator

*Beyond the Data is a must have piece of work to own. I loved the autonomy of each story yet it came full circle in how it related to the reader in one way or another. Beautifully done.*

- Gladys Kwaramba. Peer Research Associate, CHIWOS.

*This anthology is a stunning story book, where narrative meets art in the spaces where women's voices are heard in all their diversity and multiplicity. This is a feast for the senses and a privilege to read.*

- Saara Greene, PhD.

*Beyond the Data anthology is a true work of art! It's an expression of lived experiences that no numbers nor data could adequately capture. I encourage you to immerse yourself in these stories. I invite other researchers to consider such community arts-driven initiatives that open safe spaces to share reflections and meaning. Love, passion, and humility were poured into this project. Congratulations to all!*

- Mina Kazemi, CHIWOS Research Coordinator

*I was so touched by the stories and art in this book. Everything was superbly expressed and unforgettable in quality and form. From poetry to personal narrative and then to an astounding work of art, Beyond the Data promises to captivate every time it is read.*

- Shaz Islam, CHIWOS Research Associate

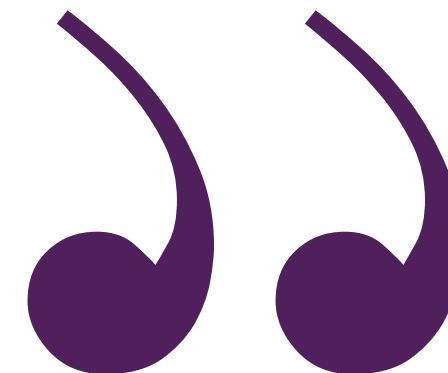




Photo by N. S.

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# INTRODUCTION

The anthology, though small in scale, remains a testament to the stories and lived experiences that each woman has brought to this juncture. It is a juncture because there is always more to express; in fact, there are endless vestiges of oral storytelling, writings on the wall, paintings and illustrations, and photos on smartphones. The dreams, expectations, goals, and intentions can make up the whole, the part, or just a tiny snippet of any anecdote or epic to be presented in front of immediate loved ones or to fervent gatherings, and everyone else in between.

Beyond the Data is the name of this anthology. It is a pilot project made up of a few contributors, and their work - snapshots, goals, accomplishments, grief, and everything else that gives their lives meaning. Sufficient and whole, each piece is a rare accompaniment to the ethos of the book. To get to individual and collective essence, each person follows the path or paths that bring them to a single answer, to multiple answers, or to more uncovering of their truths. These women find ways to write their realities, to paint them, to photograph them, and breathe light into them to say that these stories matter and are important vestibules to who they are.

Reading this book is not an escape from our own lives, but to find out how these authors have dealt with theirs, whether it be a past predicament or through self-care rituals, or perhaps a key principle that explains all the situations in one woman's life. Some are told in poetry, others are in prose, one is explained in a beautiful painting, and another using photovoice. Whatever the format, they each represent unique retellings, which ultimately attest to universal truths.

The poem by Park Sul Hae is a mesmerizing debacle of the body with all its temperamental configurations versus what's outside the house dwelling that moves around the boundaries of the body, its opposition. Park Sul Hae finds comfort and safety within the boundaries' walls. Beyond these safeguards, she is unsure about her sturdiness, but she pays homage to the streets, nevertheless, with the prospect of joining the crowd on one of these days. Caged and Conflicted encourages the reader to give it and all the others their due attention.

Six workshops outlining some of the elements of a story were explored by five participants who had met, laughed, and listened to one another's anecdotes. Myself and Angela Underhill provided the space, materials, and the food, with one additional task by Angela to facilitate the CHIWOS research powerpoints. The facilitator, Anjalee Amaan, was a contributor and participant herself, and due to her past experience in community arts-driven projects, she was familiar with presenting the learning to her group. The other contributors included women from the research team: Brenda, Breklyn, Stephanie, N.S., Angela, and M.K. Their thoughtful pieces added to the rich tapestry of the anthology.

Beyond the Data has 12 contributions of personal narrative, statement, or poetry, and 10 photovoice or photos. It is a pilot but we have hope that it will be turned into an annual project that will keep people living with and affected by HIV and AIDS contributing to, reading and/or looking through the anthology's pages, which will be different each time, and just as spectacular as this one you are about to discover.

-Shaz Islam

“*These women find ways to write their realities, to paint them, to photograph them, and breathe light into them to say that these stories matter and are important vestibules to who they are*”

“

*She waits for the next day,  
to see the outside from above again  
She promises to honour herself today,  
trap permitting*

”

Photo by Park Sul Hae

## Caged and Conflicted

by Park Sul Hae

The morning is ominous  
At least it doesn't feel luminous  
Another sleepless night  
Circadian rhythm on it's head  
Sleep - wake feeling like fight or flight  
Only to be quelled when sleep bullies its way through

Every value held dear, challenged  
Brain mangled, a lot of unlearning  
'What will people say' plays on repeat  
Only to magnify the paranoia and shrink the cage  
Trapped like a bird, the world gets scarier and scarier  
Phobias taking turns in this whack-a-mole game

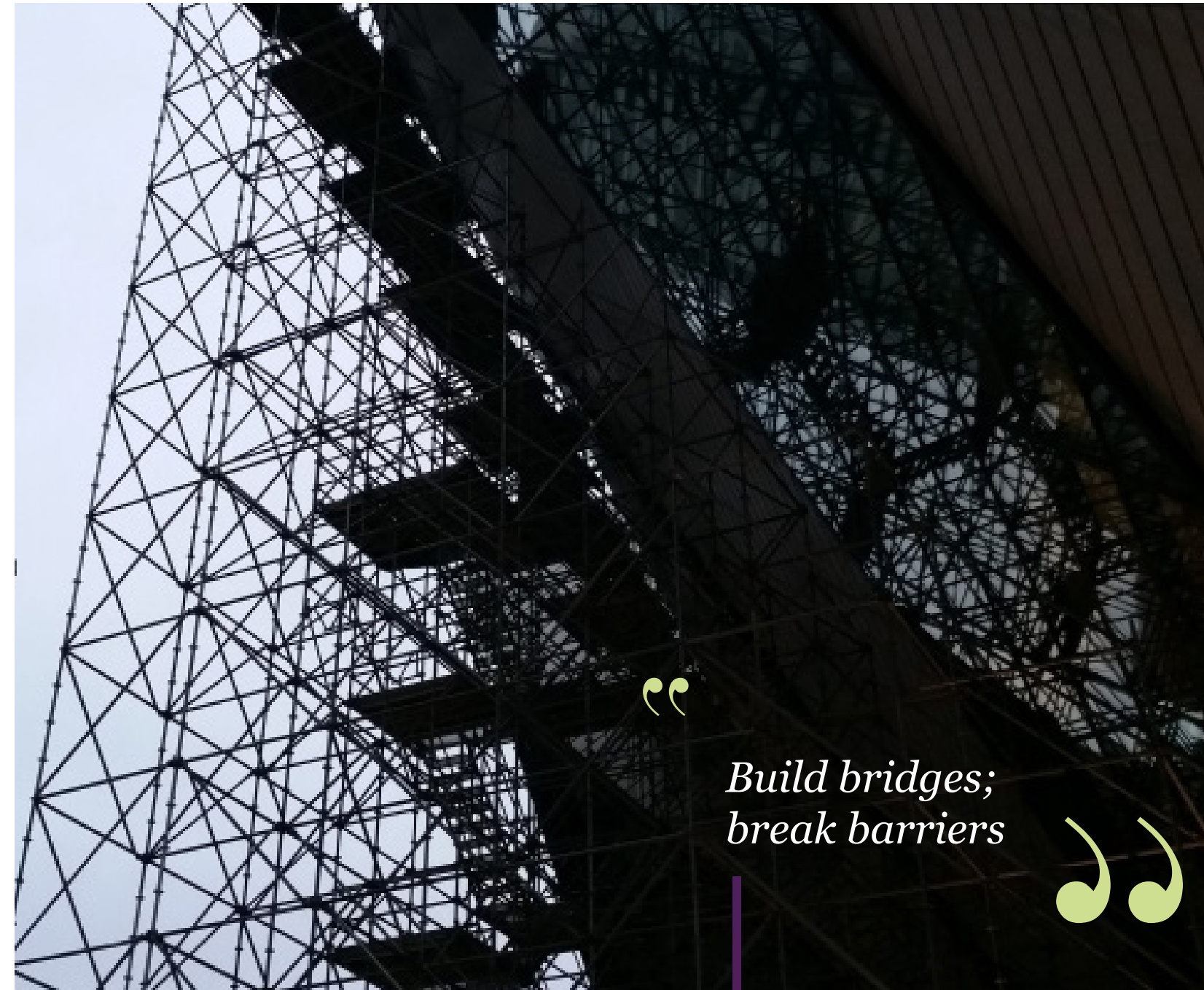
But she yearns to be outside everyday  
Yearns to be part of nature, the human race, the living  
Yet feels terrified to dare to venture out  
Time ticks as she watches from above  
The streets still empty, humans still asleep  
She feels the most normal then

The joy short-lived  
Only to be overtaken by same crippling cycle  
She wonders whether the mind or the bedroom is the stifling prison  
That has rendered brain useless and motivation a luxury  
She waits for the next day, to see the outside from above again  
She promises to honour herself today, trap permitting

## Research, for whom

-M.K.

Honour my voice; hold my stories.  
In your ivory tower is not where I belong.  
Wounds uncovered, for what?  
Intimacies disclosed, for who?  
Build bridges; break barriers.  
Reserve my space; protect it; tend to it.  
Level up! Offer me the stage.  
Legacy through action.



“

*Build bridges;  
break barriers*

”

*Photo by N.S*

*Art was and still is healing my life  
- adding beautiful colours  
to sometimes not such a colourful life.*



## Healing with Art

*By Anjalee*

It was a very different time then – when I was diagnosed HIV positive almost 30 years ago in the late 1980s. It was a time of uncertainty – a time with a lot of stigma and discrimination – a time of no medication – it was a time when there were lots of death – a dark time – a struggling time! And managing to survive this time – to have been given life to live – depression then tagged right along in daily life survival.

As difficult as it was, the 30 years lived with HIV, they've been lived with absolutely no regrets looking back at this journey. And as ironic as it may sound, it has been a learning and blessed journey. It had a purpose for me that I understand now – the purpose to share love – to share kindness – to heal lives with love and art – and most importantly, to heal myself with art – Colours of Life!

Creating art and sharing art and healing with art have been blessings. The best companion I could have received on this solo journey. Art was and still is healing my life – adding beautiful colours to sometimes not such a colourful life.

At almost 60 years of age now and having lived half of it being HIV positive – and alone – I sometimes feel that the years passed me by – being busy healing – loving – crying – depressed – and last – trying to find my place – and living.

However, now I look forward to allowing myself to take the ropes of life in my hands and embrace life with a lived experience to live all that I may have missed and filling my body and soul with “self love”, by allowing myself “simplicity”, and letting go of all excess baggage – whatever that may be – allowing healing and more life to happen.

Life is always going to give me obstacles. That is life. But how I react to these obstacles can make all the difference. I'm thankful to have survived the 1980s! Living one day at a time – sometimes one hour at a time. Always embracing and living fully with every blessed moment...called life! My life!

“Your mind is a powerful thing when you fill it with positive thoughts – your life Begins to Change!”



## For My Mother

*by Louise*

And when I reach for you,  
I feel the rough, hewn texture  
Of Love

And when I look at you,  
I see a wary lioness,  
Ready to die for her cubs,  
Not realizing that there are predators,  
Even you cannot vanquish

(1994)



*Photo contributed by Louise*



*Photo contributed by Louise*

## Living with Ghosts

*by Louise*

Everyone lives with ghosts - those of family, loved ones, and colleagues who have taken their last breaths before our eyes or in distant lands.

Those of us who were diagnosed with HIV and lived before the age of successful treatments live in spaces crowded with ghosts, of people who could not last until drugs came, who held your hand and prayed that you would live to see drugs, to be alive to remember them.

I find these ghosts anything but frightening, rather, comforting life coaches of yesteryear. When I feel depressed and wonder what my life is all about, they remind me to appreciate the experiences they never lived to have - the pride of being an elder with wisdom and recipes that younger people ask me to pass on, the touch of my great granddaughter's kiss on the cheek, or the budding of paperwhites to mark the start of another Spring. They tell me I am living for them too, so live well and fully. Sometimes I succeed and sometimes I pretend to succeed so as not to disappoint them. I hope they cannot tell the difference.

I sit at my Holiday tables with friends from that time and new friends and family, repeating the rituals we have followed all of our lives and those before us, and I am at peace. The ghosts at the table approve - my parents, my friends and colleagues, past.

Now a new ghost sits at my table, my younger sister, dead of breast cancer just this year. She, who always found me wanting, never good enough, is still welcomed by my other ghosts. Perhaps with time and in death she will soften towards me and forgive my many transgressions and failings as I did hers.

One day I too will be a ghost at someone's table, probably my granddaughter's. I was told more than once after my diagnosis that I would be gone and yet I did not leave. I lived on hope and anger and help. It is different this time because I know I cannot escape, not through medicine or positive thinking or healthy living. This time I will leave due to the ravages of age. As do most people at my stage of life, I pray for dignity in the final stretch and a death that is not too much trouble for those around me whom I love.

The ghosts tell me little about this phase - as if it is a trade secret that only a rite of passage will allow me to learn. My mother once gave away part of that secret when she returned to me in a dream telling me that she, who had been so tortured in life, was finally at peace. The touch of her hand, the tone of her voice and the line free look of her face told me it was true.

I will not go quietly into that good night. I want to feel and touch and see and love as much as I can until the very end. When that time does come though, I know that I will be welcomed into loving, comforting arms.



## Because of You

by Brenda

I participated in the PLDI (Positive Leadership Development Institute) training years ago and after one of the first weekend sessions I felt so invigorated and positive (no pun intended) that I wrote this poem.

Because of you  
I'm not so lonesome anymore  
Because of you  
Life's much more worth living for  
Because of you  
(Your love has set me free)  
Because of you  
I'M SO HAPPY TO BE ME

For the past six and a half years, I have been a Peer Research Assistant (PRA) in the CHIWOS (Canadian HIV Women's Sexual and Reproductive Health Cohort Study). The support I have received from Dr. Loutfy, the Ontario principal investigator and her amazing team, including coordinators, Mina Kazemi and Angela Underhill, have made me feel so good about my involvement in this study and consequently about myself and has added new meaning to this phase of my life.

This poem particularly applies to them as well as all of the wonderful women and PRAs involved in this study. I feel very privileged to have been a part of this amazing team.

*Because of you...*

Photo contributed by Angela

## There's always more to the story

By Angela

As a researcher, much of my time is spent reading, writing, and analyzing. I pour over articles, books, and data and try to more deeply understand what is happening in the world around me. In these settings, it's easy to disconnect from the fact that these documents are talking about real people. There's such a distance between data collection and analysis, between analysis and sharing the knowledge. What I love about community-based research – studies like CHIWOS – is that the people are prioritized. Rather than trying to always find the 'significant' differences, community-based research studies centre our similarities and humanity. It is through this research that I find evidence, over and over, that we are all so much more complex than we may appear on paper. We are all trying to find the beauty in this world (and it may be closer than we think).

When I started with CHIWOS, I learned what the term "peer research associate" meant; in this case, it was a woman living with HIV who had been trained in research. As the study progressed though, that term was picked at, unravelled, and made anew. We had hard conversations about the arbitrary nature of having one thing in common with one another, while simultaneously acknowledging that there was value in having spaces for people to bond and connect over those single (and often, many more) commonalities. Most recently, in the workshops for this anthology series, the participants discussed what a "peer" meant to them, and who they considered a peer. We talked about how that term is never permanent; rather, as we move through various stages of life and different circumstances take on more or less importance, we may need to find new people to connect with to help us navigate all that comes with those circumstances. I wonder what would happen if more of us looked for 'peers' to hold us up and to hold up. As we change, our relationships may change. We may want or need different things; our people may want or need different things. To let go does not mean to forget.



*We are all trying to find the beauty in this world, and it may be closer than we think.*

Photo contributed by Angela

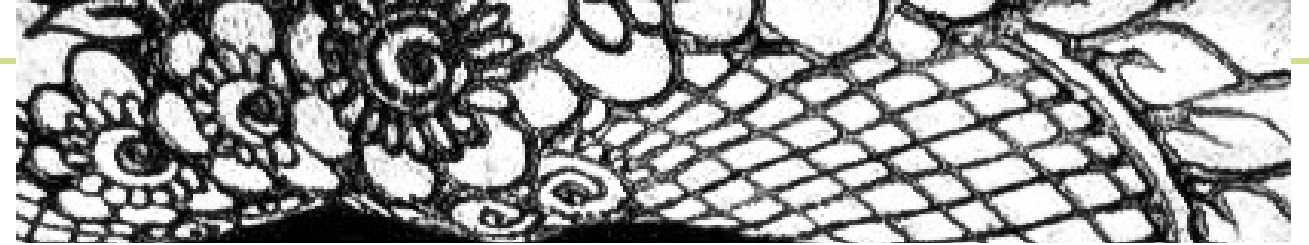
# Taking Care of Me... from the Past to Moving Forward

by Anjalee

How I have taken care of this temple called "Me" and continue to take care of me every day...more and more...So, with that said, here are the things I've done to sustain me, and some of them might be helpful to you, too!

- Acknowledging that you exist and that you must remember to live!
- Acknowledging all your health conditions!
- Taking medications as prescribed (very crucial to surviving the virus).
- Following up with all your doctors!
- Attending support groups.
- Staying connected to an ASO (AIDS Service Organization)!
- Listening to your Body!
- Healthier Diet!
- Using Supplements!
- Massages and Alternative Therapy!
- Personal Hygiene!
- Keeping Busy!
- Doing things that make you Happy!
- Things that make you Smile!
- Listen to the "I" in you!
- Please your five senses...very powerful and useful!
- Use Positive Affirmations!
- Spend time with yourself...get to know yourself!
- Having a few selective, quality friends.
- Enjoying Nature and the outdoors.
- Listening to Music!
- "Force" yourself to Smile – try it – it works like magic – you'll feel happy!
- Exercise.
- Using "Light Healing Imagery" when swallowing your medications.
- Simplicity.

Photo by Anjalee



- Decluttering...all parts of your life!
- Living in the Moment...literally!
- Having a good night's rest – sleep.
- Realizing you are part of the limitless sky!
- Watching the Moon and Stars!
- Travelling in "Mind" or in "Real time"!
- Always working on bettering yourself!
- Doing Art! Art has been very therapeutic and healing for me...a blessed companion!
- Being your Best Friend!
- Talking to yourself in the Mirror with loving, positive, beautiful words!
- Doing whatever it takes to make you feel better (never hurting yourself or anyone)!
- Having Faith!
- Balancing your body – physically – emotionally – spiritually – mentally!
- Praying!
- Believing in yourself!
- Using scents – essential oils and fragrances to enhance mood.
- Learning to love yourself!
- Creating a support system.
- Consuming a joint of cannabis every day!
- Allowing yourself to cry!
- Having supportive family was a blessing for me!
- Deflecting all negativity!
- Continue forced Smiling!
- Stop watching the news!
- Not interested in Politics!
- Using a "SAD Lamp" – white light therapy for Seasonal Affective Disorder!
- "Memento Vivere" – meaning "Remember to Live"!
- Watching a comedy!
- Laughing out loud...even if everyone thinks you're crazy! You'll be happy!
- Buying myself flowers!

As I advance into what I call the last phase of life for me...from +60 years to another 25 years, perhaps, I must notice that living in a privileged country, with a job, entitles me to self-care that costs money. However, the best self-care "costs no money", that is, "You"! Your attitude to fighting and deflecting obstacles and embracing the Power of "I" in You!



Artwork by Stephanie

## The Way I See the Painting

*by Stephanie*

The way that I envision this painting was that peer research associates (PRA) are the roots of community-based research (CBR). We hold the studies that we do close to our hearts and support other PRAs.

I used the CHIWOS study logo as the trunk as it is a strong meaningful women's study. The swing represents the children of the participants of the study. As a PRA I feel working on this study has helped ground me, helped me find a great partner, and enjoy life again and this is represented by the white picket fence in the painting.

# What Gender Taught Me

By Chhiring

I was kid and didn't know what bias and discrimination was all about. It didn't take me long to find out.

My parents had enough money to invest for my education, however, I was discriminated that time. My parents sent my elder brother to the expensive school in India, whereas I was sent to the city school in my hometown. I remembered that I asked them why they sent my brother away. I didn't want them to send him that far from us. The answer I got from my mother was, we love you, so we only sent him, not you. Innocent girl that time didn't understand the reality. I was around 8 or 9 years old.

Years passed. When my mother left this earth, my story went in different directions. My dad might have suffered through grief, I didn't know. I couldn't understand all those things at the time. But I do remember that he had a girlfriend who was a sex worker. He was staying with her without looking after his kids. But my uncle who was my father's younger brother, and who just married, stayed with us. The good part about my uncle was that he had a funny personality. He always told us jokes especially at bedtime and I still remember those. Some of his jokes I shared with my friends to make them happy and bring smiles to their faces. I think the reason he told those jokes that time could be an effort to reduce our stress.

In my teenage years, I didn't get a good chance to enjoy my life. But it helped me to know the people, some of my relatives and how they treated us when we were wealthy and when we weren't. That time I also went through some hard times when we didn't have enough food to cook and eat. My dad used most of the money for his entertainment. He was staying with his girlfriend. Due to financial issues, I was living with my elder uncle who lived in the village to continue my schooling. And my brother stayed with the younger uncle.

I lived two years in the village to finish my high school and then back to the city for my college. For my schooling at the village, we didn't have to pay the fee. All things were free of cost for the students. Not only that, luckily, I got a scholarship to continue my college, and at that time I started working as an "accountant" in the school. The word accountant is based on the real job but back in my country, it didn't require any special license. Also, I was doing my pre-Commerce and the school gave me the means to do that by being their "accountant".

As time passed, I fell in love. He was there for me when I needed support, to listen to my painful experiences. He was a good person. But as life changed, people change with it. He wasn't loyal to our relationship and HIV virus came to our life. HIV in his family's home was very tough. They blamed me and told me that I am the one who brought in the virus. I was very sick and didn't get any support at his house. Being their daughter-in-law was never pleasant and I was pressured to obey and listen. I was never asked anything related to family matters maybe because I was a woman and the daughter-in-law with the HIV virus.

*continued...*



Photo by Chhiring



*I will say that I can tolerate the pain, but it doesn't mean that I deserve it. Life gives each of us more or less, but whatever each of us has, hopefully it'll be enough.*



Photo by Chiring

But after some time, I left that house and him. Started to live in a shelter which was run by nuns for HIV positive women. I was very weak that time with a CD4 count of 74. Some of my poz friends were scared when they knew about my CD4 count. But for me my ex-husband and his family were more painful than the low CD4 count. On top of that when my family member came to meet me at the shelter, one of my relatives asked whether I had HIV or just my ex-husband. That question was an arrow through my heart and hurt me severely.

With the love and care I received from the nun sisters, my health condition improved. They were my angels at a time when I thought no one would hear me. When I got better, I started going to meetings for poz women in an AIDS service organization represented by the shelter. I thought that I would work like the nuns and help poor women like me. But some of my poz counterparts felt we should open a support group for poz women. Then I started working in the HIV field from 2003.

Being involved in many trainings and workshops on Gender-Based Violence (GBV) helped me to know more about discrimination towards women. There I realised that my parents discriminated against me because of my gender. They didn't send me to an expensive school because I was born a girl. If I didn't take these trainings, I wouldn't know. There could be women who didn't have this knowledge about GBV but are suffering with it. So, awareness is important. For me knowing my own parents did this to me was a painful moment, more so than the violence I experienced with my ex-husband and his family.

Four years later I separated from him and got married again. The good part with the new guy was that his father and stepmother were both supportive. But the new guy also gave me a hard time for two years. He was physically abusive. I prayed many times in church and asked why this was happening to me. That answer came in the form of his sudden change and his angry nature reduced. Now if he's angry, he says that he doesn't want to get angry with me. He realises that anger isn't good for the relationship. A few minutes later he would smile and explain why he got angry. This only happens once in a while. The rest of the time, he is at his best. His parents know about our HIV status. We don't have any children, but they never said anything to us.

Back home I contributed full time to the community. I enjoyed the work because it involved social work. It gave me life and it gave me hope. I love to work for women's rights issues to support poz women to help reduce some of their pain. I feel satisfaction when I was part of creating some change and brought smiles to their faces. My social work experience back home helped me to get a job in this city. I have been working at an ASO from 2012 to 2014 as a volunteer, and then in the fall of 2014 as staff. I am happy where I am right now and still have some new goals to be achieved.

When I experience any problems in the future, I will be able to handle them. I gained that capacity from my past painful time. I will say that I can tolerate the pain, but it doesn't mean that I deserve it. Life gives each of us more or less, but whatever each of us has, hopefully it'll be enough.



# Karma and Happiness

By Mar Mar

Everybody lives their lives. I live mine and now I'm happy. When I first got HIV, I hate myself. It was a deep feeling. Then another thing hit me - tuberculosis - TB, and then, cancer.

Wake up in the morning, I take blue pills, fills up the whole hand, and HIV medication. The blue pills I take for a year and four months. They were my TB pills. I had mental problems, too. No money, no friends, and no HIV community. Side effects from the HIV pills started. What people thought about me? They thought I was a bad person, they didn't learn. So, I learned for myself, and freed myself from their gaze.

Why are people so scared? Any kind of health problems, you can die. When I was diagnosed, I didn't know about dying. It's not because of HIV you die. I needed love, happiness, peace - the good things that life had to offer. My diagnosis was in 2008, and it changed my life completely. My cd4 - which was the number of white blood cells - was very low, my viral load was high, but I wasn't ready to die.

Breast cancer - it's about dying. They had to take out some tissue, but the tumour kept growing. I started taking chemo pills. A friend accompanied me to Brampton Hospital, and I remember, my insides were so tight. I had too many things inside. In Casey House, my "mother home", they took care of me. Looked like mother - daughter life.

Before I knew Casey House or anyone in the HIV community, or even had HIV, people in my country put me up like a balloon and I was floating like a god. Everyone wanted to be beside me, but as soon as they found out, they all ran away from me. I had to take care of myself. And soon, I got to know other people living with HIV, and I didn't care that I had lost one group because I gained a really big one as a result.

I have a big chosen family. I am a Queen. I follow my own religion. I learned about dying. I learned that you go to another life, with good things that follow you, and bad things, too. I am peaceful and am not worried about HIV. I go to group and have a good feeling or bad feeling. I fall down into the ocean - but I'm not dying, I'm not dead - because the ocean goes back up again.

I'm alive, and each time I fall back down again, I get back up with more information to keep me healthy and to share to whoever wants to know. It is karma - every time I'm back on the ocean floor, but it's me pushing myself, more and more, instead of others knocking me down. It's me determining for myself what I need to feel confident, secure, and happy.

Then the people who I share with are those in my chosen family and anyone else whose karma has thrown them down the ocean floor to also make them want to know all that I know, even more than I know. Karma and happiness - these are the two things that come again and again and again in my life. Karma causes many things and I use all these things to learn about the world and about me. One thing is happiness. Happiness flows from karma. It may not come immediately, but when it does come, your face will undoubtedly show it.



*“ I have a big chosen family. I am a Queen. I follow my own religion. ”*

Photo by N.S.

“*Real queens fix each other’s crowns and support each other in our ups and downs*”

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*Photo by Mariana Yarritu on Unsplash*

## **Real Queens Fix Each Other’s Crowns**

*by Breklyn*

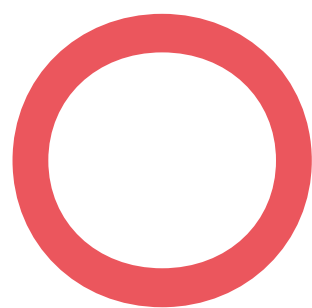
When the crown is in your possession supporting others is your secret weapon. Using what you have and what you know, can make a difference in someone’s life and help them grow.

Empathy, understanding, and compassion are some of the greatest traits, they help rid stigma, misconceptions and hate.

Being there for each other in the hardest parts of it all, picking up one another when we fall.

Being an advocate for change and good health for our peers, and a phone call away or even wiping a few tears.

Sticking together and forming a tribe, this work can fill a woman with so much pride. Real queens fix each other’s crowns and support each other in our ups and downs.



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