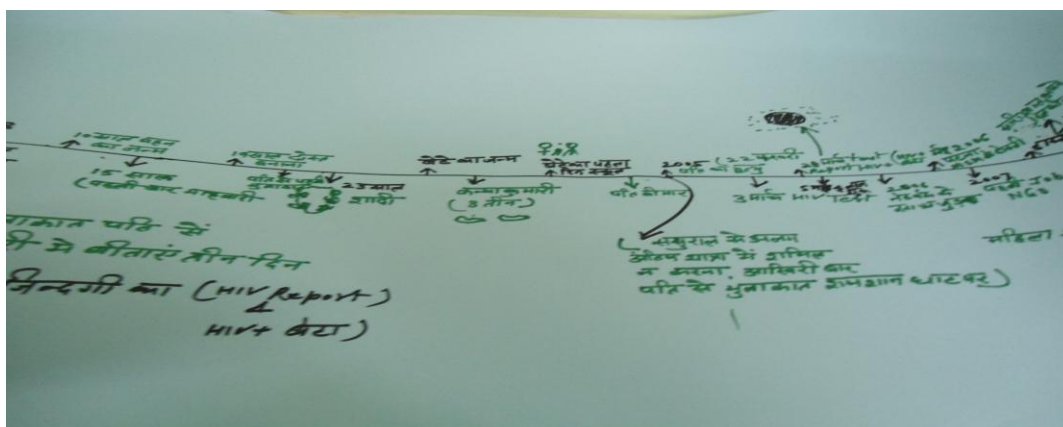




A COMMUNITY DRIVEN EFFORT - COMPILATION OF STORIES ON WOMEN AND HIV IN NORTH INDIA: THROUGH A LENS OF GENDER BASED VIOLENCE & STIGMA AND DISCRIMINATION



Organized by: ICW- Asia Pacific

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About ICW Asia Pacific

A regional network based in New Delhi, India that is affiliated to the International Community of Women Living with HIV/AIDS (ICW Global) international network and shares the same mission and values. ICW-AP's key themes and issues include researching and advocating for HIV-positive women's participation in decision making; sexual and reproductive health rights; access to care, treatment and support services; freedom from violence, stigma and discrimination; and economic justice, self-determination and empowerment.

Background:

'Violence against women' is now recognized to be a serious public health and human rights issue globally. Global population surveys indicate that between 15% and 71% of women have been physically or sexually assaulted by an intimate partner at some time in their lives, yet this is a silent epidemic. It is now well established that partner violence is linked to HIV.¹ Women are more vulnerable to contracting HIV than men, especially if they are coerced into sex. Moreover, unequal power structures in relationships often result in women being unable to negotiate safer sex practices.² Care should be taken that 'Violence against women and HIV' is seen in terms of prevention of HIV transmission and is acknowledged to be a part of the story even after the woman tests HIV positive. In

¹ Hale Fiona and Vazquez Marijo Violence Against Women Living with HIV/AIDS: A Background Paper development connections and the international community of women living with hiv/aids (icw global) with the support of un women

² Niranjana Saggurti Project Director, Population Council, New Delhi, India; Alankar Malviya National Programme Officer (State Support), UNAIDS, India HIV Transmission in Intimate Partner Relationships in India, Population Council ;UNAIDS

India, an increased number of HIV infections are emerging amongst intimate sexual partners. Women are at increased risk for HIV not only on account of their own sexual behavior but if they are partners of men belonging to most at risk population groups, that is: clients of sex workers, men who have sex with men (MSM) and injecting drug users (IDUs). Significantly, over 90 percent of women have acquired HIV from their husbands or their intimate sexual partners. Needless to say, an HIV positive diagnosis for a woman does not suddenly end partner violence. Often the violence experienced by women living with HIV mirrors that experienced by women generally. HIV however acts as one more 'determinant', pushing women further down the hierarchy of power.³

For HIV positive women, sexual, physical and psychological partner violence is a reality. In many settings, women have very little autonomy, and routinely experience violence within the family setting. Studies from India report that women living with HIV are usually blamed for their husband's death and are often evicted from their houses, with one study putting the numbers of women experiencing this as high as 91%' (NACO, cited by Development Connections, 2010).⁴

Many a times, violence against HIV positive women are framed as 'stigma and discrimination', and only rarely are they referred to as violence against women. This is true even when they are clearly within the definitions of violence against women given

³ Hale Fiona and Vazquez Marijo Violence Against Women Living with HIV/AIDS: A Background Paper development connections and the international community of women living with hiv/aids (icw global) with the support of un women

⁴ HIV Transmission in Intimate Partner Relationships in India, Population Council ;UNAIDS

above, as is the case with refusal to conduct delivery of HIV positive women, for example. This trend continues even when reproductive rights violations within the context of medical care has been identified by UNFPA as a form of gender based violence, and a growing body of evidence suggests that such reproductive rights violations are common in the case of HIV. These include: unavailability of contraceptive supplies; coercive family planning counseling; forced sterilization, refusal to conduct deliveries or provide other reproductive care; or verbal or physical abuse by health care providers that poses a barrier to reproductive health care access.⁵ This in turn will negatively impact universal access targets and the targets set by Global Plan for Elimination of New Infections in children and keeping their mothers alive adopted during June 2011 universal access meeting. Similarly, the UNAIDS Action Framework: addressing women, girls, gender equality and HIV ⁶ also recognizes that upholding women's human rights and addressing the needs of women living with HIV including comprehensive prevention approaches to HIV, sexual and reproductive health and violence against women is the urgent need of the hour .

The 11 stories documented below give a glimpse of the violence and stigma that women living with HIV have experienced at multiple levels – family, community and health care. Most of the stories focus on the vulnerabilities of women in intimate

⁵ Hale Fiona and Vazquez Marijo Violence Against Women Living with HIV/AIDS: A Background Paper development connections and the international community of women living with hiv/aids (icw global) with the support of un women

⁶ Agenda for Accelerated Country Action for Women, Girls, Gender Equality and HIV Operational plan for the UNAIDS action framework: addressing women, girls, gender equality and HIV

partnerships. They catch the hope, despair, pain, struggles, joys and aspiration and inspiration that their lives behold.

Programme strategy: Community engagement was the key strategy adopted for this project. By building capacities of the community and by providing ongoing mentoring, thereby engaging them to write the stories, the process itself has led to self realization of potentials - an essential step to building self esteem, the foundation for empowerment.

Methodology: Noteworthy is the fact that most of these stories were written by women living with HIV activists themselves. At a workshop organized by ICW Asia Pacific in New Delhi a number of them were trained to write case studies /stories centered on specific themes like gender based violence and stigma and discrimination. Post workshop they continued to develop these stories. ICW Asia Pacific provided ongoing mentoring to refine and finalize the stories. Women wrote the stories in Hindi which were then translated to English, refined and finalized by ICW Asia Pacific staff. An informed consent form was developed and used to seek their permission to edit and present their stories.



Story 1: “Can’t take this violence anymore”

Quiet and composed, this young woman listened attentively to catch every word being said at the workshop. She never spoke much but when she did, it reflected the never die attitude that she harbored within herself. I still clearly recount what she said to me “I want to write my story so that it changes the world for women. A world that is fair and just for women to live.”

32 year old Sita lives in Varanasi, Uttar Pradesh and has been living with HIV since 2004. Her story below recounts the horrors that women have to go through during their life cycle – family, community, workplace, health care facility. It mirrors a society that on the one hand makes women vulnerable to HIV and on the other bars women living with HIV from enjoying their rights –right to marry the one that she chooses to, her right to access health care and her right to lead a life of dignity and respect.

“I was married off as soon as I passed my tenth standard. Shortly I realized that my dreams about marriage have been shattered, my expectations were never met and I succumbed to a life as prescribed by my in laws. My husband often told me about his affairs with other women. I pleaded with him to refrain but he said that he won’t.....and he never did He refused to use condoms with me.

After suffering 2 miscarriages I gave birth to twins – one boy and one girl. The boy passed away immediately after birth but the girl survived.

Soon after, my husband fell sick and was diagnosed with HIV. Subsequently I too tested positive... my in laws shunned me on

hearing the news. They accused me of giving the virus to my husband.....that too at a time when I was pregnant. I was devastated!

Life seemed dark and hopeless. In the absence of any support from my in laws, I started to take my child to my parents’ house for testing. My mother in law said “Don’t ever come back here”.

I had a strong sense of self respect. Since my parents were willing to take care of me and my daughter, I made up my mind to stay back there. I decided to forego my share of property and left it for my old mother in law. Meanwhile my husband had also passed away. However, much to my relief, my daughter was negative.

In 2005, when I went to consult the doctor for my ARV treatment the doctor asked me to abort my 6 month old foetus. He said “When you have a negative child already, why do you want to take the risk of bringing a positive child into this world.” I agreed. Because of my HIV status the doctors refused to perform my abortion in the ward they did it in the gallery. I felt as if I was an outcast.

My treatment started and I was lucky enough to secure a job with a CBO. I was appreciated for my hard work and sincerity at the workplace. Eventually I fell in love with a male colleague... he was HIV negative and we wanted to get married. But to my surprise my coworkers detested this as my partner was negative and I was positive. Without even giving me a hint they disclosed my status to his family behind our backs. They said, “She has AIDS. Do you want to get your son married to her?” The family persuaded my partner to drop the idea of marrying me. I was deeply

distressed and sad and slipped into depression.

Time and again, I have experienced violence in my life..... I did not utter a word against the violence perpetrated by my in laws..... I quietly gave up my share of property there... and now workplace....I am being exploitedbut I was determined not to give up this time. I resigned from my job and was keen to be with my partner.

But wait, there was yet another hurdle.....my partner was not courageous enough to marry me publicly ... we had a secret marriage. Till date, he has not socially acknowledged me as his wife and has married another woman chosen by his family. However, he continues to be a friend and helps me financially. But some where I feel that he has also betrayed me.

I struggled for a new job My earlier employers tried hard so that I don't get one. Despite the impediments planted by them, I got a job with the Positive Women's Network to work for the betterment of women and children. I have a motto in life now - I want to earn back the money that I lost to my in laws. I wish to fight for the rights of women who have faced violence in their lives, those who have been driven away from their matrimonial homes like me..... I don't want them to go through the same painful road!

Story – 2 “Support is what I needed most”

She was quiet most of the time, a little shaky at first. But by the time we reached the middle of the workshop she was seen actively articulating her views on the challenges faced by women living with HIV.

30 years old Shahana lives in Uttar Pradesh and was diagnosed with HIV in 2007. Her story talks about the vehement stigma and discrimination that single women living with HIV face. This not only points to stigma related to HIV but also the way this stigma is often cited as a convenient excuse to deny single women of their rights and escalate violence against them. Her story looks at the profound gender based differential impact that HIV makes on the lives of women.

“I was leading a good married life till my husband fell ill and was diagnosed with HIV. His health deteriorated fast. I looked after him day and night even at the cost of ignoring my month old younger daughter. I felt tired but at the same time I felt guilty for not having looked after my daughter well. These thoughts tormented mewhat else could I do? Despite all my efforts I could not hold my husband back and he passed away.

During my husband's illness, my HIV tests were conducted in a private hospital. The test results were positive but the report was never handed over to me. My status was disclosed to my in laws without my knowledge and permission. My in laws accused me of giving HIV to their son. They said “we will not eat food cooked by you”. I used to cry often. Sometimes, when it became unbearable I demanded explanations for their behavior. They never answered directly and said that “if your husband has HIV, you must also have”. After my husband's death the discriminatory behavior of my in laws continued. No one touched my daughters as they were presumed to be infected. I felt deeply hurt but could never raise my voice against them. Eventually, my in laws started making plans of sending us back to my parents’

house. I was totally helpless and unsupported. I did not know how I would stand up. But I did that for the sake of my daughters.

They called my parents and said “take your daughter back as she has this disease “. My father retaliated “how do you know whether your son had the disease first or my daughter? “ When I was asked where I chose to stay, I expressed desire to continue living in my husband’s house.

Shortly thereafter, I got myself and my daughters tested at a government hospital. I was found to be HIV positive but my daughters were negative. I was so relieved and happy. At least my children were safe.

Then, luckily I got associated with the positive women’s network and started working as a counsellor and consecutively became the vice president of the network. Now I work for the benefits of women and children. I have a good support system.”

If a woman living with HIV is loved and supported by her family, she can overcome HIV related discrimination and move forward in life. She can also motivate other such women to live a life of respect and dignity that all women deserve.

Note: A fictitious name has been used to suppress the identity of the person as requested by her

Story 3: “Tired of allegations”

28 years old Sadhana has been living with HIV since 2008. Her story brings out the violence that a woman goes through during her life cycle and the complete lack of support from family and community that makes the impact insurmountable. This is

an account of how women are mostly blamed for bringing HIV into the family thus justifying the violence against them.

“My husband and I was a happy couple. We were much in love with each other. Life was going on very well till my husband fell ill and was diagnosed with HIV. I was devastated and confused - I did not understand what HIV was. Before I could fully absorb what was happening, I received another hard blow. Within 3 months my husband passed away. It seemed that my life had ended. I was struggling to put myself together. At a time when I needed support, I was treated very badly by my husband’s family.

They said “you don’t have children.and now you have killed your husband too!” They constantly blamed me for their son’s death. I was tired of their accusations.

After some days, I got myself tested at a private laboratory and was found to be HIV positive. The doctor said, “You have AIDS. Your life is useless. You are of no value now” I felt judged and angry. Soon I was put on treatment. When my in laws found out about my HIV status they threw me out. They said “You better go to your parents’ house. What will you do here? You don’t even have any children”. Deprived of all my matrimonial rights, I came back to live with my parents. But here too, life became a burden. Neighbors would say, “Why is she here? Why doesn’t she go back to her in laws? There must be something wrong with her.” I wanted to get out of this mess. The only time I liked were the moments that I spent at the ART center talking to other people living with HIV? I felt I was not alone.....there are others living with the virus too.

Soon after, I started working with a network and met another positive man. We fell in love and got married. I had hoped for a blissful married life but fate had something else in store for me. Within a year my second husband passed away. I suffered similar episodes and incidents of accusations by my in laws and was sent back to my parents.

I have now decided to earn money for myself and be self reliant. I want to make women aware of their rights so that they don't have to endure the hell that I experienced.”



Story 4: “Know your rights”

“Never accept injustice “is what describes the attitude of this bold young woman. Always ready to fight for a cause, she seems determined to raise her voice against any unfairness.

As 33 years old Seema’s story unravels, one can sense the transformations that she brings within herself to battle for a share that she knows is hers. Seema strongly believes in making women aware of their rights and that it is an important strategy to fight violence against them. Seema lives in Uttar Pradesh and has been living with HIV since 2006.

“I was the eldest in my family and grew up with lots of love and warmth around. By the time I was in eighth standard I was married. During the couple of years I spent at my mother’s house waiting for my gauna, I was not allowed to study.

The initial one year of my married life was spent in Mumbai with my husband where my first daughter was born. After her birth, I came back to the village to live with my in laws. Life stopped when my husband fell ill and tested positive for HIV. But he refused to admit this fact and blamed the evil power. I accepted his words and we went back home. However, after my third daughter’s birth my husband fell sick again. This time I tried hard to save my husband. I even got him admitted in BHU where I and one of my daughters tested positive. I was traumatized to hear about my child and to add to my dismay, my husband too passed away.

Subsequent to my husband’s death, my in laws accused me and threw me and my children out of the house. With three children and nowhere to go I was forced to go to my parents’ house. In order to support the family financially, I started attending sewing classes. It was during this time that I got associated with an NGO through a training programme. I always knew that I was being exploited but now I understood that these were my rights and decided to apply that to my life. I called my brother in law and said, “Now I know about my rights. Please give me my share in the house or else I will file a case against you”. It was then that they gave me possession of a room in my matrimonial home. I also want my farmland back but they are willing to give me a piece that is not of much value. I am pushing for a land that would fetch me a good price. I have not yet filed a case as I am worried of that impacting my daughters’

marriage. I long for an out of court settlement.

Since then, there has been no looking back. I established a CBO along with fellow PLHIVs. Life has not been so kind. However, I am happy that I have been able to fight for my rights and would continue to guide other women on similar issues. It gives me a sense of pride and achievement.”

Story 5: “Child marriage must end”

I still remember the bubbly young girl who we met at the workshop. Full of life and vigor she wished to prove to the world that she can be the best, treading through a tough path in life, jumping hurdles big and smallnever willing to give up . This is the story of 26 year old Anjali who lives in a small village in Rajasthan. Anjali was diagnosed with HIV at the tender age of 16. Her story gives a glimpse of the culture of child marriage in Rural Rajasthan. It portrays the devastating repercussions of early marriage on the minds and bodies of young girls. It puts a full stop to their education, increases their vulnerability to HIV and wreaks havoc on their well being, wringing the dreams out of them. It also highlights the disproportionate and debilitating burden of AIDS-related care that young girls carry especially in places with non-responsive public sector services. Anjali makes sure to end her story with a message that this social evil must end.

“I was the eldest of all siblings. When I was 11 years old studying in the sixth standard, my father passed away. The financial condition of the family worsened ... so much so that as the eldest child I had to take up the responsibility of running the family. My

mother was not in a position to work. I was forced to abandon my studies and work as a laborer. I wish my father had been alive. I would have been in school now! Thoughts like this always raced through my mind.

Sometime later my mother married me off.... I was 12 years old then. Within 2 months of my marriage my in laws took me to their house. They told my mother “Her father-in-law is unwell and wants to see the daughter in law. Please send her”. My mother considered this a better option as opposed to working as a laborer. “At least you won’t have to work outside. You would be working in your own house.” were the words with which she sent me there.

At the age of 12 I had to come to a totally unknown house..... I did not know anything....I did not know anyone I did not understand the meaning of marriage. I remembered my father’s eagerness to put me in school. He wanted all his children to be educated whether boy or girl.....I was the only girl in our “Jat” family to go to school. My father would scold my mother when my mother fussed about my studies. From a world which could have been so joyful, where have I landed? My eyes filled with tears....

Although I was so young, my mother- in-law used to make me do all household work. I used to look after the house, the farms and the animals. She was not at all sensitive or compassionate.

Time passed and at 15 years I gave birth to a boy. At that time my husband was out driving trucks ... that was his job. My son passed away within 13 days of his birth. A year later my husband fell ill and was hospitalized. When his HIV test results came positive the health care staff said to

my husband “You have AIDs and you will die soon!” My in laws never told me that my husband was HIV positive. They thought, “She is just 16 years old. If she knows she will run away. Who will look after him then?”

My husband was shifted to a private hospital where a nurse advised me to undergo HIV testing. This time the reports were shown to me. I was positive I was distraught. Even under such stressful conditions, I took care of my husband well. I truly wanted him to recover.....I tried hard. But he passed away. At the age of 16 I became a widow.

I lived with my in laws for 2 more months during which they took away my husband's insurance money without informing me. I came back to my mother's house and worked as a laborer till I got in touch with an NGO and started working in the field of HIV. My current work involves informing women about government schemes. In the process I have become aware of my rights. I have filed a case against my in laws to get back the life Insurance money and would continue to fight. I still recount the day when I was pronounced as the best student in my class. My teachers were so proud of me. I am glad that I have initiated my studies again. Life has been difficult but is shaping up well.

I want to end by telling the world out there that child marriage should be abolished. Strong legal measures must be ensured to curb this practice. Police personnel should be made aware so that they can stop child marriages from taking place. Such marriages increase young girls' vulnerability and kill their dreams. It is not fair.”

Note: A fictitious name has been used to suppress the identity of the person as requested by her

Story 6: “Alcoholism and HIV drove us to poverty”

Pallavi lives in a village in Rajasthan, She has been living with HIV since 2008. Her story talks about the impact of HIV on women headed poor families and the complete absence of support of formal social protection schemes. The story presents a classic case of intersection of alcoholism, violence, HIV, and poverty. Moreover, it points out how women are often encouraged by the society to stay with the violent partner.

“I was married way back in 1991. My husband was an alcoholic. His drinking habits were erratic. Sometimes he would drink a lot and beat me up. When I went to my parents' house to deliver my first baby, he mortgaged my jewellery to buy drinks. Even after my child's birth, my husband's behavior never improved....the same old saga went on.... drinking and throwing thingsand beating me. I was tired of this suffering .Meanwhile he had left his work and sold off all furniture to buy alcohol. Life became tougher. We could not even have 2 square meals a day. Because of financial reasons I had my two deliveries at my parents' home. I had to leave my youngest son with my mother as I was unable to afford the costs of raising him.

I returned to my village and started working as a laborer. For someone who has never stepped out of home, this was equivalent to torture. On top of that, whatever I earned was consumed by my husband on his

drinks. His drinking habits became uncontrollable and he fell sick with TB. I took him to the doctor but instead of taking the prescribed medicines, he went on and on with his drinking. Finally his poor health condition gave in and he died.

Emotional stress, long hours of physical work and irregular meal timings now started taking its toll on my health. I had frequent bouts of fever and weakness for which I consulted a number of doctors but no medicine seemed to work. I would stay well for a few days and then fall sick again. My health declined so much that I could no longer work or take care of my children. I was very upset and suffered sleepless nights. We did not have enough to eat and so much was being spent on my healththoughts like this hammered in my head. Sometimes I took my parents' help and sometimes I would seek support from my in laws. My in laws were never ready to help me. They took away our farms and wanted to throw me and my children out on the streets. But I refused to move from that house and continued to stay in my portion.

The doctor who treated my husband suggested that I do an HIV test and referred me to a government hospital in Ajmer. The results showed that I was HIV positive. Now I knew why I was so ill. The news was shocking but I breathed a sigh of relief when my children were found to be negative. Currently, I am on treatment. But I still remember the torture of my in laws-accusations, physical abuse, isolating us from the rest of family..... What have they not done? When my husband was at an advanced stage of TB, they isolated us and made us sleep outside the house. They said, "We all live in this house, what will happen if you all infect us?"

Life was anyway difficult but after being diagnosed with HIV life became even tougher. Any how we have been struggling to survive and now my hospitalization charges are also being added to household expenditures. I did not know how I would make ends meet.

Because of this constant stress, I fell severely ill and was almost on the verge of dying. By god's grace, I somehow survived but I continue to panic about the uncertain future. I am now on ARVs and working for the upliftment of other PLHIVs .I draw inspiration from them to live a good life. My struggle however, goes on...

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Story 7: "A loving family is the key to health"

Fun loving and lively, this woman treats life with a dash of humor, however hard it may get. While writing her story, Ayesha fondly states her husband as her inspiration and goes on to talk about the healing effect that a loving family has on the overall well being of a woman living with HIV. Ayesha is 44 years old and lives in Delhi.

"Since childhood, I loved socializing and made friends easily. I got married to a naval officer in 1993. I had a blissful married life. I loved travelling and my husband fulfilled my dream- I travelled to different places with my husband. Three years later my son was born. My family was complete. I was the happiest woman on earth.

I still recount the holiday that we spent in Kanyakumarithey were the one of the merriest moments of my life.

Days passed and my husband started falling ill frequently. He would feel better on taking medicines but would fall sick again. During medical investigations, I learnt that he is HIV positive. I was dumbstruck. I could not save him and within a year he passed away. It seemed that my world had fallen apart.

My in laws shunned me. They refused to let me and my son attend his funeral. They said "You are responsible for my son's death; you are the one who has brought HIV to the family". Somehow we attended my husband's funeral but after that my in laws severed all connections with me and my son. We came back to my parents' house. My family got me and my son tested for HIV. Both of us were found to be positive. My life was shattered once again– more for my son than for myself. I was completely heartbroken.

Being HIV positive changed my life completely. My in laws left me and the world seemed so dark. I felt helpless and lost all hope. 'Where will I go? What should I do?' were the thoughts that constantly plagued me. With the support of my parents our treatment started. My family supported me immensely, especially my mother. Slowly, my health improved and I began to find a new direction and hope in life.

While I was on treatment, I heard about this NGO and got associated with it. There I met many other women who were living with HIV for a number of years. I could sense my self confidence growing – 'why don't I work for these women?' I started working with this NGO.

I draw strength and inspiration from the last words of my husband, "You are my tiger and will not cry!" These words provide me with the strength to move on with life.

I want to give this message that all women living with HIV should receive the family support that I got. Family's support could sometimes prove to be more effective than medicines."

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Story 8: "Motherhood is my right as a woman"

She was hesitant at first to speak. But once she started, she seemed to have immersed into the narration. 27 year old Richa was determined to tell her tale that captures the attitudes of health care providers towards women living with HIV. Her story revolves around the gross violation of reproductive rights experienced by women living with HIV including denial of their right to have children, the challenges that they face in accessing care during pregnancy amounting to refusal of treatment and the emotional aftermath that they endure following such violations.

"I was tested HIV positive in 2006 when I fell very sick and my CD4 count dropped. Two years ago my husband had been diagnosed with HIV and had passed away. But I did not know about my HIV status then, even though I was 6 months pregnant. I lost my child within a month of her birth to pneumonia.

After I was diagnosed positive, an NGO was kind enough to sponsor my treatment. An old man who I had started calling "Baba" adopted me and looked after me as his daughter. I was glad to find a home. But this happiness did not last long and Baba passed away. I was a lonely soul again.

Days went by and I found a partner. I got married again to an HIV positive man. Soon after, I became pregnant. I was elatedI had always wanted to be a mother.

I wanted my child to be healthy and safe and I registered myself at a government hospital for my regular antenatal checkups. At my first antenatal check-up the doctor said, "You are HIV positive. Don't have this child. You might infect her!!" I was keen to be a mother. I retaliated "All women have a desire to be a mother and I also want to have a child." But he was still adamant "You have this disease and now you want to transmit this to your child. You must terminate this pregnancy". I tried to reason with him "I don't need three or four children, just one child." Though the doctor continued to insist on aborting the child, I stuck to my decision of bringing this child to the world. I firmly said "I won't be happy if I don't have this child. My family also wants a child". The next day I went along with an NGO worker, but to my surprise the doctor again commanded me to abort the baby. She did not even inform me about any PPTCT prophylaxis. Contrary to my expectation, the NGO worker did not provide any support. I could no longer contain myself and started crying. Seeing my tears, the doctor reluctantly agreed to conduct my check up and asked me to come back after one month. I did not have to go back. Unfortunately my battle was lost half way....in between I lost my baby.....I

had a miscarriage. I was distressed and disturbed.

The great news is that now I am pregnant again. I am going to the same hospital and the doctor is different. But the discriminatory behavior is the same and never seems to change. Whenever I visit the hospital for my antenatal checkups, they make me wait outside the whole day. When I question, they make remarks in front of all "You are HIV positive, we will look at you later". I feel angry... why do I have to go through this? ...I keep silent as I harbor these thoughts. At the end, when my turn arrives, I feel dizzy sitting all those long hours....sometimes I just come out of the hospital. The doctor took my blood a number of times but did not share the reports as many times. They refuse to respond to my questions. They treat other patients badly too but when it comes to being HIV positive, they exhibit more stigma and discrimination.

Doctors here have told me that I should deliver through a C section and that I should not breast feed my child. They initially told me that one dose of free medicine will be given to the baby after birth. However the baby has to be on continuous medication for 18 months and this medicine has to be bought from outside. I am confused as to where I can buy the medicine from? They don't tell me properly. I am always skeptical lest something happens to my baby. I have lost 2 babies, what if something happens this time? The thought itself makes me feel dreadful.....I pray that my baby is born healthy. The last time we went, the nurse at the hospital asked us to buy Nevirapine (dose at birth) for the baby from outside. She said "the hospital does not have it in stock. Keep it arranged as much in advance

as possible. You may not get it later. If you don't arrange for them, we will not take any responsibility for the health of the baby". I can still recall the stressful phase that I and my husband went through.

I came back to my sister's house. I was so worried about the medicine. My sister tried to reassure me but I was tense. I thought if the medicine is not available anywhere I will beg for it in all hospitals. I will request them to somehow arrange for the medicines. If I don't get this medicine, I will kill myself along with my child. I could not eat or sleep..... I was weeping uncontrollably... I was in a state of panic. My husband went from shop to shop before he could finally procure the medicine. I heaved a sigh of relief when he succeeded. Currently, we are in touch with the local network who has agreed to help us in demanding free medicines the hospital.

I want to tell the world that all women have the right to be a mother and that if she desires to have children, adequate, free and good quality discrimination free services should be there to help her do so."

Note: A fictitious name has been used to suppress the identity of the person as requested by her

Story 9: "Being positive meant stigma"

33 years Prema's story throws light on HIV related discrimination that still grips our society. As she writes, it becomes evident contrary to the age old belief, education does not change people's stigmatizing attitude towards HIV. Her story also reflects the issue of self stigma that women living with HIV experience – that erodes their self

esteem and stands in the way of realizing their rights.

"I belong to a small village in Maharashtra. I was the eldest among my siblings. Life was good. I passed tenth standard and went to Pune to do an ANM course.

By the time I was 19, I was married. My husband's family was well educated. He worked at a hospital. Since I had done this course on ANM, my father had always hoped that I would work and he felt it would be convenient as my husband was also employed in a hospital. But in the second year of my marriage I was pregnant. I told myself that now I have to look after my home and my children and that I should quit working. As per the custom, I was supposed to go to my parents' house for my first delivery. My mother in law was initially reluctant to send me. She said "This is the first delivery in our house. We won't allow her to go". Finally after much pleading she agreed to let me go to my parents' house.

My father brought me home. I was 7 months pregnant then. I was very happy that I didn't have to work. I can stay as I please and eat whatever I wanted to.

The next day, my father took me to the hospital. The nurse examined me and scolded me, "Why have you come so late? You are very weak. You need blood transfusion. Who will take up your responsibility?" They made fun of my husband, "Where's your husband? He doesn't know how to take care of his wife and he wants to be a father!"

They registered me in but I started my labour soon after. They admitted me and asked my father to make arrangement for blood. My blood group was AB + .It was a rare group and my father had to run from

pillar to post to organize it. Finally he was able to procure blood. I underwent blood transfusion and delivered a healthy baby girl. My husband and my in laws were very happy to bring their first grandchild home.

A year later, I became pregnant again. This time, my husband registered my name in a private hospital. But he hid that from my mother-in-law and used to take me for my checkups behind her back. My mother in law wanted my delivery to take place in a missionary hospital. As the time for my delivery came close the doctors and nurses at the missionary hospital were very rude to me. They did my HIV test without informing me and I was found to be HIV positive. I was in labor and was about to deliver my baby. In that condition, they threw me out along with the bed sheets and blankets on which I was lying. It was past midnight and I was in great pain.

The hospital staff also told my in laws, "She has AIDS. We will not conduct her delivery here. You better stay away from her. Otherwise you will also have this disease!" My in laws treated me like an outcaste. I can't even describe what I was going through... confusion, pain, Then my husband said, "Let's take her to another hospital and get her delivery done. Then we will see what needs to be done".

He took me to the private hospital, where he used to take me secretly. I was unconscious and in that condition, delivered my son. No one except the doctor and nurse touched my son.

My parents were called and without giving any reason I was sent back to my parents' house. I was drifting in and out of consciousness. Whenever I was a little awake, I would wonder why I am here. But

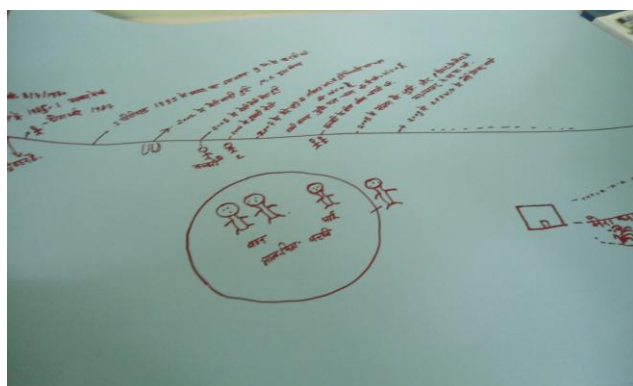
neither my parents nor I knew that I was HIV positive. Six months passed in this haze. My husband never bothered to find out about me .They did not let me meet my daughter. I missed her so very much. I was angry and upset. At the same I was unable to understand the reason for their behavior. I was not happy at my parents' house. My siblings also started considering me as a burden. I thought of going back to my in laws. I decided to ask them what was wrong with me and why they behaved badly with me. I still did not know that I was HIV positive. When I questioned my husband he said, "We can't live together now!" He did not provide me with any reason.

My parents were affluent. They decided to get my health checked. I underwent HIV test too and was found to be HIV positive. In the false hope that the virus would go out of my body, I got my HIV test done 140 times. Then everyone understood that I will remain HIV positive forever. I now knew why my in laws detested me and my baby.

It was then that I decided to leave my parents' house. I did not want them to be unhappy because of me. I thought if I left then my siblings could get married and carry on with their lives. I searched for a shelter home and fortunately was able to trace a care home for people living with HIV. I and my son started living there. I also began working. I was happier to be with other people going through similar circumstances in life as me. I was also glad that I was earning. I felt content that I was supporting other people living with HIV. I also got full and accurate information on HIV. Now I know that HIV does not spread by touching an HIV positive person. I wish I had the correct information earlier. I would not have then left my house and my family. But now what's the use of crying over bygones?

If I or my family members had the information, they would have tried for blood units from a safer source. I wish ...they had the information...I would have led a happier life, a different life. They would not have discriminated against me.”

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Story 10: “My sexual and reproductive rights were violated”

The story of 24 year old Archana throws light on the vulnerabilities of young spouses of key populations like MSMs to HIV and violence. The story unfolds to illustrate the denials of her sexual and reproductive rights – each of which has been an episode of remorse, confusion and pain in itself. It shows that whether it is continuation of pregnancy, lack of sexual relationship between husband and wife or HIV, the fault always rests with women. As she narrates, it becomes only evident that while women living with HIV are particularly vulnerable to gender-based violence for reasons including stigma, more often HIV seems an excuse for escalating violence against women. Archana lives in Maharashtra.

No sex life

“I had an arranged marriage. For a long time, my marriage was not consummated. We used to sleep together but there was no sex between us. Sometimes I felt good about it but sometimes I used to question myself. Is something wrong with me?”

My cousin sister got married at the same time as me and used to talk about the good times between her and her husband. I was dying to tell someone about my condition and decided to tell her...she got a little worried and informed her mother who was the person behind our alliance. Her mother tried persuading my husband but to no avail. My husband’s behavior never changed.

I tried talking to my husband several times. I was worried that I would be blamed for not becoming pregnant.... I also wanted to have sex with him. After much pleading he finally agreed to have penetrative sex just enough to make me pregnant. He never spent additional time with me.... We just had intercourse.....I never got any pleasure... it was all so mechanical and quick. I longed for pleasure .He never allowed me to touch him or kiss him. In my desperation I even told him, “If I go to another man, it will be a shame to you and your family” But he remained unperturbed.

Pressures to be pregnant:

Meanwhile I noticed that my husband fell sick frequently for which he blamed me. I could not understand how I was to blame? But I was worried about his health. Tension was building up for other reasons too. My mother-in-law had started questioning as to why I was not getting pregnant. She gave me all sorts of medicines so that I could become pregnant soon. But how could I

explain to her? We hardly had sex During the time of his illness he did not get erections.....how do I get pregnant? The pressure to have a child became unbearable.

Finally I told my mother-in-law "It is not me but my husband who needs a doctor. He does not want to have sex." My mother-in-law then requested my husband to visit a doctor. He obeyed his mother but never wanted to take me along. I knew that he was given some medicines but the situation did not improve. The next time, I forced him to take me with him. At the clinic, I came to know that those medicines were for inducing erections and that the doctor had asked him to try having sex. I was frustratedhe was not even trying ... so much money was being spent. Eventually with continuous medication, he was able to have sex but like earlier he made it clear that he would only engage in intercourse for procreation.

Positive and pregnant!

His health condition started to worsen. In between I had started doing some stitching work from which I had saved some money. With this money I took him to the doctor. When the doctor prescribed a number of tests for HIV, TB, urine, etc, he refused to comply initially. With much pleading from relatives and friends he finally agreed to get the tests done. I told the doctor to share the report with me first and he did. The reports showed that he is HIV positive and had TB. Next, the doctor advised me to go through an HIV test. The reports revealed that I was positive and pregnant! I could not enjoy the news. I was so upset ...there was no one to help me. My parents were not in the same city. After knowing my status, I cried continuously for 3 months but not a single

soul came forward to console me. I felt angry that my husband was responsible for giving HIV to me. I never felt any love for him...I felt as if I have been cheated.... I felt as if I was being used. My husband never expressed any concern for me or his unborn child. My husband's family only took care of my husband well and his condition improved considerably. It felt as if all have distanced themselves from me. I felt neglected, lonely.

At the hospital, I was told that there is a possibility that my child might be positive despite prophylaxis. With absolutely no support from my husband's family and no surety of the child being negative, I decided to abort the baby. When I was on the examination table, I told my gynecologist that I would like to rethink about my decision to abort. I went back home expecting my husband and my in laws to support me in keeping the child. My husband did not utter a single word. Everyone said, "If your child is negative, we will support you. If not, it's your responsibility". I came back to my room and cried inconsolably. This time I finally decided to abort the baby. My husband and mother-in-law accompanied me to the hospital.

Abortion pills were inserted into my vagina and soon after I started feeling intense stomach cramps also experienced bleeding. The doctor was taking the bloody pieces out and keeping them on the floor. As the entire foetus did not get aborted, doctors decided to conduct a surgical procedure on me. I was HIV positive and the sweeper refused to clean my blood and the tissues on the floor. I was about to clean them on my own but the doctors asked me not to and advised that I get ready for the surgery. I requested my sister-in-law to clean the place. She did by wearing double gloves.

Shocking revelations:

After my abortion, I decided to spend a few days at my parents' house. When I met my mother I wept and wept. After a long time I received words of consolation from someone. My brother supported me do a computer course. I was happier and decided to stay back longer. While I was with my mother, I came to know that my in laws knew about my husband's HIV status before I got married to him. They still persuaded him to marry an HIV negative girl. I was shocked. So was my family. My parents fought with my in laws on the matter and told them to transfer some property in my name. They did not listen...I still came back to live with my in laws.

I often thought, "None of them have any remorse for spoiling my life! Why me? Other girls married into this household are fine. Why does my husband not love me?" I started hating all of them and lived a mechanical life. Though I and my husband slept in the same room, he never tried to speak to me or approach me for sex. He refused to give me any money.

Moving forward

One day I got a phone call asking about my interest to work in an HIV/AIDS project. I readily agreed. Here, I got full information on HIV and I was proud that I was earning. When I mentioned about my husband to my colleagues, they said that they knew that he was an MSM and is involved with an MSM group. If only I knew before! - was the first thought that came to my mind. I was trying to find out why my husband could not make me happy. I knew it was not because of me. I was not willing to leave him. I wanted to stay with him even after he was HIV positive. I gathered more information on

MSM and understood that he would never get attracted to me or for that matter to any woman. I now knew that it's best to part ways. I filed for a divorce and have asked for maintenance too. Through his MSM friends I have come to know that my husband has agreed to grant me divorce and transfer some property in my name. I have now decided to complete my Bachelors and Masters in Social Work and will think of re- marrying in due course."

Note: A fictitious name has been used to suppress the identity of the person as requested by her

Story 11: "HIV escalated my struggle as a single woman"

Veena is 33 years old and belongs to Bihar. She has been living with HIV since 2005. Her story reveals the extensive stigma and discrimination that women living with HIV face within the health care sector and how this acts as a barrier for them to access reproductive care. The story also shows the devastating impact that HIV makes on livelihood options of single women living with HIV

It has been 10 years since I have separated from my husband. After I was diagnosed with blood cancer, my husband left me. I got to know later that my husband is HIV positive but I was not aware of his status when I was living with him.

Since then, I have been living with my three children. When my blood cancer was diagnosed in 2002, my father received a deep shock and passed away soon after due to a heart attack. I felt so guilty and responsible for his death. He was a big support but I lost him.

Discrimination while seeking health care:

I did not want to be a burden on anyone. So I came to Delhi and started living in a rented house. To earn a living I worked as a maid. But three years later, when I fell quite ill I could no longer work. Fortunately I was referred to an NGO who took me to a hospital where I tested HIV positive. I was never counselled on HIV and did not have any information on what it is. Frankly speaking, I did not at that time could fully absorb the news. I was then referred to another hospital for my treatment. The staff there accused me of being HIV positive and turned me away. My brother in law had followed me to the hospital and when he saw the staff accusing me and scolding me, he in turn argued with staff. The doctor then explained to my brother in law about my condition. I was advised a number of tests. It was a pain to move around so muchmy health condition was not permitting me to undergo such physical stress... but I had to undergo those tests to procure my medicines that I received finally. While I was procuring my medicines a thought struck me like lightning. I recalled my husband saying that AIDS killed a friend's entire family. That very moment I did not feel like living any more. I went and stood in the middle of the busy roadI wanted to die.....but my brother in law saved me. He was very supportive....he explained to me that every health condition has treatmentso why worry so much. His reassurance had a healing effect on me. Later I was courageous enough to even tell my children about my condition. I told them "your father had this disease and I have got it from him". They were very supportive.

But I remember being very stressed.....I had 3 children to look after..... I had to raise money to pay rent

.....how will I make both ends meet? Desperately, I was trying to put my children under institutional care. My sister advised me not to make a hurried decision regarding my children. She also agreed to adopt all my children

Discrimination made me hesitant to seek care:

Days passed by and one day I discovered that I had developed a uterine infection. Tests were done and the doctor advised the removal of my uterus. But they would keep postponing the surgery dateI don't know why they did this..... I presume that it was because of my HIV status. I approached an NGO and requested their support. It was only when the NGO intervened did the doctors finally agreed to operate on me. I came on the said date, but when the surgery time arrived, they sent me back asking me to come back the next day. I was furious.....they were just trying to play with me....they were harassing me.... I could not take my cancer or HIV drugs regularly because of their callousness. Next day when I was again made to sit till five in the evening only to be informed that the surgery has been cancelled, I fought with all the doctors and even slapped one of the senior doctors. I told them "you should have said no in the beginning. Why are you making me run around? Now you have to perform the surgery" I complained against them to the hospital authorities and threatened to press charges against them. Finally, my surgery was performed. The NGO workers were constantly by my side. However, when I regained consciousness after the surgery, I was shocked to see "HIV positive" written on my bed and on all my utensils. I felt angry and judged. I was worried that others including my cancer specialist would come to know that I have

HIV. What if he stops treating me? I don't want the entire world to know that I am HIV positive. Hurriedly I removed the writings but the hospitals staff rewrote. The staff would wear three gloves before attending me. I fought with the staff.....I told them you won't get the disease like this.....you will get it only through my blood.....by that time I had some information from this NGO. But the discrimination continued. As opposed to 15 days, I was discharged from the hospital within 3 days. I never went back for any follow ups. I feared the same treatment and I did not have the energy to fight such an exhaustive battle again.....but my stitches tore and I had to go back. After re stitching, the doctor refused to bandage my wounds. When I pleaded they somehow covered the woundsfor the next 15 days my brother in law changed my bandages regularly at home.

Moving ahead in the midst of struggles:

I have tried working for 2 years as an outreach worker but now I can't work anymore. My poor health condition does not permit me to work. My elder son now works and I have been able to put both my daughters in the church hostel. Thankfully the church bears all their expenses. A public hospital in Delhi provides me with free cancer drugs but I have to spend money for other tests. I forego them because of dearth of money.

I have gone through numerous struggles in life and I want to seek justice. My husband has spread in the community that I have AIDS and is trying to avoid giving my children their share in his property. But I will keep fighting till I can restore my children's rights. I hope I am soon able to start a

network of my own to fight such injustices that women living with HIV face.

In the end, I would like to emphasize that doctors and the counsellors must be sensitive to the needs and feelings of women living with HIV. Discrimination against them must end within the healthcare system. HIV affects one's livelihood and that prevents them from paying for services. I want government to provide free health care services for people living with HIV especially for single women living with HIV.

Note: A fictitious name has been used to suppress the identity of the person as requested by her

Story 12: "HIV made me more vulnerable to violence"

Shobha's story points to the violence that single women living with HIV experience and the emotional repercussions they suffer due to violence. As indicated in the earlier stories HIV pushes her further down the power ladder, making her more vulnerable to violence. Shobha belongs to a small village in Uttar Pradesh and is 25 years old.

The economic situation at my home was poor, due to which my parents married off all of us early .I could afford to read only till the fifth standard. In 2004, I was married off to a man 10 years older than me. I was only 17 years old then.

My husband worked in Mumbai and I lived in the village with my in laws. He visited me in the village twice or thrice a year. There, I had to do all household chores and work on the farms as well. Meanwhile because of

health reasons, my husband also left his work and returned to the village. My in laws accused me for my husband's illness. His health worsened and subsequently he was diagnosed with AIDS. The doctor asked me to have an HIV test too. I was scared and refused. My husband's health deteriorated further and he passed away.

Soon after I got an HIV test done and was found to be HIV positive. I was damn panicked. I was worried as to who would look after me and my child. My in laws did not support me at all. They never talked to me and isolated me. They would often beat me up and throw allegations at me.....it was becoming unbearable.....sometime I felt I could take it no more. I would ask them "what is my fault if I have HIV?" But to no avail....the answer remained the same....I had HIV!

I did not want to live in this hell but what else could I do? My parents were poor and I did not want to trouble them. Sometimes they supported me for my treatment.

I was thus struggling in my life hoping that I would die soon. Meanwhile, I got associated with the local positive people's network and started visiting them. I started working with them and got full information on HIV. My emotional stress decreased and my condition improvedI was happier and healthier.

I currently live with my 2 children. "I wish my husband had correct information on HIV earlier. With right information, treatment and support, he would have lived longer" is the thought that crosses my mind again and again.

Note: A fictitious name has been used to suppress the identity of the person as requested by her

Story 13: Support and love is critical to fight with HIV

Anuja's story is an affirmative one and shows how it is possible to lead a fulfilled life with HIV if there is a strong support system within the family and community. Her story also reveals the significance of access to technologies like PPTCT drugs in addressing the reproductive rights of women living with HIV like the right to have children. AJ is 36 years old and lives in Uttar Pradesh.

I am from Allahabad, Uttar Pradesh. I have an elder sister and a younger brother. I had a wonderful childhood. I consider myself really lucky to have such loving parents who reared me with such love and care. My family was very progressive and the environment at home was liberated. Days passed and I completed my post graduation. Soon after my post graduation, I got married. My husband was a very understanding, sensitive, progressive and open minded personI was very happy in my marriage.

A few months after our marriage we relocated to Mumbai for work. For 2 years everything was well. But in 2003, my husband suddenly fell ill and the doctor, among other tests, advised an HIV test. His reports showed that he was HIV positive.

At that time we did not have any information on HIV. We had heard that HIV means death. When we learnt about my husband's HIV test results, both of us criedwe were shocked and our life seemed meaningless.

After 2 months, I also underwent an HIV test and what I feared came true. The result was positive. These tests were conducted at a private hospital and a lab technician there

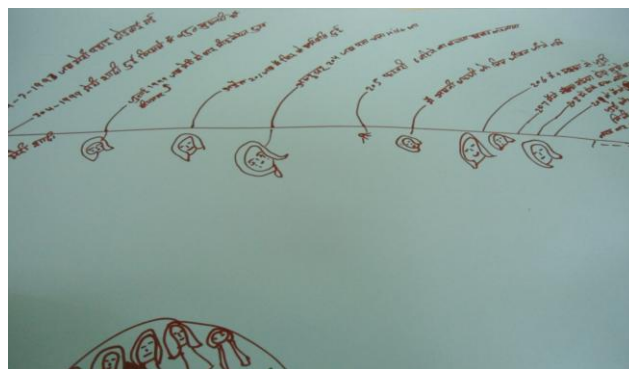
provided us with ample information on HIV. It was then that we also got to know that if we plan a baby, the baby could be born infected with HIV. Both of us decided to not have any children. Although we were sad, our hands were tied. We could not risk having a positive baby.

During those bad times, my in laws stood by us. In fact, my brother in law was supporting my husband's treatment at a private hospital in Mumbai. My husband's health improved and two years later, we returned to Allahabad. We wanted to look after my mother in law and father in law and to begin a new venture. In 2006, we met an NGO worker through whom we got associated with a PLHIV network. This significant turn of events brought several positive changes in our lives. We met other fellow PLHIVs and got lots of information on HIV. Filled with new hope and enthusiasm, we initiated a new network of PLHIVs in Uttar Pradesh. Now both of us are supporting other people living with HIV and guiding them to lead healthier and happier lives. Such work gives us immense joy.

There is only one hitch. Sometimes I and my husband repent over our decision to not have children. Through our work we got to learn about PPTCT and how with the help of appropriate drugs, an HIV positive woman can also give birth to an HIV negative child. We strongly hope that one day we will also be the proud parents of a healthy child.

Walking through the ups and downs of life has been enlightening for us. We, wish that all people living with HIV have adequate support system to lead healthier lives.

Note: A fictitious name has been used to suppress the identity of the person as requested by her



Lessons learnt:

We found that the women were at varying levels of wanting to be visible. A few were eager to publish their stories (with their names) worldwide to create an influence in the policy space and to serve as role models for the rest of the community. However, for most, this was the first time they shared their personal lives and were reluctant to share their real names. None were willing to be filmed. Most agreed that using real names and photographs would create a more powerful advocacy impact but that they had not yet reached that stage. It seems an ongoing process of building capacities and creating more such opportunities could move them towards lending their voices more actively towards the HIV movement.

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