



Walking in our shoes

Perspectives of pregnant and breastfeeding women living with HIV
on access to and retention in care in Malawi, Uganda and Zambia



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Executive Summary

In 2016 in Eastern and Southern Africa, 89% of pregnant women living with HIV received antiretroviral treatment to prevent vertical transmission of HIV.ⁱ Despite this scale-up, in the same region an estimated 77,000 children (aged 0–14 years) acquired HIV in 2016.ⁱⁱ AIDS-related illnesses also remain the leading cause of death for women of reproductive age (15-49 years) globally.ⁱⁱⁱ

With countries now providing lifelong treatment to pregnant women living with HIV, one of the biggest challenges is for healthcare systems to retain women living with HIV in lifelong care. But investments in programmes to prevent vertical transmission of HIV decreased by 7% from 2015 to 2016, to US\$41 million.^{iv}

While many studies have explored and defined the challenges faced by women living with HIV in accessing and being retained in care and studies, such as INSPIRE,^v have focused on approaches to improve retention in care, few studies have focused on the perspectives and lived experiences of women living with HIV in evaluating and identifying factors that facilitate retention.

This community-led study was coordinated by the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV (ICW). The research was conducted in country by peer researchers from ICW Malawi, ICW Eastern Africa and the Network of Zambian People Living with HIV/AIDS (NZP+). The study sought to understand the factors that facilitate women to adhere to treatment and return to health facilities for routine care from their own perspective. The researchers focused on Malawi, Uganda and Zambia, early adopters of the global guidance to provide lifelong treatment for pregnant women living with HIV (Option B+) and spoke to women living with HIV, healthcare workers and programme managers to discover which factors and practices show promise in supporting women to initiate and remain in care.

Through a series of focus groups discussions with women living with HIV and in-depth interviews with key informants¹ this research set out to answer three key questions:

1. **What are the factors that help pregnant and breastfeeding women living with HIV remain adherent to treatment and remain in care? (At an individual, inter-relational and institutional level)**
2. **What is the role of healthcare workers in promoting adherence and retention for women living with HIV in lifelong care and treatment?**
3. **What are the strategies currently in place to promote adherence and retention and how can they be improved?**

The health facilities at the centre of this research have initiated large numbers of women living with HIV in services to prevent vertical transmission. More importantly, they are also striving to find ways of ensuring that those women continue to adhere to their treatment and access care. This study found that women living with HIV who access these services to prevent vertical transmission have a strong sense and understanding of what factors support their retention and how health facilities, the wider community and their friends and relations can best support them.^{vi} This report shares their words to describe how it feels to walk in their shoes on the path of life long treatment.

¹See Research Methodology for more detail

Key findings

The research shows that, at an individual level, when women are provided with complete information and allowed the time to absorb and understand it, they are strongly motivated to adhere to HIV treatment for their own health and that of their baby.

As members of the focus groups discussions held in Malawi highlighted, most women are determined to continue their HIV treatment:

“The moment I accepted that I would take them my entire life, I told myself that I would walk the journey without looking back” Woman living with HIV, Lambulira, Malawi

“I tell myself that no matter what challenges I face, I will stay on treatment”
Woman living with HIV, Makata, Malawi

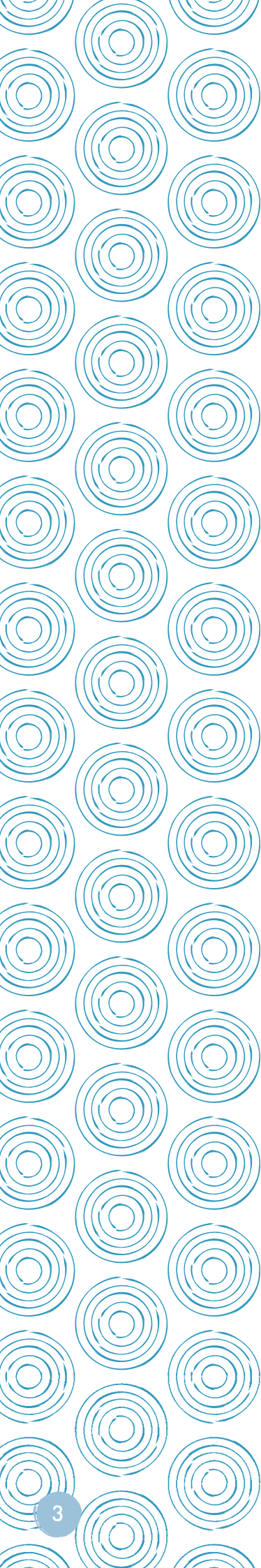
Yet, this research also supports the reality that determination alone is not enough. For health systems to retain women living with HIV in care, it is vital that we understand what facilitators women need to support them along their treatment journey. Our research revealed three primary factors play a critical role in facilitating adherence and retention:

1. **assisting and empowering women living with HIV with practical and emotional support**
2. **improving the quality of services, and**
3. **respecting the rights and dignity of women living with HIV by addressing stigma and discrimination.**

At an inter-relational level, women who have both practical and emotional support from either family or friends find it improves their ability to remain in HIV care. Stigma and discrimination at the community level continue to make it difficult for many women living with HIV to disclose their status to even their closest relations preventing women from being able to access important family support.

At an institutional level, women living with HIV feel that psycho-social support from counselling and through peer support schemes is a key factor in facilitating their retention in care.^{vii} Ensuring that women can afford their treatment, offering important tools such as free CD4 count testing, as well as providing robust nutritional supports were identified by focus group participants as practical facilitators. Our research also strengthens the call for increased investment in support groups and peer support as key facilitators of adherence and retention.^{viii}

Like all women, women living with HIV have the right to the “highest attainable standard of health”^{ix} and to realise their full sexual and reproductive health and rights including the right to choose if and when to have children. At the institutional level ending stigma and discrimination in healthcare settings would be a key facilitator for women to access and remain in care.



Prioritising the realisation of these rights in the context of PMTCT programmes is essential to creating an environment that facilitates adherence and retention. Women in this study felt supported by services and facilities that reflected their needs and concerns. Encouraging and sympathetic staff and volunteers were a source of strength and confidentiality was of paramount importance. Initiatives that adapted services to make them more women-friendly were welcomed, in particular differentiated service delivery, short waiting times and community-based services.

Recommendations

Throughout this report we have shared the individual, inter-relational and institutional factors that these women identified as facilitators for their care. The focus group participants were also asked to explain what more could be done to support their treatment adherence. The recommendations below combine their suggestions with those of the people who work to provide HIV services.

Support and empower women living with HIV:

1. Provide comprehensive counselling

High quality counselling is of paramount importance to facilitate adherence from the point prior to testing through to treatment and care. Counselling must be available for women diagnosed with HIV during pregnancy or breastfeeding to support them to understand the diagnosis and the benefits and challenges of treatment. They may also need counselling and support to disclose their status, if they choose to. Staff providing counselling services must be well-trained and the cadre of counsellor should be recognised and integrated among the staffing requirements for facilities.

2. Invest in peer-support initiatives at community and health facility level

Programmes that enable women living with HIV and their families to gain support and learn from their peers are invaluable in all their forms including: support groups, peer mentors, mentor mothers, male mentors, etc. A variety of peer support should be offered to address the differing needs of women, i.e. adolescents, breastfeeding women etc. Peer support should also extend beyond a narrow HIV focus to offer support for other aspects of women's lives, including skills training, savings schemes, and income generation. Staff and volunteers need to be given training and support to ensure that the guidance they provide is high quality and based on the latest evidence. Peer support initiatives, that are shown to be effective, should be fully financed – especially those that are led by networks or groups of women living with HIV.

3. Scale-up comprehensive treatment literacy programmes

Pregnant or breastfeeding women diagnosed with HIV, must be provided with all the information they need to understand the benefits of treatment, the possible side effects and the need for adherence. Equally, each woman must be given time and support to absorb and understand that information so that she can make informed choices. This is particularly critical as women with HIV embark on lifelong treatment during their pregnancy when often the focus is on the baby's health. Treatment literacy programmes can be delivered most effectively by peer educators, networks of women living with HIV and other community groups – they need adequate funding and support to ensure that they reach all communities in rural and urban areas.

4. Ensure male involvement initiatives are sensitive to women's realities

Initiatives to encourage male partners to engage in HIV and PMTCT programmes can benefit women and their families. However, these initiatives need to be designed and implemented in ways that do not have negative consequences for women (such as

facing violence, being thrown out of their homes or being turned away from services because they do not have a male partner).

Improve the quality of health services:

5. Design and implement health services that are person-centred

Differentiated service delivery approaches are needed to meet the specific needs of women who are accessing HIV, PMTCT and maternal health services. Service delivery should also minimise inconvenience and ease access. This may include use of mobile clinics, drug distribution points, moonlight and weekend timings, appointment tracking, task shifting and linkages between services.

6. Invest in adequate numbers of trained and motivated healthcare workers

HIV treatment and care services must be safe, accessible, acceptable, affordable and appropriate. Minimum standard of care policies and standards should be set at the national level and comprehensively adhered to by programme staff. In order to deliver high quality services, healthcare workers, including community healthcare workers require ongoing training, support and recognition for their work. Staffing levels must also match the demand for services.

7. Ensure that all women have access to healthcare

Poverty should not be a barrier to healthcare; services must be accessible to all. Wherever possible treatment and care should be free at the point of use. All efforts should be made to support women, including social grants to cover transport costs, nutritional support and schemes to encourage income generation.

Respect women's rights and dignity:

8. Invest in efforts to end stigma, discrimination and violence

Retention levels and uptake of health services will continue to be held back so long as women face stigma, discrimination and violence. Programmes to reduce these are needed at every level addressing partners, community members, faith and traditional leaders and health workers. These programmes also need to be supported by policies and laws that promote the rights of people living with HIV and key populations to access services and not criminalise them.

9. Embed respect for human rights in service delivery

All staff and volunteers providing services must be well trained and supported to respect the human rights of women living with HIV and treat them with dignity. Services should be designed and delivered in a way that guarantees confidentiality and respects informed consent. Rigorous mechanisms, such as a confidential complaint system are required to respond to complaints of discrimination and other human rights abuses by health workers, such as reports of mandatory testing or forced or coerced sterilisation of women living with HIV.

10. Meaningfully involve women living with HIV

The principle of engaging affected communities meaningfully needs to be put into practice. Women living with HIV understand what works and what does not and can help design and implement programmes that are effective. There is also a need to ensure opportunities for monitoring and feedback from women and the wider communities utilising services so as to improve programmes.



Background

The global picture

17.8 million women in the world are living with HIV.^x These women need treatment and care to meet their own health needs. Many of them are of reproductive age and also need support to help prevent vertical transmission of HIV. Two key global initiatives have spurred progress in both these areas. Launched in 2011, the *Global Plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive*^{xi} galvanised action to improve services to prevent vertical transmission in 22 priority countries. The plan helped set targets, drive political commitment and increase financial investment to reduce the number of new HIV infections among children and the number of HIV-related maternal deaths. Alongside the Global Plan, the World Health Organisation (WHO) announced a significant change in its 2013 Consolidated Antiretroviral Guidelines,^{xii} recommending that countries provide antiretroviral therapy to all pregnant women living with HIV regardless of their CD4 count, either for the duration of the transmission risk period (Option B) or lifelong (Option B+).^{xiii} Many countries adopted the latter option of lifelong treatment as their preferred approach. WHO's 2016 Consolidated Guidelines^{xiv} moved away from "options" and recommended that all pregnant and breastfeeding women living with HIV should initiate ART and remain on lifelong treatment, regardless of CD4 count or clinical stage of disease.

Throughout this report we shall use the phrase *lifelong treatment* to refer to the recommendation originally known as Option B+.

Where possible, we have chosen to use *prevention of vertical transmission* in this report rather than the more common *prevention of mother-to-child transmission (PMTCT)* to avoid adding to the stigma faced by a woman living with HIV.

Now, a new global initiative led by UNAIDS and PEPFAR, "Start Free, Stay Free, AIDS Free" recognises the need to do more to build on the momentum achieved through the Global Plan and other initiatives, including the implementation of lifelong treatment. "Start Free, Stay Free, AIDS Free" has set a target to reach and sustain 95% of pregnant women living with HIV with lifelong HIV treatment by 2018 regardless of their CD4 count.^{xv}

Introducing lifelong treatment

Malawi began offering lifelong treatment (Option B+) in 2011 – before the release of WHO's global guidance.^{xvi} Many other countries swiftly followed the WHO guidelines, and Malawi's lead, offering lifelong antiretroviral treatment to pregnant and breastfeeding women living with HIV. Uganda launched its policy based on lifelong treatment in 2012, rolling it out nationally throughout 2013.^{xvii} Zambia began offering lifelong treatment nationwide in 2014.

Lifelong treatment was particularly recommended for countries with a high incidence of HIV and limited access to CD4 testing, in the hope that a simplified approach would enable more women to access ART (antiretroviral treatment).^{xviii} The latest WHO data seems to confirm that this has occurred; between 2010 and 2016 the percentage of pregnant women living with HIV accessing ART to prevent vertical transmission rose from 47% to 76%. Specifically, pregnant women living with HIV accessing ART rose to 84% in Malawi, 83% in Zambia and over 95% in Uganda.^{xix} Increased ART uptake between 2009 and 2014, led to a 45% decline in the number of

THE NUMBER OF NEW HIV ACQUISITIONS AMONG CHILDREN AGED 0-14 ^{xxi}

Country	Year	2011	2013	2016
Malawi	2011	13,000	8,900	4,300
	2013			
Uganda	2012	16,000	5,300	4,600
	2014			
	2016			
Zambia	2014	12,000	7,900	8,900
	2015			
	2016			

HIV-related deaths among women of reproductive age in the Global Plan countries. During the same period, the number of babies born with or acquiring HIV in infancy in these countries halved.^{xx}

Problems still to overcome

While significant advances have been made since countries began to implement lifelong treatment, AIDS-related illnesses remain the leading cause of death worldwide for women of reproductive age.^{xxiii} There are also persistent programmatic challenges such as retaining women living with HIV in care and preventing women from acquiring HIV (sero-conversion) during their pregnancy. When WHO issued its initial guidance on Option B+ (lifelong treatment), it warned that it was “no easy fix” for the challenges of increasing access to treatment for women living with HIV and supporting their transition from services to prevent vertical transmission of HIV to HIV treatment and care services.^{xxiv}

As more pregnant and breastfeeding women embark on lifelong treatment for HIV, adherence is critically important: to improve their own health and suppress the virus; to avoid developing HIV that is drug resistant; and to reduce HIV transmission. UNAIDS data, and numerous studies, show that although increasing numbers of women are beginning antiretroviral treatment while pregnant, after their baby is born significant numbers of them stop accessing services and are not retained in care.^{xxv}

For example, in Malawi, research showed that 17% of women who started antiretroviral treatment during pregnancy or breastfeeding were no longer retained in care six months later. Also, compared to patients who started ART for their own health, women who started ART while pregnant were five times less likely to return to the clinics after the initial visit and women who started ART while breastfeeding were twice as likely to miss their first follow-up visit.^{xxvi} In Uganda, an assessment carried out by the Ministry of Health in 2013 revealed that 28% of mothers newly initiating ART did not return to the clinic after their initial visit.^{xxvii} A study of longer term adherence in Zambia revealed that adherence to ART declined after giving birth.^{xxviii}

Considerable research has been done to understand the operational and clinical challenges, as well as the personal, interpersonal, and social barriers that affect adherence and reduce women’s ability to fully participate in HIV care.^{xxix} There is sufficient evidence that clearly demonstrates the challenges that limit retention across many countries.^{xxx} However, less is known about the converse - what factors at the institutional, interpersonal, and individual levels support retention and facilitate long-term engagement in care.

A deeper, more nuanced understanding of the facilitators and effective strategies that promote adherence and retention in care is needed to ensure that the promise of lifelong treatment is achieved. While studies have explored these issues from the perspective of service providers^{xxxii}, few have examined promising practices from the perspective of women living with HIV who have used services to prevent vertical transmission.

Building on our research

In 2013, ICW and GNP+ carried out research to understand the perspectives of women living with or affected by HIV regarding Option B+. ^{xxxi} Focus group discussions were held in Uganda and Malawi and a report outlining the findings was published in 2013. The research showed that women living with HIV had concerns about the implementation of Option B+. They feared: adherence difficulties; lack of counselling, information and support; a risk of coercion; adverse side effects and drug resistance.

“Maintenance of viral suppression with ART—achieved by supporting continued adherence to the ART regimen—is crucial to the additional benefits of the Option B and B+ interventions and to minimizing adverse consequences.....It is particularly important for programmes implementing Option B+ to develop strong systems to support adherence and retention and to build evidence of successful practices through implementation science.” WHO^{xxxii}

This research

This study builds on previous research into the challenges facing women embarking on lifelong treatment and uses as a foundation other research into adherence and retention.^{xxxiii} This report focuses on the perspectives of the ultimate beneficiary of lifelong treatment, women living with HIV, and looks at the factors that influence their adherence to treatment and retention in care.

Ten focus groups discussions were held in locations across Malawi, Uganda and Zambia, to hear directly from women what factors they felt helped them to be retained in care. A full description of the site selection process can be found in the Research Methodology. In summary, the locations were chosen because they have relatively high retention rates (higher than the national average) and have been implementing lifelong treatment for more than 18 months. The majority of the women who participated were pregnant or had given birth within the preceding 12-24 months and all were living with HIV.

The research was conducted and led by community representatives from ICW Malawi, ICW Eastern Africa and NZP+. In addition to the focus groups, interviews were carried out with 25 key informants at district level - healthcare workers and community leaders engaged in PMTCT programmes, nurses, facility-based counsellors, peer educators and community health workers. While it was not possible to secure interviews with each stakeholder in all three countries, researchers also interviewed key stakeholders at national level – PMTCT programme managers at the Ministry of Health, implementing partners, UN agencies and leaders of community organisations².

All research participants were asked for their views on the factors facilitating retention and their recommendations to overcome any remaining challenges. The following report explores the results of the focus group discussions and interviews to identify the individual, inter-relational and institutional factors that the participants believe support the retention of women living with HIV in lifelong treatment.

²More detail on the selection criteria can be found in the Research Methodology.



The Findings

The women who participated in the focus group discussions, and the key informants were predominantly very positive about the introduction of lifelong treatment for women diagnosed with HIV during pregnancy or breastfeeding. In particular, they highlighted the benefits of an approach that prioritises the health of both the mother and the baby:

"In the old days, out of five pregnant women, three might deliver HIV positive babies, now I challenge you to find a positive baby. It is very successful!"

Healthcare worker, Chitipa, Malawi

"It's better this way. In the old days, you took a tablet when labour started to protect the unborn child, these days, the treatment is for good health of the mother and the child. The mother's body stays strong and the baby is born healthy and strong too."

Woman living with HIV, Chimtende, Zambia

The participants explained that women living with HIV now appeared to have more confidence to breastfeed. They welcomed the health benefits breastfeeding brought for the baby and described how it also helped reduce some of the stigma attached to being a mother living with HIV:

"Mothers breastfeed until the baby is about one year, that's when they wean which is good for nutrition. Way back they would wean at six months and the baby would suffer with malnutrition and [being] underweight"

Healthcare worker, Chimtende, Zambia

"They know that with Option B+ it is ok to breastfeed, so long as they take their drugs very well. They do breastfeed, they avoid that stigma of people saying, this one is not breastfeeding, it is an HIV positive"

**Healthcare worker,
Nsangi, Uganda**

The women living with HIV who participated in this research were fully aware of the challenges associated with starting treatment for life during pregnancy or the breastfeeding period. While they spoke openly about the problems women faced, they also identified factors that they believe have helped to support women to remain adherent to HIV treatment.

Knowing the health benefits

During the focus group discussions, the participants described how they wanted to continue taking antiretroviral treatment because they could see the advantages it brings; they identified three key factors that motivate them to adhere to their treatment. First, they want their children to live free from HIV. Second, they wish to be healthy themselves and live long and full lives. Finally, they want to be able to care for their children - this includes being able to breastfeed safely, to support their children emotionally and practically, and to provide for them financially. In each country, women emphasised the need to make sure that pregnant and breastfeeding women living with HIV are given a clear understanding of the health benefits of antiretroviral treatment. They believe this information will motivate women to begin treatment and adhere to it.

“The women want their babies to be negative; they have responsibility for their families and want to be alive longer to keep (their) family.”

Healthcare worker, Mukono, Uganda

Having a healthy baby

While the desire to prevent their babies being born with HIV is a strong motivator for many women, it can also lead to challenges for retention in HIV care. After the baby is born, evidence shows that many women stop taking their treatment. One implementing partner in Uganda explained that 12 months after beginning treatment around 88-90% of people are still adherent to their treatment. For pregnant women, who initiated treatment when they were pregnant, the adherence rate at 12 months drops to between 70% and 75%. Different factors may contribute to this, such as women not feeling the need for medication if they are asymptomatic and a lack of quality counselling at treatment initiation (see psycho-social support section below) and relocation after giving birth, but one key factor seems to be that some women cease to be motivated to adhere to treatment once their baby is born without HIV.

“No woman would ever want to have a baby who is HIV positive. Even if they do not disclose their status, women will find a way of taking their medication ... to ensure the safety of their babies. Those who leave the programme tend to do so if they know/or are assured that their baby is HIV negative.”

Community Leader, Uganda

Staying healthy

Often PMTCT programmes focus on telling women how ART can prevent HIV transmission to their babies. Many of the participants in this study shared their conviction that women living with HIV must fully understand the benefits of treatment for their own health if they are to be retained in care after their baby is born. Women who began treatment, and experienced good health as a result, were motivated to continue to adhere to treatment. They wanted to feel well themselves, and they wanted to stay in good health to be able to care for their families.

“What really motivates me is, I have to look after the kids, I have to stay alive until they are independent.”

Woman living with HIV, Chimtende, Zambia

"What motivates me to take this medicine is that I want to see my children going to school. I want to see them healthy. I want them to go further in life while I am still alive. I want to educate them and take care of them."

Woman living with HIV, Entebbe, Uganda

"If you do not take it, you fall sick but when you take it, you stay healthy. It motivates you because you wake up in the morning energized to do the things you want to do."

Woman living with HIV, Mukono, Uganda

"I have seen HIV positive people do amazing things because they are on treatment and are well"

Woman living with HIV, Kaete, Zambia

"When you see how well other women are looking ... you are encouraged. Some are open and actually tell you they have been on these treatments for many years, that really encourages you"

Woman living with HIV, Kaete, Zambia

Positive role models were another strong motivator for women. Seeing other women living with HIV leading healthy and productive lives, inspired them to begin treatment themselves.

It is worth noting that "fear of side effects" was listed by many women as a reason for not adhering to treatment. Both the focus group participants and the key informants highlighted the importance of understanding possible side effects before treatment is begun so that women are fully prepared.

"If they have side effects, help them to manage them, otherwise the woman will make the decision to stop treatment."

Healthcare worker, Lambulira, Malawi

"Though I do experience hallucinations, I have continued treatment because I was forewarned at the clinic that it will go with time." **Woman living with HIV, Chitipa, Malawi**

"Women should get good counselling and encouragement. They should be told how they will feel when they start taking treatment They should be told the benefits, this is not the same for everyone; sometimes you can be sickly if you do not take medication however, with medication that can stop."

Woman living with HIV, Chimtende, Zambia

Encouragement from family and friends

The attitudes and reactions of friends and family play a significant part in helping women to adhere to treatment. Post childbirth all women require support and care to recover from the pregnancy and labour and to attend to their new-born. For women who are recently diagnosed with HIV, the need for support is heightened as they come to terms with their HIV diagnosis and their treatment. For some women in the focus groups, their friends and family were a great source of strength, offering emotional support and encouragement alongside practical support such as transport to the hospital, financial assistance, food and help with childcare.

"Sometimes my son is the one who goes to collect medicine on my behalf and he reminds me when it is time to take it."

Woman living with HIV, Lambulira, Malawi

"My husband helps me look after the children and do household chores during my appointments and sometimes gives me transport money to use when going to the clinic."

Woman living with HIV, Chitipa, Malawi

"For me it is my grandmother who helps me. She buys me milk which I take and also buys me food ... she reminds me and even tells to come on my date of appointment. She also gives me money for transport here."

Woman living with HIV, Mukono, Uganda

In each of the three countries, fear of stigma and discrimination remains a considerable problem. Women shared their experiences of discrimination and rejection by their family and friends and spoke of the isolation they felt coping with all aspects of their HIV status on their own and in secret. As the quotes below show, disclosure support programmes are critical, as are programmes to sensitize men. When women do not have support from their partner(s) it can be particularly difficult for them to adhere to treatment. In each of the countries the issue of male involvement arose time and time again.³ In Malawi, key informants attributed a male mentor scheme with the increased sensitization of men.

"We take turns to look after children. On her clinic days, she leaves kids with me, and I also leave mine with her on my clinic day." **Woman living with HIV, Katete, Zambia**

"Previously, women reported keeping drugs at home without talking to husbands and fear of husbands finding out. Now, women are encouraged to bring partners; (there is) information and advice for discordant couples" **Healthcare worker, Zomba, Malawi**

Although voluntary male involvement programmes can be beneficial for some women, for others the risks of disclosing to their partner are too high - for example, the possibility of abandonment, violence or being thrown out of their home. In these situations, requiring or mandating male involvement is unlikely to provide any support for adherence and could instead have damaging consequences. Every woman must be treated as an individual and her rights and autonomy respected while supporting her decision-making regarding disclosure.

"My ex-husband used to be violent when he is drunk, so I didn't disclose my status to him. Instead we worked a plan with my sister. She used to keep the drugs for me."

Woman living with HIV, Makata, Malawi

³ See sections below on psycho-social support and support from peers and wider community

Support from peers and the wider community

Women spoke candidly of the impact their communities have on them and the attitudes of their friends, neighbours and community leaders. As discussed in the previous section on family and friends, the role of community can be both positive and negative. Where stigma is low and messages from community leaders are positive, women feel emboldened and able to draw on their family and community members for support. Where stigma is widespread and discriminatory behaviour common, women feel afraid to disclose their status and face additional difficulties adhering to HIV treatment.

“Some don’t come because of stigma. They say, I can see too many people there.” Healthcare worker, Mukono, Uganda

“I faced stigma from other family members who later accepted due to the availability of messages which are being preached through support group members when they are doing community sensitization meetings and in the radios.” Woman living with HIV, Makata, Malawi

“My challenge is with the people around me. Once they get to know that you are on medication, they may go around telling everyone that you are infected.”

Woman living with HIV, Entebbe, Uganda

Support groups and one to one peer support:

Participants in the research spoke very positively about the advantages of initiatives that brought healthcare services into the community, making it easier to access treatment and care. These included services such as community drug distribution points, village health teams, community volunteers and peer counsellors.

Community-level support groups were discussed in each of the focus groups; they were identified as a significant source of support at both a psychosocial and a practical level. Beyond medical support women also spoke of initiatives that helped them materially and financially, such as micro-credit schemes and food banks. Support groups that included an element of skills development, income generation or savings scheme were seen by many to be the most valuable.

Community-led interventions

Services provided by community members that key informants believe help to improve retention among women living with HIV

- support groups /networks for women living with HIV
- treatment literacy programmes
- adherence clubs (including specific adolescent clubs)
- treatment buddies, community-based volunteers
- income generation activities
- village savings schemes
- community and religious leaders giving health messages
- promotion of partner / male involvement / male motivators
- sensitization / anti stigma education

“At the support group, we do have Village Savings Loan programme which has helped us to grow economically. I am able to support my family because of that. Though it’s not enough but at least we are trying” Woman living with HIV, Makata, Malawi

“The support group meets every Friday. We loan each other money, we do many income-generating activities. We encourage each other to stay on treatment even despite messages from church.”

Woman living with HIV, Lusaka, Zambia

The community was seen by most participants as a potential source of psychosocial support, through a variety of different initiatives including women's groups, peer counsellors, expert clients and couples counselling. A community leader in Malawi described how valuable expert clients were as **"they have walked in the shoes of the client"**. Women shared their experiences of the different types of support they had received.

"At the support group, we share with each other the challenges that we are facing while taking the ARVs and encourage one another on how we can overcome them."

Woman living with HIV, Makata, Malawi

"There is a group for the parents and caretakers of HIV positive children, called emitito. It is for parents and care takers of HIV positive children where they save for them so they can have a better future."

Woman living with HIV, Nsangi, Uganda

Increasing peer support

Women in all three countries called for more support groups to be set up. Key themes emerged across all the countries; women spoke of their desire for groups that were led by women, where confidentiality was maintained and practical support could be offered. In Malawi, when asked what intervention would be most helpful, one woman said: the

"formation of women-led support groups so that we are able to share best practices and get training in treatment literacy, IGA [Income Generating Activities], nutrition and village savings loan relevant trainings"

Woman living with HIV, Chitipa, Malawi

Peer support

Throughout the three countries, much of the work that is done to counsel and support people living with HIV is conducted through peer support programmes. These vary in each country, with different names and assorted roles, but usually they involve people who are living with HIV drawing on their personal experiences to offer counselling and adherence support to other people living with HIV. The peer counsellors often work out of clinics as well as in the community and offering home visits.

In Malawi, the term expert client is used as well as, peer counsellor, mentor mother and male mentor.

In Uganda, they are sometimes described as peer educators, peer counsellors, peer mothers or expert clients.

In Zambia, they have Safe Motherhood Action Groups (SMAGs) that work both within clinics and in the community offering services and support relating to family planning, ANC, HIV testing and PMTCT. The terms lay or peer counsellor are also used in Zambia.

"If only we could form a sacco [savings/credit union] to foster development or to also remind each other about the time to take medicine."

Woman living with HIV, Entebbe, Uganda

Among the women who participated in the Ugandan focus groups, there was very little awareness of any support groups for women living with HIV. The participants thought they would benefit from the creation of such groups.

Across the Zambian focus group discussions, women also called for the creation of more peer support groups. In one, region, the women unanimously agreed they had no such groups available to them.

“We can make a support group amongst ourselves – it would help even those who are ashamed. Some issues are difficult to offload to someone who is HIV negative. If the clinic or any organisation would help us to set up that would help.”

Woman living with HIV, Katete, Zambia

Engaging and informing local leaders

In all three countries, women consider church leaders, headmen and elders to have a powerful voice in their community. Both focus group discussion participants and key informants spoke of local leaders setting a tone that shaped how women living with HIV were viewed and treated within the community. In some cases, they recounted feeling harshly judged by members of their community and thus attempting to hide their HIV status, making it harder for them to adhere to their treatment. Conversely, other participants gave positive examples of community leaders openly supporting them.

In one Zambian region, a specific workshop had been held to talk to village chiefs about the importance of involving men in the care of their partners and children who are living with HIV. As a result, the headmen urged men in their communities to escort their partners to the ANC clinic and other health facilities. In Malawi, male study circles had been organised. These male-focussed days highlighted initiatives at the health facility and encouraged men to be involved in the care of their partners and their own healthcare.

“Headmen can be made aware of all the programmes happening at the clinic, so that they can help with the awareness. It is good when the headman knows and says things, because then the people will follow. For example, male involvement has really taken up because the headmen were involved. They can still do more for the few men who do not come.”

Healthcare worker, Chimtende, Zambia

“There should be women support groups for PMTCT, where they will meet and interact ... so they will support each other on adherence. They should have support from NGOs, CBO’s etc. ... Even the newly -enrolled women would feel at home by meeting peers. They would feel less discouraged” Healthcare worker, Chimtende, Zambia

“Through our support group we have good relationship with village headmen of this area, such that there was a market adjacent with the clinic, and people used to laugh at us, but when the village headmen learnt about it they shifted it to another place.”

Woman living with HIV, Makata, Malawi

Supportive, woman-centred health facilities

When a woman starts HIV treatment for life, she needs to regularly attend health facilities and interact with health workers. The quality of the facilities, the types of services offered and the attitudes of personnel in the facilities contribute to whether a woman feels supported to continue her treatment. Across the three countries, the women engaged in this research gave examples of successful practices alongside suggestions for improvement for healthcare facilities.

Woman-centred services

The women in the focus groups repeatedly asked for services to be designed in a way that meets their needs. They spoke of user-friendly approaches that have facilitated their adherence to treatment. Many clinics have put in place systems designed to reduce the number of times that women need to attend a clinic and to shorten waiting times within health facilities. These were widely welcomed.

“There is a separate room for ART clients. We don’t wait with everyone else, so we spend less time at the clinic.”

Woman living with HIV, Nanga, Zambia

RETENTION INTERVENTION	Number of sites where intervention was used to support retention		
	Malawi	Uganda	Zambia
Home visits to follow-up	All 4	All 3	All 4
Support groups at health facilities	2 facilities	All 3	None
Involvement of peer counsellors	All 4	All 3	2 facilities
Mothers groups	1 facility	2 facilities	None
Couples counselling and testing	All 4	All 3	All 4
Partner letters	None	None	None
Nutritional support (based on assessment)	3 facilities	All 3*	3 facilities

*Some nutritional support is offered but it may not be accessible to all.

“The fact that the hospital combined under-five clinics with ART appointments motivates me to stay on treatment because I have time to do other personal things” **Woman living with HIV, Chitipa, Malawi**

“The clinic has special days for appointments i.e. teenagers come on Saturdays, breastfeeding and pregnant mothers on Tuesdays and the rest of the clients on Thursdays. As a result, we do not wait long on the queue.” **Woman living with HIV, Lambulira, Malawi**

Flexible ways to distribute medication were also well received by the women in the focus groups. In some facilities antiretrovirals no longer need to be collected in person, in others larger refills were being given to increase the time before the next appointment and in a few districts drug distribution points had been set up within communities removing the need to travel to a more distant clinic.

“Our friends help us - they collect medication on our behalf” **Woman living with HIV, Lusaka, Zambia**

“Soon, instead of women coming to the centre, volunteers will be taking medications to the homesteads. So, the excuse of forgetting the date will not exist” **Healthcare worker, Chimtende, Zambia**

In each country, the key informants described the systems that are in place at their health facilities to monitor retention and boost adherence. In every facility, this includes appointment reminders and follow-up to urge women who have begun ART to continue with their treatment.

“The phone calls to remind clients of appointments [are] the most helpful”

Healthcare worker, Mukono, Uganda

“Registers are the key tool. All appointments are written in the register. There are files where appointments for each month are noted. Health Surveillance Assistants and Expert clients follow up those that don't attend.”

Healthcare worker, Malawi

Tools used to monitor retention

- Appointment books/registers
- Community-based monitoring and follow-ups (adherence support-ers/volunteers, health surveillance assistants, expert clients)
- Support groups
- Home visits
- Monitoring registers
- Appointment systems (Data entry packs, card/passport systems, activity books)
- Phone calls
- SMS messaging systems

“If you miss an appointment some people come to the community to ask why. They follow up and ask why you have not been seen at the clinic. They will come and inform you if you need to go to the clinic or if you need to take the child. If you have a problem they may come take your card and collect medications on your behalf - they help out.”

Woman living with HIV, Chimtende, Zambia



All the health facilities involved in the research organised some form of home visits to encourage treatment adherence. These visits are often conducted by volunteers. In Zambia, Safe Motherhood Action Groups (SMAG) meet in communities to help support and educate women.

“The home visit is good to assess where the person is coming from and it shows that this person has disclosed, because we don’t just go there we discuss: ‘When I come there, are you going to introduce me?’ It helps the health worker to assess the environment at home ... whereby there is still stigma, someone says: ‘When you come, don’t talk about HIV, you come and visit me as a friend!’ So, we visit as a friend, assess the environment at home.” **Healthcare worker, Nsangi, Uganda**

“Lay counsellors come home but will make an excuse or pretend to know me from church in order not to arouse suspicions.” **Woman living with HIV, Lusaka, Zambia**

“Systems of registers monitor retention and a lot of volunteers help to provide the service: support groups provide encouragement; expert clients provide counselling and do follow-ups.”
Healthcare worker, Makata, Malawi

“For me, I experienced the challenge (not from here) ... the health workers were rude and were handling us badly. You would find a health worker throwing medicine to you. It affects us badly!”

Woman living with HIV, Nsangi, Uganda

Respectful and considerate health workers

All the key informants (healthcare workers, counsellors and programme administrators) were asked to outline the mechanisms that are in place to support women living with HIV who report experiencing stigma or discrimination from a healthcare worker. In each country, health workers had received relevant training and faced certain consequences if they discriminated against people living with HIV but the systems varied greatly between health facilities. In a few facilities, detailed procedures were followed to ensure that any complaints of discrimination were dealt with seriously. In other clinics, the approach was more ad hoc and in some facilities the staff claimed not to have instances of staff being accused of discrimination. Some focus groups participants spoke of the stigmatising treatment they had experienced in other health facilities.

“Sometimes nurses are too harsh - can shout status in public waiting room.” **Woman living with HIV, Lusaka, Zambia**

For the most part, the women involved in the focus group discussions welcomed the care they received and repeatedly singled out the positive attitude of health workers as a facilitating factor in their adherence to treatment.

“What motivates me to come for medication is that the doctors do not treat us badly. They do not bark at us and order us around saying, “I told you to go there”. The doctor handles you very well. He or she cares to look for your file if it gets lost so that you leave this place with medication.” **Woman living with HIV, Entebbe, Uganda**

The women in the focus groups frequently discussed confidentiality – for them it is critical that healthcare workers respect their privacy and enable them to attend health facilities without their HIV status being made public.

“Because of the friendliness of the healthcare workers, we are encouraged to come and get our medicine.”

Woman living with HIV, Makata, Malawi

“The health workers are very friendly and they don’t discriminate against us.”

Woman living with HIV, Lambulira, Malawi

“There is confidentiality. Previously files were given to us while on a queue, and everyone would see that we are here to get ARVs but now we find our files in the consultation room” **Woman living with HIV, Lambulira, Malawi**

“At first, we used to sit in the open, where everyone could see us. And they used to call us all sorts of names, but that has changed now. The room has some curtains.” **Woman living with HIV, Lambulira, Malawi**

Well-staffed and equipped facilities

The women placed much importance on well-run health facilities with short waiting times. All the key informants recognised how important it is for women to be able to attend health facilities and receive the service they require with minimal inconvenience.

“When they come, you should attend to them quickly, because when they stay (long), they don’t feel like coming back ‘we are wasting time here’. If you attend to them quickly, they even tell others ‘when you go there, they deal with you fast fast’. Maybe that’s one of the reasons why we have a lot of clients. If they come for drugs we give them there and they go – they don’t have to stay the whole day” **Healthcare worker, Katete Urban, Zambia**

“What helps women to be retained is that if they come for the service they receive the service. Because if they come and you tell them that there is a shortage of ARVs, come back, or there is a shortage of test kits come back they will not come back” **UN agency representative, Uganda**

"Me, what I want is to increase the number of health workers to avoid delaying here. That will attract us because you get to know that you will come early and leave early for other work."

Woman living with HIV, Nsangi, Uganda

Even in the health facilities involved in this study, that have achieved high levels of retention in care, there remain problems with service delivery. The healthcare workers interviewed expressed their frustration at not having enough time to deal with their patients and the women living with HIV talked of long waits and frustration with over-crowded facilities.

"I am not satisfied with the time I give my clients. On some Fridays I see 300 clients a day."

Healthcare worker, Makata, Malawi

"When you come, the staff are very busy. Sometimes, whilst you are there, they may receive a woman needing to deliver, or you may have another emergency. You usually wait for your appointment. You may have arrived early, but you end up being here all day."

Woman living with HIV, Chimtende, Zambia

"We only have a single day when you can collect treatment, so you all come on the same day. You all make one big queue. Sometimes you see some women who keep going around without joining the queue because they are ashamed. We should have a system where you can come to collect drugs any day so that you can come to the centre at the time that is most convenient to you. Even those who are ashamed or scared would come on quieter days."

Woman living with HIV, Katete, Zambia

Areas for improvement

Despite advances in service provision, women in the focus group discussions believed more could be done to make it easier for women to access the services that they need. One issue, raised across all three countries, was the problem with the distance and cost of travelling to clinics. They pointed to this and other remaining problems with the current services and offered solutions such as mobile clinics, transport support and flexible treatment collection systems.

"I would like to see the introduction of mobile clinics, so that we don't walk or spend a lot of money on transport to the clinic."

Woman living with HIV, Chitipa, Malawi

"For PMTCT mothers, most try to come, the only problem is issues with transport. They may not have the money – husband doesn't have money. Some women don't work, they have transport issues, but when they have money they come." Healthcare worker, Entebbe, Uganda

"In some places, to get our CD4 count they require money. But here, they take your blood sample check your CD4 count for free. They do not ask you for any money!"

Woman living with HIV, Entebbe, Uganda

"All family planning methods are available including the coil. Everything is available. You can get any kind free of charge." **Woman living with HIV, Entebbe, Uganda**

Free services and nutritional assistance

In the regions of Malawi, Uganda and Zambia involved in this research, poverty can affect a woman's ability to access the care that she requires. In each focus group, women said that the provision of free treatment, diagnostics and other tools and services helps them to adhere to treatment. They also spoke of the benefits of additional financial and practical support.

Some women highlighted problems with systems that caused delays and frustration. One health worker said they were experimenting with using text messages to disseminate test results to speed up the process. In Uganda, some health workers called for equipment to be installed on site to enable them to conduct viral load tests and avoid the delays involved in sending tests to a laboratory.

"When it comes to infant testing we have a challenge of having the results back. Sometimes it would be three or four months. Worst case was six months instead of one month before the results come back. We need to strengthen the linkages between facility and lab"

Healthcare worker, Zambia

"We have a challenge with results (infant testing or viral loads) not coming back to the clinic on time which puts off women. One laboratory is covering too many areas" **Healthcare worker, Zambia**

"I have seen in other hospitals the mothers who come to the health facility are given some porridge which does not happen here. The mothers stay with their children crying without anything to eat. They should get us that support." **Woman living with HIV, Mukono, Uganda**

"In the old days, we would get treatment and supplements, soya and proteins. These medications are strong especially when you are starting them new." **Woman living with HIV, Lusaka, Zambia**

Consistently throughout the focus groups discussions, women asked for more nutritional support. In each country, they discussed how food supplements had been given in the past and that these had helped women to adhere to their treatment. In Zambia, most of the health facilities that took part in the research offer some form of nutritional support, yet women in the focus groups still felt more was needed. In Uganda, fewer of the health facilities were providing nutritional support. Here, the focus groups all raised concerns about the difficulties that women face taking their medication when they have food shortages. While the health facilities in Malawi were offering some nutritional support, again the Malawian women maintained that more food support was needed.

"Government and other partners should provide us with nutritional food supplements."

Woman living with HIV, Chitipa, Malawi

Psycho-social support

The need for ongoing counselling and psycho-social support was a strong theme throughout the focus group discussions and interviews, whether at an inter-relational or institutional level. The women involved in this research asserted that, when it was provided in a space free from judgement and shame, psycho-social support facilitated their retention in care. The women gave examples illustrating how counselling has helped them come to terms with their diagnosis, understand the health benefits of treatment, take decisions about disclosure and remain adherent to their treatment.

“Following what I was told during counselling makes me conquer all the challenges that I face when taking ARVs.” **Woman living with HIV, Lambulira, Malawi**

“Its [the Community Volunteer], she really encourages me. Sometimes I am discouraged and want to stop medication but she encourages me. She gave me an example of a lady that would give birth and the children would die – eight pregnancies in total. However since that woman started on treatment and followed the instructions, she has had five children, all of them negative. With that encouragement, I was strengthened.” **Woman living with HIV, Chimtende, Zambia**

These opinions were reinforced by the comments from key informants who felt counselling not only played a critical role in supporting women to begin treatment but also in encouraging them to continue to adhere to it.

“I think at national level, if we had a say, we would ensure that a counsellor become part of the staffing within every facility, so that that person can handle

counselling services. We have lobbied for so many years, but the counsellor has not become part of the structure we would love to see counselling taken as part of healthcare.”

Government representative, Uganda

“If a woman is well counselled and prepared well for what she is going into then it really motivates her to take her treatment and also adhere.”

Community Leader, Uganda

“We have seen better retention amongst those enrolled in the support groups, because they are able to get the peer counselling ... stigma is still very high, but you realise that if you enrolled within the psycho-social support groups, then stigma can easily be addressed.”

Implementing partner, Uganda

One problem raised by numerous participants was a concern that women who were tested for HIV in pregnancy received inferior quality counselling⁴. Key informants described how pregnant women are offered an HIV test when they attended the antenatal clinic. Outside the antenatal setting, individuals who have had an HIV test recommended to them or are seeking an HIV test receive individual counselling, time to think about whether they want to have the test and an opportunity if they wish to discuss it with their family members. However, in some settings pregnant women were given a group talk explaining about HIV and then asked to take the test immediately.

⁴ Previous ICW / GNP+ research also raised concerns from women who said they were put under pressure to being treatment on the day they were diagnosed, with a lack of sufficient counselling. GNP+, ICW Global, ICW East Africa, & COWLHA. (2013, March). Understanding the perspectives and/or experiences of women living with HIV regarding Option B+ in Uganda and Malawi.

“When they come to the facility, like any other woman, they expect to be told about the good news about how the baby is and whether the baby is really kicking well [etc]. But then because you are told to test and then get your results, and if you are found positive, you are there and then started on treatment. It is a complex situation where there are so many things happening at the time ... So, they are really not prepared and they are not given that time to make a decision.” **Community Leader, Uganda**

Some of the key informants in Malawi reinforced this point, explaining that women are often unprepared when they are expected to start treatment on the same day that they have taken the HIV test. One government representative in Malawi referred to some studies that have shown better retention for clients who delay starting treatment, but this is not yet conclusive.

“With Option B+ sometimes people don’t have time to mentally prepare and accept their status” **Healthcare worker, Lusaka, Zambia**

“The way it is supposed to be is that you have to counsel them and then ask them to come back, but we have been advised to start treatment there and then- before they go home..... Mostly, it was to prevent transmission to baby, but also, there was a perception that if they went home to think about it, there would be voices from the family members saying ‘No. Don’t start.’So it is good to tell her to start immediately.” **Healthcare worker, Chimtende, Zambia**

Participants also spoke of the need for couples counselling. Most of the health facilities already offer this service, but with mixed success. As is noted throughout this report, the focus group participants and the key informants all felt strongly that women gained a great deal of support when their partner understood about HIV and encouraged them to adhere to their treatment. In Malawi, one key informant described a programme they had implemented specifically to engage and sensitise men. Following the programme they had seen an increase in male involvement. In Zambia, one key informant explained that women who were given couples counselling were less afraid, distrust within the couple was reduced and there was better adherence to treatment.

“If community leaders continue talking about HIV testing and counselling people will also stay in care. If they emphasis couple testing, people will also stay in care.” **Healthcare worker, Mukono, Uganda**

“Couples counselling and male involvement has been very helpful. It encourages mothers and mothers take treatment well because they are free and have no fears of telling; men also start treatment early if positive” **Healthcare worker, Malawi**

However, many examples were also given where men were reluctant to engage and programmes attempting to force male participation had negative consequences. The key informant from the Ministry of Health in Malawi described how many men are still not comfortable attending health facilities with their partners as a result uptake of couples counselling is low.

All the health facilities involved in the research organised some form of home visits to counsel women on treatment adherence. These visits are often conducted by volunteers and peers.

Focus on Malawi

Malawi - UNAIDS data snapshot ¹	
Number of people living with HIV	1,000,000
Percentage of adults living with HIV receiving ART	68%
Coverage of pregnant women living with HIV accessing antiretroviral medicines	84%
Number of mothers receiving effective PMTCT regimen	46,400
New infections in children	4,300

UNAIDS estimates that in 2010, the coverage of pregnant women living with HIV accessing antiretrovirals was only 23%.² In 2011, Malawi was the first country to implement Option B+ at the same time significantly stepping up its PMTCT service provision. Despite the considerable progress that has been made, a recent study found that women who started ART under Option B+ were about 1.5 times more likely to adhere inadequately than those who were not pregnant or breastfeeding.³

“Initially there were lots of issues of acceptability, with concerns about violence from partners and fears of divorce. With time, these are dying out. Currently, at 12 months, 80% of women initiated are still in care”

UN agency representative, Malawi



¹All figures are estimates for 2016 from UNAIDS HIV Estimates 2017.

²UNAIDS HIV Estimates 2017.

³Haas, Msukwa, Egger et al. *Adherence to Antiretroviral Therapy During and After Pregnancy: Cohort Study on Women Receiving Care in Malawi's Option B+ Program*. Clin Infect Dis. 2016 Nov 1; 63(9).

Factors women believe help them to stay on treatment

Personal motivation

- To protect their own good health
- Have felt the health benefits
- Baby born without HIV

Family and friends who provide

- Practical help – transport, child care, reminders, collecting medicine
- Emotional support and encouragement

Support groups that provide

- Treatment literacy
- Nutritional support
- Encouragement
- Village savings loans

Community providing

- Positive messages
- Sensitization to reduce stigma

Health facilities that provide:

- Free medication and services
- Reliable supply of medicines
- Confidentiality
- Integrated services so less trips needed to the clinic
- Short waiting times
- Understanding / forewarned about side effects so able to cope with them better
- Simpler drug regimen
- Encouragement from, and positive attitude of, health workers
- Treatment literacy

Initiatives to facilitate retention

In health facilities - Task shifting, introduction of new cadres, fast track refills (some given in the community), well patients given drugs for longer, reduced waiting times at the facility, clear messaging on adherence, better post-partum support (repeated infant testing)

“There is a culture of people coming to the rural areas to their elder parents to deliver, especially for the first child, so they return after delivery. We are better at capturing that information now” Healthcare worker, Makata

In the community - Health surveillance assistants to follow up clients, male study circles, mentor mothers / expert clients, couples counselling, chiefs encouraging male participation and attendance at ANC, male mentors, stigma training, support groups.

Facilitating retention: recommendations from women living with HIV

For the women who participated in the focus group discussions, they believed their retention in care was supported by the provision of convenient services.

“The clinic combined the antenatal clinic and appointment of mother and the baby. As a result we come here once a month”

Woman living with HIV, Chitipa

They called for:

- Mobile clinics
- Better staffing levels in facilities
- Health workers with a positive attitude
- Food support
- Support groups led by women living with HIV
- Income generation activities

“I would like to see the introduction of mobile clinics, so that we don’t walk or spend a lot of money on transport to the clinic.”

Woman living with HIV, Chitipa

Facilitating retention: recommendations from key informants

Male involvement and couples testing were seen by the key informants as a key facilitator.

“Chiefs were recruited to notify the men in the community to attend ANC with their wives. When they come couples counselling is provided. Couples counselling and male involvement has been very helpful. It encourages mothers and mothers take treatment well because they are free and have no fears of telling; men also start treatment early if positive”

Healthcare worker, Makata

Key informants were interviewed about factors within health facilities that might help. In general, Key informants felt they had the facilities required to support women living with HIV to adhere to treatment but almost all of them felt they did not have enough staff.

“I am not satisfied with the time I give my clients. On some Fridays I see 300 clients a day”

Healthcare worker, Makata

They called for:

- High quality counselling and services
- Respect for clients
- Male involvement
- Women-centred services (integrated services, linkages, more mobile clinics)
- Continuous training and supervision for staff and volunteers, including as new directives and updates come in.
- More specialist services (e.g. introduce mother and infant pair clinics, improve paediatric and adolescent services)
- Better staffing levels (shorter waiting times)
- Improve linkages between HIV and nutrition
- Cover transport costs for outreach and tracing
- Case management system in the community and improve tracing systems
- Initiatives to challenge stigma and discrimination
- Train more community cadres / scale up expert clients and male mentors
- Political commitment to health needs
- Good information / Scale up treatment literacy

“Health centres should be funded for transport costs for following up clients in the community”

Healthcare worker, Chitipa

“There should be funding for training and refresher courses for all staff and volunteers”

Healthcare worker, Chitipa

Stigma is “a social disease”

Implementing partner, Malawi

Focus on Uganda

Uganda - UNAIDS data snapshot¹

Number of people living with HIV	1,300,000
Percentage of adults living with HIV receiving ART	69%
Coverage of pregnant women living with HIV accessing antiretroviral medicines	>95%
Number of mothers receiving effective PMTCT regimen	115,000
New infections in children	4,600

UNAIDS estimates that in 2010, the coverage of pregnant women living with HIV accessing antiretrovirals was only 27%.² Uganda rolled out a policy based on Option B+ throughout 2012 and 2013. Uganda is now one of five priority countries that have reached the major milestone of diagnosing and providing lifelong antiretroviral therapy to at least 95% of pregnant and breastfeeding women living with HIV.³



“Those who leave the programme tend to do so if they know/or are assured that their baby is HIV negative.” **Community Leader**

“In a day, say if we get seven positive women, one or two may refuse to be initiated. Or they may accept, but refuse to come back or refuse to give us contact number. So, at the end of last year, retention was at 67% at 24 months.”

Healthcare worker, Mukono

¹All figures are estimates for 2016 from UNAIDS HIV Estimates 2017.

²UNAIDS HIV Estimates 2017.

³UNAIDS. *Ending AIDS: Progress towards the 90-90-90 targets*. 2017

Factors women believe help them to stay on treatment

Personal motivation

- To protect their own good health (including to be able to care for their children)
- Have felt the health benefits
- Baby born without HIV

Family and friends who provide

- Practical help – transport, food, reminders, collecting medicine
- Emotional support and encouragement

Health facilities that provide:

- Confidentiality
- Encouragement from, and positive attitude of, health workers
- Free medication and services
- Family planning services
- Medication supplied in larger quantities so less trips needed to the clinic
- Counselling
- Home visits (particularly to maintain confidentiality)

“When you come here, you are given medicine for about three or two months which is better than going to a place every month yet you sometimes may not have the money for transport” **Woman living with HIV, Entebbe**

Initiatives to facilitate retention

In health facilities - Home visits, couples counselling and testing, support groups and peer counsellors, food support (in North Eastern region), community engagement, village health teams

In the community - Mamas kits, transport vouchers to cover those costs, male champions, community leader engagement, peer support groups (male and female), individual peer mothers

Facilitating retention: recommendations from women living with HIV

For the women who participated in the focus group discussions, they believed their retention in care was supported by supportive and understanding health workers.

“The doctors here care for us and that motivates us to come back”
Woman living with HIV, Mukono

However, the women also felt strongly that there were not enough health workers to attend to them and waiting times were unacceptably high.

Women, in all three districts, said they were not aware of any support groups that could help them. They were keen to have opportunities to meet with their peers and to provide practical and emotional support to each other, but concerns were raised about privacy and many women preferred the idea of groups based in health facilities believing they would be more confidential.

They called for:

- Food support
- Better staffing levels in facilities
- Confidentiality in facilities
- Prescriptions for longer duration to reduce need for frequent visits to clinic
- Quicker CD4 and viral load test results (Nsangi)
- Income generating activities
- Support groups

“What I want is to increase the number of health workers to avoid delaying here. That will attract us because you get to know that you will come early and leave early for other work.”

Woman living with HIV, Nsangi

Facilitating retention: recommendations from key informants

Many of the key informants that were interviewed in Uganda highlighted how women living with HIV were more likely to be retained in care if they felt assured of confidentiality. When one key informant was asked what she believed most influenced a woman living with HIV to stay on treatment she replied:

“First of all, it is confidentiality. When these people they have confidence in you, in the organisation, that can maintain them in care.” Healthcare worker, Entebbe

The key informants also emphasised the need for more staff.

“There is not enough time to interact, we are overwhelmed, we try our best though. There are too many clients.”

Healthcare worker, Mukono

They called for:

- Better staffing levels (shorter waiting times)
- Improved clinic spaces – to ensure privacy and comfort
- Training and motivation for staff and counsellors
- Peer support groups and peer mothers
- Social grants and support - including transport, nutrition, income generation
- Ensure commodities supplies
- Pay staff well and award good performance
- Male involvement
- Differentiated service delivery (mobile services, community drop in points, allow others to collect medication, fast tracking for those who are well)
- Initiatives to challenge stigma and discrimination
- Disclosure support
- Respect for clients
- High quality counselling

“We know that these men are the reason that women are not coming. We have developed the strategy but we would love to see everyone taking it up and getting support from the high level.”

Government representative

Focus on Zambia

Zambia - UNAIDS data snapshot¹

Number of people living with HIV	1,200,000
Percentage of adults living with HIV receiving ART	67%
Coverage of pregnant women living with HIV accessing antiretroviral medicines	83%
Number of mothers receiving effective PMTCT regimen	68,700
New infections in children	8,900

The implementation of Option B+ has taken place in stages in Zambia, beginning in 2014. The number of AIDS related deaths in children has dropped from 7,200 in 2013 to 5,700 in 2016. Although there has been a significant increase in PMTCT service provision, there are some indicators that progress is faltering.² In 2012, 2013 and 2014 the percentage of pregnant women living with HIV receiving effective ART was above 90 but it has now dropped to 83%.³



“[There are] very few cases of women that don’t come back. We keep counselling until they understand the benefits, ask them to look at the interests of the child”

Healthcare worker, Lusaka

¹UNAIDS HIV Estimates 2017.

²Avert. *HIV and AIDS in Zambia*. Available at <https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/zambia>. Accessed November 2017.

³Ibid.

Factors women believe help them to stay on treatment

Personal motivation

- To protect their own good health (including to be able to care for their children)
- Have felt the health benefits
- Baby born without HIV
- Positive role models

Family and friends who provide

- Practical help –food, transport, child care, reminders, collecting medicine
- Emotional support and encouragement

Support groups that provide

- Encouragement
- Income generation

Health facilities that provide:

- Appointment reminders
- Encouragement from, and positive attitude of, health workers and volunteers
- Confidentiality
- Medication can be collected by others
- Reliable supply of medicines
- Family planning services
- Treatment literacy
- ART supporters in the community
- Safe motherhood groups
- Food support
- Short waiting times

Initiatives to facilitate retention

In health facilities - Couples testing and counselling, family-centred home visits, SMAGs, lay counsellors

In the community – ART supporters, community volunteers

“Soon, instead of women coming to the centre, volunteers will be taking medications to the homesteads. So, the excuse of forgetting the date will not exist”

Healthcare worker, Chimtende

Facilitating retention: recommendations from women living with HIV

For the women who participated in the focus group discussions, they believed their retention in care was supported by individual staff and volunteers who encouraged them and gave them practical support such as appointment reminders. However, confidentiality remained a big concern for them. **“Everyone knows and hears everything that is going on. A bigger clinic would help.”** **Woman living with HIV, Nanga**

They also felt they would benefit from more flexible services.

“We only have a single day when you can collect treatment. So you all come on the same day. You all make one big queue. Sometimes you see some women who keep going around without joining they queue because they are ashamed. We should have a system where you can come to collect drugs any day so that you can come to the centre at the time that is most convenient to you.” **Woman living with HIV, Katete**

They called for:

- Confidentiality in facilities
- Food support
- Improved clinic facilities – particularly space to avoid over crowding
- All medicine and associated test / equipment to be free
- Community workers to help with appointment reminders
- Local drug distribution points
- Support groups
- Stigma reduction in communities

Facilitating retention: recommendations from key informants

Key informants were interviewed about factors within health facilities that might help women living with HIV to adhere to lifelong treatment. In all locations, they said that staffing levels were inadequate and in most they also spoke of a lack of sufficient interaction time with clients.

In all the settings, they spoke of the importance of maintaining confidentiality but it was pointed out that this can be difficult within small, over-crowded facilities.

They called for:

- Initiatives to challenge stigma (particularly at community level)
- Support groups
- Male involvement
- Improved clinic facilities – more space, better privacy
- Faster test results (particularly for infant testing)
- Better staffing levels (shorter waiting times)
- Differentiated service delivery – allow others to collect medication
- Respect for clients
- High quality counselling
- Support groups



Research Methodology

This report summarizes the findings of a study conducted between October 2016 and April 2017 in Zambia, Malawi and Uganda. The study was granted ethical approval by the national ethics committee in each country. GNP+, ICW Global, ICW Malawi, ICW Eastern Africa and NZP+ engaged the Ministry of Health where possible in site selection, informing sites prior to research and ensured that the necessary approvals were in place for site visitation.

Primary study objectives:

1. To describe factors (individual, inter-relational and institutional) that help pregnant and breastfeeding women living with HIV remain adherent to HIV treatment and remain in care.
2. To describe healthcare workers' roles in promoting adherence and retention for women living with HIV in lifelong care and treatment.
3. To document strategies that are currently in place to promote adherence and retention and to elicit suggestions for how services may be improved.

Study design and methodology

The study used qualitative methods to gain an understanding of the context, and experiences of pregnant and breastfeeding women living with HIV and their families with respect to treatment adherence and retention in care. Data was collected through key informant interviews and focus group discussions. The project embraced a community consultation approach, engaging women living with HIV to gather the perspectives of their peers and adhering to the Greater Involvement of People Living with HIV (GIPA) principles.

Site selection

Recognizing that the specific factors that facilitate retention and adherence may vary by context, this study selected Zambia, Malawi and Uganda as countries with established Option B+ programmes. A review of available country-level data was conducted to help identify sites for inclusion based on accessible retention data for the sites from past 12 months, and on retention promoting strategies (e.g. community-based interventions such as peer support groups) being used at the target sites.¹ The promising practices outlined by UNICEF and UNAIDS² was used as a checklist of the range of community-based interventions.

Within each country, a minimum of three sites were chosen. The criteria for site selection included:

1. Option B+ programme implemented for at least 18 months;
2. Sufficient patient load of women living with HIV to allow for the recruitment of focus group discussions consisting of 7-12 women;
3. A mix of urban and rural sites;
4. A mix of health facility types (e.g. tertiary, secondary, and primary health care facilities);
5. Sites that have high retention rates, above national average to identify facilitating factors;
6. Sites that are linked to at least one community-based intervention to promote retention (i.e. community-based peer support groups, community health workers, community health committees, etc.).

¹ Community-Facility Linkages to Support the Scale Up of Lifelong Treatment for Pregnant and Breastfeeding Women Living with HIV UNICEF 2015 <http://childrenandaids.org/publication/community-facility-linkages-support-scale-lifelong-treatment-pregnant-and-breastfeeding>

² Promising practices in community engagement for elimination of new HIV infections among children by 2015 and keeping their mothers alive, UNAIDS 2012 Available at: http://www.unaids.org/sites/default/files/media_asset/20120628_JC2281_PromisingPracticesCommunityEngagements_en_0.pdf UNAIDS/JC2281E (Accessed 3 May 2015)

Focus group discussions

Focus group discussions (FGDs) were organised to understand the experiences of women who have received PMTCT services in the past 12-24 months. Questions explored the individual, inter-relational, and institutional factors that facilitate better adherence and retention.

Participants were identified through networks of women living with HIV, support groups, community health workers and local partners and recruited using a purposeful respondent-driven sampling method.

In each country, the study aimed to capture the perspectives of women with different socio-demographic profiles and different stages of care (i.e. pregnancy and post-partum). Efforts were made to recruit women who initiated PMTCT 9-12 months prior to data collection. All participants were women living with HIV and had accessed PMTCT services within the last 12-24 months. They were all aged 16 (or age of majority) or above.

In each country, at least three FGDs were held at different PMTCT sites in a neutral, private location. Each focus group was comprised of 7-12 women living with HIV and was facilitated by trained moderators. Informed consent was sought and participants' confidentiality was respected throughout.

Key informant interviews

In order to identify and describe community interventions that promote retention in more detail, key informant interviews (KIIs) were conducted with health workers who provided MNCH/PMTCT services to women and children living with HIV at the time of the study. Any health worker who was a recognised member of the health centre staff team was eligible to participate, including nurses, midwives, PMTCT coordinators, clinic directors, facility-based counsellors, peer educators and community health workers.

Up to 12 KIIs were conducted in each country (approximately 2-3 at each site, and another 2-3 at the national level). At the national level, KIIs were held with representatives of the Ministry of Health (leading on PMTCT) UN agencies, implementing partners as well as community leaders predominantly representing networks of women living with HIV.

Data analysis methodology

Standard thematic analysis of the FGD and KII transcripts was conducted to identify and examine core themes and concepts. This involved manual transcript review, identification of common themes and sub-themes, sorting or labelling of quotes according to themes, and synthesis of main themes and differences in concepts emerging from the sub-themes.

Study limitations

There are some limitations associated with the research methodology used for this study. The selection of FGD participants was not random, which presents some bias. Additionally, given the smaller sample size the FGDs, and surveys are limited in their ability to produce results that can be generalised to the broader population.

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