PEP Adherence

The Gender Based Violence programme, funded by the Global Fund, supports community based organisations to place social auxiliary orkers (or first responders) and social workers at Thuthuzela Care Centres (TCCs) and designated centres to support government service providers and to fill the gaps in the provision of psychosocial services to survivors of sexual violence.

Whilst the dispensing of PEP medication at TCCs is carried out by health care professionals from the Department of Health (DoH), this case study focuses on the value of psychosocial follow-up services provided by NGOs in ensuring survivors adhere to and complete their PEP medication; and factors which influence a survivor's ability to access and adhere to PEP medication.

Considering the associations between sexual violence and risk for HIV infection, Thuthuzela Care Centres (TCCs) play a critical role in supporting survivors of such violence in responding to HIV within the context of post-rape care. Generally, responses to HIV are informed by the survivor's HIV status prior to the rape:

- Survivors who **test positive** for HIV are referred for further counselling regarding living positively and possible Antiretroviral Treatment (ART).
- Survivors who **test negative** and who report the rape within 72 hours of its occurrence may be prescribed a 28-day course of post-exposure prophylaxis (PEP) to prevent infection with HIV.

"...at that time when the client comes in, understand that the client is still traumatised and maybe they [the nurse] can tell her something but she won't absorb all the information." Social Worker

The role of NGOs in PEP

Generally, a similar overall model of service is utilised for PEP initiation and follow-up at TCCs.

Intake: When a survivor first arrives at a TCC first responders provide initial debriefing and support and prepare survivors for the next steps of the visit.

HIV testing and PEP initiation: Survivors then see a nurse and/or a doctor who:

- Offers HIV counselling and testing (if clients are not already diagnosed with HIV).
- Depending on the outcome of the test, initiates the survivor on PEP.
- Sets a date for a follow-up appointment.

Short-term counselling: Survivors sometimes return to the first responder for further support and counselling before returning home.

First follow-up visit: Usually done 3-7 days after initial visits to provide:

- More thorough counselling via a session with a social worker.
- PEP education and addressing issues relating to side effects
- The results of the initial blood tests and provide survivors with the rest of the 28-day course of medication for PEP (at some TCCs).

6 week, 3 month & 6 month follow up visits: To test for HIV and determine the success of the PEP treatment.

First responders offer a range of active follow-up and support services during this time ranging from in-person conversations during visits to a series of phone calls and home visits.

Tailoring services to survivors' needs

Given the traumatic circumstances of a survivor's first visit to the TCC, it may be difficult for first responders and nurses to properly educate and counsel survivors during initial intake.

This is an important reason to have the first follow-up visit 3-7 days after intake at a time when survivors have had a chance to recover from the immediate impact of the trauma and can better understand the next steps that lie ahead.

Although there is a standard model of care, it is important to deliver services in a way that fits clients' needs. This is particularly important when there are challenges around transport, or when survivors are particularly vulnerable and in need of more frequent contact and support.

"We give them a letter to come back to the centre but also reminding her to go for ongoing counselling and that will be also monitoring their post exposure prophylaxis... It's very important that our clients that have tested negative, they really remain negative." Programme Manager

Multidisciplinary model

A multidisciplinary model in the provision of PEP can bring a number of benefits. This offers combined expertise from first responders, social workers, victim assistance officers, site coordinators, nurses, and doctors and integrated care to survivors. This approach was perceived to:

- Address the many different needs of survivors
- Cover critical gaps in availability of DoH services by operating at nights and over weekends
- Prevent survivors from "falling through the cracks" and out of care
- Ultimately, be much more effective and efficient.

As part of this model, first responders and social workers funded by the programme offer distinctive kinds of support to survivors and often do so after hours and on weekends when most sexual assaults occur.

Active follow-up

One of the most important activities provided by first responders is the active follow-up of clients via a combination of phone calls and home visits.

"If the victims go to [the hospital] over the weekend, on Fridays, you are there at night, the chemist is not opened which means you're not able to get the prophylaxis. How many people are we going to sit with now, that would be HIV positive after a week? So, now with the service of the NGO, that is going to assist us, so that the people will be able to be followed-up, to be called and be able to get the treatment." Site Coordinator

The importance of these phone calls and home visits were widely reported by all categories of evaluation participants. DoH health care providers felt that this kind of follow-up filled a critical missing gap in their ability to support clients and appreciated NGO support in this aspect of care.

Preparing survivors for home visits

First responders noted the importance of preparing clients for these calls and visits, and the need to sometimes negotiate with them around the timing and location. Not all clients are comfortable with home visits given the inadvertent disclosure of the incident and/or use of PEP that these visits could prompt.

Home visits are an important opportunity to:

1. Develop a more holistic understanding of the psychosocial context of a survivor
2. Offer more comprehensive and tailored forms of support and advice to promote PEP adherence practices.

During follow-up calls and home visits, first responders focus on:

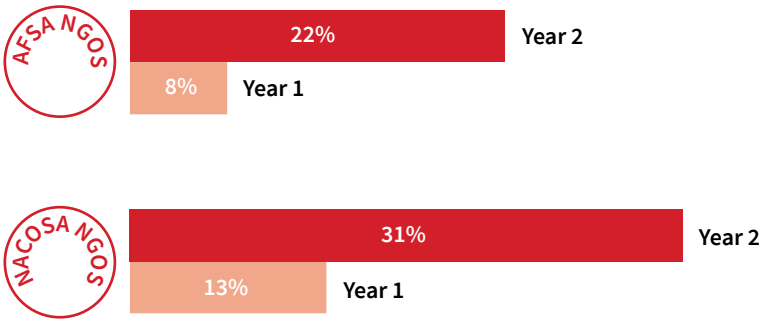
- Further educating survivors about PEP
- Providing advice on sexual health, managing relationships, disclosure issues with partners, and other psychosocial issues
- Encouraging survivors to continue taking the PEP medication
- Reminding survivors about upcoming TCC visits
- Helping survivors identify and manage side effects.

Identifying PEP supporters

Including a survivor's family and/or friends in follow-up conversations and home visits was seen by first responders as critical in the effectiveness of follow-up support. For child survivors, these supporters were generally the child's caregiver(s) or parent(s).

"That is very tough in that we ask the person [the supporter] that is our ear and eye that they must see to it that they [the client] really took [the] medication or that they… see that they swallowed it." Social Worker

PEP completion rates



Quantitative monitoring data collected by NGOs at TCCs demonstrates that reporting on PEP completion rates has improved over the first two years of the grant as illustrated in the figures above.

Completion rates are consistent with other research which finds that adherence to PEP to prevent HIV-infection after rape is low both in sub-Saharan Africa, as well as in more developed countries.

Barriers to PEP adherence

TRANSPORT

- Survivors have difficulty in mobilising sufficient funds for transport for follow-up visits.
- Further medication and support not received
- HIV status not determined
- Consistent for rural and urban areas

SIDE EFFECTS

- Side effects mistaken for signs of HIV infection rather than the result of PEP medication
- PEP is a psychological reminder of rape
- Effects of trauma in maintaining regular adherence

"Yes because always when I take those pills I was reminded, I was thinking about the things that happened to me. So sometimes it feels like I don't want to take those pills but because my kids are there for me to take those pills, I was able to take those pills." Survivor

FAMILY & COMMUNITY

- Frequent problem of incorrect numbers and addresses a result of stigma and denial around rape and HIV in families and communities
- Survivors do not want others to know of rape
- Weak family support and increased social isolation may reduce motivation to adhere to PEP

TCC EXPERIENCE

- Poor treatment, service quality, and patient-staff relationships at health facilities are barriers to follow-up and linkages to care
- Survivors fear to return to TCC as a result of lost clinic cards or medication defaults.

"Some of them are ashamed of going back because people will label them you know that they are a rape victim and they are HIV positive... then they feel ashamed going back because they don't want people to know, they just want to forget about it." Social Worker

FOOD SECURITY

- Many survivors reported households with problems of hunger and food insecurity
- Taking PEP on an empty stomach causes intensification of side effects which could, in turn, cause discontinuation of medication.

"I would be dizzy and get hungry very quickly and other times I don't even have enough food at my place so I choose to skip a day without taking them because of the after effects, so I'll find myself not taking them other days. I felt weak and I would vomit." Survivor

"The services are excellent because they are doing a lot, counselling and giving them transport and doing home visits and in most of the cases they do the calls. They do call them to come for the results... they even give us reports to say they were able to reach which people and which ones didn't return back and we work hand in glove with them nicely." Nurse

Factors facilitating PEP adherence

The evaluation identified four key facilitators of successful PEP adherence reported by evaluation participants.

1. PSYCHOSOCIAL SUPPORT

- ***Supporting the well-being of survivors while on PEP***
- ***Role of PEP treatment supporters***
- ***Broader family (mothers/children), peers and community support***

2. MOTIVATION

- ***Fear of contracting HIV a strong motivation for adherence***
- ***Reminders that staying negative is an achievable goal***
- ***Adherence as a method of regaining control and empowerment***
- ***Dedicated adherence counsellor solely responsible for telephonic follow-up with survivors***

> ***"And my mom at home she always reminds me, sometimes I forget that time. Did you take your pills? Then I'd say no I didn't. Come and take your pills."*** Survivor

3. TCC EXPERIENCE

- ***Good patient-staff relationships, empathy and support received from TCC service providers***
- ***Being treated with care is a crucial facilitator for remaining in care***

4. FINANCIAL SUPPORT

- ***Transport for follow-up visits and further support***
- ***Food to minimise PEP medication side effects***

> ***"I think they are given a space where they can offload. I think it's the counselling that keeps them coming back, 'cause when they go back, it's noted, they are not the same as when they came in."*** First Responder

This case study is part of a process evaluation conducted between 2017 and 2018 to assess the progress and quality of the implementation of services provided by NGOs in Thuthuzela Care Centres as part of the Global Fund grant, Investing for Impact against Tuberculosis and HIV. The evaluation was conducted by Creative Consulting and Development Works for the AIDS Foundation of South Africa (AFSA) and the Networking HIV & AIDS Community of Southern Africa (NACOSA) with funding from The Global Fund to Fight AIDS, Tuberculosis and Malaria.