PEP Adherence and Follow-Up for Rape Survivors
Background

The Global Fund ZAF-C grant, implemented from 1 April 2016 to 31 March 2019, intends to strengthen South Africa’s national response to HIV, TB and STIs within the GBV sector. As Principal Recipients of the grant, NACOSA and AFSA manage this via the disbursement of funds to NGO implementation partners who are responsible for direct service delivery through strategic interventions.

Within the broader Global Fund GBV grant, the Thuthuzela Care Centre (TCC) programme provides finances to community-based organisations to place Social Auxiliary Workers (or first responders) and Social Workers at TCCs and designated centres to support government service providers and to fill the gaps in the provision of psychosocial services to survivors.

This case study was developed as a part of a process evaluation conducted in between 2017 and 2018 to assess the progress and quality of the implementation of services provided by these NGOs. The focus was on identifying factors that were affecting implementation and providing recommendations that aim to assist in strengthening the programme via the improvement of the implementation quality of psychosocial services for the remainder of the grant periods.

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 are highlighted.

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.

Whilst the dispensing of PEP medication at TCCs is carried out by health care professionals from the Department of Health (DoH), this case study highlights the valuable role played by AFSA- and NACOSA-funded first responders and Social Workers in PEP counselling and follow-up support.

The Role of NGOs in PEP Initiation, Follow-Up, and Adherence

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

When a survivor first arrives at a TCC, first responders provide initial debriefing and support and prepare survivors or the next steps of the visit. 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
- Set a date for a follow-up appointment

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

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)

To test for HIV and determine the success of the PEP treatment.

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.

“ … 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

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 fit 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.
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. The evaluation found that 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; and
- 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.

“…if the victims go to [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 we be able even to be followed-up, to be called…and be able to get the treatment and the social work services.”

- Site Coordinator or Victim Assistance Officer

Active Follow-Up: Phone Calls and Home Visits

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. 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.

“The services are excellent because they are doing a lot, very good job to our clients, 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 and whatever, like counselling … 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.”

- TCC Nurse

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; and
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:

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

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Reporting on 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 below.

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.

**Factors Facilitating PEP Adherence**

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

**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

**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

**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

“...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...Yes when I saw I didn’t have enough food because when I took the pills I had to eat so when I didn’t have enough food I would be very hungry, I felt weak and I would vomit.”

- Survivor

“...the counselling we’re offering them, yes. I think they are 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

**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

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

**Barriers to PEP Adherence and Follow-up**

**Five Key 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**
- Survivors are ashamed of going back because people will label them you know that they are 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

“Some of them are ashamed of going back because people will label them you know that they are 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

“...if you take your pills? Then I’d say no I didn’t. Come and take your pills... [And did you have any other way than your mom to remind you to take the pills?]

[Laughs] My, my, my daughter.”

- Survivor

“...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.”

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Recommendations for strengthening the facilitating factors for PEP adherence and completion are provided in case study 5.

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