

# Factors Affecting Adherence to Post-Exposure Prophylaxis in the Aftermath of Sexual Assault: Key findings from seven sites in Gauteng Province

by

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## **Executive Summary**

Concerned by rape survivors' low rates of adherence to post-exposure prophylaxis (PEP) to prevent HIV infection, the Gauteng Department of Health (GDoH) commissioned research investigating possible reasons for this state of affairs.

Between February to September 2004 the Centre for the Study of Violence and Reconciliation conducted 105 interviews with rape survivors and health workers and 26 observations at seven health facilities. We found that patients defaulted due to side effects, forgetting to take their medication, and not taking their medication properly. We also found that some health workers are not sufficiently trained around the medication and provide patients with incorrect information or insufficient information; other health workers are adequately trained but do not spend sufficient time giving patients all the information required, checking that patients have understood how to take the medication, or asking about side effects; and some patients are in no condition to absorb much information at the time of the examination.

Based on these findings the following recommendations are made: increasing rape survivors' understanding of how to take the drugs; and strengthening health workers' support to rape survivors. We also recommend that GDoH revise its current method of calculating adherence and track individual patients instead. On this method, completion rates may be both better and worse than GDoH currently calculates.

## **Introduction**

In April 2002 Cabinet announced that it was making anti-retroviral drugs to prevent HIV infection available to rape survivors. A protocol for Gauteng Department of Health (GDoH) was subsequently developed in early June 2002 and implementation began at the end of that month. At the time of the study some 30 sites in Gauteng were offering post-exposure prophylaxis (PEP) to sexual assault victims.

The objectives of the GDoH PEP programme are threefold:

- To strengthen existing services to survivors of crime;
- To provide PEP to victims of sexual assault; and
- To investigate the efficacy of anti-retrovirals (AZT and 3TC specifically) in

preventing transmission of HIV following a sexual assault (Gauteng Department of Health Status Report, undated: 1)

Key components of the programme include trained healthcare workers/service providers; the provision of PEP and other STI prophylaxis, emergency contraception, anti-emetics and pain killers; staff debriefing; trauma counselling and follow-up programmes for clients, as well as referrals to support programmes for clients that test positive; an effective voluntary counselling and testing (VCT) programme for victims of sexual assault; and finally, a research programme to ascertain the efficacy of the drugs and effectiveness of PEP (ibid: 2). Monitoring by GDoH of the uptake of PEP by rape survivors during the period 30 June 2002 - 31 May 2003 found that just 16.2% of rape survivors provided with the drugs completed all 28 days of treatment (GDoH Status Report, undated). Concerned by this low rate, GDoH commissioned research to investigate factors affecting adherence to PEP in the aftermath of rape.

This report, the outcome of that research, is structured as follows. The first section of the report outlines both the methodology used to gather data as well as the key assumptions informing design of the interview schedules. The next section of the report describes the seven government facilities we visited and presents the findings from interviews with health workers at each site. To provide some basis for comparison, we conclude this section with two case studies, one of a service run by a non-governmental organisation (NGO) and another of a service provided by a private hospital. Having presented the views and experiences of service providers, we then turn to findings about rape survivors' actual experience of taking PEP. This is followed by a discussion around different methods of calculating adherence. The last section of the report makes recommendations aimed at assisting GDoH to increase the effectiveness of the PEP programme.

### **Methodology**

Both quantitative and qualitative methods were used to gather information, including interviews with health workers and rape survivors, data collection schedules tracking rape survivors' adherence to PEP, semi-structured observations and analysis of secondary data. Our secondary source of data was GDoH's monthly reports for the eight month period January – August 2004.

Drawing from multiple sources of data as well as using different methods to collect the same data allowed us to triangulate our findings. Thus if the same finding consistently emerged across the observations, health worker interviews and rape survivor interviews, this indicated strong support or corroboration for this particular finding.

Selection of these methods (which are discussed in greater detail later) was based on a literature review around compliance with anti-retroviral drugs which aimed to identify those factors thought to affect adherence to PEP. These findings were particularly important to the design of the various interviews.

### ***Literature review***

The literature review found unpleasant side effects associated with the use of PEP to be the most common explanation for low adherence. Other factors also thought to affect

adherence included patients' perception of their risk of HIV infection; the (non)availability of counselling and support to the survivor; the nature and quality of relationships between health care staff and patients; patient knowledge and understanding of the drug regimen and the necessity of taking it; and the stigma attached to both sexual assault and HIV (Kachienga, 2004). Kistner (2003) identified other factors also thought to affect adherence, such as the extent of patients' access to reliable primary medical care, as well as their ability to keep appointments for follow up consultations; and finally, how able they are to fit the medication into their daily routine and take it in front of others.

Drawing on these hypotheses, we developed the interview schedules to ask questions around the following key themes:

- drug side effects, their impact on patients and health care workers' ability to treat such side effects;
- health worker and patient knowledge of the drugs and their use. In relation to these points, we also asked about the training health workers had received around both rape and PEP, as well as their knowledge of the protocol and policy to be followed around care and treatment of rape survivors;
- the nature and quality of relationships between health workers and patients; and
- support and counselling received by rape survivors after the rape.

In addition, we asked health workers and patients to identify any other factors they thought affected adherence. Interviews were analysed according to these key themes.

### *Research sites*

Six sites were initially selected from the 30 providing PEP at the time of the study. One site was selected from each of the five health districts in Gauteng Province. In selecting these five sites, we tried to ensure both a mixture of the urban and peri-urban, as well as variation in patient load, with some of these sites being amongst the busiest in the province and others less busy. A sixth site was specifically chosen because of its reputation for securing the highest adherence rates in the province. A seventh site was added in phase two of the study. This site was chosen on the basis of the high number of rape survivors it treats and our need to include as many rape survivors as possible in the study in the time available.

For comparative purposes, we included a case study of one non-governmental organisation (NGO) and one private facility, both of whom were offering PEP. Selection of the NGO was based on its reputation for offering a comprehensive model of care which was thought to result in a high degree of adherence to PEP. It was thought that analysis of this service might assist in identifying elements of an effective PEP service. The private facility selected is one of a number of rape crisis centres established by this particular health care chain, which appears to be the only private health care chain making such services available to women, irrespective of whether or not they have access to medical aid. This particular chain had previously played a pioneering role in providing PEP to rape survivors.

### *Interviews*

A total of 104 interviews were conducted, including 37 health care workers and 67 rape survivors.<sup>1</sup> The health workers' interview consisted of a semi-structured questionnaire

comprising both open and closed-ended questions administered during a face-to-face interview lasting approximately an hour. The 37 health care workers included 7 doctors, 18 nurses, 7 counsellors, 4 social workers and 1 psychologist, all of whom worked at one or other of the seven sites selected for investigation.

Interviews with rape survivors taking PEP were key to determining those factors which either promote or discourage adherence. However, the distressing and traumatic nature of rape makes it difficult for women to talk about and as a result, few women initially made themselves available for interviews. A number of different approaches were attempted in our efforts to recruit rape survivors. Letters explaining the purpose of the study and requesting assistance with recruiting rape survivors for the study were sent to organisations in Gauteng known to provide counselling to rape survivors. One hospital (not included as a site of investigation) which kept records of patients' contact details also provided us with a list of 20 names and telephone numbers. Many of these numbers turned out to be incorrect however. Ultimately, fifteen rape survivors were recruited either by health care staff or researchers for in-depth, semi-structured interviews.

Another 52 rape survivors aged 14 years and older were interviewed during phase 2 of the study. These interviewees were recruited by researchers based at three PEP facilities. Researchers spent every Monday and Friday at the selected sites for a period of three months, amounting to 74 days in total. While stationed there they approached rape patients presenting at these sites to ask if they would be willing to take part in a short interview around their experience of taking PEP. Of the 60 patients approached, eight declined to be interviewed. Thus the 52 patients participating in the study represent 87% of all rape survivors aged 14 years and older attending these health facilities during this period on Mondays and Fridays. Information obtained from the short, face to face standardised interviews was coded and captured for statistical analysis with SPSS.

### *Observations*

A minimum of two structured observations lasting between two to six hours each were carried out at the initial six sites. Observations were conducted at different times of the day and night, as well as over weekends and during the week. We were also able to observe at one clinic two hours of a support group for rape survivors. In total 26 structured observations were conducted at these six sites.

During phase 2 researchers were based two days per week at 2 of these sites and at the new seventh site. We spent 26 days at each of the former two sites and 22 days at the latter site – the reduction in the number of days due to an initial delay in gaining access to this site.

### *Phases of data collection*

Data were collected in two phases: February to May, and mid-June to mid-September 2004, with preliminary findings presented to GDoH early in May. Initially, CSVr researchers conducted both the observations as well as the interviews while health facility staff were asked to complete the data sheets recording patients' reporting and adherence schedules. However, because much of the reporting and adherence data proved unusable, it was discarded at the end of phase 1 and our approach revised. Instead, three researchers were each placed at a clinic twice a week as described in the previous section, and a revised,

simplified patient tracking schedule was then distributed to clinics.

While patient tracking schedules were distributed to all seven sites, only four clinics maintained and returned these forms. Ultimately, because the data gathered at two of these four sites were contradictory and thus unreliable, data from only one site was used for the period June - August was used, and data from another site used for July and August.

### *Limitations of study*

Resource constraints prevented us from basing a researcher at the most rural of the PEP facilities in Gauteng. This means that our findings do not capture those factors more likely to affect rural women's adherence rates than those factors affecting women in urban settings. The ethical challenges of obtaining consent from children to participate in research meant that we also excluded them from the study which, therefore, does not explore factors affecting children younger than 14's adherence to PEP. Further, it was very difficult to recruit rape survivors who had defaulted on their treatment. Thus our findings are more characteristic of women who adhere to their medication than those who do not.

We conducted the research at seven PEP facilities, representing 23% or just under one in four of the 30 sites operational at the time of the study. Our findings are therefore not necessarily generalisable to all PEP facilities. Those findings made most frequently at most sites and which are also corroborated by the literature review are obviously likely to be the most generalisable. Further, the secondary data we have relied upon is limited by its accuracy. Certainly, in analysing this data, we became aware of discrepancies and missing information. Finally, that so few accurate patient tracking schedules were maintained and returned by the study sites obviously limits our ability to calculate the extent of adherence to PEP in Gauteng.

### **Findings from the Health Facilities**

This section of the report introduces the seven sites we visited and includes information about their respective rape patient profiles. We then discuss the common issues identified across the various sites. This is followed by findings from the interviews and the two case studies.

#### **Site descriptions**

According to our analysis of GDoH data a total of 3 160 rapes were documented by the seven sites between January – August 2004. Sites 3 and 7 were the busiest while sites 2 and 6 were the quietest of our sites. Adult rape survivors reporting at [Site 6](#) were most likely to be HIV positive at the time of the rape (40%), followed by 30% of rape survivors reporting at [Site 7](#). [Site 4](#) recorded the lowest number (13%) of adult rape survivors who tested HIV positive at the time of the rape. At the same time, [Site 4](#) also reported the greatest number of children testing HIV positive on presentation (24%, or almost 1 in 4 of all children reporting at the clinic).

One in five (21%) adults at [Site 7](#) refused either VCT or PEP, making it the site with the greatest proportion of such refusals. At all sites, with the exception of [Site 1](#), more adults than children refused either VCT or PEP. At [Site 1](#), 1 in 4 children (or 26%), refused either

VCT or PEP. The sister responsible for managing [Site 1](#) speculated that this high rate of refusal reflects the parent's fear about what a positive result in the child implies about the adult's status.

[Site 3](#) was the only facility where more children than adults were seen. At every other facility, adult victims outnumbered child victims. Across all sites, with the exception of [Site 2](#), children were also more likely than adults to report after 72 hours had elapsed. At 43%, [Site 3](#) recorded the greatest proportion of children reporting after 72 hours. This was followed by [Site 1](#) with 39% of children reporting late. The greatest proportion of adults reporting after 72 hours was also recorded by [Site 3](#) (1 in 3 or 33%).

#### **Site 1: Hospital crisis centre**

*According to statistics submitted to GDoH by Site 1 for the period January - August 2004: A total of 443 rapes (311 adults and 132 children) were documented by the clinic during this period. Of these:*

- 11% of adults and 39% of children reported after 72 hours had elapsed
- 17% of adults and 4% of children tested positive
- 14% of adults and 26% of children either refused VCT or PEP
- 60% of adults and 24% of children were provided with PEP

Note: No figures were provided for February therefore these statistics cover seven and not eight months.

When the study began, [Site 1](#), a crisis centre, was situated in a house on the grounds of the local hospital. The house comprised 11 rooms which were utilised as consulting rooms, a comfortable waiting area with a television set, radio, and heater, and a children's play room. Not all rooms were in use. Some seven people staffed [Site 1](#) including four VCT counsellors (2 female and 2 male), one nurse, one doctor (a district surgeon) and a cleaner.

In May 2004, hospital management decided to use the house as a facility to treat people living with HIV and AIDS and the centre was moved into the casualty section of the hospital. It now consists of three small rooms (a waiting room, examination room and counselling room) located off the central passage to casualty. During the day it has a staff of three - one chief professional nurse and two counsellors. The nurse manages the centre and is also responsible for the forensic examination of patients and collection of evidence. When she is busy, staff from casualty assist her to conduct the medico-legal examination. The counsellors provide the VCT service and inform patients about PEP. No dedicated staff serves the centre at night which is then reliant upon the district surgeon for the examination and the casualty nurses for the HIV test, VCT and provision of PEP. This sometimes results in long waits for the patients before they are examined.

The hospital serves a large geographical area on the north-east rand. For counselling around the rape, patients are either referred to the hospital social workers or to services in an adjacent municipality.

## Site 2: Hospital casualty

*According to statistics submitted to DoH by Site 2 for the period January - August 2004:*  
A total of 45 rapes (39 adults and 6 children) were documented by the clinic during this period.

Of these:

- 3% of adults and no children reported after 72 hours had elapsed
- 18% of adults and 1 child tested positive
- 2 (5%) adults and 1 child refused either VCT or PEP
- 72% of adults and 3 children were provided with PEP

[Site 2](#) is a primary health care clinic and level one hospital. Staff do not perform medico-legal examinations, referring rape survivors to two nearby private hospital facilities instead. If patients are on medical aid, these private facilities will provide them with pre- and post-test counseling as well as PEP. Those without medical aid are provided with a twenty-four hour supply of antibiotics and PEP and sent back to [Site 2](#)'s casualty section for VCT and PEP. This separation of functions will require rape survivors who have reported the rape to make at least two trips<sup>2</sup> to have all their needs addressed. Survivors are reliant on either the police or their own means to make these trips.

At the time of the interview, there appeared to be no formal relationship between [Site 2](#) and the two private hospitals, making it impossible to track patients and calculate the number of patients lost in this process of referral. On our estimates, this procedure excludes most rape survivors from access to PEP. The unit manager at one of these private hospitals estimates that the hospital examines some 20 rape survivors every month. Only one or two of these are on medical aid, meaning that some eighteen rape survivors should be seen at [Site 2](#) every month. Accepting that this estimate is correct, then [Site 2](#) should have seen some 144 patients over the eight month period between January to August. GDoH statistics for this period show that 45 patients were seen at [Site 2](#).

At the time of the interview one doctor and one nurse from [Site 2](#) had attended training around medico-legal examinations and plans were in progress to open a facility designated for rape survivors in the casualty section.

## Site 3: Specialist one-stop facility

*According to statistics submitted to GDoH by Site 3 for the period January - August 2004:*  
A total of 1 031 rapes (422 adults and 609 children) were documented by the clinic during this period. Of these:

- 33% of adults and 43% of children reported after 72 hours had elapsed
- 23% of adults and 5% of children tested positive
- 13% of adults and 3% of children refused either VCT or PEP
- 55% of adults and 33% of children were provided with PEP



[Site 3](#) was established specifically to cater to victims of sexual assault. Situated on the grounds of one of the largest public hospitals in Gauteng, it is a satellite service of one of the hospital's clinics and functions independently of the hospital. Being a specialist one-stop facility, [Site 3](#) has the services of the police, the counselling NGO People Opposing Women Abuse (POWA) as well as representatives from the Department of Justice and Constitutional Development based on-site. The on-site location of all these service providers should, in theory, prevent rape survivors from having to make numerous different trips to these agencies. Thus if a rape survivor arrives at [Site 3](#) without having reported to the police first, s/he is not sent back to the police station for a case number and docket; her (or his) statement can be taken by the police officer based at [Site 3](#). The one service that [Site 3](#) lacks, is that of a full-time dedicated doctor, with doctors summoned from the main clinic during the day and a doctor on call after-hours.

From the outside the Centre looks like a house. Inside it has a very comfortable reception area and a number of rooms including the examination room, a VCT room, statement-taking and play therapy rooms, an office for the police as well as one for the chief nurse, a staff kitchen, sick bay and ablution block and a waiting room. A further three offices appear to be allocated to POWA from which to provide counselling. A separate passage leads from the waiting room into the police section and the justice section. There are many posters and pamphlets about rape and domestic violence on the walls and tables in the waiting area. Patients are also given reading material to take home.

[Site 3](#) refers children to a social worker from Teddy Bear Clinic who comes in twice a week and sees nine patients a day. Childline also provides counselling for some patients. Three counsellors from POWA based at the centre provide counselling to adults experiencing domestic violence. The [Site 3](#) social worker appears to be counselling adult rape survivors.

#### **Site 4: Clinic crisis centre**

*According to statistics submitted to GDoH by Site 4 for the period January - August 2004: A total of 291 rapes (186 adults and 105 children) were documented by the clinic during this period. Of these:*

- 7% of adults and 28% of children reported after 72 hours had elapsed
- 13% of adults and 24% of children tested positive
- 1 adult and no children refused either VCT or PEP
- 85% of adults and 23% of children were provided with PEP

[Site 4](#), a rape crisis centre is based at a clinic located some 40 kilometers outside of Pretoria. In addition to providing medico-legal services as well as PEP to survivors of sexual assault, the clinic offers most other primary health care services including curative care, maternal health, mental health services, social work services, full time and sessional doctors' services, dental services, and TOP services. The clinic is open 24 hours.

[Site 4](#) contains a waiting area and two private consultation rooms and caters both to victims of domestic violence and rape. It is staffed by two nurses, a professional nurse and an auxiliary nurse with VCT and HIV training. These two nurses offer all PEP services and run

a support group for survivors of sexual assault. Two volunteers are also available to provide counseling services to survivors of domestic violence. The medico-legal examination is conducted by either full time or sessional doctors at the clinic. Patients are sent to the curative section of the clinic for this examination.

After 4pm and over weekends sexual assault survivors are treated by the nurses and doctor on duty in the curative section. During this period only emergency treatment and a starter pack of PEP are provided to patients. Patients are then told to come to the centre on Monday to be given more PEP and to receive VCT and the HIV test.

[Site 4](#) refers patients to a social worker from Women Against Women Abuse (WAWA) as well as an on-site psychologist.

#### **Site 5: Hospital crisis centre**

According to statistics submitted to GDoH by Site 5 for the period January - August 2004: A total of 629 rapes (418 adults and 211 children) were documented by the clinic during this period. Of these:

- 8% of adults and 35% of children reported after 72 hours had elapsed
- 28% of adults and 9 (4%) children tested positive
- 4% of adults and 3 (1%) children refused either VCT or PEP
- 52% of adults and 46% children were provided with PEP

Note: In March, no children or adults were recorded as having been provided with PEP. If this is a data recording error, then slightly more children and adults may have received drugs than we have calculated.

[Site 5](#) is situated in the Vaal and is the only hospital in the area offering medico-legal and PEP services to survivors of sexual assault and child abuse. It too has a designated crisis centre which only operates during normal working hours. Week-end and after-hours patients are treated by the casualty section of the hospital.

The crisis centre has three professional nursing sisters able to conduct VCT and HIV testing. In addition to co-ordinating the PEP services, these nurses also recently started a support group for survivors of sexual assault. Four volunteers also assist with the VCT counselling. No doctor is based at the crisis centre during the day either and one must be called from casualty (which is some distance from the centre) to attend to patients.

Unlike the other sites which primarily provided weekly dosages of PEP to patients, [Site 5](#) predominantly gave patients monthly dosages of PEP. The reason for this was not explained.

#### **Site 6: Hospital crisis centre**

According to statistics submitted to GDoH by Site 6 for the period January - August 2004: A total of 173 rapes (111 adults and 62 children) were documented by the clinic during this

period. Of these:

- 12% of adults and 44% of children reported after 72 hours had elapsed
- 40% of adults and 1 child tested positive
- 10% of adults and 5 (8%) children refused either VCT or PEP
- 45% of adults and 55% of children were provided with PEP

[Site 6](#) is a Crisis Centre situated in a hospital in a mining area on the West Rand in Gauteng and serves both peri-urban and rural areas. Although primarily responsible for treating sexual assault survivors, the centre does sometimes serve other people as well.<sup>3</sup>

The Crisis Centre is both spacious and comfortable. It consists of the reception area, a bathroom and toilets, a kitchen, a store room and sluice room, an administration room, a 'victim's' room with two single beds, the examination room, a counselling room stocked with pamphlets on rape, PEP, HIV and STIs and a children's play room furnished with toys, a bed and children's table and chair set. A room with two beds is also available to volunteers who work night shifts. There is also a relaxation room with a television set and other entertainment equipment. This room is available both to volunteers and those who occasionally accompany victims, as well as rape survivors themselves. The Centre receives food donations from Checkers to provide food to rape patients when the hospital kitchen is closed; otherwise the kitchen provides meals for victims.

The Crisis Centre is co-ordinated by a professional nurse who is also assisted by volunteer counsellors who work shifts (3 per shift). The volunteers are responsible for advising patients on the use of the various drugs. The different medicines are distributed in separate packs with written instructions. Instructions for follow-up visits are also given. As with the other sites, the Centre does not have a full-time designated doctor at its disposal but relies on doctors who are on-call.

#### **Site 7: Specialist medico-legal facility**

*According to statistics submitted to DoH by Site 7 for the period January - August 2004: A total of 548 rapes (437 adults and 111 children) were documented by the clinic during this period. Of these:*

- 4% of adults and 22% of children reported after 72 hours had elapsed
- 30% of adults and 7% of children tested positive
- 21% of adults and 2 (2%) children refused either VCT or PEP
- 43% of adults and 40% of children were provided with PEP

[Site 7](#) is located in inner city Johannesburg. It was established as a medico-legal centre and serves both victims and perpetrators of crime.

The medico-legal centre is housed on the ground floor of a building on the far end of the hospital grounds. It has a very spacious foyer, with two sitting areas, one presumably for victims and the other for perpetrators. There is one staff administration room, one staff tea

room, one victim examination room, one perpetrator examination room, the doctors' sleeping room and a counselling room. The toilets are down the passage (one for staff and one for patients); the toilets are not filthy but neither are they clean. There is no toilet paper and no soap at the basin closest to the patient toilet. Although there is what appears to be a bathroom, it does not appear to be in use.

Sexual assault patient files are kept in the victim's examination room. There is no filing cabinet and files are kept in a display cabinet. Files of patients that have tested positive lie in a box on the floor.

As a specialist service, the centre has a doctor on the premises 24 hours a day. According to staff at the centre, there should ideally be 5 nurses on duty per day. However this is not always possible and sometimes only two nursing staff are on duty. Two nursing sisters work straight shifts (7am – to 4pm) while one nurse and one doctor are on duty at night. The chief medical officer for the region is based at the clinic. In addition to her administrative and management functions, she also sees patients and often works night shifts. A social worker is based at the clinic two days a week. There are no lay counsellors or volunteers working at the clinic.

The clinic serves patients from the greater Johannesburg area as well as Alexandra. Referrals are usually made to Transvaal Memorial Institute (TMI) and sometimes to Ikhaya Lethemba.

#### **Discussion of observations across all sites**

In the next section, we discuss factors observed to impact negatively upon the provision of services to rape survivors at these sites. Because more time was spent at Sites 7, 3 and 1, a greater amount of information is available about these sites.

#### ***Staffing of facilities for rape survivors***

While some of these services can be described as 24-hour by virtue of their attachment to casualty, only one ([Site 7](#)) has all designated staff available on a 24-hour basis. Thus at almost all facilities rape survivors wait for examinations, HIV testing and VCT for longer or shorter periods of time. These waits appear to be longest at night and over week-ends when services are most dependent upon casualty staff or district surgeons. VCT counselors are not available at night so this additional task is also placed on casualty nurses. Casualty staff appeared to see their services to rape survivors as an add-on (if not burden) and their work in casualty as their first priority.

Some of the longest waits were observed at [Site 4](#), [Site 1](#) and, on one occasion, at [Site 3](#) (where the patient waited some three hours for the examining doctor to arrive). On two separate occasions the researcher arrived at [Site 1](#) to find patients asleep on the couches. They had been brought by the police during the early hours of the morning but not yet attended to by the district surgeon. To avoid these long waits at [Site 1](#), police officers were sometimes taking patients to facilities in different municipalities where the waits were apparently shorter.

Attempts had been made at two sites to address these difficulties. At both [Site 4](#) and [Site 5](#)

week-end patients were given a starter pack and told to come back on Monday for VCT and the HIV test.

Rape survivors did not only wait for the doctor, but they also waited to be taken home by the police. One patient spent four-and-a-half hours being shuttled between two police stations before finally being taken to [Site 4](#). Once there, she waited close to two-and-a-half hours before being examined by the doctor. (It should be noted that this woman was raped on a Saturday). She then waited another two hours before being taken home by a police officer.

Waits of up to three hours were also observed at [Site 1](#), as was an altercation between health workers and two police officers, neither of whom was willing to take the particular patient home. This argument occurred in front of the patient, who had already spent a number of hours waiting for casualty staff to examine her.

#### ***Privacy and confidentiality***

All people entering the hospital grounds where [Site 1](#) is located are asked by the security guards at the entrance what their business is at the hospital. This question is repeated again by the security guard at the entrance to casualty. Benches are also placed down the passage leading to casualty, including directly opposite [Site 1](#). It is thus possible for general casualty patients to observe people in the waiting section of the crisis centre. Under the circumstances, confidentiality and privacy are not guaranteed rape survivors.

The VCT counselling room at [Site 2](#) also doubles as a storage room. Nurses and other staff were observed walking in and out of the room to fetch things while a patient was being counselled.

At [Site 3](#), a rape survivor was asked to provide details of the rape in the waiting section of the facility while others were present. On another occasion at the same facility, an adolescent girl was lectured on the shortness of her skirt, with the nurse stating that fewer rapes had occurred in her day because longer skirts had been worn. On a third occasion, when three alleged perpetrators were brought in for examination, a nurse was heard telling them that they could now look forward to being raped themselves in prison.

#### ***Blaming rape survivors***

An instance of blaming behaviour towards rape patients was observed at [Site 5](#). The doctor repeatedly asked the woman whether her boyfriend or some other partner had raped her. He did not want a nurse to assist him with the examination and instead allowed the male police officer to remain the room while conducting the examination. The nurse assisting the doctor apparently reported him to the matron because he refused to complete the J88.

Volunteers at [Site 6](#) also mentioned a particular doctor who was in the habit of berating victims, asking whether they had been raped as a result of partying at bars. Insensitive, disrespectful doctors were also mentioned by a nurse at [Site 4](#).

### *Knowledge of policy and procedure, including the drug regimen and treatment*

Despite GDoH's policy that sexual assault survivors do not require a police case number in order to be treated, we observed patients at Sites 1, 3, and 4 being refused treatment until they reported the rape to the police. This finding is not unique to this study or Gauteng; Human Rights Watch (2004) made a similar observation of other provinces.

At [Site 1](#) it appeared that some of the casualty doctors were unfamiliar with the use of the crime kit and were asking the VCT counsellors to assist them with completing the crime kits. A consequence of this practice which we observed, was a female rape survivor being examined by the male doctor with the male VCT counsellor also in attendance.

Presumably because anti-retroviral treatment (ART) is very new, many health workers are still learning about the drugs. On one occasion, not knowing how to treat a child or obtain her consent, the staff asked the researcher's advice. There were also other times when health workers requested further information about PEP from the researchers.

### *Counselling and support of rape patients*

[Site 5](#) and [Site 4](#) had started support groups combining both rape survivors and patients from the HIV clinic. At [Site 5](#) the support group was being run twice a week by volunteers from 10 am to 3 pm. At the time, five sexual assault patients and a few HIV positive patients were attending the group.

We were able to observe one session of the monthly support group run at [Site 4](#) by a social worker from an NGO, three volunteers and a nurse from [Site 4](#). The objective of the group was to provide support to all victims who had been sexually assaulted. A total of 26 people attended the session: four boys and their mothers, one young adult male and two teenage girls. The remainder of the group consisted of adult women.

Much of the speaking during the group was done by the nurse and the social worker. What they had to say consisted of giving the group updates on planned activities and reiterating the necessity of taking PEP. The social worker then saw individual members separately about the possibility of working in the NGO job creation programme run in partnership with a corporate company. She also gave out food parcels to those who had been told to come and collect them. The session ended with R5,00 being collected from every member as a contribution towards buying refreshments for group members' birthdays as well as an annual outing. (This money was collected every month.) As it happened to be the nurse's birthday on this particular occasion, the group enjoyed a cake.

Observation of the support group as well as other rape survivor-health worker interactions at [Site 4](#) suggested that a limited amount of time was spent actually talking to patients and counseling them. Follow-up visits observed at [Site 4](#) generally took less than ten minutes. At [Site 3](#), it was observed that about five minutes was spent with patients returning for repeats of their PEP. Similarly, nurses at [Site 7](#) also spent about five minutes with patients returning for PEP. Patients at [Site 1](#) spent, on average, between 10 – 15 minutes with the nurse. However, when patients demonstrated visible distress, nurses spent between twenty to thirty minutes with them.

At the time we conducted our observations, only Sites 3 and 6 had posters and pamphlets educating survivors and their family members about either HIV or rape. These two sites, along with Sites 7 and 1, also provided patients with information to take home.

### **Findings from health facility interviews**

This section summarises key findings from the 37 interviews conducted with health care staff across the 7 sites. Interviews were conducted over the course of the study, beginning in February and concluding in September 2004.

#### ***Training received by health workers***

Interviews with health care staff across the seven PEP facilities highlighted disparities in training. Some staff and counsellors had received training on the medico-legal examination, VCT and the provision of PEP, whereas at other PEP facilities staff had limited, if any training on the treatment of sexual assault survivors.

Ten staff had attended the ten day training provided by GDoH. Of the staff working with rape survivors, six nurses and one doctor had received training around conducting the medico-legal examination. Across all sites it was primarily the doctor who conducted the medico-legal examination. At one site the trained nurse spoke of her disillusionment with the hospital, saying that her training had been wasted because she was not given an opportunity to practice. At two sites, doctors were encouraging trained nurses to assist with the examination. Doctors at six of the seven facilities asserted that most of their knowledge has been gained through experience and through self-education.

Fifteen health workers had received some form of training on VCT and PEP. The duration of these training sessions varied from half a day to 3 weeks.

#### ***"There's one you take two, four times a day and the one that you take twice a day": Knowledge of drug regimen and its side effects***

Generally, levels of knowledge varied both within and across sites. Predictably, casualty staff were also generally less familiar with the treatment and its side effects than the staff specialising in the management of rape survivors. Five of the mental health staff (three social workers, one counsellor and one psychologist) also had minimal knowledge of the medication.

Twenty-one health care workers directly responsible for the PEP treatment were unsure of the protocol around treatment of rape survivors. At one site, the nurse had put the protocol up on the door for casualty staff to read and this was how one nurse knew what she had to do. At another site where nurses had also put up the protocol on the board for casualty doctors to read, they apparently did not do so. One nurse did not know the names of any of the PEP medication and also provided the interviewer with the incorrect dosage. Another nurse maintained that she had received no training on PEP; she was merely told what to do by other staff and did not clearly understand how the treatment worked.

At one site health workers were advising patients to take three AZT pills twice a day rather than the prescribed two pills three times per day. This deviation was recommended in an



effort to help those patients who found it difficult to take their midday dose of AZT. Thus one doctor said:

If she is a street vendor she must take the tablets regularly whenever she needs them.... sometimes it's better to say take it three in the morning and in the evening. (HCS 1)

Of the health workers, twenty-six were able to identify at least some side effects of the medication (with one counsellor saying she had learnt about side effects from the CSVN adherence schedule provided to health facilities during phase 1). Nausea, vomiting and headaches were the symptoms most frequently identified, followed by diarrhoea, dizziness and tiredness. Three health workers mentioned changes in appetite, while two health workers also included allergic rashes and anaemia within their list of side effects. One doctor included peripheral neuritis, having had to stop a patient's PEP for this reason. Another health worker referred to hepatitis and haematological abnormalities.

Asked what they would advise patients who were experiencing side effects, six said they would tell them to take their medication with meals while three recommended that patients drink lots of fluids and one recommended that patients spend time resting. Nine said there was medication or treatment for side-effects, with only three specifying what they would provide to patients. One health worker said that patients should continue with their medication regardless and gave no advice for dealing with side effects.

Two health workers, one a doctor working in casualty and the other a nurse, did not appear to be at all familiar with either the medication or its effects.

A very few health workers knew enough about the drugs to recommend Combivir as a more convenient alternative to the combination of AZT and 3TC.

*"Those volunteers who are admitting the patients they don't know how to handle the patient": Counselling and support to rape survivors*

The interviews suggested that counselling is being conflated with what is actually the provision of information on HIV and VCT provision, and PEP and its side effects. More attention is therefore being paid to HIV than the trauma of rape.

[Site 4](#) had an on-site psychologist, [Site 3](#) a full-time social worker and [Site 7](#) a part-time social worker. The other four sites did not have strong links with the mental health staff at their facility and typically understood referral to mean putting patients in contact with an HIV support group. At these sites, it seemed as if the nurses were providing the counselling. However, at two of these sites it did not seem as if even this counselling was happening with nurses saying time constraints and short staff prevented them from providing this type of support (although they recognised its importance).

Even when a social worker was on-site, staff did not necessarily refer to them. At one particular site the social worker said she constantly had to ask if there were any patients in need of counselling. Her perception was borne out by the two interviews with nurses at the same facility. Asked where they would refer patients requiring trauma counselling, interviewees did not mention the social worker but spoke of a nearby counselling facility



instead.

Most sites did not have working relationship with NGOs (sometimes because there were no NGOs in the area) or other civil society organisations. Some were keen to collaborate with outside organisations with the expectation they would provide counselling and follow-up to patients. Strengthening relationships with the police was highlighted across all interviews. While some sites reported having a good working relationship with the police services, others reported that police attitude and lack of understanding of the service impacted on their work and the patients. At one site, staff had run education workshops with the police educating them of the service and this seemed to result in the police bringing rape survivors to the facility more timeously.

Nurses commented on the inexperience and limited skills of the volunteers, while the psychologist and a social worker commented on the inexperience and limited skills of both the nurses and lay counsellors.

***"Maybe it is 4 out of 10 will complete the treatment": Health worker thoughts around factors affecting rape survivors' adherence***

Thirteen health workers attributed non-adherence to patients' inability to pay transport costs to the health facility. Fourteen identified side effects as contributing to non-adherence. Fourteen said that patients did not sufficiently understand the treatment, or the importance of taking it. Three said patients' state of mind (referring to the feelings arising from the rape) made it difficult for patients to adhere while three said patients tire of the drugs.

Seven interviewees attributed patient defaulting to health worker attitudes and lack of knowledge.

Sometimes you find that maybe I did not talk to the patient, stress everything to her - then you find that it is difficult for her. Sometimes I stress everything to her but she decides not to take. (HCS 18)

You can find that there are a few nurses who are not explaining to their patients on defaulting. You will find always when the patient is reporting, she is irritable. (HCS 4)

Those that recognised the importance of providing adequate information were aware of needing to do so in a succinct, simple way. However this awareness did not necessarily translate into spending more time with the patient.

You must know what impact you had on this patient - have you given her enough information? Because I believe the most important thing is the information. If she has not understood anything, you have wasted your time. (HCS 1)

Because we are doing too much...we see that there are many patients...we don't counsel for a long time. Sometimes the patients don't understand. (HCS 4)

One of the social workers had come to realise the link between both the trauma counselling

and the HIV counselling but she was the exception amongst the mental health staff:

I do reinforce [adherence] counselling, because I've picked up that with some, the level of understanding is not good. (HCS 16)

A few staff thought patients' fear of being stigmatised by coming to get PEP treatment played a role in adherence. Other staff thought it patients' responsibility to complete the medication and provide adequate information to staff so they could follow up on non-adherence. According to one nurse, a patient had been told by her aunt that the drugs would give her HIV and that she should not take them.<sup>4</sup>

Not having had the opportunity to speak to a patient who had defaulted on her medication, three health workers declined to speculate on reasons for non-adherence.

At one PEP facility staff attempted to increase adherence by calling patients to remind them of appointments. At two other sites staff initiated support groups to assist patients with the trauma of the incident and support them through taking the treatment.

*"After hours and weekends they really suffer, because we are not enough"*

At all sites health workers identified staff shortages and limited resources as their biggest constraints. Staff shortages had the greatest impact on those facilities based in or attached to casualty, with casualty staff needing to attend both to rape survivors as well as patients presenting in casualty. Noisy, busy casualty sections which lacked privacy and offered little comfort to patients were also identified as a barrier to good service. Stated one health worker:

...because there's no privacy. Because you're sitting with the patient, the patient is still talking to you and there comes somebody. It really disturbs you and also the patient. (HCS 26)

Her view was echoed by another nurse:

You could hardly sit down with a client and comfort up to your satisfaction. And when you are still busy with that client you are called 'please come and help.' (HCS 29)

As had already been observed, interviewees also highlighted the long periods patients waited before being attended to and/or taken home.

At specialist PEP facilities understaffing resulted in staff burn-out. One nurse recommended that staff within specialist facilities should be rotated more regularly so that they are able to do administrative duties one day, VCT another and medico-legal examinations on other days, rather than every day.

Staff at four PEP facilities reported that they sometimes ran out of the actual treatment, particularly over week-ends. This led to their referring patients to other PEP facilities for treatment. At one of these sites, a health worker said that the drugs they received had

sometimes expired, which had encouraged her to get into the habit of checking dates on the pack.<sup>5</sup> At another site they sometimes ran out of diluent over week-ends making it impossible to do rapid HIV tests. Patients were then given starter packs and asked to return on Monday for tests.

A social worker at one site commented that staff did not always recognise the patient's need to be consulted with in privacy; discussions about and with patients were often held in a common room with a number of people present:

You don't ask patients in that room - we call it a public room - you don't ask the patient in there.... It is confidential and people want privacy. No one wants to be asked in front of other people what is wrong. (HCS 3)

Inappropriate, judgemental attitudes of staff were highlighted by interviewees at two sites to be a deterrent to patients returning. It also emerged from the interviews that staff were refusing to treat patients who did not report the rape as a means of distinguishing the 'real' rape survivors from the liars who merely wanted medication. 'Real' rape survivors, they believed, would report the attack – just as 'real' rape survivors would complete a course of PEP.

#### *Relationships between staff*

Staff relations may impact on the quality of service to patients. At one site where staff enjoy an amicable relationship it was observed that patient care often came secondary to staff socialising. A nurse at this site thought the management style too lenient, with staff being given too much freedom. At the other extreme, staff at three PEP facilities reported tense relations. At one of these sites, suspicion existed that the doctors were stealing drugs, while the doctors appeared suspicious of the nurse's involvement in assisting patients secure grants. At this same site, a counsellor claimed that one sister preferred to carry out all tasks herself, which resulted in patients waiting long periods to consult with her:

She will keep them in that room from the morning till 2 o' clock. Maybe five people, she goes up and down. When we want to counsel she says "This is mine, this is mine." (HCS 6).

At another level, relationships between staff at service delivery level and those in management also appeared to present challenges. Health workers at one site thought senior management did not sufficiently prioritize medico-legal services, with the result that resources were not allocated to the facility. Nurses at two other facilities spoke of disillusionment, poor support and negative attitudes towards the PEP service, which appeared to have a demotivating effect - the effects of which may ultimately be felt by patients seeking help.

People are treating you like...I don't know - like you are not important. But nevertheless, whether I am important or not to them, I feel that the service that I am rendering is important to the client. (HCS 27)

You have initiative and that initiative is being killed. It's being destroyed and

you can't do it further. (HCS 3)

### *Ways of improving the service*

Two staff members maintained that computers would make their working environment more efficient, particularly in relation to record-keeping.

Approximately 10 health care workers recommended that more training was needed for staff. One nurse interviewed felt she had no counselling skills despite being responsible for conducting the pre- and post-test counselling with survivors. This was a source of frustration for her and she attributed some non-compliance to inadequate counselling and information to patients.

If we have properly trained personnel, or if they can send us for training and then we know how to deal with sexual assault, then we would be better off.... Maybe our listening skills are poor and we don't give patients the support they're supposed to get. (HCS 28)

Health care staff at some PEP facilities reported that they had been for trauma debriefing once since they had begun working with rape survivors, while other sites reported no debriefing or supervision. The lack of debriefing was highlighted by a psychologist as well as nursing sisters at the sites. This was reiterated by a doctor at another site who remarked that she had identified the need to have regular debriefing sessions with nurses and doctors working with rape survivors and had discussed starting weekly debriefing sessions with them.

A number of interviewees maintained that only staff with a special interest and competence should be selected to work with rape survivors, as not all people had the necessary skill and personality to deal with such patients. If no such selection occurred, unsuitable staff treated rape patients in an abrupt, cursory manner, which may deter them from coming for repeats. Integrated, holistic service centres were also suggested as a possible mechanism for improving services.

With regards the actual treatment, staff suggested that perhaps the treatment regimen needs to be investigated and the possibility of providing the combination drug Combivir considered. Additional dispensing PEP facilities or mobile clinics were also recommended to make collection more convenient. Additional PEP sites in busy areas were also seen as one way to alleviate pressure at existing sites and thereby improve services.

The need for patient education and public awareness also emerged, with many interviewees proposing that various forms of media be utilised to educate the public about PEP. Developing and distributing information pamphlets about the correct way to take the pills was also seen as important.

### **Case Study 1: Interview with NGO offering PEP services**

Before concluding this section, we present a case study of an NGO service, which provides a useful basis for comparison. This NGO is based in Limpopo Province, and has centres at two hospitals. Each Trauma Centre has a staff of ten including a manager, six debriefers,

two fieldworkers and an administrator. The fieldworkers at both sites are volunteers. A professional nurse co-ordinates the PEP programme across both sites.

Sexual assault survivors who present at the Trauma Centre within 72 hours of being sexually assaulted receive VCT from trained debriefers (lay counsellors). If the baseline test is negative, a full course of PEP is provided to the survivor. The debriefers assist the survivor to lay charges and call the police, who accompany the survivor for a medico-legal examination.

Survivors are given the option of either returning to the hospital or receiving home visits by the nurse and fieldworkers who monitor any side effects and compliance with PEP. Patients who wish to return to the hospital but cannot afford to do so are then provided with bus tickets. The home visits are designed to support and encourage survivors to complete their medication. Fieldworkers administer questionnaires at each visit to ascertain what side effects, if any, are being experienced and whether the medication is being taken as prescribed. Where survivors experience side-effects, fieldworkers provide advice to minimise the negative effects of the drugs. Where the medication induces nausea and vomiting or hallucinations, survivors are referred to the doctor for anti-emetics or a change to the PEP drugs prescribed. If sexual assault survivors choose not to have home visits, the nurse conducts telephonic follow-up to monitor compliance and to provide support. E-pap is also given to those patients who do not have food regularly.

According to the coordinator, a total of 1 145 survivors (494 adults and 651 children under age of 16) have received PEP at both sites since 2001. She provided us with following statistics for the one year period August 2003 – July 2004.

Number of cases reported	383
Adults testing positive	23 (6%)
Children testing positive	3
Declined test or PEP	11 (3%)
Adults presenting > 72 hours	26 (7%)
Children presenting > 72 hours	100 (26%)
No. adults receiving PEP	135
No. of children receiving PEP	91
No. of adults defaulting	3
No. of children defaulting	0

The coordinator believes that the organisation's home visit programme is a factor that assists sexual assault survivors comply with PEP. The regular face-to-face contact, encouragement and assistance in dealing with the side-effects and encouragement help sexual assault survivors through a difficult course of treatment. The case monitoring system also assists the organisation to keep in touch with survivors even after the 28 day course of medication is completed.

Apart from the home-visit programme, the coordinator cites thorough pre- and post-test counselling and effective treatment literacy as factors that foster compliance with PEP. In their experience many survivors also cite the fear of contracting HIV as a factor which promotes high compliance with medication. Support and supervision by relatives also assists with compliance. The coordinator notes that minors have the best compliance rate because an adult supervises the taking of medication and ensures that it is both taken timeously and completed.

Factors contributing to defaulting include that families and the community do not consider rape a serious matter and nor do they consider HIV to be a potentially life-threatening virus. Severe side effects of the medication and lack of family support also work against treatment compliance. The coordinator also cites a very high workload as a challenge for her because she is the only professional nurse for both sites.

#### **Key elements of good practice in PEP according to the NGO**

- Well trained staff, both professional and volunteer, are key to the success of a PEP programme. The organisation believes that medical staff need to be responsible for such a programme because it involves drug therapy. However this needs to go hand-in-hand with the home-visit system that encourages compliance with a treatment regimen. A good working relationship between medical and lay staff within such a programme is integral to coordinate an organisation's PEP programme.
- The use of materials like pamphlets and questionnaires that elicit information on compliance, side effects, and how the survivor is coping with her experience are important. Calendars to remind survivors of important dates for re-testing and court dates are also helpful. These materials assist staff to keep records and statistics and help survivors keep track of their treatment.
- The organisation works in collaboration with the provincial Department of Health by virtue of being based in public health facilities. The relationship goes beyond this, with health department officials represented on the organisation's board of directors.
- Community awareness of rape and HIV as serious issues, support from all stakeholders, well-trained staff and follow-up of survivors are essential to a PEP programme.

#### **Case Study 2: Private Hospital**

This private hospital, which houses one of four rape crisis centres in Gauteng managed by this chain of healthcare facilities, is situated in Johannesburg. The busiest of these centres sees between 30 to 40 sexual assault patients every month. The overall Director of the various Rape Crisis Centres managed by this private health care group as well as the coordinator of the programme at this particular hospital were interviewed. An observation visit was also made to the hospital.

#### **Background to the programme**

Initially only those rape patients on medical aid were given the full 28 day course of PEP. Patients unable to afford the treatment were given a three day starter pack and referred to

government facilities offering the entire course of treatment at no cost. In May 2003 the group's rape crisis facilities began offering all patients the full 28 day treatment at no cost. At the same time the centres began offering combination therapy i.e. Combivir (2X per day) in combination with Crixivan (3X per day), in accordance with the World Health Organisation regulations.

When this new regimen was implemented, patients were required to take almost 20 pills at their first visit. However, as many patients became nauseous, patients are now first given the PEP, followed approximately 6 hours later approximately 6 hours later by emergency contraception. Patients are given a meal, followed by the remainder of the pills.

Patients are not given the full 28 day course at one time. To monitor intake, patients are first given a three day starter pack, followed by a course for a further 10 days, and thereafter the remainder of the medication.

### ***Referrals***

An observation noted by the Director was the long waiting period's sexual assault victims had to endure before being brought to the hospital by police officers. He added that often patients are made to wait for 3 to 4 hours before being brought to the hospital. He described an incident where the police did not want to relinquish the rape victim to paramedics who arrived to pick the patient up from the station as they had not completed taking a statement. He stated that they are now trying to inform the public that they should first come to the hospital and then go the police station if they want to.

It was both observed and reported that patients rarely wait for long before being examined. If patients have to wait for results or medication they are allowed to go home and return later. Patients are also supplied with a change of underwear and bathing facilities are available for patients' use. No reading materials regarding treatment are given to patients.

Most patients are referred by police and other counselling centres. Although hospital policy states that patients are not required to have a case number, not all staff are informed on the correct procedures and some may insist that patients have a case number.

No volunteers are based at these facilities.

### ***Training***

The coordinator at the hospital site reported that 9 staff members attended a 3 day crisis intervention and counselling course and some of the nursing staff had received training on HIV testing. At most of the sites, psychologists and social workers provide counselling services to victims. According to the Director none of the staff were trained to conduct the medico-legal examination, he added that as the test was self-explanatory, staff were self-taught. Despite this the director was of the opinion that training might make things easier in that doctors would not be so afraid to conduct such examinations.

### ***Adherence Rates***

At the time of the interview, this group did not appear to be routinely maintaining statistics around adherence to PEP. It was the director's perception that adherence was not good with, on his estimation, only about 40% of patients returning after three days. His sense was that

approximately 25% of those seen return for follow up HIV tests. At this point they are not conducting any follow-up calls or visits and strongly feel that it is the individual's responsibility to complete the full course of treatment.

Asked what problems were encountered in the delivery of this service, the director said that some staff had judgmental attitudes towards rape victims and refused to treat them. This attitude was evident during this interview and the interview with the centre coordinator, both referred to the tendency for patients to 'fake' rape for treatment only to not comply and one commented on the drinking habits of the patients which place them at risk. He stated that the attitude of many of the patients have led him and other staff to think that people have actually not been raped but were just presenting for the free treatment. In addition to biased attitudes was the poor training received by staff, doctors feels adequately trained to do the examination and also are very reluctant to appear in court. As a result many refuse to treat rape patients.

Lack of knowledge of services offered was also a problem at these private facilities; although staff should be aware that they offer the PEP service, at some sites they were refusing to treat patients not on medical aid and referring them to public hospitals instead.

The director stressed the need for education of the public regarding such facilities and the necessity of the medication and also spoke to the need to train hospital staff on correct medical procedures as well as the manner in which to treat the patient.

### **Concluding discussion**

Of the three different types of service, the NGO clearly had the best adherence rate. Admittedly, it has more dedicated staff than some of the GDoH sites we investigated and its patient load is considerably smaller. It should also be noted that while problems were present at all GDoH sites, and the quality of service varied across sites, a good deal of effort was being put into ensuring the service worked effectively. Some very hard-working and dedicated staff were observed doing what they could with what was available to them. These efforts took different forms and met with varying degrees of success. However, what the NGO identifies as crucial to helping survivors complete PEP, is often absent from the GDoH sites.

Firstly, less than half of health workers interviewed had received training around rape and PEP. Indeed, it appeared that the best trained and most committed staff were on duty during the day while less effective service appeared more likely at night and over week-ends when casualty staff were responsible for providing services. Given that the majority of rapes are reported at night and over week-ends, this is likely to result in many rape survivors having their first contact with less-trained and less-knowledgeable health workers. While some casualty staff are trained and knowledgeable, by their own admission, they rush through procedures and provide the bare minimum due to the competing pressures of casualty. Thus at least some – perhaps even many - patients will leave without fully understanding the importance of the medication, or how to take it. This suggests that while training may address some of the problem, it is also necessary to ensure that staff work in an environment that supports the implementation and application of their knowledge and skills.



Information materials are also not readily available for patients to take home and read later. Further, the interviews also suggest that most health workers have a limited understanding of the side effects of the medication, as well as how to treat them.

Finally, four of the seven sites had few or no referral links to rape trauma counselling services. They also had limited contact with organisations that could potentially assist in supporting an adherence programme.

While the private facility certainly had more staff than GDoH facilities, offered a more inviting environment and did not leave patients to wait as long before being attended to, their adherence rate did not appear to be any better than that of public hospitals. Staff attitude and bias towards sexual assault patients are evident as does problems with police officers.

### **Findings from Interviews with Rape Survivors**

This section presents findings from the two sets of interviews with rape survivors - the 15 in-depth qualitative interviews and the 52 standardised adherence interviews conducted with rape survivors returning for repeats of their PEP. Dominant themes are discussed below with a view to determining what factors impact on the rape survivor's decision to complete her/his treatment.

#### **Adherence Schedules**

In total, interviewers spent 74 days over a three-month period at [Site 7](#), [Site 3](#) and [Site 1](#) and interviewed 52 patients, representing 87% of all rape patients aged 14 years and older presenting at the facility on these days. The greatest proportion of patients were interviewed at [Site 3](#) (39%), followed by [Site 7](#) (35%). A total of 27% rape survivors were seen at [Site 1](#). Slightly under half of those interviewed were aged between 14 and 19 years (48%). Approximately 38% of patients were aged between 20 - 29 yrs and 12% were between 30 and 39. Forty-eight women and four men were interviewed.

The majority of patients had reported the incident to the police (96%) and most (88%) waited less than 6 hours before being taken to a hospital. Of the patients seen, 4 were asked to report – three of whom did not want to do so. The one patient who did want to lay charges struggled to find someone willing to take his report. He first went to [Site 3](#) where he was told to go to the police station to make a statement. (Apparently no police were on duty at [Site 3](#) on this particular occasion.) When he went to the station closest to where he lived, he was referred to the station closest to where the incident occurred. Concerned that time was running out, he went back to the clinic but was once again turned away. He went to another police station and was finally taken to [Site 7](#). This patient spent about 12 hours trying to access a PEP service.

More than half of patients (24 or 56%) were completing their second week of PEP while 10 (23%) were in their third week of treatment. Six (14%) patients had completed their first week of PEP and three had just completed all 28 days.<sup>6</sup>

While pre-test counselling was conducted with three-quarters of patients, only 58%

received post-test counselling. Slightly more than one in three (19 or 37%) patients reported having missed pills at some point. In five cases treatment was stopped because patients had defaulted. Of this group, three stopped because they had skipped a number of pills, while the other two stopped due to side effects. One of the two reported that although she felt terrible about stopping the treatment, her constant vomiting made it impossible to continue.

Some nine in ten patients (46 or 89%) experienced side effects but only 14 (34%) told staff about these side effects. Having been told to expect side effects, they did not think they should mention them to the nurse. Of those that reported the side effects, 92% reported that nothing changed in their treatment. Only one patient was given other medication to help address the side effects. In 85% of cases, rape survivors experienced more than one side effect. The most common side effects were nausea and vomiting, with 34 survivors complaining of these. Tiredness and drowsiness was the next most frequently mentioned side effect, reported by 18 survivors. Other side effects included feeling dizzy and weak (14 patients), stomach upsets and soreness (10) and headaches (7). Twelve patients reported changes in their appetite, with nine losing their appetite while three thought their appetite increased. One reported painful lungs and another said she developed a rash around her genital area. Two reported changes in their periods but this is likely to have been the result of the other medication they were provided with.

Patients appeared to find their own ways of coping with the side effects, usually through changing their eating and drinking patterns. Most often, this was timing their pills with their meals. (This was a particular challenge for those who had lost their appetite.) One took sweets with her pills while three others added different types of drinks – tea, soda water and ginger ale - to their diets to help deal with the side effects.

Almost nine in ten (88%) patients interviewed could not name the pills they had been given. Patients from [Site 3](#) in particular were however, able to describe their pills accurately. When asked to describe how many pills they were taking, responses varied from between 6 pills a day to 15 pills a day. (The correct number of pills is eight.) Approximately one in three (33%) reported taking the incorrect number of pills. One patient for example, had not clearly understood that she was meant to take both 3TC and AZT and was taking pills from only one of the packets. It was observed that staff found it difficult to tell the patient that her treatment was to be stopped. She was given no further pills but allowed to complete those still remaining.

One patient said the nurses did not explain to her how the pills needed to be taken. When she asked whether they should be taken before or after eating, the nurse shouted at her, saying 'everybody knew pills should be taken before meals.' Another patient, thinking that the medication had only to be taken for a week, had decided to stay away from school for that week to ensure that she took her pills properly and did not miss any doses. It was noticeable across the majority of interviews that patients did not know when the treatment was to end and were merely taking their medication from week to week with no clear understanding of when it would be completed.

Slightly more than one in three (37%) patients reported having missed pills at some point. Forgetfulness was the most common reason cited for missing pills (6); this was linked with the next most common reason for missing i.e. patients not being at home when they were meant to take the pills (5). Four patients skipped pills to cope with the side-effects (one

patient specifically excluding AZT) and one patient said she did not understand how the pills were supposed to be taken. Another reported that she couldn't get to the clinic to get more pills because she was at school.

The basis on which health staff took decisions to stop treatment was not clear. In some instances patients that had missed one day's worth of pills were refused further treatment while in other cases patients who had missed at least 16 pills were allowed to continue. One patient had missed as many as 27 pills but was still continuing treatment.

More than half of patients (28) identified side effects as the factor which made it difficult for them to take the pills. Another factor which made it difficult for five patients to take the pills was that they reminded patients of the incident. Three patients did not like the taste and smell of the pills and four found the number of pills they had to take overwhelming. Thirteen said they did not have any difficulties taking the pills.

When asked what helped them take their pills, 15 patients cited fear of contracting HIV as their motivating factor, while 11 maintained that family members reminding them made it easy. One interviewee stated that she reminded herself by setting her alarm clock when pills were meant to be taken, while two said nothing made it easier to take their pills.

Of those interviewed, 90% reported having told someone about the need to take the pills. In all of these cases the survivor received support from those they had told, which included family members, school teachers, work mates and friends. In one case where it appeared that the survivor's parents blamed her for the rape, her sister assisted her and often kept her pills for her. One patient was hiding her pills and concealing that she had been raped out of fear that her parents would assault her for having been raped. Another patient felt that having others remind him when to take his pills would help, but was adamant about not telling anyone.

Of the 52 patients interviewed more than half (56%) had not been for any counselling. Patients at [Site 3](#) were most likely to have gone for counseling, mainly because there was a social worker on-site. One patient however, highlighted how facilities may inadvertently be increasing transport costs for patients by arranging that they come for counseling on one day and collect their pills on another.

#### **In-depth rape survivor interviews**

A further 15 rape survivors agreed to participate in longer, in-depth interviews. The youngest rape survivor was 16 and the oldest 45. Four women were aged 19 or younger at the time of the interview while two were over thirty. The majority of interviewees (9) were aged between 20 and 29. Standard five (or grade 7) was the lowest level of education recorded while one interviewee had a degree. Three women had completed their matric. The remainder had some high school education. Three interviewees were employed (one running her own business) and three were still at school. The remainder of the women were unemployed.

Of the 15 in-depth rape survivor interviews, all said they completed the entire treatment regimen. Of those that completed, only two patients reported having missed taking pills - one because she forgot and the other because she tired of the pills. It is very likely that a

third patient may also not have adhered to her PEP. This patient, although maintaining that she did not miss any pills, said she took her pills only once a day which suggests that she did not understand how to take her pills and is therefore very likely to have missed a number of pills.

### *Women's understanding of PEP*

Women exhibited varying degrees of understanding of the treatment. All however, knew that the pills were to prevent HIV and most knew how the pills should be taken and though they did not recall the names, most were able to describe the pills. A small number confused PEP with Nevirapine.

Information on PEP was provided by either nurses or counsellors. One approach nurses and counsellors used to explain PEP was to focus on its ability to clean the body, with side effects such as vomiting and discharge used as evidence that the pills were indeed working and letting out the 'dirt.' This conceptualisation of PEP may prove problematic, as is implied by one woman in the section on side effects.

*"Even if she explained, I wouldn't remember. You know, when something like this happens, you think about other things"*

At least three patients maintained that they were in no fit state to listen to instructions when given information about the treatment. Only after they went home were they able to sit down and look at the pills and determine from the packs how they should be taken.

No, I don't remember them explaining. I know I just had to get them and go home and sleep. At that time, I don't remember any explanations. (RS 7)

It was also clear from the interviews that some rape survivors were actively engaged in a process of repressing their memory of the rape. They could not recall the date or month in which they were raped and remembered little of what had happened in the immediate aftermath. At least one stated that she was deliberately trying to forget.

Rape survivors stressed the importance of being provided with accurate information regarding the pills and one recommended that the information be given in written form. Another recommended that information be given in a visual format for people with limited levels of literacy.

*"The first week of tablets I vomited the whole week. I did not even go to work": Drug side effects and impact on survivors*

As with the rape survivors interviewed around adherence, almost all interviewees (14) experienced side effects, with 12 suffering multiple side effects. The most common side effect was nausea and vomiting, followed by tiredness. The presence of these side effects tempted patients to stop their pills. The degree to which these side effects incapacitated survivors varied, with some maintaining that it was constant throughout the 28 days and others saying that they experienced side effects in the first week or two only. Some patients stopped taking their pills for a day or two until some of the side effects subsided and then started again.

The two rape survivors who did alert staff to the unpleasantness of their side effects were not treated by the health facility but told to get medication from a pharmacy instead. One of these patients stated that she had not been able to afford this medication and therefore would have appreciated the hospital providing her with treatment. A third patient sought help for her side effects from a private doctor.

Two women provide very different reasons why side effects could cause patients to default. One, a 17-year old scholar, commented:

The smell was just making me sick when I open the container. And every time I walk into my bedroom I would just smell it and that was making me sick...I vomited and then I saw the pills there and I was like, "Oh no"...I just got this disgust feeling of "No, I'm not going to take this anymore." (RS 10)

Because she had only three days left of her medication, she justified defaulting on the basis that she was very close to the end of her pill regimen and it would make little difference if she stopped now.

For another patient, the absence of side effects and the fact that she did not feel unwell, encouraged her to think that she no longer needed the medication. Had her cousin not insisted and checked that she had taken her pills, this patient would have defaulted.

#### *Other factors affecting adherence*

Five women found getting to the hospital difficult. One was reliant on a friend to get her to the hospital while a further three did not always have money for taxi fare readily at hand. In the 17 year-old's household, only her father worked. He was paid on a weekly basis, usually on Thursday but sometimes on Fridays. She collected her PEP on the day her father was paid. The other women gave some insight into the sacrifices made to obtain PEP:

Sometimes there is no money in the house and there are lots of things that are short. But if you think that your life is important and it's important to take the treatment, then you have to take the last money you have and go to the hospital. (RS 2)

Even if I don't have money - but I try and get some money, take a taxi and fetch my pills. So I put money aside for transport to get to the hospital. (RS 9)

The fifth patient spoke of how fear for her safety made it difficult for her to come to the clinic. The rapists had not been arrested and she feared that they were following her. Although questions around fear were not included within the adherence questionnaire, one woman in this group was too fearful to come to the clinic alone. Thus for some women fear may be constraining their likelihood of leaving their homes and travelling, sometimes back to the same area in which they were raped.

Another woman highlighted how patients' perceptions of health facilities could impact upon adherence. Asked what made it difficult to take her pills, she replied:

You know, when people see you they criticise you and say "These pills from

Tembisa are this and that" but I don't want to listen to people. They say that you take these pills from Tembisa until you get tired but they don't do anything – you know, things like that. I won't get tired and I never think the way they think because this thing happened to me so I need to look after myself and not take what other people say about the treatment. (RS 9)

She went on to say that people who had used this particular hospital said it was "Bad and they don't treat people well." This however had been her first contact with the hospital and she was happy with the way staff had treated her and therefore trusted what they told her. It may be inferred from her account that people's prior experience of a particular hospital determines how credible they find that hospital's recommendations and whether they comply with its treatments or not.

#### *Rape survivors' experience of health facilities*

Of the 15 women, four were unhappy about the way they were treated and the manner in which they were attended to by staff at the PEP facilities. At one site, the patient reported being screamed at by the nurse when she went for the first visit:

While she was busy doing the blood test she kept asking me questions like what happened...and she was like shouting. So I had to tell her what happened. That's when she told me that "As a 17 year-old girl what you were thinking? You deserve things like that." So I just kept quiet because T. had already warned me that the sisters will shout at me and told me to just ignore them." (RS 16)

Said another of the doctor who examined her:

He said, "You shouldn't drink then"...When you get to hospitals you are already traumatised and then you get doctors who would be saying, "Why were you doing this? You shouldn't be doing this...." (RS 7)

In general, rape survivors were complimentary of the crisis centre staff:

They were very patient. When you had a problem you were able to talk to her and she would advise you. (RS 5)

They did however, distinguish crisis centre staff from casualty and other hospital employees:

The nurses, they think you are here because you need to irritate them or something. They don't take the time to actually ask you nicely what you need. (RS 10)

Another maintained that whilst staff at the site were "very nice" and tried to be helpful, language differences presented a problem and she was unable to understand anything.

At specialist PEP facilities staff were often not very busy and yet patients were made to wait for staff to attend to them.

Look, I understand that he has to take lunch but I don't think he was very busy ... my general impression of the clinic was that nobody was really particularly concerned about doing anything in a hurry...just another day, another job. (RS 13)

Said another:

The thing is, we had to wait. I got here at past 8 (am) and we only saw the doctor at about 3 in the afternoon. (RS 10)

Three interviewees were unhappy about the way the hospital looked, the equipment and the general atmosphere of the hospital. One respondent was appalled at the "filthy" conditions, saying that the waiting room, the doctor's coat and the examination bed were all dirty, increasing her sense of discomfort. This patient tried to seek an alternative place to get her medication.

Another maintained that the hospital was 'horrible', the centre did not have the necessary equipment to draw blood, and the toilets were not clean. This resulted in her being unable to give a urine sample and wanting to leave the hospital as soon as possible. She added that the place needed an upgrade and a scrubbing brush. The third patient maintained that the hospital was like a 'madhouse'. Two of these patients were seen at casualty sections and the third at a specialist medico-legal centre.

At some PEP facilities basic equipment ranging from toilet paper to crime kits and PEP were not available. At most PEP facilities patients were not offered anything to eat, nor given the choice to shower or change clothes. Where patients were offered tea and a place to sit in privacy and comfort, they were grateful.

Patients attending non-specialist facilities could not get their pills at the particular crisis centre but had to go to the dispensary. This practice entailed a loss of confidentiality. Other patients in the queue wanted to know why rape survivors cards' had a stamp different to theirs, or when nurses tried to help rape survivors bypass the long dispensary queues by taking them directly to the dispensary, wanted to know why rape survivors were getting 'special treatment.' Unsurprisingly, rape survivors we interviewed wanted the PEP service to be more integrated so that they did not to and fro from the crisis centre to the casualty and dispensary.

***"I think what made me remember taking my pills is that I've been scared that if I forget that I might get HIV"***

Of the fifteen women, twelve said that their fear of contracting HIV was the reason they complied with the drug regimen. One patient remarked that the pills 'helped clean the dirt in me', which served to motivate her to keep taking the pills.

All except one of the survivors interviewed told family and friends of the incident and the necessity of taking pills. All of these individuals reported receiving support and encouragement from their families and friends. One of the survivors recalled her family encouraging her to continue taking pills when she was tempted to stop, another remarked that her mother scolded her after she told her that she had missed taking her pills. A few of

the school-going patients reported telling their teachers, who reminded them about having to take their pills.

One woman set a reminder on her phone while another used a pill dispenser to help her remember to take her pills.

*"I think it is our responsibility to make sure we get here and take our pills"*

Individual responsibility and choice was stressed by the survivors interviewed, with the majority asserting that it was their responsibility to take the pills as their health and futures depended on it.

If I decide not to go and fetch, then it's my problem - they don't have any problem. I'm the one who will have a problem so I don't see why they have to remind me over the phone to come and fetch my pills. (RS 9)

With the exception of three rape survivors, most women were in favour of the weekly visits to the hospital for repeats, saying they encouraged them to continue taking their pills, and provided an opportunity for their health to be monitored. These patients spoke of the psychological benefits of weekly visits to the clinic.

You actually hope that by going there they will make you feel better about the problems you have... I think every week - because somehow it gives you hope going back there, and I thought it would make me feel better. (RS 15)

Two patients said that receiving their pills in weekly dosages was less overwhelming than receiving the full course at one go. One woman said so many pills made it easier to forget as one could not tell if pills had been missed or not. One patient remarked that she was very emotional when she visited the clinic. Staff at the site were helpful and allowed her to cry and encouraged her to continue taking the pills. Another patient thought that staff counselling and talking to patients when they came for weekly visits were essential in helping them move on. Survivors stressed the importance of on-going support and counselling and suggested that more referrals be made to counselling services.

However when asked about the usefulness and necessity of follow-up calls, the majority of respondents said they did not require follow up calls; they knew they had to take the medication and did not require anyone calling them.

I'm a very responsible person so I know exactly when to come back. (RS 6)

It would make me angry because I know I have an appointment. (RS 14)

One patient was not in favour of nurses/counsellors making follow up calls as these would have reminded her of the rape.

Only 3 of those interviewed recommended that they be called and reminded about the pills. One woman who had been called did say that she was grateful for the call made to her.



## Concluding discussion

Patients in this study defaulted due to side effects, forgetting to take their medication, and not taking their medication properly.

Almost all rape survivors reported side effects, some of which were debilitating and did not improve. However, ineffective treatment of side-effects is a key finding from this study, emerging from the rape survivor interviews, the health worker interviews and reinforced by our observations. While all health workers knew that the drugs caused side effects, the interviews found that few knew how to treat such side effects adequately. Patients were also not telling nurses about side effects, who in turn were not asking. The five to ten minutes that health workers spent with rape survivors collecting their repeats was not sufficient to enquire about patients' well-being.

The other key finding affecting adherence is rape survivors' lack of understanding of the drug regimen. Three reasons for this lack of understanding are suggested by the study: some health workers are unfamiliar with the drugs so it is possible that they provide patients with either inaccurate or insufficient information. Secondly, while other staff may be sufficiently knowledgeable, by their own admission, they do not spend sufficient time explaining PEP to patients. Finally, some patients are in no condition to absorb all this information in the immediate aftermath of the rape.

Fear of contracting HIV emerged as this group of women's strongest reason for completing PEP. Interviews also suggested that the support of others was crucial to helping many women persevere with treatment. Because their motivation sometimes fluctuated and they did not always remember their medication, adherence was helped by having supportive others (such as family, friends and workmates) assist women and girls to take PEP. It can be inferred then, that a lack of support and encouragement may increase the difficulty of taking the medication.

The weekly return visits also helped motivate at least some patients to continue their treatment. However, working women may find it difficult to return on a weekly basis and may prefer the monthly pack.

The in-depth interviews in particular suggested that these women took pride in their sense of responsibility and would not have welcomed calls from health workers. For one woman, such a call would have been an unwelcome reminder of the rape, while for others such calls suggested that they could not be relied upon or trusted to take their medication. However, because these women completed their PEP, they are the exception rather than the rule and may well be a group for whom being reliable is more important than it might be to other women.

For some patients transport to health facilities was difficult to afford. The study will not have captured the extent to which the inability to afford transport impacted upon patients' ability to get to health facilities; they simply will not have returned. The interviews also highlighted other factors potentially influencing adherence: belief that PEP gives people HIV; health facilities' reputation for (not) caring and curing; not feeling ill (meaning that medication was no longer required); and finally, fear which may prevent some patients from going anywhere at all.

## Calculating Adherence

This final section of the findings discusses the challenges around calculating adherence.

As the interviews with rape survivors suggest, while they may be completing their 28 day course of drugs or returning when they should for repeats, they are not necessarily adhering to the drug regimen. Thus a distinction needs to be made between completing or returning, and adhering.

Ideally, patients should take two AZT pills at six-hourly intervals throughout any one 24 hour period. One 3TC tablet should be taken at twelve-hourly intervals over one 24 hour period. This regimen should be repeated over 28 days. It is not known with scientific accuracy how strictly this regimen should be complied with. Should a patient who has skipped one day be considered to have defaulted and her medication stopped? What if a patient skips dosages over the 28 day period amounting to three days? Will PEP also be ineffective? There does not appear to be any scientific data settling these questions.

Thus in order to capture adherence in addition to returns or completion of PEP, it would be necessary to ask all patients at every visit how many pills they have skipped. It was our observation that this kind of questioning was not happening consistently across all sites on all occasions.

Apart from this distinction, the other key issue to resolve is how adherence and completion of medication should be calculated. Currently, GDoH calculates the percentage of those who complete PEP by dividing the total number of those who are given PEP with the number of patients collecting PEP in the fourth week of the month. We would argue that this method should be changed. Firstly, if one is calculating adherence on the basis of visits made in the fourth week, then it is necessary to calculate this as a proportion of those who received PEP in the first week only, and not the total number who received PEP over the month. It is also necessary to know which patients returning in the fourth week were given PEP in the first week. If this is not known, then it is possible that one is including in that fourth week those returning for their first or second visits, rather than their final visit. The number of return visits in any one week is therefore not the most accurate way of calculating adherence and appears to result in unreliable calculations, as we show below.

Between 1 June – 31 August, [Site 1](#) maintained the patient tracking charts provided by the CSV. Analysis of the charts is tabulated below.

Category	June	July	August	Totals
Presented > 72 hours	6	12	12	30 (16%)
Tested positive	9	8	12	29 (15%)
Declined to be tested	7	5	8	20 (10%)
Defaulted on treatment	19	19	20	58 (30%)
Completed treatment	12	11	13	36 (19%)

Unknown (incl. monthly treatment and transfers)	7	6	5	18 (9%)
Total	60	61	70	191

It would be incorrect to conclude that only 19% of those presenting at [Site 1](#) during June to August completed their medication. In order to calculate the percentage of those who complied, it is necessary to calculate this figure in relation to the total actually eligible for PEP, as set out below.

Month	Eligible – unknown	Completed	% of those eligible who completed
June	38-7=31	12	39%
July	38-6=32	11	34%
August	38-5=33	13	39%

During the three months under review, between 34% - 39% of rape survivors eligible for PEP completed their 28 day course of PEP. These figures need to be contrasted with those provided by GDoH, as we have done below.

Month	No. given PEP	No. at 4 <sup>th</sup> week	% GDoH completed	% CSVr completed
June	35	15	45%	39%
July	27	18	67%	34%
August	45	4	9%	39%

#### Site 6

Category	July	August	Totals
Presented > 72 hours	0	4	4
Tested positive	2	5	7
Declined to be tested	0	3	3
Defaulted on treatment	9	8	17
Completed treatment	0	0	0
Other (incl. unknowns, monthly treatment and transfers)	7	2	9
Totals	18	22	40

As this table shows, no patients in [Site 6](#) completed their treatment. One 8 year-old patient returned for two out of three visits in July, while two patients returned for two out of three visits in August. In both months the majority of patients receiving PEP did not even return during the first week. GDoH's calculations are the same as ours due to the fact that no patients returned in the fourth week.

## **Concluding discussion**

Completion rates may be both better and worse than GDoH currently calculates. They also differ across sites. While we note that some of the figures supplied to us and those given to GDoH differ, this does not cast doubts on the accuracy of the method of calculation but on the quality of record-keeping.

## **Recommendations**

Factors influencing adherence appear to be dependent upon the skill, knowledge and attitudes of health facility staff, individual characteristics of the rape survivor, and the nature of support they receive in their immediate environment. This last section of the report presents recommendations aimed at helping PEP facilities improve their adherence rates.

### **Increase understanding amongst survivors of how to take the drugs**

Limited information and understanding of the drugs is affecting adherence rates, according to findings from both the health worker interviews and the rape survivor interviews. There seem to be three reasons for this:

- Some health workers are not sufficiently trained around the medication and provide patients with incorrect information or insufficient information;
- Other health workers are adequately trained but do not spend sufficient time giving patients all the information required, checking that patients have understood how to take the medication, or asking about side effects; and
- Finally, some patients are in no condition to absorb much in the way of information at the time of the examination.

## **Recommendations**

### ***a. Training***

- All staff coming into contact with rape survivors must have some minimum level of knowledge and skill to deal with rape survivors. Such knowledge and skills should not be confined to HIV, PEP and the medico-legal examination alone but should also encompass trauma and the psycho-social impact of rape. GDoH should develop such minimum standards and ensure that all training meets these standards.
- Staff should be assessed and tested after their training to ensure that they fully understood what they have learnt and are able to explain it to patients in a succinct yet comprehensive manner. Suitability of staff to work with such patients should be assessed.
- Counsellors and other lay workers should also be thoroughly trained and evaluated on their knowledge, skills and attitudes before being allowed to counsel sexual assault survivors. Lay counsellors should also be screened for their suitability.

### ***b. Information to patients***

- It is necessary to provide patients with information to take home and read when they

are less traumatised. Information should include a simple background on the treatment and its purpose, instructions on how to take the treatment and its duration. Information on side effects should be included, along with a reminder to patients that side effects must be reported to health care staff. This insert should also tell patients about available over-the-counter remedies for some of the side effects. Written as well as visual information should be made available in all the relevant languages.

- At each visit health workers should enquire how the patient is doing. Like the NGO in case study 1, they could follow a protocol that investigates patient's understanding of the medication and its side effects. This would provide an important opportunity to clarify misinformation and provide treatment to ameliorate side effects.

### **Strengthen health workers' support of rape survivors**

At most sites it appeared as though health workers' primary focus was on providing the drugs, with less thought and time being spent on the emotional needs of the survivor. Furthermore, interviews with health care workers suggested that counselling is primarily centred on VCT. In addition to the lack of counselling, it was observed that health workers were not always equipped with the necessary skills and attitude to counsel rape survivors, or run support groups.

In this regard, it would be helpful to clarify the extent of health workers' involvement in counselling. We would suggest that they be trained in basic support work skills, rather than as counsellors. Their work load does not make it feasible for them to be undertaking counselling in addition to their other duties. Ideally the trauma counselling should be provided either by trained social work staff at the health facilities or NGOs specifically dealing with victims of rape and trauma.

Support is not only necessary for patients, but also for PEP facility staff, some of whom appear demotivated and discouraged. PEP facilities also appear to be functioning in isolation, with relations between health, the police and NGOs relatively undeveloped.

### **Recommendations**

- Health care services for rape survivors should not only focus on the provision of PEP. The emotional and psychological impact of the trauma suffered should be acknowledged and counselling expanded to include trauma counselling as well. In addition to ensuring that health care staff are equipped with the necessary information on the PEP regimen, efforts should be undertaken to ensure that the quality, attitude and approach of staff are suited to patients' needs. Health care workers should be closely evaluated for their suitability; screening of all potential counsellors should be undertaken by trained professionals and supervision of all those providing the counselling service set in place.
- Efforts should be made to ensure that all service providers have regular debriefing sessions with trained professionals.
- The organisation and functioning of some facilities needs to be evaluated; evidence

suggests that the casualty department is unsuited to rape survivors.

- Health care staff should be encouraged to make trauma counselling referrals to specialist rape crisis organisations in the area. Whilst counselling forms an essential component of the treatment of survivors, it should be delivered by skilled counsellors. This makes it essential for specialist rape crisis NGOs to work more closely with health services around the provision of PEP services to rape survivors.
- At some sites service providers have initiated support groups to assist patients with the emotional impact of the rape and to monitor the patients' levels of compliance. Such initiatives may be encouraged – although closely monitored and supervised if possible by trained, experienced mental health counsellors so that facilitators are provided with the skills, support and knowledge to conduct such groups.
- Although not all rape survivors welcome follow-up calls, they may be recommended under some circumstances. Health workers should first ask patients if they would mind being called however. These calls should not be punitive in nature.
- The provision of weekly packs should be continued – although flexibility should exist to allow for monthly packs. Patients should not be treated with suspicion when they say they are unable to attend weekly visits.
- It is recommended that attempts be made to strengthen relations between SAPS and health facilities. SAPS need to be trained on how to treat sexual assault survivors promptly so that they understand the need for urgency, as well as how best to treat sexual assault survivors.
- Relationships with NGOs should be encouraged and fostered. This will ensure that service providers can make referrals where necessary. NGOs may be able to assist with follow-up programmes, support and counselling to patients. It is further recommended that best practice models used by NGOs working in partnership with health be further investigated and where possible replicated.
- Counselling appointments and repeat visits need to be co-ordinated for the same day wherever possible to prevent patients having to make two trips in one week to the hospital. This obviously places a further financial burden on patients.
- The option of dispensing Combivir should be investigated. It is a less complicated regimen and may be easier for patients to remember.
- If patients are unwilling to make a police statement and report the case, they should not be requested to do so and their refusal should not hinder their access to treatment. It is recommended that the GDoH reiterate to service providers that police case numbers are not a requirement for treatment.
- Family and friends are clearly integral to assisting rape survivors and if patients require the support of family, this should be allowed at all points of the service. It is recommended that materials also be developed for family members around being a

'treatment helper.'

- Finally, we recommend that GDoH not only revisit its method of calculating adherence but also find ways of improving the quality of information collected. Computers and a custom-designed data collection software programme may help in this regard.

#### **Notes:**

<sup>1</sup> In this report we have used the terms 'rape survivor' and 'patient' interchangeably.

<sup>2</sup> This is the minimum if they present at the private facility first. If they go to the public hospital's casualty first, three trips will be required.

<sup>3</sup> During the observations it was noticed that a homeless woman was housed at the centre.

<sup>4</sup> The Greater Nelspruit Rape Intervention Project (GRIP) in Mpumalanga has also encountered patients saying that the drugs will give them HIV. (Personal communication, Barbara Kenyon).

<sup>5</sup> The shortage of crime kits at one site in particular led to staff either using outdated crime kits or not conducting the medico-legal examination at all.

<sup>6</sup> In the case of 9 patients it was not clear how many weeks they had completed.

#### **References**

Kachieng'a, M. (2004) *Factors promoting or limiting adherence to post exposure prophylaxis (PEP) regimes internationally and nationally*. Johannesburg: Centre for the Study of Violence and Reconciliation.

Kistner, U. (2003). *Rape and post-exposure prophylaxis in South Africa*. Johannesburg: CADRE/Department of Health.

Schleifer, R (2004). *Deadly delay: South Africa's Efforts to Prevent HIV in Survivors of Sexual Violence*. Human Rights Watch, 16 3(A).

Status report: PEP for the period 30 June 2002 – 31 May 2003. Prepared by Beverly Pepper for the GDoH.