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COMMUNICATING AIDS NEEDS PROJECT • CAN

Post-Exposure Prophylaxis (PEP) in South Africa: Analysis of Calls to the National AIDS Helpline

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The administration of post-exposure prophylactic antiretroviral therapy is an established treatment for the prevention of HIV seroconversion in HIV-negative individuals following potential exposure to HIV. Administration of post-exposure prophylaxis (PEP) for HIV prevention is a standard procedure in cases of occupational exposure in many countries, and is being used in a growing number of countries in cases of non-occupational (sexual) exposure. The South African government provides PEP for occupational exposure of health care workers in health care settings, and in April 2002 committed itself to providing PEP treatment to all rape survivors. The challenges involved in making PEP available nationwide – including training health care workers and other service providers, raising awareness about PEP and how and when it can be accessed – are considerable. This report draws upon focus group sessions with counsellors at the South African AIDS Helpline to highlight the informational needs about PEP reflected in calls to the Helpline. The research findings point to a growing awareness of PEP among the South African population, but continuing information needs about eligibility for PEP and procedures for accessing treatment. On the basis of these findings, the paper makes recommendations for enhancing PEP-related communications.

The administration of Post-Exposure Prophylaxis (PEP) – a short course of antiretroviral (ARV) drugs – has been linked to the prevention of HIV seroconversion in HIV-negative individuals following potential exposure to HIV through sexual or occupational contact (Cardo *et al* 1997; Roland 2002, 2004a, 2004b; Wulfsohn *et al* 2003). During the 1990s, PEP emerged as the standard of care in many countries in cases of occupational exposure, such as needle stick injuries. When administered shortly following exposure, PEP treatment has been shown to reduce the risk of HIV infection by 81% (Cardo *et al* 1997).

The use of PEP in cases of non-occupational exposure – such as coerced sex, rape or unprotected consensual sex – varies between and within countries. A study of 27 European countries found that six of them had national guidelines recommending the systematic use of PEP after certain types of non-occupational exposure (such as rape); in 13 countries PEP was not recommended, but could be accessed in certain circumstances; and in the final eight countries PEP was not available at all (Rey *et al* 2000). The US Centers for Disease Control (CDC) recommend that PEP be administered for non-occupational exposure only in cases where specific criteria indicating a high risk of HIV infection are met (CDC 1998). However, according to experts on PEP and gender violence, these indicators have been relaxed in recent years and health services in many developed countries now make PEP available for both occupational and non-occupational exposure (Kim 2002).

PEP treatment consists of single drug or combination (dual or triple drug) therapy taken over a period of four weeks. The exact treatment regime is informed by factors including the patient's medical history (including drugs previously taken and known or possible resistance to therapy) and the seriousness of the exposure (WHO 2004). Therapy should be initiated as soon as possible following exposure, ideally within 2-4 hours (WHO 2004). Although there is no consensus on the upper limit for administering PEP, various guidelines suggest

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periods of up to 36, 48 and 72 hours following exposure (Rey *et al* 2000).

Post-Exposure Prophylaxis in South Africa

In 2002, South Africa had an overall HIV prevalence rate of 11.4%, and a prevalence of 15.6% in the 15-49 year age group (Shisana *et al* 2002). It is also a society marked by high levels of gender-based violence – including rape and coercive sex (Jewkes & Abrahams 2002) – which heightens the risk of HIV transmission among affected populations (Denny 2002; Kim 2000; Kistner 2003; HRW 2004). More than 52,000 rapes and attempted rapes were reported to South African police in 2002 (SAPS 2003), but many rapes are not reported. A 1999 study found that seven percent of South African women (ages 15-49) reported having been raped or forced to have sex; only 15 percent of these women reported these crimes to the police (Jewkes & Abrahams 2002).

In April 2002, the South African government announced that all rape survivors would be eligible to access PEP free of charge as part of a comprehensive approach to supporting survivors of sexual violence (Cabinet 2002). While PEP for occupational exposure has been the standard of practice in South Africa since 1999, it was available to survivors of sexual violence on only a limited basis from 1997 through private clinics, NGOs and health facilities in certain parts of the country (HRW 2004).

Protocols for the provision of PEP to survivors of sexual violence are outlined in the government's *Policy Guideline for Management of Transmission of Human Immunodeficiency Virus (HIV) and Sexually Transmitted Infections in Sexual Assault*, which was published in May 2002 (DOH 2002). The guidelines state that PEP should be made available, on request, to all men and women over 14 years of age who present to a health facility within 72 hours of being raped and who test HIV-negative. Rape survivors under 14 years of age are eligible for PEP treatment, but may only be tested for HIV with the consent of a parent or legal guardian.[1] A negative HIV test is a prerequisite for accessing PEP treatment.

According to the national policy, all rape survivors should be counselled on the risk of HIV transmission, what is known (and not known) about the efficacy of ARV prophylaxis, and the common side effects. Pregnant women should be counselled about the possibility of HIV transmission to their unborn babies, about possible risks to the baby of undergoing PEP treatment, and about the option of pregnancy termination (DOH 2002).

National guidelines are that rape survivors opting for PEP treatment should be given a one-week supply of AZT and 3TC ('starter pack') and should then return in one week for further evaluation. At this time, the remainder of the AZT and 3TC doses are supplied. Survivors are advised to return for follow-up visits at six weeks, three months and six months after the rape. HIV tests are conducted at each visit (DOH 2002).[2]

Rape survivors testing HIV-positive at the outset are not provided with PEP treatment. National policy is that they should be counselled about their HIV-positive status and referred to appropriate health care facilities or other service points for assistance in long-term management of their HIV status (DOH 2002).

Key Issues Surrounding PEP in South Africa

Studies suggest that the roll-out of universal access to PEP treatment in South Africa will need to take into account several issues and challenges:

- ❑ Developing and strengthening the human and infrastructural resources required to administer PEP, including among frontline health care workers and other service providers such as police;
- ❑ Raising awareness about PEP, the cases in which it is indicated, and the ways in which it can be accessed;
- ❑ Monitoring, evaluating and ensuring quality control of PEP administration and compliance with treatment (Kistner 2003; HRW 2004).

Other research findings include: access to PEP is uneven, with people in rural areas having lesser access; knowledge about PEP is limited amongst key constituencies (including the general population); training on PEP protocols needs to be expanded; there is a lack of clarity amongst service providers with regard to whether a rape needs to be reported to police before PEP can be administered (this is not necessary); it is unclear what steps should be followed in the case of children under 14 who have been raped, but do not have parental/caregiver consent for an HIV test; there is a lack of coordination among service providers in many areas and only a few one-stop centres[3] in operation; and little is known about levels of compliance with PEP treatment (Kistner 2003; HRW 2004).

Findings from the Helpline

Methods

The Communicating AIDS Needs Project (CAN) focuses on individual and community-level responses to HIV/AIDS with a view to understanding communication and resource needs at both levels. The project includes a number of in-depth research activities in selected South African communities, as well as reviews of service provision and communications systems. One component of the project is research and analysis of calls to the national AIDS Helpline.

The AIDS Helpline was established by the South African Department of Health in 1992, in partnership with Life Line. The Helpline service was consolidated into a centralised call centre in Johannesburg in 2000. It is staffed by full-time, trained counsellors and can handle up to 24 incoming calls at a time. Calls are monitored through data capture forms, and also through automated electronic call counting. It provides callers with basic information, counselling, and referral to services in all 11 South African languages and is available 24 hours a day, seven days a week.

The Helpline has received close to seven million calls since May 2001; approximately seven percent of these are 'genuine calls' (currently defined as calls that are more than one minute in duration) where information, referral and counselling is provided. A quantitative analysis of calls to the Helpline between July 2000 and December 2003 found that slightly more than half of genuine calls to the Helpline are for information, but the proportion of counselling calls has been rising over time. Seventy-five percent of callers are under the age of 30. A growing proportion of callers to the Helpline are disclosing their HIV status (Katz 2004).

During the latter half of 2003, a series of focus group discussions was conducted with AIDS Helpline counsellors with a view to assessing call trends and exploring key issues raised by callers. The focus groups were conducted with five to six counsellors at a time and followed standardised protocols. Most counsellors had worked at the AIDS Helpline for two or more years, and were thus able to reflect on a large body of calls to the line. All counsellors had completed relevant counselling training courses and received ongoing supervision, training and debriefing.

The duration of the focus group sessions ranged from one and a half to two hours. Sessions were mostly conducted in English, although allowance was made for the use of other languages as the need arose. Facilitators prepared discussion guides prior to each session and discussions were tape-recorded, translated where applicable, and transcribed. All transcriptions were checked for accuracy.

Focus group transcripts were read a number of times by a senior researcher to allow for an understanding of the material and to develop a strategy for coding. The data was then coded and categorised electronically by two researchers using HyperRESEARCH OSX 2.6.

Strengths and limitations

The focus group discussions with Helpline counsellors were conducted as a counterpart to a quantitative analysis of data on calls to the Helpline, the results of which have been published separately (Katz 2004). The qualitative research was intended to highlight key issues and gaps in understanding about HIV/AIDS on the basis of actual cases and examples recounted by Helpline counsellors.

It is important to underscore that the findings of this research are not uniformly generalisable. Whilst calls to the AIDS Helpline are made by callers countrywide, callers are primarily individuals inclined towards information seeking. The issues raised in this report emerged from subjective recall of participating counsellors.

The strength of the approach is that it provides a relatively simple means through which to assess concerns and misunderstandings in relation to HIV/AIDS, drawing on national level perspectives. The calls allow for analysis of gaps in understanding, which in turn provide useful reflection on potentials for communication campaigns and local and/or service-level communication support. Novel perspectives also emerge through the capacity to develop an understanding of the experience of HIV/AIDS within individual contexts. It is also acknowledged that the AIDS Helpline service plays a valuable role in reducing misunderstanding, and also providing a mechanism to address individual level concerns and contexts – communication processes that are only matched by face-to-face counselling.

Findings

Analysis of the focus group data revealed that PEP-related calls to the Helpline generally fell into one of four themes, with related sub-themes:

- Information needs
  - Preventing HIV transmission after exposure
  - Procedures for accessing PEP
  - Myths and misunderstandings about PEP
- Specific contexts where PEP may be indicated
  - Occupational exposure
  - Rape and sexual violence
  - Unprotected consensual sex
- Accessing PEP
  - Experiences with police
  - Experiences with health care workers
  - Access in rural areas
  - Access by teenagers
  - Access through private medical aid
  - Failure to access PEP
- PEP protocols and treatment
  - The baseline HIV test
  - Time period for accessing PEP

Information needs

Preventing HIV transmission after exposure

Counsellors described calls from individuals in a variety of contexts inquiring about how to stop the transmission of HIV following potential exposure. According to counsellors, callers generally do not ask about PEP by name, but are sometimes aware that there is treatment available to prevent HIV transmission and want to know whether it is possible to access it in their circumstances.

> *The majority of callers know that there is a treatment that can stop HIV at a certain time. They don't know what this is – they don't know whether it's PEP or what. It's us who interpret their stories, that is how we know that this particular caller wants PEP.*[4]

> *They know that there is something which can stop the HI virus from spreading in the body if you go there within 72 hours, [and that] they need to get that.*[5]

Counsellors noted that callers do not understand details about how PEP treatment works to stop HIV transmission. They also described instances in which

callers who had potentially been exposed to HIV would confuse PEP with the government roll-out of anti-retroviral treatment.

> *[People] call in because they want to know about PEP. But what it actually does – they don't know. Maybe they do not know that it [stops] the process of [transmission of] HIV. Or that the possibility of turning positive is there, the possibility of not being positive is there. They don't know – they want to gather information from our side to know what is happening around PEP.*[6]

> *The ARV roll-out issue – people will rush to those questions and say, 'There's this roll-out – how can I help myself? I can pay for it.' And that's how we get involved and start engaging in PEP topics with them – even though initially they are not talking about PEP.*[7]

Procedures for accessing PEP

Callers seek guidance from Helpline counsellors on how to access PEP treatment. Counsellors' explanations take into account several factors: the caller's eligibility for PEP treatment, the time-sensitive nature of accessing PEP, and the various avenues (public and private) through which PEP can be accessed.

> *Some people engage in unprotected sex and then they will call the Helpline with the hope that provincial or public hospitals are going to help. They ask if they will get help if they go to the hospital – they had unprotected sex at a party the previous night.*[8]

> *I once got a caller who thought you receive PEP at the police station. So I told her, 'No, at the police station the police are there to gather the statement and then they will refer you to the clinic or hospital.'*[9]

> *[Some callers] want to know if they can purchase it over the counter. …Not go through the procedures – to the police station, hospital, testing – just go straight to the pharmacy to buy it.*[10]

In some cases counsellors explore the caller's individual circumstances to determine whether accessing PEP privately is a feasible option. Counsellors describe instances when a caller may not be able to access PEP at a public clinic on time (for example, due to opening hours on a weekend).

> *[Much] depends on where the person accesses [PEP]. During weekends on the Helpline, you assess the affordability to the individual. There are callers who call and after a thorough assessment, you can advise a person and say, 'If you can afford this, you can see your private practitioner around this subject. But if you are going to do that, you've got a very limited time.'*[11]

Myths and misunderstandings

In discussions with counsellors, it emerged that some callers voice misunderstandings about PEP, what it is and how it works. Counsellors drew attention to two particular misconceptions:

- PEP cures HIV infection. *'Some people think it's a cure.'*[12]
- PEP is confused with the government ARV roll-out.

Contexts where PEP may be indicated

Occupational exposure

Counsellors report calls from people concerned about possible exposure to HIV in occupational settings, particularly medical contexts. In some instances, the callers have consulted with their superiors in the workplace following possible exposure and have been given incorrect information.

> *This morning I was talking to a caller. She is a nurse and apparently her daughter is a student nurse. Some time ago she was involved in an accident when she was doing practicals at a hospital. [A patient's] blood spurted up and part of the blood got into the eye. She went to the occupational therapist and he said, 'No, just wash with water and you will be okay.' And then they did the rapid test and found out she is negative. Now they called again and said the problem was that the person did an Elisa test after some period of time and that person is HIV positive.*[13]

In other instances people in medical settings had to weigh up the pros and cons of taking PEP following possible exposure, in light of the risk of developing drug resistance.

> *I also had a call like this with a similar situation. The guy is working in the EMS [Emergency Medical Service]. The same thing happened. He wanted to know what should he do if something like that has happened? And whether there are ways that a person can be infected and if something like that has happened, can he take PEP? The answer would be, for safety sake, yes, you can do that. But there are other [things] that you need to understand. Something might happen – you might develop a resistance to the medication.*[14]

Counsellors voiced personal frustration in dealing with calls from health care workers who had been given improper advice at the workplace following occupational exposure. They noted that medical facilities had a responsibility both to prevent incidents of occupational exposure and to offer PEP as the standard of care in cases where it is indicated. Some counsellors suggested that such calls led them to question the degree of knowledge and understanding of HIV transmission risks among health care workers.[15]

Rape and sexual violence

Counsellors described receiving calls about PEP from women who were survivors of rape. Among the callers were teenagers and women who had been raped by their husbands or boyfriends.

Most of the ladies who will be calling and talking about this [PEP] are ladies who are rape victims.[16]

[The caller] was somebody who had been in a very long-term relationship. All of a sudden, marital problems arose and she decided to take matters further because she had insisted on using condoms for several times and all of a sudden she was maritally raped. She took steps further and tried to find out if she could access PEP. She didn't want to report the husband and she went and tried to access PEP, only to find that she was already infected previously, before she got there.[17]

One [call] that I had – the girl was raped by her boyfriend, knowing that the boyfriend is HIV positive. The boyfriend raped the girl without using a condom for protection.[18]

Sometimes these calls come immediately following the rape, in time for the caller to be advised to seek PEP treatment, while in other cases too much time has elapsed for PEP to be effective. In these instances counsellors explain about PEP and procedures for accessing it to the rape survivor, but underscore that the treatment is only effective in preventing HIV transmission if it is taken within 72 hours of exposure.

The [rape survivor] will maybe report a case to the police six days or so after the rape. Then she will call and talk. Obviously you are going to end up touching on the subject [PEP] – whether she knows about it or she doesn't know about it. Sometimes you feel that it's your responsibility to empower her and to let her know about it… but being realistic that it's too late for the PEP. In case she is in a similar situation again she will be better informed.[19]

Unprotected consensual sex

Apart from rape survivors, counsellors reported that most calls about PEP come from people concerned about possible HIV transmission following unprotected consensual sex. Such calls come from a variety of callers and reflect diverse individual scenarios. However, a common feature is a belated recognition by callers that the consensual sex in which they have engaged might have put them at risk of HIV infection.

Sometimes they know nothing about PEP, but they will have been involved in unprotected sex last night and want to know is there any kind of help under these circumstances. What kind of help can they take?[20]

Most of the callers that speak of PEP are men … it's either they slept with sex workers or cheated on their wives during the day or had a one night stand somewhere.[21]

One [call I had] was from a guy who went to his village to visit some relatives. He met a girl around there and he eventually met other people that he made friends with. They went to a shebeen and got drunk and he and the girl went out and had sex. The following day he was told by the friends that the person he slept with was HIV positive. He didn't use a condom. So, he wanted to know how this [PEP] works.[22]

People will have a question – they know there is PEP and they think that it's for everyone who has had unprotected sex. And then you start to explain to them,'No, if I as a person had unprotected sex, the government, the state will not give me PEP. It will not administer PEP on me. It's only for people who are raped.'[23]

Counsellors described calls about PEP from men and teenage boys who had been involved in homosexual sexual encounters:

Usually homosexual guys call, especially from Cape Town and Durban. They call and say, 'I slept with a prostitute,' or, 'I slept with another man yesterday and I don't know what the chances are of me being infected. What should I do now? I know there's treatment – what should I take now?'[24]

The call that I remember [was from] this boy who was so young. There was a friend of his father who used to come around. One time the family was not around and that guy came to visit, knowing that the family is not around. He noticed that the boy wasn't like the other boys who used to hang around with the guys and go out with girls. And so he ended up having sex with this boy. The boy did not know what was happening. He was not aware whether it was right or not. And he started questioning transmission – whether HIV can be transmitted. They had anal sex. So he wanted to know are there any means to prevent transmission after it had happened. Then I started talking about PEP and how to access it.[25]

One counsellor expressed the opinion that knowing about PEP may lead some people to engage in unprotected sex in the mistaken belief that they will be able to access prophylactic treatment as a matter of course:

You find some people obviously do not carry condoms and feel because there is this post-exposure prophylactic treatment that they can do it [have unprotected sex] quite often with its help. Unfortunately it is not for everyone, but for people who are victims of rape. Those are the ones who can get it in hospitals. But people who just get into an act deliberately without thinking are not given, unless you have medical aid or money to pay a private doctor.[26]

The counsellor suggested that some people may confuse PEP treatment with the 'morning-after pill,' which can be accessed by women following unprotected sex to prevent pregnancy.

Accessing PEP

Experiences with police

Calls to the Helpline highlight the difficult experiences of some rape survivors when reporting cases of rape and sexual violence to the local police. Counsellors reported that fear of the police – and the failure of some police to follow correct procedures in cases of rape – prevent some rape survivors from accessing PEP treatment.

Within our police stations there is no victim empowerment. If somebody has been raped, there is no empowerment on what process they should go through. You're not given support, you're just left like that. You go to your police station and you are asked, 'Were you raped?' – you know, in front of people, things like that… People also fear going to the police station – that's why some of them do not have access to PEP.[27]

Counsellors noted cases where police did not follow the standard procedures in dealing with rape victims, including their obligation to transport the victim to a district surgeon or hospital where forensic evidence can be collected:

The general feeling is that [the police] are not trained enough to deal with these kinds of cases. Because the procedure is that if a rape victim comes to your police station, first and foremost, before anything else, the victim must see the district surgeon. … As long as the person told you that she was raped, first and foremost, the person has to get straight to the surgeon, collect the medical data and then we can come and talk. But it's the other way around in most cases. … The police have to take you to the district surgeon, but sometimes you are not even taken to the district surgeon. [28]

The experience is that [rape victims] don't get fair treatment from all their respective helpers, starting from the police to the district surgeons. A person can report a case and can end up leaving the premises without having done an HIV test or without having even been referred for an HIV test.[29]

Counsellors explained that some rape survivors felt that they are blamed by the police for the crime committed against them. They noted that some police do not fulfil their responsibility to explain to rape survivors their rights and the various options they have to seek prophylactic treatment:

The police – I mean, [sometimes if you] report a case and he feels because he is a policeman that he doesn't want to go through all these things, explaining all that [procedures for accessing PEP]. Sometimes they feel you might be responsible for [what happened]. 'What were you doing in the streets at 8 o'clock?' Nowadays there are people who work till late at night. Instead of protecting them, they [the police] feel they are responsible.[30]

One counsellor described an instance where a caller had been raped by a policeman and felt unable to report the case at the local station. She called the Helpline wanting to know if it was possible to purchase PEP over-the-counter.

And they also want to know if they can purchase it over the counter.

Facilitator: You mean not go through the procedures?

Not go through the procedures – to the police station, hospital, testing – just go straight to the pharmacy to buy it. Because say, for an example, the lady was raped by a policeman.

Facilitator: Is this an actual example?

Yeah, it's an actual example. She was raped by a policeman, so it would be difficult for her to go to the police station because, even if she gives a statement, they won't believe that she was actually raped by a policeman.[31]

Experiences with health care workers

Counsellors describe calls from people who have tried to access PEP treatment at health facilities and have encountered negative attitudes from health care workers.

One counsellor explained that people who are not confident of their rights and not assertive in demanding PEP may have difficulty in accessing it at public health facilities:

The other thing is, they [health care workers] judge people. They look at you when you enter, when you come seek help, they look at you and they want to see how far [how much] you know about it. Do you know why are you here? Do you know your rights? If you don't know your rights, they will make sure that you won't be treated very well or maybe they can even abuse you. But once you start showing them that you know why are you here, they'll start giving what you came for. But if they realise that you don't know why are you here…[32]

Another counsellor described a call from a woman whose HIV-positive boyfriend had raped her. She failed to receive PEP on time, despite presenting to a health facility and requesting treatment.

The girl went to Joburg Gen… and they told her, 'You were supposed to go to the police station. They were supposed to call a district surgeon.' You know, talking about the district surgeon – she didn't understand what they meant. Talking, saying to her, 'The district surgeon, he needs to check whether this and that, gather all the evidence.' So she was very frustrated. She was even crying. She was denied and now it's after a week. There is nothing that she can do.[33]

Counsellors expressed the view that some health care workers are inadequately trained and not knowledgeable about PEP protocols:

They are not always informed or they are not implementing what they [the protocols] are, what they know...[34]

Access in rural areas

Counsellors noted that HIV-related information, services and resources – including knowledge about how to access PEP treatment – appeared to be more limited in rural areas:

We also shouldn't forget in the rural areas most people do not have information: where to access it, is there anything like PEP. Some people don't know about it. Or you can get

a call and somebody says, 'I've been raped, what do I do?' [It requires] education, because they don't know.[35]

I think you find in the rural areas people in positions take advantage of their power and take advantage of the other person's ignorance… Most people in rural areas are not as assertive as people in towns and are not as well informed about their rights… because of educational standards or exclusion from some other information.[36]

It is a little bit difficult for rural areas; you find that there is no counselling in the clinics – nothing at all – so you become shocked. How are you going to refer such callers, moreover in rural areas? … In urban areas there is no problem because we normally have a resource list so you go to this place for further counselling, go to a clinic there are counsellors there. You find that in urban areas there are counsellors in all the clinics probably, but not necessarily in rural areas. The problem is in rural areas.[37]

Access by teenagers

PEP-related calls to the Helpline highlighted specific challenges facing teenage rape survivors seeking to access PEP. Counsellors reported that some teenagers do not report cases of rape to police and/or do not present themselves at health clinics – and therefore do not receive PEP treatment.

And in the case of rape you find that most of the teenagers that have been raped don't even go to their clinics. They don't even go to open cases. Therefore it is difficult for them to get their PEP… There are drugs that maybe could help them not to get infected if they were raped by somebody who was infected. So they need that information. Others, they do have that information, but they are afraid. [38]

And again we go back to the attitude of the workers. Like the stakeholders – the police – kids are afraid to go to the police to report because you will be asked in front of people. Even the nurses.[39]

Access through private medical aid

Counsellors describe calls inquiring about the relative ease of obtaining PEP through state hospitals versus through private facilities or medical aid schemes:

The callers want to know the difference between their hospital, and private hospitals and the government hospitals. Is it easy in a government hospital to get PEP? Is it easy? Because when you look at around private hospitals, it may be easy for you to access it, because [people] have medical aids and all that. If you don't have medical aid, you cannot – it's not easy for you to access it in the government hospital.[40]

Because in reality the people with medical aid and people from certain classes do not wish to use the state hospital. The people from medical aids and upper classes – they use purely the private hospitals, because of the long queues and so on and so forth.[41]

Counsellors describe cases in which they advise callers who have had unprotected sex and are on medical aid to approach their private doctor in order to access PEP. They emphasised, however, that the option of accessing PEP after unprotected sex is only available to people who can pay for the treatment themselves or have it covered by medical aid.

Failure to access PEP

Counsellors described callers who knew about their rights to PEP treatment, but who were unsuccessful in accessing PEP through public health facilities:

I had a caller last week from around Pretoria who was raped. She went to the police to report the case and was taken to the nearest hospital. She was promised to be given PEP and she was never given. She was transferred to another hospital and seemingly the 72-hour period was due. She was worried about what she could do now, because she was being taken from pillar to post and there is nothing that they are doing to her…. They didn't even give her the information that she could go somewhere private if she wanted to.[42]

PEP Protocols and Treatment

The baseline HIV test

Counsellors reported receiving calls from people who had tried to access PEP and had been turned down because they tested HIV-positive. Callers express confusion about why a baseline HIV test is required for accessing PEP and why those who test HIV-positive are deemed ineligible. Counsellors further noted that callers who tried to access PEP often did not know their status prior to seeking treatment and did not always understand that a positive result on the baseline test means that they were previously infected – not as a result of the incident which prompted them to seek PEP.

[Callers] don't understand when they have to administer PEP, what is it that is supposed to be done on them – that they need to be tested before. They don't understand why if they are tested and they test HIV-positive they are not going to be given the antiretrovirals. So they don't understand the whole thing.[43]

[The caller who had unprotected sex] at a party – he asked what he must do within 72 hours. Then when he gets there he finds out that he is positive. He will phone back and say, 'I went there and they told me that I cannot get the prophylatic treatment because I'm positive.' Then you explain that the antibodies do not show up during [such a short] time, so it means he'd been previously infected. You cannot get prophylactic treatment. I mean, you are already positive – how do you get something preventative?[44]

One call I had was from this gentleman – he was frustrated because he went for PEP, but he was refused PEP for one good reason – the guy tested positive. So he couldn't understand why he was not given PEP. So then

you have to get to work around the fact that the person is positive.[45]

People don't know their status until they are raped or something like that happens to them and they start looking for this post-exposure prophylactic treatment. But when they are tested at the moment when they need this, they become surprised – why they cannot have access.[46]

One counsellor described a call from a woman who received a PEP starter pack from her private doctor, but was afraid to contact the doctor to find out the results of her baseline HIV test. The counsellor had to explain why it is important to understand one's status before completing a course of PEP:

I had this lady who went to the doctor after having unprotected sex with her partner. The doctor gave the person the antiretrovirals and she was tested with VCT. When she was supposed to go back and get the results, she didn't go because she already had the package with her. She brought the package from the doctor and she was to start taking the drugs that evening. She said she was scared to call the doctor and ask for the results. I told her that if it happens that you are already HIV positive and you take those drugs, you must know that at later stage you are going to have a problem. You are going to have resistance to drugs, to treatment. Because you are going to take this course for a month and then stop. HIV doesn't work like that and if it happens that you don't take them today [and should], know that it's going to be bad. … I said to her, 'You know, there is need for you to call your doctor so that you can know whether to take the drugs or not to take the drugs.'[47]

With the more widespread use of rapid HIV test kits, such scenarios will likely become less common as people will learn their HIV status immediately and know whether or not to begin treatment.

Time period for accessing PEP

Counsellors reported receiving calls about PEP from individuals after the 72-hour window period has passed. In some instances, callers were unaware of the importance of the time window, while in other cases they did know and were frustrated that they hadn't succeeded in accessing treatment.

So she was very frustrated. She was even crying. She was denied and now it's after a week. There is nothing that she can do.

Facilitator: So this time window is very important.

Yes, and people are not aware of it. They think that if this happened today, I can [wait] for seven days or three months, then I can call. They can still give me PEP.[48]

Facilitator: So do you receive calls from people, say a week after exposure, wanting to know about PEP?

Ya, usually it's rape victims, because of the trauma they go through.

Discussion

The findings from focus groups with Helpline counsellors suggest that awareness of PEP is growing in South Africa. However, misconceptions about PEP remain. The main findings of the research include:

- There is confusion about the eligibility for PEP treatment, including whether it can be accessed following unprotected, consensual sex;
- It appears not to be well understood that an individual must test HIV-negative in order to access PEP treatment;
- Rape survivors may be insufficiently aware of their rights to access PEP free of charge, through the public health system, regardless of whether they have reported the rape to the police; and
- Access to PEP treatment is constrained by various factors, including a lack of information about PEP among potential beneficiaries, inadequate training in PEP protocols among some frontline service providers, and barriers to accessing PEP in certain areas and by certain populations.

PEP-related calls to the Helpline were clustered into several main areas: information requests about PEP procedures; specific contexts where PEP treatment is indicated; accessing PEP; and PEP protocols and treatment.

Information requests constituted one of the main categories of PEP-related calls to the Helpline. Counsellors reported that, for the most part, callers to the Helpline had little or no specific knowledge of PEP, beyond the fact there is a treatment available that can help to prevent HIV transmission following possible exposure to the virus. However callers understood few details about eligibility for PEP via the public health system, or about procedures and requirements for accessing PEP. In some cases callers understood that PEP must be accessed within a 72-hour period for it to be effective, while in other cases the need for timeous action was not understood. This suggests that considerable information gaps about PEP exist among the general population, which may be limiting access to PEP by specific populations, such as rape survivors, who are legally entitled to the treatment.

Counsellors described three different contexts in which people would call the Helpline with concerns about possible HIV infection: following occupational exposure, rape or sexual violence, and consensual unprotected sex. They noted that PEP-related calls came through most frequently from rape survivors and from people who had recently had unprotected sex. Counsellors used different approaches in dealing with these two categories of callers, as their legal rights to access PEP treatment differ. Rape survivors are automatically eligible for free PEP treatment through the public health system in South Africa if they present within 72 hours of the incident. People who are potentially exposed to HIV in contexts that fall outside

of the domain of state provided PEP – for example, exposure to blood outside of health-care settings, and unintended or 'accidental' exposure during sex – may access PEP through private medical facilities, with the proviso that it is paid for.

Several issues linked to accessing PEP treatment were raised in discussions with counsellors. Counsellors described calls to the Helpline from individuals who had experienced poor treatment from frontline service providers such as police, district surgeons and other health care workers when attempting to access PEP. In some cases, there was a lack of basic knowledge and training about PEP protocols and procedures on the part of professionals who play key roles in its provision at the local level. In other cases poor treatment appears to have been linked to negative attitudes and insensitivity of frontline service providers towards those seeking treatment. Whilst the findings from research on Helpline calls cannot be taken as an indication that such experiences are widespread, they do highlight the need to ensure that guidelines are well disseminated to front-line service providers, and that potential clientele are aware of their rights.

The challenges to accessing PEP described by callers point to some of the obstacles to PEP roll-out in South Africa that have been noted in the literature (Kistner 2003, HRW 2004). For example, the national protocol on prevention of HIV transmission to victims of rape and sexual violence states that rape victims are entitled to PEP treatment upon presentation to a health care facility within 72 hours of exposure, regardless of whether they have reported the rape to the police. However counsellors noted that some callers who had attempted to access PEP at clinics without a police case number had been turned down.[49]

A third area of concern by callers related to technical aspects of PEP treatment, particularly the requirement to test negative on a baseline HIV test. Counsellors cited numerous examples of people who had tried to access PEP and were denied on the basis of their HIV-positive status. The confusion expressed by callers around this issue points to low levels of understanding around both the role of prophylactic treatment (intended to prevent something from taking place) and the timeline according to which HIV antibodies can be detected in the human body. Counsellors described calls from people who had learned of their positive status when trying to access PEP and who had difficulty understanding that their positive status could not be a result of exposure that had only just occurred.

It appears from the focus group discussions that a number of information gaps exist amongst callers in relation to PEP. Many of these gaps can readily be addressed through communication campaigns, as well as local level communication and practices linked to PEP service provision.

However, in the absence of a promotional campaign and/or informational materials about PEP, many people who are eligible to access treatment and who would benefit from it are unaware of the existence of PEP, do not know how or where to access it, or do not understand critical aspects of how PEP works (e.g. the time during which PEP must be accessed to be effective, the meaning of the baseline HIV test, etc.).

Recommendations

This paper has identified a number of communication needs regarding the provision of post-exposure prophylaxis in South Africa. On the basis of these findings, the following recommendations are made:

- There is a need for information about PEP to be incorporated into communication campaigns, including specific attention to:
  - Situations in which PEP is indicated;
  - Eligibility for PEP treatment through the public health system and the availability of PEP through private means;
  - Procedures for accessing PEP through the public health system;
  - The role of the baseline HIV test; and
  - The time period within which PEP must be accessed for it to be effective.
- There appears to be a lack of access to printed materials – such as pamphlets, posters, and booklets – about PEP. A range of communication materials to support PEP should be made available in all South African languages.

Given that the present research has limitations in terms of scope and generalisability, further research into PEP implementation and take-up is recommended. The above findings provide insight into possible areas of investigation, including: levels of demand and acceptance of PEP treatment; levels of patient compliance with the PEP treatment regimes; and unmet training needs for service providers involved in PEP implementation.

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Footnotes

1 Some provincial-level PEP protocols contain provisions for bypassing this requirement. According to the Child Care Act, in the event of an emergency, the medical superintendent of a hospital may give consent for a child under 14 to be tested or medically treated, provided that this testing or treatment is essential to preserve the life of a child or save him or her from permanent or lasting physical injury or disability. Some provincial-level PEP protocols, including that in KwaZulu-Natal, consider HIV testing for child rape survivors to be a lifesaving treatment (HRW, 2004).

2 In practice, the growing use of rapid HIV tests (in which results are available in as little as 20 minutes) means that some rape survivors may immediately be issued with the full 28-day pack if they test HIV-negative. In cases where rapid tests are not used, but where rape survivors might have difficulty returning to the clinic after a week, for economic or logistical reasons, the full 28-day pack is sometimes issued immediately.

3 A 'one-stop centre' is an integrated facility that provides rape survivors with medical care, a forensic examination, HIV testing, PEP treatment (if indicated), counselling, and follow-up support.

4 34528 PEP FG 2 June.txt
5 34836 PEP FG 2 June.txt
6 34047 PEP FG 2 June.txt
7 4027 PEP FG 2 June.txt
8 2961 PEP FG 2 June.txt
9 21974 PEP FG 2 June.txt
10 24883 PEP FG 2 June.txt
11 19219 PEP FG 2 June.txt
12 34999 PEP FG 2 June.txt
13 1096 PEP FG 2 June.txt
14 2428 PEP FG 2 June.txt
15 14297 PEP FG 2 June.txt
16 9302 PEP FG 2 June.txt
17 18685 PEP FG 2 June.txt
18 20026 PEP FG 2 June.txt
19 21055 PEP FG 2 June.txt
20 4027 PEP FG 2 June.txt
21 8975 PEP FG 2 June.txt
22 7758 PEP FG 2 June.txt
23 41543 CAN HL FGD 2 Sept.txt
24 37781 PEP FG 2 June.txt
25 39730 PEP FG 2 June.txt
26 2961 PEP FG 2 June.txt
27 10285 PEP FG 2 June.txt
28 26556 PEP FG 2 June.txt
29 9302 PEP FG 2 June.txt
30 12661 PEP FG 2 June.txt
31 24883 PEP FG 2 June.txt

32 15322 PEP FG 2 June.txt
33 20026 PEP FG 2 June.txt
34 14608 PEP FG 2 June.txt
35 22214 PEP FG 2 June.txt
36 12196 PEP FG 2 June.txt
37 25229 CAN HL FGD 30 Sept.txt
38 18761 CAN HL FGD 3 Oct.txt
39 18761 CAN HL FGD 3 Oct.txt
40 36195 PEP FG 2 June.txt
41 36956 PEP FG 2 June.txt
42 10328 CAN HL FGD 5 Sept.txt
43 41543 CAN HL FGD 2 Sept.txt
44 7184 PEP FG 2 June.txt
45 5402 PEP FG 2 June.txt
46 6448 PEP FG 2 June.txt
47 41543 CAN HL FGD 2 Sept.txt
48 20697 PEP FG 2 June.txt
49 17685 PEP FG 2 June.txt