SHORT REPORT

SUPPORTING RAPE SURVIVORS IN ADHERING TO POST-EXPOSURE PROPHYLAXIS (PEP) TO PREVENT HIV INFECTION: THE IMPORTANCE OF PSYCHO-SOCIAL COUNSELLING AND SUPPORT

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Eleven years after it was first mooted in 1996, the Criminal Law (Sexual Offences and Related Matters) Amendment Act (32 of 2007) came into effect in December 2007. Law-makers proudly lauded sections 28 and 29 of the Act, which set out how post-exposure prophylaxis (PEP) to prevent HIV infection should be made available to rape survivors.* These clauses are, however, neither particularly novel nor innovative, Cabinet having already approved (in April 2002) the provision of antiretroviral drugs to prevent HIV infection following rape.

Subsequent to Cabinet's decision, a few studies were conducted examining various facets of providing PEP as part of a health response to rape.[1-4] In theory, these findings should have provided legislators with some insight into what was required by rape survivors from a PEP service, particularly in relation to psycho-social support. This was not the case, as we will show in this article, which draws on unpublished findings from 67 interviews with rape survivors† exploring their adherence to PEP.

STUDY METHODS

Monitoring by the Gauteng Department of Health (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.[5] Concerned by this low rate, GDoH commissioned research from the Centre for the Study of Violence and Reconciliation (CSVR) (where the two authors were based at the time) to explore factors affecting adherence to PEP in the aftermath of rape.

A number of different approaches were attempted to recruit rape survivors. Letters explaining the study purpose and requesting assistance with recruiting victims were sent to organisations that provide counselling to rape survivors. One PEP site in the province which kept records of patients' contact details also provided us with a list of 20 names and telephone numbers (many of which however turned out to be incorrect). Ultimately, 15 survivors were recruited either by health care staff or researchers for in-depth, semi-structured interviews.

Another 52 rape victims aged 14 years and older were recruited by researchers based at three PEP facilities in the province, two located in greater Johannesburg and one on the East Rand. Selection of these sites was based on convenience, as well as the high number of rape survivors they treated. Over a period of 3 months, amounting to 74 days in total, researchers spent every Monday and Friday at the selected sites. While stationed there they approached rape patients 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, 8 declined to be interviewed. The 52 patients participating in the study therefore represent 87% of all victims aged 14 years and older attending these health facilities on Mondays and Fridays during this period. Information obtained from the short, face-to-face standardised interviews was coded and captured for statistical analysis with SPSS.

*These clauses came into effect on 25 March 2008.
†We use the terms 'patient', 'victim' and 'survivor' interchangeably in this report. 'Victim' is used to recognise that a violent crime has been inflicted upon someone, 'survivor' to acknowledge the long-term work required to cope with rape, and 'patient' because rape survivors are also using a health service.

Both interview schedules focused on the following key themes: patient knowledge of the drugs and their use; drug side-effects and their impact on patients; and support and counselling received by rape survivors after the rape. Interviews were analysed according to these key themes.

The ethical challenges of obtaining consent from children to participate in research meant that they were excluded from the study, which therefore does not explore factors affecting adherence to PEP of children younger than 14. Further, it was very difficult to recruit rape survivors who had defaulted on their treatment. Our findings are therefore more characteristic of women who adhere to their medication than of those who do not.

RESULTS

DESCRIPTION OF OUR SAMPLE: PEP FACILITIES

Fifty-two respondents, comprising 48 women and 4 men, were interviewed. Slightly under half of those interviewed were aged between 14 and 19 years (48%). Approximately 38% of patients were aged between 20 and 29 years and 12% were between 30 and 39. 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 by hospital staff to first report the incident to the police before they could be treated – of these, 3 did not want to do so.[‡]

More than half of the patients (24 or 56%) for whom information was available 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 3 had just completed all 28 days.[§]

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 5 cases treatment was stopped because patients had defaulted. Of this group, 3 stopped because they had skipped a number of pills, while the other 2 stopped because of side-effects.

IN-DEPTH INTERVIEWS

In-depth interviews were conducted with 15 survivors. The youngest rape survivor was 16 and the oldest 45, with most (9) being in their 20s. Four women were aged 19 or younger at the time of the interview, while 2 were over 30. All said they completed the entire treatment regimen, with 2 reporting that they had 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 doses.

WOMEN'S KNOWLEDGE OF PEP

Women exhibited varying degrees of understanding of the treatment. Almost 9 in 10 (88%) of the PEP facility sample could not name the pills they had been given (although a small number thought they were taking nevirapine). Patients from one particular site, were however able to describe their pills accurately.

Asked how many pills they were taking daily, responses varied from between 6 pills to 15 pills. (In terms of the regimen prescribed by GDoH at the time, the correct number of pills would have been 8.)[¶] Approximately 1 in 3 (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 two pills from only one of the packets instead of one pill from each of the packets.

One patient said the nurses did not explain to her how the pills needed to be taken. Another patient, thinking that the medication had only to be taken for a week, had stayed away from school for that week to ensure that she took her pills correctly 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.

Women who participated in the in-depth interviews provided further insight into additional factors affecting their understanding of the drug regimen. At least 3 patients maintained that they had been in no state to listen to instructions about the treatment. Only after they went home were they able to sit down and determine from the package inserts how the pills should be taken.

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

[‡]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.

[§]In the case of 9 patients it was not clear how many weeks they had completed.

[¶]This included two AZT pills at 6-hourly intervals and one 3TC tablet at 12-hourly intervals over one 24-hour period. This regimen should be repeated over 28 days.

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.

Some women 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 the entire experience.

SIDE-EFFECTS

Some 9 in 10 patients (46 or 88%) experienced side-effects, but only 14 (27%) 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 the 14 who 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.

The most common side-effects were nausea and vomiting, with 34 survivors (65%) complaining of these. Tiredness and drowsiness were reported by 18 survivors (35%). Other side-effects included feeling dizzy and weak (14 or 27%), stomach upsets and soreness (10 or 19%) and headaches (7 or 13%). Twelve (23%) patients reported changes in their appetite, 9 losing their appetite while 3 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. Of the rape survivors 85% experienced more than one side-effect.

Like those women interviewed at the PEP facilities, almost all interviewees (14) experienced side-effects, with 12 suffering multiple side-effects. The presence of these side-effects tempted patients to stop their pills. One woman commented, 'The first week of tablets I vomited the whole week. I did not even go to work'. The degree to which these side-effects incapacitated survivors varied, 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.

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 was not able to afford this medication and would have appreciated the hospital providing her with treatment. A third patient sought help for her side-effects from a private doctor.

Patients usually coped with the side-effects by changing their eating and drinking patterns, typically timing their pills with their meals (a particular challenge for those who had lost their appetite). One took sweets with her pills while 3 others added various types of drinks – tea, soda water and ginger ale – to their diets to help deal with the side-effects. A few patients stopped taking their pills until some of the side-effects had subsided and then started again.

FACTORS AFFECTING ADHERENCE TO PEP

Slightly more than 1 in 3 (37%) patients interviewed at PEP facilities reported having missed pills at some point. Forgetfulness was the reason most commonly cited for missing pills (6); this was linked to the next most common reason for skipping, 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 could not get to the clinic to get more pills because she was at school.

More than half of patients (28 or 54%) interviewed at PEP facilities identified side-effects as the factor that made it difficult for them to take the pills. Two women who participated in the in-depth interviews 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 any more.'

Because she had only 3 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.

The other woman did not experience any side-effects in taking PEP, but having been told to expect side-effects, she assumed that their absence meant she was 'cured' of HIV and could therefore stop taking the drugs. A family member persuaded her to continue.

Over and above side-effects, there were other factors that made it difficult for patients to take the pills. These included not liking the taste and smell of the pills; finding the sheer number of pills overwhelming; and the role they played in reminding patients of the incident. Thirteen patients said they did not have any difficulties taking the pills.

Fear also emerged as a barrier to accessing PEP facilities, with a small number of women being frightened of leaving home to come to the clinic, particularly if the rapist/s were still at large.

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 2 said nothing made it easier to take their pills.

COUNSELLING AND SUPPORT

Almost all of those interviewed 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, workmates and friends.

In one case where it appeared that the survivor's parents blamed her for the rape, her sister assisted her to take her medication and often kept her pills for her. Another patient was hiding her pills because she had not told her parents of the rape out of fear of their reaction.

Of the 52 patients interviewed, more than half (56%) had not been for any counselling. Patients at one particular site were most likely to have gone for counselling, mainly because there was a social worker at the facility.

At the time of the study, patients were collecting their PEP from the facility on a weekly basis. During the in-depth interviews, we asked survivors what they thought of this practice. With the exception of 3 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.*

One patient remarked that she was very emotional when she visited the clinic. Staff at the site were helpful, allowing her to cry and encouraging her to continue taking the pills. Another patient thought that staff counselling and talking to patients when they came for weekly visits was essential in helping them move on. Survivors stressed the importance of ongoing support and counselling and suggested that more referrals be made to counselling services.

DISCUSSION

The interviews suggest that adhering to PEP is neither pleasant nor easy, and almost all of the rape survivors in this study required encouragement and support from health workers, family, friends and counsellors to do so. The interviews also illustrate how the trauma and distress caused by rape may affect adherence. Shock in the immediate aftermath of the event made it impossible for some women to recall what they had been told about PEP, while for others the drugs brought back unpleasant memories of the rape. Collecting PEP was also a fear-filled exercise for some women. The in-depth interviews also suggest that when women went to health facilities, they were not only hoping to be treated in relation to PEP but also wanted to be helped with their distress and trauma. However, it would seem that the health response to these survivors was primarily being shaped by concerns around HIV, rather than their health care needs globally after the rape.

Other studies have also highlighted counselling as an important component of a PEP service. One study investigated, from rape survivors' perspectives, what services they consider most necessary. They found that respondents most valued the availability of HIV post-exposure prophylaxis (with an HIV test) and having a sensitive health care provider who could provide counselling. They did not make choices based on travel time. The study suggests that patients are willing to trade off access to services (time travelled) for attributes such as HIV PEP, counselling, and a thorough examination.[2]

The second study sought to develop an integrated model for integrated post-rape care and HIV PEP. Among other things, the intervention focused on expanding the role of nurses in the management of sexual assault by equipping them to document the rape history, provide acute trauma debriefing, provide a stat dose of PEP, take a pregnancy test, dispense the treatment package and provide medication counselling and make follow-up referrals. Whereas 61.5% of patients found the health care worker's counselling helpful before the intervention, this number rose to 98.5% after intervention. PEP completion rates rose from 20.0% to 58.3% (although this was not due to the counselling alone).[6]

CONCLUSION

Taken together, these three studies highlight counselling, or emotional and psychological support, as an integral component of a PEP service. Yet in finalising the Sexual Offences Act, counselling services turned out to be what legislators were unwilling to provide. The South African Law Commission, in its discussion paper on reforming the law applicable to sexual offences, recommended that the State provide psychosocial support and health care to victims of sexual offences.[7] The Department of Justice and Constitutional Development did not accept this recommendation and excluded it from the Sexual Offences Bill introduced to Parliament in 2003. Removal of this clause minimises the seriousness of the physical and psychosocial trauma resulting from sexual offences

and ignores the currently differential availability of, and access to, services for wealthy and poor South Africans.

It is not necessary to pass legislation before psychosocial services can be provided to rape survivors. But in passing legislation which treated PEP as rape victims' only health service need, legislators reinforced the separation of HIV from other health concerns, rather than seeing them as intimately intertwined, and elevated HIV over other health concerns. It is to be hoped that health care workers do not repeat this error.

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