



South African MEDICAL
RESEARCH COUNCIL



BUILDING A HEALTHY NATION THROUGH RESEARCH

Exploring the role of stigma of rape and HIV on women's compliance to PEP after rape

Naeemah Abrahams

Rachel Jewkes

Gender & Health Research Unit

Introduction

- Post Exposure Prophylaxis (PEP) to prevent HIV after rape has been available in the public health services since Dec 2002 in South Africa.
 - Poor adherence to PEP has been reported internationally and locally.
 - Levels between 15-59% has been reported in South Africa.
 - Research on adherence to medication has burgeoned in response to the challenges of the HAART era and huge efforts has been put into developing strategies to support adherence to HAART.
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Adherence research

- Adherence research is complex and systematic reviews identified barriers:
 - **patient related barriers:** feelings of hopelessness, fear of disclosure, depression, suspicions of treatment, tablets being a reminder of HIV and not understanding the treatment
 - **drug-related barriers** included side effects, complicated regimens, doubting efficacy
 - **daily schedule factors** including disruptions to routine, difficulty to incorporate HAART into lifestyle, not able to coordinate pill taking with work, family and care giving activities, being busy or distracted
 - **interpersonal relationships** such as lack of trust in health care provider, social isolation, discouraging social networks
 - **health sector**
 - Many of these are of relevance to PEP after rape
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Strategies to support adherence

- Strategies to support adherence is a critical aspect of initiating HAART
 - Support and counseling are essential aspects of such strategies.
 - But such psycho-social supportive strategies and specific focus on adherence support have largely not been available as part of the care given to rape victims
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PEP and medication after rape

- Combination therapy of Zidovudine (AZT) and Lamivudine (3TC) for 28 days
 - Started within 72 hours of the rape/exposure
 - HIV test done immediately or within 3 days of starting PEP
 - Dispensing of drugs depends on when HIV test done, resources for return visits
 - 3 day start-up pack, 7, 14 & 28 day packs
 - Emergency contraception
 - Treatment of STI
 - Anti-emetics
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Research study

- A study was conducted to explore PEP use after rape including the circumstances that facilitate and obstruct its use
- Qualitative study using semi-structured in-depth interviews
- 29 participants (women >15 years) recruited at sexual assault services at two research sites
 - 13 women in urban Cape Town – Western Cape Province
 - 16 women in peri-urban and rural Mthatha- Eastern Cape Province
- Repeat interviews done with most of the women in Cape Town
 - A total of 39 interviews
 - Interviews conducted during the 28 days of taking the PEP as well as soon after the completion of the PEP
 - Women asked to report on their ability to complete the medication
- Interviews recorded, transcribed and translated
- Data analyzed inductively

SOUTH AFRICA

Capitals:
Pretoria, administrative;
Cape Town, legislative and
Bloemfontein, judicial

- ⊛ National capital
- ⊙ Provincial capital
- Town, village
- ✈ Major airport

— International boundary
- - - Provincial boundary

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Taking PEP

- *'The first packet I use to take three times a day, the other one two times a day and the last one in a bottle two times a day... But there [in the clinic] they gave me four, I think they were four and they said I must swallow them all together. Four tablets and then the other ones were also four and then two.'*
 - This above shows the enormously complex process of taking multiple forms of medication following rape.
 - Information about the PEP and its use is given to the women at the 1st visit but this is not followed up and supported with IEC material specific to taking PEP after rape
 - It is not surprising that only 9 of the 29 women adhered to the drugs.
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Perceptions of rape and blame

- Fear of being blamed influenced help seeking and disclosing of the rape to important others
 - Perceptions of rape impacted on adherence. If the 'rape' was contested by women, or their social networks, HIV prevention became of secondary importance.
 - Blame was assigned depending on who the victims were, who the perpetrators were, the circumstances of the rape, family cohesion and the community perceptions of sexual violence. These all influenced women's credibility and responses from others
 - Women who were not blamed and who were believed received support, but such support was influenced by the notion of 'deserving victimhood' e.g. age of victim/context of the rape.
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Stigma of rape

- An identity of '*being raped*' was sometimes resisted because it was stigmatized as one woman explained she '*did not want to be associated with rape*' and taking the PEP meant she had to accept that she was raped
 - Silence and non-communication from others were also perceived as stigma and blame
 - Women who spoke about rape stigma were often already marginalized and were therefore not considered worthy of support and sympathy.
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Stigma of HIV

- HIV stigma was a dominant barrier to taking medication and a group of women became distressed because *'ARVs are only given to people that are HIV positive'*.
 - These women knew they tested negative, understood the concept of prophylaxis but the association between the ARV drugs and HIV operated in a very powerful and irrational way and prevented the taking of medication.
 - A woman explained *' I took the tablets and when I got home it was like they said I was HIV positive. For two weeks taking the tablets became more and more difficult knowing that I am taking HIV tablets...I think may be if I did not know that they were for HIV may be I would have taken the tablets with more enthusiasm.'*
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Focus knowledge gaps

- **Knowledge of HIV and PEP had a complex relationship with adherence.**
- **A group of women demonstrated poor understanding of the concept of prophylaxis.**
 - One explained *'I believe that I should not take the pills as people who are HIV positive take them to keep them healthy. I was not HIV positive so that is why I stopped taking the tablets because I was negative.'*
 - Some women were also notably ill-informed but had a great deal of uncomplicated faith in the treatment which was facilitated by good relationships with service providers and they adhered
- **Another group demonstrated very clear understanding of the purpose of the PEP and took their medication**
 - but some had only HIV- related knowledge gaps.
 - This is appeared to be another manifestation of HIV stigma and was deployed by the survivors as a way of enabling them to comply with treatment which they would have found more difficult if they had made themselves face up to the HIV implications of taking ARV.

Side effects

- Nausea was a common side effect but with anti-emetics many could cope and considered this minor compared to other aspects of coping with the rape.
 - The research suggest that side effects alone does not explain the low levels of adherence,
 - A woman's explanation of why she stopped the PEP shows the combination of side effects and the psychological trauma *' Once, after talking the tablets in the morning I vomited then I tried to take another tablet during the day but still I was vomiting and at night I took the tablets but I could not sleep. I realized that what would be troubling me was to know why I was taking these tablets, what happened to me then I decided to stop....*
 - The combination of nausea and the notion of taking *'HIV tablets'* also created distressed and tormented the women bringing to mind images of developing HIV related illness. Some responded to the fear of HIV by taking the pills once a day instead of twice and continued taking the medication far longer than 28 days.
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Emotional responses

- Blame and self-blame had profound psycho-social impact on women. This disempowered them and reduced their self-efficacy and together with absence of support impacted on adherence
 - In addition the acute fear and anxiety that follows rape creates an overwhelming desire to avoid memories of the traumatic event and this can impact on the 28 days of taking PEP.
 - A woman described why she could not take the PEP medication *'one moment I remember... and then I can't.... One moment I want to remember everything – and the next moment I want to wipe it all out... I should have been taking more (tablets) than I have done... but I really can't... it's like a reminder of something bad. Often I did not take the tablets on time – especially if I want to just be myself – then the tablets really are in my way. Now, there are days when I take it and there are days when I don't...*
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Support

- Women who adhered had support from important others
 - Support was demonstrated in different ways.
 - A woman complained about the PEP medication to her sister who said *'leave it, don't take it'* which was possible her uninformed manner of providing support.
 - Similarly her boyfriend also asked her why she bothers to go to the clinic when she complained about it being *'stressful'*.
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Conclusions

- The study have shown that even though rape survivors get to services on time to receive PEP, its effectiveness is undermined by low levels of adherence.
 - Women are not receiving the highly prized protection from HIV transmission.
 - The medication regimen after rape is complicated and the first days and weeks after rape are a very difficult time for women and health services did not adequately support the taking of PEP with none of the participants actively followed up and supported in the taking of PEP.
 - Few women received psychological support beyond the initial post rape visit.
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Conclusions

- Rape stigma is often spoken about but it has received no research attention- especially how to mitigate it at individual, service provider and community level.
 - HIV stigma interfered with the women's ability to take the drugs because it evoked fears of HIV that are so powerful that they eventually paralyze rape survivors and undermine the very pill taking practices.
 - Fear of HIV did not promote adherence but rather undermined the taking of medication.
 - This has not been recognized previously in discussions of barriers to taking of PEP after rape and must be taken into account in developing post-rape services.
 - Research is needed to develop effective interventions that addresses these powerful and overwhelming fears.
 - Core aspect of such interventions are the psycho-social support in this period to support both adherence and the trauma of the rape
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