

Keeping a grip on HIV: collaborative medication and symptom management experiences of persons with HIV

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Aim:

The purpose of this explorative qualitative study was to gain understanding of PLWH's symptom and medication management with a focus on their collaboration with close support persons and health care providers

Methods:

- Study part of mixed methods project with critical hermeneutical approach
- From main sample, 13 PLWH were purposefully selected (gender, route of transmission, 4 centers)
- In-depth interviews were conducted
- Content analysis techniques were used (Dickelman & Allen 1998)

Results:

An overview of results with the main theme “I have a grip on HIV—HIV has a grip on me” and four relational themes is presented in *figure 1*.

I have a grip on HIV—HIV has a grip on me

- Overall impression of being able to manage symptoms and medications
- Already small changes influenced participant's impression of ‘having a grip’ on HIV to ‘losing it’ (continuum)
- ‘Having a grip on HIV’: feeling of being able to manage the difficulties and keep up a meaningful life
- ‘HIV has a grip on me’: feeling overwhelmed by difficulties and unable to manage



Four relational themes reflect participant's ongoing work to “keep a grip on HIV”:

Generate Images

- participants constantly monitored their own health and behavior
- Interpretations of their observations based on frames of references, regarding knowledge of symptoms, their bodies, their labs and adherence

Generate Expertise

- Expertise based on a difficult learning process (try and error) was developed
- Processes included: learning decision making, finding strategies, organizing medications and understanding HIV

Work with Providers

- To strengthen unsatisfactory self evaluation and management, active strategies to work with health care providers were described
- Collaboration could be supportive or non supportive:

Example of a 42 year old women:

“I had this awful itching and was really stressed about it. But I got the impression they took it seriously, I liked that”

Example of a 28 year old women:

“I had awful itching, but no one took it seriously. I even had bleeding legs and told them many times but no one reacted”

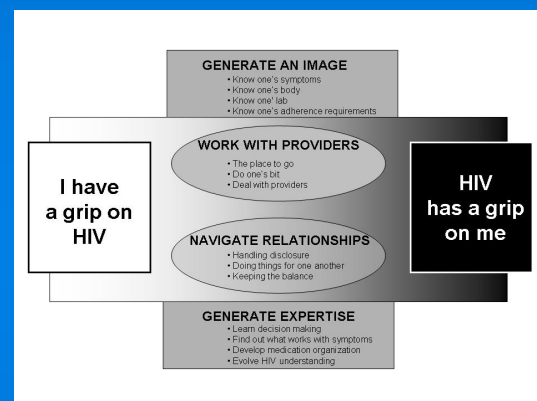


Figure 1

Navigate Relationships

- To better manage medications and symptoms, relationships with significant others were carefully navigated
- This included decision about disclosure, balancing own needs and doing things for one another

Conclusions:

- PLWH demonstrate active self management and a need for working partnerships with health care providers
- To be supportive, providers have to combine medical expertise in HIV with expertise in support of selfmanagement task and skills
- Assessment of PLWH impression of “having a grip” could guide support interventions and should be further developed