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

Dunja Nicca1,2; Jan Fehr3; Pietro Vernazza2; Rebecca Spirig1,4
1Institut of Nursing Science University of Basel; 2St. Gallen; 3University Hospital Zürich; 4Department of Clinical Nursing Science, University Hospital Basel

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 (Diekelman & Allen 1998)

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

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

Figure 1

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