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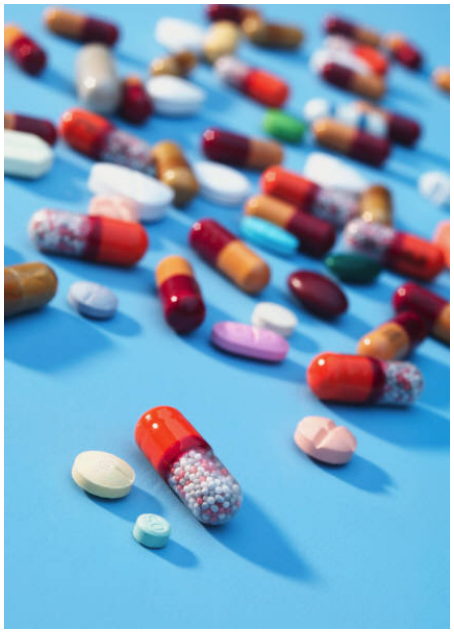
HIV-positive persons' perceptions of taking HIV medication:

An exploratory study



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Background & Statement of Problem

- HIV: Serious public health issue, with est. 1.04-1.19 million HIV+ persons in US and 40,000 new cases/yr. (CDC, 2005)
- Importance of HIV medications
  - HAART has dramatically increased survival
  - Near-perfect adherence (>95%) is associated with positive health outcomes
  - Good health outcomes are 3X more likely in adherent patients (DiMatteo et al, cited in Holzemer et al., 2007)
- Conceptual base: Health Promotion Model*
  - Self-care: universal condition for health, ongoing activity, and competence one may develop

*Pender, Murdaugh, & Parsons, 2002

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Study Purpose & Methods

- Study purpose:
  - To deepen & enrich understanding of HIV+ persons' perceptions of medication-taking
- Study Design:
  - Descriptive study
  - Blended approach (quantitative & narrative data)
- Setting: southwest USA
- Data collection time: 2005
- Study approval: university Institutional Review Board (IRB)

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Methods cont'd.

- Sample:
  - Non-random
  - Recruited from large HIV/AIDS specialty clinic and surrounding community with a diverse population
  - Inclusion criteria:
    - HIV+ persons
    - ≥18 yrs. of age
    - Able to communicate in English
    - Living in the community

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Methods cont'd.

- Quantitative Data collection:
  - Self-report questionnaires

    Demographic data form
    - Included a 1-item visual analogue scale measure of taking HIV/AIDS medications on time

    Self-Reported Medication-Taking Scale (SRMTS) (Morisky, Green, & Levine, 1986)
    - 8 dichotomous (yes/no) items & 1 Likert-type item
    - Higher scores indicate better adherence
    - Reported predictive &concurrent validity
    - Prior use in studies of chronic illness (Lorig et al., 1996; Morisky)
- Quantitative data analysis: frequencies, percentages, measures of central tendency

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Methods cont'd.

- Qualitative/narrative data collection: Interviews
  - Face-to-face
  - In private setting on campus (not clinic where get care)
  - Conducted by research team,
  - Using standardized semi-structured interview guide,
  - Audiotaped & transcribed verbatim
- Qualitative/narrative data analysis: Miles and Huberman's (1994) methodology
  - Concurrent data reduction,
  - Data display,
  - Conclusion drawing & clarification

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Quantitative Findings

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Demographics

Gender (n=18):
- Males: 16
- Females: 2

Race/ethnicity (n=18):
- Black: 9
- White: 5
- Other: 3
- Hispanic: 1

Employment (n=17):
- Full time: 1
- Part time: 3
- Not employed: 13

Education (n=18):
- <9th grade: 1
- 9-12 (no degree): 3
- HS grad/GED: 4
- Some college: 8
- Bachelors degree: 2

Age in yrs (n=18):
- 25-34 1
- 35-44 5
- 45-54 9
- 55-59 1
- 70-74 2

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Demographics cont'd.

Diagnosis:

- HIV: 7
- AIDS: 11

Other Health Problems: 15

- None: 3
- One: 8
- Two: 2
- Three: 3
- Five: 2

Types of Health Problems:

- Hepatitis: 7
- DM: 4
- Asthma: 3
- Overweight: 3
- Underweight: 1
- High cholesterol: 2
- HTN: 2
- Anemia: 1
- Other: 5

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Demographics cont'd.

- Participants with HIV meds prescribed: 15
  - HIV-positive: 4
  - Diagnosed with AIDS: 11
- No HIV meds prescribed: 3
  - HIV-positive: 3
- Range of # HIV meds prescribed: 0-11

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Taking HIV/AIDS medications (n=15)

- 1-item visual analogue scale: frequency of taking medications on time

  *Possible score: 0-100; ↑ scores = ↑ frequency taking meds on time
  - Range: 20 - 100%
  - Mean: 81.5%
  - Mode: 90%
- *Self-Reported Medication-Taking Scale* (SRMTS)

  (Morisky, Green, & Levine, 1986)

  *Possible scores: 0-13; ↑ scores indicate ↑ adherence
  - Reliability (alpha) for current study: .722
  - Range: 4 -13
  - Mean: 9.27 (SD 2.60)
  - Mode: 9

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Findings from SRMTS (n=15)

Item	No.	%
Sometimes forgets to take medications	8	53.3
Didn't take medications every day within past two weeks	6	40.0
Has ever cut back/stopped medications without telling doctor, because felt worse when taking them	4	26.7
Sometimes forgets meds when away from home or traveling	3	20.0
Didn't take meds yesterday	4	26.7
Doesn't have a reminder or routine	10	66.7
Sometimes stops medications when cell count is high	3	20.0
Has felt hassled by sticking to treatment plan	7	46.7
How often has difficulty remembering to take all HIV/AIDS meds		
Never/rarely	7	46.7
Once in a while	5	20.0
Sometimes	3	33.3

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Narrative Findings

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Unintentional medication modification

- Forgetting and unable to adjust (1)
  - ◊ [Staying at a shelter], "If I miss [meds], I can't go back in and get it because they lock the doors at seven, and you can't get back in till four. And if you forget to take it at night, and they throw you out in the morning,…you can't get back in 'til the next day. And, sometimes I'll end up staying at somebody's house, and I'll walk off and leave 'em there….This homelessness …makes it real hard for your adherence."

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Unintentional medication modification cont'd.

- Forgetting and adjusting

◊ "I slip up in small ways…either 30 minutes late, an hour, 2 hours late, so frequently now, that I've quit worrying about the few occasions where I've missed a dose for maybe 8 hrs. before I could get around or get back to take it….If it's 6 hrs. late, I'll adjust my next dose; like 12 hrs. later, I'll start again. I'll trim an hour off to kind of bring it back into balance instead of just taking long breaks between."

◊ "Sometimes I will forget to take my medicine, or just am not in the place to take my medicine, and, if I wait too late during the day, I just wait till the next day, 'cause I usually take my medicines in the morning."

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Unintentional medication modification cont'd.

- Running out (1)

◊ "I always took my medication…but the problem was that I used to not count my days on it, with what I had left, before I get the refills….might go one or two days without it"

- Forgetting due to drinking (1)

◊ "I have forgotten to take my meds…'cause I was doing something…I had no business doing….I am an alcoholic, see, and I'm gonna drink, but I take my meds, though [now]"

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Choice: Purposeful modification

- Using own judgment
  - ◊ "I juggle my medication…the way I think I should do, 'cause, I'm not no doctor, but I've learned enough by studying it that I've got a pretty good handle on it."
  - ◊ "Sometimes if I really feel like [meds are] doing me harm, I will stop…."

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Choice: Purposeful modification cont'd.

- Using own judgment, based on lab

◊ "I have tried [modifying medication]…without permission from the doctor, and I'll just see from the newest lab work about that….I mostly do that on my own. Say, for instance, I take this medication at bedtime. I just won't take it….I may skip a week….I may see the doctor every 90 days, but, in those 90 days, I may take the medication about a week."

◊ I probably miss an average of 3-4 times a week…. 'Cause my t-cells have gone up so good, I think, 'I just have these things to do!'"

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Choice: Purposeful modification cont'd.

- Uses own judgment, based on how feeling

◊ [Missed by choice because medication] "makes me sleepy."

◊ "This month I missed maybe 4-5 evenings…I was so tired, I just didn't [take it]."

◊ "I don't like the effects….the high feeling…those side effects that the medicine may cause is just why…I won't take it…or may break pill in half. "

◊ "Once I start getting sick and once I've lost enough weight, then I know that I'll do it the doctor's way for a while."

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Choice: Purposeful modification cont'd.

- Social reasons

◊ "I usually balance things off…. depends on what kind of people I'm around, or, if it's people that understand me, then I'll be more okay to take my medicine with me and take it. But if not, if I'm going to go for a few days, then I just don't take it for a few days. "

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Choice: Purposeful modification cont'd.

- Social reasons cont'd.

◊ "A couple of times I went out [to a party], and then I have to wait about two hours after I get home, and I might not take my second dose, and sometimes I'll not take the second dose 'cause I might drink a couple of wine coolers….But then I take it all the time….I'm always taking it, so no problem….I might not want to [take meds], but I don't forget….And, then, sometimes I don't, 'cause I either went out or had a lady friend….but I make sure I take both doses the next day…the day after."

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Things that help medication-taking

- Reminders
  - Takes at mealtime or with coffee
    - ◊ "I take one set in the morning, I'm through for the rest of the day. I usually try to eat my breakfast and take my medicine, and I'm through."
    - ◊ "I got my cup of coffee, I'm looking at the news, I'm taking the caps off, I'm capping one, two, three. Boom, in my mouth, and I wait till my coffee cools off, and I take 'em….It's over with. It's only once a day. It's done. "

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Things that help medication-taking cont'd.

- Reminders
  - Telephone alarm (1)
    - ◊ "I got an alarm on my telephone, and it goes off three times a day."
  - Clock alarms (1)
    - ◊ "I got a clock. I set it. When it goes off, …I know it's time to take my medicine."
  - Pill packs/box (2)

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Things that help medication-taking cont'd.

- Carrying medications on person (2)

◊ "I got 'em in my pocket. I carry some. I always carry my evening dose in my pocket in case I don't be home."

- Simpler regimen

◊ "I'm on a wonderful twice-a-day regimen."

- Someone else provides them (1)

◊ [Mother] "controls the medication in the house…she just takes them out of the bottle and give to me."

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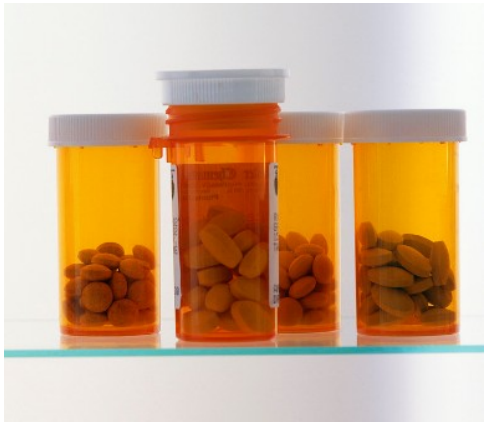
Things that help medication-taking cont'd.

- Being incarcerated (2)

◊ "When I was locked up,…I never missed a dose."

- Stable living environment (1)

◊ "A stable living environment, meaning an apartment or a house….the last place I had…I put the medication in the ice box and never forgot to take it. Every time I opened the ice box, there it was, although it didn't even have to be refrigerated."



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Views: Medications as lifesaving

- "All the while I've been positive, I've always taken some type of medication, have some type in my system, and I personally feel that, since I've had them in my system, even though my adherence wasn't too good, …it was something that…has kept me around, so to speak."
- "People all over would kill you just to have…what's in that bag, 'cause it [meds] would prolong your life five years--three to five years. It did me…. dropped my viral load from 750,000 to non-detectable in 30 days and [raised] my CD4 from 12 back up to 200….that's a lifesaver."

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Views: Medications as lifesaving cont'd.

- "It don't bother me to take it, 'cause I know I got to take it…got to take it all or get…worse."
- "All of a sudden, we took the medicine, and [the viral load] just went away."
- "I don't like taking it, I'm not a medication person, but…supposedly it's …making me better, so I'm taking it."

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Other views about medications

- Doesn't hurt to miss
  - ◊ "As long as I get back on it, that little short period of time [without meds] doesn't hurt."
- Depending on clinical indicators
  - ◊ "If my numbers ever go bad enough, where they're too bad, and I feel like that it's from… [non-adherence to] my medications, I would have to be strict on taking them then."
  - ◊ [If t-cells went down] "Oh, then I would probably get on it and try not to miss at all."

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Other views about medications cont'd.

- There's always something else

◊ "Probably rendered this particular medication useless because of my adherence difficulties, but Dr….seems to think if I mess up on one class of drugs we can alter to make it better…."

◊ "My doctor has tried several different medications on me over the last few years, and he always says, like, 'this is your last chance. If you don't take this on time, if you don't do this,' –and then they'll come up with something new, and he'll tell me the same thing over and over."

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Other views about medications cont'd.

- Medications as harmful

◊ "It's easy if you make it easy, but, if you want to make it harder on yourself, … you look at them pills as …toxic…rat poison."

◊ "Half the time, you and your doctors aren't sure if it's the virus or treatment that's causing [sx]"

- Drug resistance

◊ [Drug resistance is] "one of the main things I'm worried about right now, so that's why I say, the next time I go I may have him [MD] put me on other medications that I can tolerate better and see how it …affects."

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Views of those not on meds

- Strength to refuse
  - ◊ "If I had been a weaker person, if I hadn't been so strong when I first found out about [HIV], and so adamant that I was not going to rush into anything, I think my life would be very different today. I mean, I could have all of these medication-related side effects, when I've managed to live the last several years without any of that."
- Plan to be adherent
  - ◊ [A friend] "was not following the program of taking his meds correctly, and I don't plan to do that."

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Partnering with providers

- Can talk with my doctor
  - ◊ "I was honest with him [MD], and he was honest with me, and he worked with me, and there's no secrets, you know, with my addiction or anything else, and I could tell him straight up."

- Providers don't really listen
  - ◊"In many instances the people who provide healthcare need to allow patients to make more decisions on their own, without really clouding their judgment….I wish they would provide everybody with the information and really let them have more of a say in their own decisions, and then listen."

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Partnering with providers cont'd.

- Letting the provider know

◊ "I tell my doctor, too, when I've been missing and stuff."
◊ "I let them know, whether they like it or not, on how I'm doing it."
◊ "I do trust my doctors, but I know the doctors don't know everything so I take as much, as much judgment, much as they tell me, and try to put it in, and try to work it along, with what I want to do also. I will let the doctor know eventually."
◊ "Like last week, I had to go to the doctor that week, so that week before, I started taking every maybe once or twice a week….And that's what I spoke with the PA about it and he said that's not good. And which I read, and I see that it's not good, but I do it, you know."

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Discussion & conclusions

- Limitations preclude generalization
  - Non-random
  - Small sample
- Though general congruence was noted in data collected either quantitatively or qualitatively, some differences exist, suggesting:
  - Possible differences in how participants:
    - Interpreted words/questions, or
    - Responded to written vs. oral modalities
  - How participants responded to interviewers
  - Possible effect of using both quantitative and qualitative modalities

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Discussion & conclusions cont'd.

- None of the measures used provided data re: ≥95% adherence*, but most participants (12) reported some non-adherence.
- Though participants indicated accidental omission of medication, there was a greater tendency within this sample to describe purposeful modification (i.e., choice), though for a variety of reasons.

*Further exploration needed/indicated

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Discussion & conclusions cont'd.

- Though most participants viewed medication taking as important, that belief did not always equate to taking medications as ordered.
- Those with reminder systems tended to report better adherence scores, but few used them.*

*Further exploration needed/indicated

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Discussion & conclusions cont'd.

- Though briefer medication delays were more common, three persons mentioned being off meds for more than 1-2 days.*
- Though some participants indicate a "good" relationship with healthcare providers, some participants don't see patient-provider relationships as a true partnership.*

*Further exploration needed/indicated

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Questions?

Thank you!

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