

HIV/AIDS Patient Involvement in Antiretroviral Treatment Decisions

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Supporting Grants:

- Universitywide AIDS Research Program
- National Institute of Mental Health (NIMH)
- Faculty Support Grant, CSU Fullerton

STUDY OBJECTIVE

- ☞ To investigate how involved those with HIV/AIDS typically are in their antiretroviral therapy treatment decisions with their healthcare providers

STUDY BACKGROUND

- ☞ Past research in chronic diseases (e.g., cancer) suggestive that patients do not want to be involved in their treatment decisions. How might HIV/AIDS populations differ?
- ☞ Sociology suggests those who are sick with various illnesses may play a “sick-role” -- including taking a passive stance on treatment involvement. Again, how might HIV/AIDS populations differ?
- ☞ Recent research has suggested an increase in patient empowerment (i.e., patients getting more involved). Has this movement had an effect on those with HIV/AIDS?
- ☞ Past research suggests that patient motivation can influence whether antiretroviral therapy is started (Marelich et al., 2000)

HIV/AIDS and Treatment in the U.S.

☞ As of December 31, 1999 (from the CDC):

- 733,374 total cases
 - 604,843 are male
 - 119,810 are female

☞ Treatment: NRTI's (e.g., AZT)

☞ Treatment: Protease Inhibitors (e.g., Crixivan)

- When combined with NRTI's, actually reduce HIV particles in the blood
- Can lead to reduction of symptoms related to HIV, and longer survival
- This combination is known as 'The Cocktail,' combination therapy, or antiretroviral therapy

STUDY DESIGN AND METHOD

- ☞ Four focus group interviews performed
- ☞ Total combined sample size of 39 patients

STUDY REQUIREMENTS FOR PARTICIPANTS

- ☞ 18 years of age or older
- ☞ HIV diagnosis
- ☞ currently prescribed antiretroviral therapy

PARTICIPANTS

Mean Age	40.9 years (33 to 54 yrs)
Race/Ethnicity	44% African American 39% White 6% Latino 6% Other/mixed race
Gender	69% Males
Avg Length Receiving Antiretroviral Therapy	4.3 years (2 months to 12 years)
Most Common Antiretroviral Med	D4T (56%) 3TC (49%) Nelfinavir (33%) Ritonavir (33%)
Most Common 3-drug Combination	Nelfinavir, DDI, D4T (4 patients) D4T, 3TC, Nelfinavir (4 patients) Ritonavir, D4T, Saquinavir (4 patients)

ANALYSIS

- ☞ Structured interview protocol with key-word probes
- ☞ Multiple readings of focus group transcripts to identify major ideas or themes (Strauss & Corbin, 1990)

RESULTS

- ☞ Study participants were asked “*When you were prescribed your current HIV therapy, how much did your doctor or healthcare provider involve you in that decision? That is, did you feel like you were part of the decision-making process?*”
- ☞ Participants noted at least some level of participation with their providers regarding antiretroviral treatment decisions

DECISION-MAKING INVOLVEMENT: THEMES FROM FOCUS GROUP PARTICIPANTS

- ☞ Joint decision-making
- ☞ Patients taking control
- ☞ Initial passivity then involvement
- ☞ Patients as knowledge gatherers

JOINT DECISION-MAKING

☞ Joint decision-making reflects patients and their providers working together to make the antiretroviral treatment decision. In other words, both contribute to the final treatment decision.

“There’s a marriage there, ya know? We’re constantly learning from each other. I learn something, I tell him. He learns something, he tells me.”

“Well, it’s a team . . . its teamwork and my doctor’s always there for me in answering the questions . . . I have no problem discussing issues with my doctor or treatment with my doctor.”

“The two of us are very in sync. We’ve created quite a relationship between the two of us . . . I’ve been on [protease inhibitors] for five years . . . and whatever idiosyncrasies you can think of I came down with . . . and [we] fine tuned . . . where I’m at today.”

“I told [my healthcare provider] I want to get off these . . . drugs. I specified which ones I want to get off of. And over time, we have gotten off of those drugs . . . so it works both ways . . . its not just the doctor [who is in charge].”

PATIENTS TAKING CONTROL

☞ This theme illustrates patients doing more than simply working with their healthcare providers. Three sub-themes were noted that show patients taking a very active stance in requesting treatment options:

- Being Assertive
- Listening then deciding
- Provider/organization shopping

Being Assertive:

- ☞ Some patients reported taking a very aggressive role with their providers

“I essentially probably take the more aggressive role, and I think the doctors [at the clinic] attest to that. I get quite feisty in terms of dictating what I want.”

“I push for something, I get it, and I try it out and if it works for me, it works for me. If it doesn’t work, I let the doctor know to do something different.”

Listening then Deciding:

- ☞ Instead of ‘pushing’ for regimen changes, a few patients noted listening to their providers recommendations, then making up their own minds

“I usually just listen to what the doctors will say, but then make up my own mind . . . I was given choices of what [regimen type] would work best for me. And I chose the schedule I’m on right now. I chose it myself.”

“I listen to the doctor . . . [but] I feel that I pretty much get to make the decisions as to what I want or don’t want to take.”

Provider/Organization Shopping:

- ☞ In some cases, when patients felt they were not receiving optimal treatment or had conflicts with their healthcare, they would change providers or healthcare agencies.

“I just want to say what changed my life was changing doctors because initially, I didn’t have a very good relationship with the doctor that I had before.”

“I hate private doctors so I’m trying to encourage all of my friends who go to these private doctors to leave them and go to an HIV clinic because they [can get to know] the doctors.”

“I went from being in a clinic where, every time I went there was a different doctor or a different nurse practitioner (they never knew me and I had a bad experience with that), to a private doctor where I’m feeling terrific and my life changed.”

INITIAL PASSIVITY THEN INVOLVEMENT

- ☞ Some participants relayed incidents where they were first passive about their treatment options (letting their providers make all the decisions), then became more involved

“And I was just recently diagnosed . . . this year, so kind of what you said, I haven’t had any information on anything. I totally put my trust in [the provider] over here at the immunology clinic because I was diagnosed right here . . . so I just really put my trust in them and just said forget it.”

“I had no clue as to what was going on. There was not so much involvement. But as you live with this on a daily basis and you become more aware of what’s going on, then I became more involved.”

“I don’t let the doctor make full decisions for me. I did in the very beginning, but once I started to learn about the medication and what it was doing to me, then I got on-board with them.”

PATIENTS AS KNOWLEDGE GATHERERS

- ☞ Patients who were active in deciding their treatment regimens noted a strong desire for HIV/AIDS related treatment information. Various sources were ‘tapped’ for this information, including HIV-positive peers, friends/family members, health professionals, and the media

“Everybody’s experience, listening to what people say, reading, a little of everything.”

“[I talk to people] whenever possible, whenever I can hook up with someone who has some opinions . . . you know, I will milk them. I will just corner them and milk them.”

“I discuss it with people who are further along with AIDS than me.”

“I told [my doctor] what to give me because my boyfriend’s brother is infected and he has an excellent doctor. So [my boyfriend’s brother] writes his bags of stuff down and I take his note into my doctor and he just writes a script.”

“I went to a treatment advocate . . . someone that’s skilled in the different uses of HIV medications, they generally can tell you what some of the side effects are . . . a lot of places have treatment advocates now and the treatment advocate will say ‘Don’t [do] what I say, I’m just saying that this is something you may want to ask your doctor about.’”

“I’d read about Viracept in all of the ads in like POS magazine and other AIDS related magazines.”

“I’ve tried to get as many of the AIDS publications that I can, I try to check out the web site.”

“Before I started taking medications . . . I found myself . . . [getting information from] television [and the] newest studies . . . involving all these different drugs. I would read voraciously in the newspaper anything that came out in the AIDS conferences that happened once a year.”

“They prescribed for me AZT by itself before I got into a study group . . . I read a lot of papers and the briefs that come out every month about all the medications and everything that’s out.”

CONCLUSIONS

- ☞ Those with HIV/AIDS reported various levels of involvement when interacting with their providers regarding antiretroviral treatment decisions
- ☞ Joint decision-making may be a function of length of time with their healthcare providers. Further, joint decision-making suggests that patients and providers are working together, with a common enemy of HIV.
- ☞ Patients who reported making their own treatment decisions (through 'pushing' their providers) reflect patient-provider interactions where trust may be lacking. Hence, patients feel like they must guide themselves.
- ☞ Patient passivity (as noted in other health research areas) noted for study participants only when initially diagnosed. Suggests that when patients have lived with the disease for a period of time, they become more knowledgeable and experienced with their medications, and hence want to become more involved.
- ☞ Patients active in their treatment regimens were vigorous knowledge gatherers. Information gleaned from friends/family members, others with HIV/AIDS, and various media sources, including the Word-Wide-Web.

PENDING RESEARCH