An instrument to assess HIV-related knowledge and adjustment to HIV+ status, and their association with anti-retroviral adherence

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PLAIN LANGUAGE SUMMARY

We developed a questionnaire for people with HIV. General knowledge about HIV wasn't related to whether people took their medications, but specific information about treatment was. People with lots of bad feelings about living with HIV were less likely to take medications as prescribed. People who liked to think more about their decisions were more likely to take their medications.

ABSTRACT

Background: Findings on the association between health literacy and anti-retroviral (ARV) adherence are inconsistent. Health literacy is usually operationalized with simple tests of basic literacy, but more complex conceptions of health literacy include content knowledge. People living with chronic illness also conceptualize and experience illness in ways other than biomedical or mechanistic models of disease.

Objective: There are no instruments that comprehensively assess knowledge of people living with HIV concerning HIV disease and treatment; or psychological adjustment to being HIV+. Little is known about the relationship between factual knowledge, or positive identification as HIV+, and anti-retroviral (ARV) adherence.

Methods: Formative work with in-depth semi-structured interviews, and cognitive testing, to develop a structured instrument assessing HIV-related knowledge, and personal meanings of living with HIV. Pilot administration of the instrument to a convenience sample of 101 respondents.

Key Results: Respondents varied considerably in their expressed need for in-depth knowledge, the accuracy of their understanding of relevant scientific concepts and facts about ARV treatment, and psychological adjustment and acceptance of HIV+ status. Most knowledge domains were not significantly related to self-reported ARV adherence, but accurate knowledge specifically about ARV treatment was (r=0.25, p=.02), as was an adapted version of the Need for Cognition scale (r=.256, p=.012). Negative feelings about living with HIV (r=.33, p=.0012), and medication taking (r=.276, p=.008) were significantly associated with non-adherence.

Conclusion: The instrument may be useful in diagnosing addressable reasons for non-adherence, as a component of psychoeducational interventions, and for evaluation of such interventions.

1 Consistent adherence to antiretroviral (ARV) regimens by people living with HIV

2 (PLWH) is of compelling importance to their own long-term health (Glass et al., 2008;

3 Lima et al., 2009), and to public health (Das et al., 2010; Fang et al., 2004; Granich,

4 Gilks, Dye, De Cock, & Williams, 2009; Montaner et al., 2006). Among patient

5 characteristics commonly hypothesized to be associated with ARV adherence is health

6 literacy, which in practice is typically measured by simple tests of general reading

7 ability. Some studies have concluded that low health literacy, operationalized using the

8 REALM (Davis et al., 1993) that tests pronunciation of medical terms, or the TOFHLA

9 (Parker, Baker, Williams, & Nurss, 1995), a test of reading comprehension, have found

10 that low literacy is a significant independent predictor of non-adherence (Kalichman et

11 al., 2008; Kalichman, Ramachandran, & Catz, 1999; Osborn, Paasche-Orlow, Davis, &

12 Wolf, 2007; Wolf et al., 2007). However, other studies have found that health literacy is

13 not associated with ARV adherence (Murphy et al., 2010), or indeed that lower health

14 literacy is positively associated with ARV adherence (Paasche-Orlow et al., 2006).

15 Others have concluded that any association between health literacy and ARV

16 adherence is due in whole or part to confounding factors such as self-efficacy (Colbert,

17 Sereika, & Erlen, 2013) or stigma (Waite, Paasche-Orlow, Rintamaki, Davis, & Wolf,

18 2008).

19   A review concluded that understanding of the connections between health

20 literacy and outcomes was limited, and proposed a causal model incorporating

21 numerous inputs and outputs to health literacy (Paasche-Orlow & Wolf, 2007), which

22 expands the definition of health literacy to include the *knowledge and beliefs* people

23 hold about their health conditions. Information about the relationship of content

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1   knowledge to ARV adherence is scant, however. One observation is that some PLWH

2   believe that ARVs should not be taken when a person drinks alcohol, which is

3   associated with non-adherence (Kalichman et al., 2012; Kalichman et al., 2009).

4   These inquiries are based implicitly on the assumption that people reason in a

5   manner consistent with the Health Beliefs Model (Becker & Maiman, 1975), balancing

6   perceptions of the likelihood and costs of adverse events against the costs and benefits

7   of adopting a protective behavior. However, people may make decisions based on other

8   kinds of knowledge and reasoning. In medical sociology, it is conventional to distinguish

9   between "disease" and "illness" (Caplan, McCartney, & Sisti, 2004; Arthur Kleinman,

10   1981; A. Kleinman, Eisenberg, & Good, 1978). Disease is a biomedical category,

11   referring to entities which are similar regardless of the psychosocial setting or the

12   afflicted individual. Illness refers to experience which is particular to the individual and

13   patterned by psychological, social and cultural factors. In Kleinman's terms, both

14   disease and illness incorporate explanatory models for processes and experiences

15   (Arthur Kleinman, 1981; A. Kleinman et al., 1978).

16   While patients' may explain pathophysiology, for example, in ways that do not

17   accord with their physicians, the term nevertheless implies causation and mechanism.

18   Other studies of illness experience use different framing. A commonly studied element

19   of illness experience is stigma, defined by Goffman as "an attribute that makes [a

20   person] different from others in the category of persons available for him to be, and of a

21   less desirable kind" (Goffman, 1963) (p. 3). Stigma has perhaps been the most common

22   organizing frame for studies of the HIV illness experience (Mahajan et al., 2008).

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1   Much of the literature on the experience of living with chronic illness other than

2   HIV has been framed by identity theory, of which stigma is only one component (Bury,

3   1982; Charmaz, 1983). In one common formulation, the "self" is relatively stable, as

4   people think of themselves as remaining the same person throughout the life course;

5   but "identity" is comprised of one's various social role relationships (Kralik, Koch, &

6   Eastwood, 2003; Stryker & Burke, 2000). Diagnosis of HIV can be highly disruptive of

7   statuses and relationships, for example through forced disclosure of sexuality or illicit

8   drug use to family members, and stigma.

9   There have been few studies of identity reformation in people with HIV since the

10 availability of effective therapy in the late 1990s. One found that incorporation of the HIV

11 diagnosis into identity included a period of what the author calls "denial" lasting as long

12 as 5 years, after which respondents experienced a "turning point," accepted that they

13 had HIV and moved on in the process (Baumgartner, 2007). This suggests that people

14 who have yet to reach the turning point may not be motivated to engage in self-care

15 including adhering to medication regimens.

16   In previous qualitative research, we found that most respondents had limited,

17 largely erroneous understanding of the scientific concepts concerning HIV and HIV

18 treatment. Nevertheless, accurate scientific understanding was not generally associated

19 with treatment adherence, with the exception of some specific erroneous beliefs (Laws,

20 Danielewicz, Rana, Kogelman, & Wilson, 2015). We also found that non-biomedical

21 categories of meaning and explanation were more salient for most respondents and of

22 far more importance in their treatment decision making and adherence. These could be

23 understood in terms of identity formation (Laws, 2016). In sum, motivation to adhere to

1   HIV regimens may be associated with both accurate biomedical understanding; and

2   ways in which taking anti-retroviral medications is experienced in a person's lifeworld.

3   The "need for cognition" construct in social psychology (Petty, Briñol, Loersch, &

4   McCaslin, 2009), defined as "a stable individual difference in people's tendency to

5   engage in and enjoy effortful cognitive activity," (Cacioppo, Petty, Feinstein, & Jarvis,

6   1996) (p. 198) suggests that accurate factual knowledge would be more important in

7   predicting self-care behavior for some people than for others.

8   Little research directly assesses how information, values and personal meanings

9   shape the medication practice of people living with HIV. We therefore drew on our prior

10   qualitative research to develop a structured assessment of the factual knowledge and

11   beliefs of people living with HIV about HIV disease and treatment; the personal

12   meanings of being HIV positive and HIV treatments, including negative and positive

13   impacts on identity; and how these are associated with ARV adherence.

14

15   **METHODS**

16   **Instrument development**

17   Relevant formative work has been described elsewhere (Laws, 2016; Laws et al.,

18   2015). Briefly, we conducted semi-structured interviews with a convenience sample of

19   32 people living with HIV in two cities in New England. The interview covered domains

20   based on Kleinman's classic components of explanatory models. We harvested content

21   from the interviews to create a structured instrument.

22   **Instrument content**

1 We found that components of explanatory models could be essentially

2 biomedical in character, though often inaccurate (Laws et al., 2015); or could refer to

3 other domains more pertinent to people's lived experience such as responsibility or

4 stigma (Laws, 2016). As we analyzed the data, we classified responses in both

5 categories, and created structured items to assess agreement with particular factual

6 beliefs, or personal meanings. We organized the draft instrument as follows:

7 1. *Sociodemographics:* Demographic background and medical history.

8 2. *ARV adherence:* A previously validated scale based on an index of three items

9 (Fowler, Lloyd, Cosenza, & Wilson, 2014; Wilson et al., 2014; Wilson, Lee, Michaud,

10 Fowler, & Rogers, 2016).

11 3. *Need for cognition:* As we found in the formative interviews that respondents

12 expressed varying degrees of interest in technical understanding of HIV disease and

13 treatment, and in making decisions based on formal reasoning, we included the short

14 form of the need for cognition scale (Cacioppo, Petty, & Kao, 1984).

15 4. *General feelings about HIV and ARV medications*: Items representing personal

16 meanings of being HIV+ and taking HIV medications, corresponding to elements of

17 illness experience expressed in the qualitative interviews. (See Table 1 for retained

18 items.) These were scored on a four-point scale from Strongly Agree to Strongly

19 Disagree. Based on the formative research, we hypothesized that people who report

20 more negative feelings about being HIV+ would report poorer ARV adherence.

21 5. *Reasons for taking HIV medications*: Examples of the 6 items in this section are

22 "I want to take my HIV medications because I've seen what happens to people who

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don't take them," and "I want to take my HIV medications because my doctor thinks they will help me." These are scored on a 3-point scale from Very Important to Not Important.

6.   *Reasons why people might not want to take HIV medications:* Examples of the 10 items in this section are "I don't have to think about having HIV if I don't take the medications" and "It's good to give your body a break from the medications every once in a while." These were scored as the above section.

7.   *HIV knowledge "quizzes":* Four sets of items focusing on knowledge about HIV.

a. *Factual statements about HIV*: A quiz on biomedical knowledge, and common conspiracy theories. Examples include "HIV infects specific cells in your blood that your body needs to fight infections," and "There is a cure for HIV, but they're keeping it a secret." These are scored on a 3-point scale from "Correct" to "Not at All Correct," with a "Don't Know" option. We assigned a truth value to each statement and scored answers as correct or not, with "don't know" counting as incorrect.

b. *Knowledge about T-cell count and viral load*: We asked respondents to select their own most recent test results from a list of ranges. We then presented a series of factual statements about T-cell count and viral load, with the same response options as the previous section.

c. *Statements about anti-retroviral medications*: Again, a knowledge quiz with a three point response option plus "Don't Know."

d. *Knowledge about viral drug resistance*: We first asked if people had ever heard of the concept of "drug resistance." (In the formative interviews, many said they had not.) For those who had heard of it, we again presented a knowledge quiz with the same response options as the previous 4 sections.

Cognitive testing

We recruited 6 additional respondents. The first author read each item to the respondents. After they responded, he asked them to reflect on why they chose their answer, whether there was any ambiguity or confusion about the meaning of the item, and if the response categories were adequate. The interviews were audio-recorded and transcribed for analysis. We made some minor modifications to question wording, instructions, and phrasing of responses as a result.

The most substantial modification was to the need for cognition scale. Respondents consistently said that their process for deciding on HIV treatment might be different from the way they make other decisions. Accordingly, we reworded items to refer specifically to HIV treatment.

Instrument pilot testing

We implemented the instrument as an on-line Computer Administered Survey, using Illume™ software (DatStat corporation). We had members of the Consumer Advisory Board at a local HIV clinic complete the instrument and provide comments. In response, we clarified some instructions. We then recruited respondents and implemented administration through a link placed on the website of a local AIDS Service Organization, allowing people to complete the instrument anonymously on-line; and by having a Research Assistant recruit respondents at the clinic and administer the questionnaire as an interview.

IRB approval

Both methods of questionnaire administration were approved by the IRBs of the parent corporation of the HIV clinic, and [our] University. Respondents read an informed

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1   consent statement and signaled consent before proceeding. As this was an anonymous

2   survey, signed consent was not required.

3   **Analyses**

4   We computed descriptive statistics for all variables. For the knowledge questions,

5   we computed the percentage of correct and incorrect answers for each section. We

6   conducted factor analyses of the various sections. We computed Cronbach's alpha for

7   derived scales based on the factor structure. Finally, we tested the correlation of scale

8   and knowledge scores with self-reported adherence, and knowledge scores with need

9   for cognition, using Pearson's r. We then derived a parsimonious instrument retaining

10   those components that were significantly associated with self-reported adherence.

11   **RESULTS**

12   **Participant characteristics**

13   We administered the questionnaire in 2014. One hundred five people responded.

14   Due to attrition among respondents who self-administered, 99 people completed section

15   4 and 94 completed section 6. Only 63 of the remaining respondents indicated that they

16   had ever heard of the concept of drug resistance, of whom 61 completed section 7.

17   Of 105 total respondents, 45 (42.9%) indicated that they were diagnosed with

18   HIV in 1995 or earlier; 18 more were diagnosed in 2000 or earlier. Four were newly

19   diagnosed in 2014, with the others distributed throughout the intervening years. Only 1

20   respondent indicated not having a current ARV prescription. 71% of respondents were

21   male, the mean age was 49 years with a range from 18 to 73. Fifty-three percent

22   identified as non-Hispanic white, 19% as African American, 11.4% as Latino, 4.8% (5

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1   individuals) as Cape Verdean, and 9 people as various other ethnicities. Nineteen

2   individuals (18%) were foreign born.

3   **Item and scale characteristics**

4   Responses to most items in the section *General feelings about HIV and*

5   *medications*, had good variation, although one item, "Taking my HIV medications makes

6   me grateful that I have access to them," elicited disagreement from only 3 respondents.

7   We deleted it as uninformative. As expected, factor analysis revealed a first factor on

8   which 12 statements of negative feelings about living with HIV and taking medications

9   had the highest loads. Most of these loadings ranged from .489 to .69. We retained

10   items with smaller loadings because they contributed to the association of the scale with

11   self-reported ARV non-adherence. We originally included both negatively and positively

12   framed versions of an item intended to assess internalized stigma: "I don't want most

13   people to know that I have HIV," and "I don't mind if people know I have HIV, I'm very

14   open about it." Both loaded fairly weakly on Factor 1, with opposite valence. We

15   retained the second, positively framed item (with reversed scoring), because the derived

16   scale that included it was more strongly correlated with self-reported adherence. Four

17   items expressing positive adjustment to living with HIV loaded on a second factor. The

18   item "Most of the time I try not to think about having HIV" was not associated with either

19   factor. We deleted it. (See Table1 for the retained items and their factor loadings.) The

20   composite score for Factor 1 (sum of responses scored from 1-4) was significantly

21   associated with self-reported ARV adherence, r=-.33, p=.0012. (Higher scores were

22   associated with non-adherence.) Although the four items representing positive

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1 adjustment were not correlated with adherence, we retained them to avoid encouraging

2 a positive response set.

3 Table 1 about here

4 Responses to the section *"The importance of reasons for taking HIV*

5 *medications"* were less variable, with most respondents endorsing all of the listed

6 reasons. Since this section was uninformative, we deleted it.

7 There was more variation in the section "Possible reasons for not wanting to take

8 HIV medications." (See Table 2.) This constituted a scale with high internal consistency,

9 which was significantly correlated with non-adherence, r=.276, p=.008.

10 Table 2 about here

11 For the *HIV knowledge quiz,* of the 10 items we deemed to have a definitely

12 correct answer, the mean number of correct answers was 5.8. As we expected from

13 formative research, accurate knowledge in this domain was not associated with ARV

14 adherence, so we deleted the section. Respondents' knowledge about T-cell count and

15 viral load was often poor. Again, however this knowledge was not associated with self-

16 reported ARV adherence.

17 The mean score on the knowledge quiz about ARV treatment was 7.5 out of 12

18 items, with considerable variance. The score of correct answers on this section was

19 significantly correlated with self-reported ARV adherence (r=.25, p=.021). (See Table 3.)

20 Table 3 about here

21 More than one quarter of respondents said they had not heard of the concept of

22 drug resistance. Of the 65 who went on to answer questions in this section,

23 misconceptions were very common. There was no association between accurate

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1   knowledge about drug resistance and adherence. (All deleted items are available from

2   the corresponding author.)

3   **Need for Cognition**

4   The score on the modified Need for Cognition scale was highly significantly

5   correlated with the quiz on HIV treatment (r=.39, p=.0002). The Need for Cognition

6   scale was also independently associated with ARV adherence (r=.256, p=.012).

7   Controlling for the Need for Cognition score, the correlation between the knowledge

8   quiz and adherence was no longer significant (r=.17, p=.118). Controlling for the quiz

9   score, the correlation between Need for Cognition and adherence was also attenuated

10   (r=.196, p=.07). (See Table 4 for the adapted Need for Cognition scale.) The causal

11   relationship among these variables is unclear, but it appears that the correlation of

12   adherence with Need for Cognition is partly mediated by knowledge and partly

13   independent.

14   Table 4 about here

15   **DISCUSSION**

16   This instrument identifies gaps in knowledge and misconceptions about HIV and

17   HIV treatment; and measures more and less successful psychological adaptation to the

18   HIV diagnosis and treatment burden. In the pilot sample, it appears that misconceptions

19   about HIV treatment, and failure to successfully integrate living with HIV into a positive

20   self-identity, are both associated with non-adherence to ARV regimens. Accurate

21   knowledge about HIV pathophysiology and mechanisms of treatment, including

22   understanding of viral drug resistance, were not associated with non-adherence. The

23   findings are consistent with hypotheses that emerged from our formative work.

1   The instrument may be useful to directly inform clinicians about patients'

2   misconceptions that may undermine adherence, and psychological barriers to

3   adherence. It may also be a useful tool for individual or group psycho-educational

4   interventions for people living with HIV, as a way of provoking and structuring

5   discussion, and as a pre-test/post-test evaluation.

6   For clinicians, the implication of this work is that it is important to correctly

7   diagnose the reasons why people may be non-adherent to ARVs or fail to engage in

8   treatment. Clinicians often respond to non-adherence by re-emphasizing the biomedical

9   facts about HIV and treatment (Wilson et al., 2010), but this is unlikely to be effective for

10   many people.

11   Developing and evaluating interventions to promote adherence and other effective

12   self-management is more likely to yield results if they can be tailored to individual

13   needs. People who do not accept their HIV status and are not motivated to protect their

14   health will not benefit from supports designed for people who need information,

15   reminders or other practical aids to adherence. Conversely, people who are motivated

16   to protect their health but hold misconceptions that cause them to behave discordantly

17   with their physicians' beliefs about treatment may benefit from an educational or

18   information intervention. This structured assessment is intended to make those

19   diagnoses.

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16

1 Table 1: Factor analysis of items pertaining to personal meanings of living with HIV.
2 (Original variable names are shown to reveal the location of deleted items.)
3

		Factor1	Factor2
Q2_1a_inv	Inverse: Taking my HIV medications reminds me that I have the disease.	0.460	-0.082
Q2_1c	In some ways, finding out that I had HIV was a good thing, because it made me make better choices.	-0.166	0.290
Q2_1d_inv	Inverse: It makes me angry that I have to take medications.	0.696	-0.026
Q2_1e	Learning I had HIV wasn't a death sentence, it was a new start on life.	-0.004	0.568
Q2_1f_inv	Inverse: Taking HIV medications reminds me that I made a mistake.	0.681	--0.208
Q2_1g_inv	Inverse: Taking my HIV medications makes me feel angry because somebody gave me the disease.	0.661	-0.153
Q2_1h_inv	Inverse: Having HIV makes me worry about my health.	0.603	-0.081
Q2_1i_inv	Inverse: Having HIV makes me worry about giving it to somebody else.	0.458	-0.328
Q2_1j_inv	Inverse: Having HIV makes me worry that people will reject me.	0.551	--0.194
Q2_1k_inv	Inverse: I'm scared I might die from AIDS.	0.630	-0.027
Q2_1l_inv	Inverse: I can't stand having to take so many medications.	0.418	-0.106
Q2_1n_inv	Inverse: HIV is likely to shorten my life.	0.489	0.315
Q2_1o	I can live a normal life with HIV.	0.306	0.514
Q2_1q	HIV is just a disease like any other, you can learn to cope with it.	0.342	0.681
Q2_1r	I don't mind if people know I have HIV, I'm very open about it.	0.234	0.112
Q2_1s_inv	Inverse: I still haven't really accepted that I have HIV.	0.410	0.170

4
5 Note: Items expressing negative feelings about living with HIV have scores inverted so that higher scores
6 indicate agreement. Q2_1R is not inverted, so the association is with disagreement.
7
8 Correlation of scale score derived from Factor 1 with self-reported ARV adherence: r=-.33, p=.0012
9 Factor 2 is not significantly correlated with adherence.
10

16

1   Table 2: Reasons for not wanting to take ARVs and scale consistency

2

Cronbach Coefficient Alpha with Deleted Variable		
Variable	**Correlation with total**	**Alpha**
I don't want to take my HIV medications when I'm depressed.	0.439	0.837
If I can't get something to eat, I don't take my HIV medications.	0.384	0.841
I'm afraid somebody might see me taking my HIV medications.	0.342	0.844
There are some kinds of HIV medications I don't want to take because I know somebody who tried it and it didn't work for them, or it made them sick.	0.507	0.832
I don't want to take HIV medications because of side effects.	0.646	0.821
I don't think I should take HIV medications when I drink alcohol.	0.588	0.826
I don't think I should take HIV medications when I use hard drugs such as cocaine, heroin or opioids, or methamphetamine.	0.615	0.824
I don't have to think about having HIV if I don't take the medications.	0.628	0.823
I sometimes forget to take them.	0.294	0.847
I can't stand having to take so many medications.	0.610	0.824
I feel fine so I don't think I need to take any medications.	0.539	0.829
It's good to give your body a break from the medications every once in a while.	0.525	0.830

3

4   Correlation with adherence r=.276, p=.008

5

1   Table 3: ARV knowledge quiz

Item	"correct" answer
You shouldn't take ARVs when you drink alcohol	F
You shouldn't take ARVs if you don't have something to eat	F
You shouldn't take ARVs when you use cocaine or heroin and other opiates	F
If you take ARVs for a long time, you won't have to take them any more.	F
It's important to take your ARVs on schedule to keep a consistent level of the medications in your blood	T
If you keep taking ARVs for a long time, your body becomes saturated with the medication, and you should stop for a while	F
Different ARVs work in different ways, so a combination works best	T

2   Mean % correct 58%

3   Correlation of % correct with self-reported adherence r=.25, p=.021

4

1   Table 4: Adapted Need for Cognition Scale

2

	Scoring direction
a. It is important to me to understand as much as I can about my diagnosis.	+
b. It is not important to me to understand how medications work; I do what the doctor tells me to do.	-
c. I invest a lot of time learning about HIV and HIV treatments.	+
d. I try to learn all the facts about medications and make up my own mind about taking them.	+
e. I don't like to think very much about my health and medical care.	-
f. I would rather do something that requires little thought than something that is sure to challenge my thinking abilities.	-
g. I like to understand the issues about my medical care and make my own decisions.	+
h. It's enough for me that a medication gets the job done; I don't care how or why it works.	-
i. Learning about health and diseases doesn't interest me very much.	-
j. I like to understand concepts and ideas about medical treatments.	+

3

4   Correlation with self-reported ARV adherence r=.211, p=.039

5

6