



UNC CFAR Social and Behavioral Science Research Core SABI Database

INSTRUMENT TITLE: Caregiver-reported ART Adherence for HIV-Infected Children Scale

SOURCE ARTICLE: Vreeman, R. C., Nyandiko, W. M., Liu, H., Tu, W., Scanlon, M. L., Slaven, J. E., ... & Inui, T. S. (2015). Comprehensive evaluation of caregiver-reported antiretroviral therapy adherence for HIV-infected children. *AIDS and Behavior*, 19(4), 626-634.

POPULATION: Women, men, HIV-positive, youth, caregivers

RESPONSE OPTIONS: Visual analogue; # of missed doses.

SCORING: Not reported.

SURVEY ITEMS: Please see attached PDF for formatted questionnaire.

RELIABILITY INFORMATION: No reliability information reported.

VALIDITY INFORMATION: Content validity was assessed. Criterion-related validity was assessed via comparison with Medication Event Monitoring Systems (MEMS). Confirmatory factor analysis identified two factors: adherence barriers and adherence.

TERMS OF USE:

Individuals may use this information for research or educational purposes only and may not use this information for commercial purposes. When using this instrument, please cite:

Vreeman, R. C., Nyandiko, W. M., Liu, H., Tu, W., Scanlon, M. L., Slaven, J. E., ... & Inui, T. S. (2015). Comprehensive evaluation of caregiver-reported antiretroviral therapy adherence for HIV-infected children. *AIDS and Behavior*, 19(4), 626-634.

When presenting results using any survey information you obtained from the SABI, please acknowledge the University of North Carolina at Chapel Hill Center for AIDS Research (CFAR), an NIH funded program P30 AI50410.

leDEA ACE Study – ICAMP ADOLESCENT Adherence Questionnaire

Study ID: - - Date: _____ Interviewer initials:

Clinic: MTRH Module: <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> Rafiki Centre <input type="checkbox"/> Kitale <input type="checkbox"/> FACES Lumumba Health Centre / Kisumu <input type="checkbox"/> Other: _____	
Are you enrolled in a Nutrition Program? <input type="checkbox"/> Yes <input type="checkbox"/> No	
ADHERENCE QUESTIONNAIRE	
1. Who gives you your medicines? (tick all that apply) <input type="checkbox"/> Mother <input type="checkbox"/> Father <input type="checkbox"/> Grandparent <input type="checkbox"/> Auntie/Uncle <input type="checkbox"/> Guardian <input type="checkbox"/> Relative who lives in home <input type="checkbox"/> Relative who lives outside of home <input type="checkbox"/> Neighbor <input type="checkbox"/> Sibling <input type="checkbox"/> House help <input type="checkbox"/> Child takes meds themselves <input type="checkbox"/> Other (specify) _____	
2. Do you know why you are taking the medicines? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know	3. How many people in your household take medicines for HIV? _____ <input type="checkbox"/> Don't know
4. Do you ever have problems keeping time with the medicines? <input type="checkbox"/> Yes <input type="checkbox"/> No When? <input type="checkbox"/> Mornings <input type="checkbox"/> Evenings <input type="checkbox"/> Weekends <input type="checkbox"/> Weekdays <input type="checkbox"/> Other: _____	5. Do you ever have problems with taking the medicines? <input type="checkbox"/> Yes <input type="checkbox"/> No What problems do you have? (explain)
6. Some families tell us that their child worries them or makes it difficult to give them the medicines. Have you not taken medicines for any of these reasons: <input type="checkbox"/> I do not know why taking am taking the medicines or keeps asking questions about the medicines <input type="checkbox"/> I forgot to take medicine <input type="checkbox"/> I felt ill or was vomiting <input type="checkbox"/> I was playing or at school or work <input type="checkbox"/> I refused to take medicine <input type="checkbox"/> I have problems with 1 formulation (tablets, liquids) <input type="checkbox"/> I find medicines too bitter <input type="checkbox"/> I can't take without food <input type="checkbox"/> None of the above <input type="checkbox"/> Other (specify): _____	
7. Sometimes, a child does not take their medicine every day or at the same time every day because of difficulties for the caregiver, parent, or guardian. I am going to read a list of issues that may be problems for your caregiver, parent, or guardian. Tell me when you hear a problem mentioned that applies to you or your caregiver. My caregiver or I: <input type="checkbox"/> Was away from home (work, field, etc.) <input type="checkbox"/> Had difficulty with the instructions for the medicines <input type="checkbox"/> Was not always around with the child <input type="checkbox"/> Was too busy and forgot <input type="checkbox"/> Did not want others to see <input type="checkbox"/> Had trouble with timing or giving the doses on time <input type="checkbox"/> None of the above <input type="checkbox"/> Other (specify) _____	
8. Sometimes, problems at the clinic make it difficult for you to take these medicines every day. Have any of these things been a problem for you: <input type="checkbox"/> There was no money to purchase medicine (if not offered at AMPATH) <input type="checkbox"/> The medicine was not available in the pharmacy. Which medicine? <input type="checkbox"/> ARVs <input type="checkbox"/> Septrin <input type="checkbox"/> Other (include abx) <input type="checkbox"/> I finished or ran out of the medicines <input type="checkbox"/> Other (specify) _____ <input type="checkbox"/> None of the above	
We are now going to ask you a few questions about missing doses. What we mean by a "dose" is any of the medicine that you are supposed to take in the mornings or evenings. If you took your medicines in the morning but missed even one medicine in the evening, then you would have taken one dose and missed one dose. If you missed any of the medicines in the morning and missed again in the evening, you would miss two doses. If you have questions about doses, please ask as we go along.	
9. In the past week, a. On how many days did you miss at least one dose? <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> Don't know b. On how many days did you take a dose more than an hour late? <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> Don't know c. How many <u>extra</u> doses or syringes of medicine did you take? _____ <input type="checkbox"/> Don't know	
10. How many doses of medicine did you miss in the last month? _____ <input type="checkbox"/> Don't know	

leDEA ACE Study – ICAMP CAREGIVER Adherence Questionnaire

Study ID: - - Date: _____ Interviewer initials:

Relationship of person answering questions to child:	
Clinic: MTRH Module: <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> Rafiki Centre <input type="checkbox"/> Kitale <input type="checkbox"/> FACES Lumumba Health Centre / Kisumu <input type="checkbox"/> Other: _____	
ADHERENCE QUESTIONNAIRE	
1. Who gives [name] his/her medicines? (<i>tick all that apply</i>) <input type="checkbox"/> Mother <input type="checkbox"/> Father <input type="checkbox"/> Grandparent <input type="checkbox"/> Auntie/Uncle <input type="checkbox"/> Guardian <input type="checkbox"/> Relative who lives in home <input type="checkbox"/> Relative who lives outside of home <input type="checkbox"/> Neighbor <input type="checkbox"/> Sibling <input type="checkbox"/> House help <input type="checkbox"/> Child takes meds themselves <input type="checkbox"/> Other (specify) _____	
2. Does the child know that he/she is taking the medicines for HIV? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know	3. How many people in your household take medicines for HIV? _____ <input type="checkbox"/> Don't know
4. Do you ever have problems keeping time with the medicines? <input type="checkbox"/> Yes <input type="checkbox"/> No When? <input type="checkbox"/> Mornings <input type="checkbox"/> Evenings <input type="checkbox"/> Weekends <input type="checkbox"/> Weekdays <input type="checkbox"/> Other: _____	5. Do you ever have problems with getting your child to take the medicines? <input type="checkbox"/> Yes <input type="checkbox"/> No What problems does child raise? (explain)
6. Some families tell us that their child worries them or makes it difficult to give them the medicines. Has your child [name] not taken medicines for any of these reasons: <input type="checkbox"/> He/she does not know why taking the medicines or keeps asking questions about the medicines <input type="checkbox"/> He/she forgot to take medicine <input type="checkbox"/> He/she felt ill or was vomiting <input type="checkbox"/> He/she was playing or at school or work <input type="checkbox"/> He/she refused to take medicine <input type="checkbox"/> Has problems with 1 formulation (tablets, liquids) <input type="checkbox"/> Finds medicines too bitter <input type="checkbox"/> Can't take without food <input type="checkbox"/> None of the above <input type="checkbox"/> Other (specify): _____	
7. Sometimes, a child does not take their medicines every day or at the same time every day because of difficulties for the caregiver. I am going to read a list of issues that may be problems for you as a caregiver in having the child take the medicines. Tell me when you hear a problem mentioned that applies to you or the child's caregiver: <input type="checkbox"/> I was away from home (work, field, etc.) <input type="checkbox"/> I had difficulty with the instructions for the medicines <input type="checkbox"/> I was not always around with the child <input type="checkbox"/> I was too busy and forgot <input type="checkbox"/> I did not want others to see <input type="checkbox"/> I had trouble with timing or giving the doses on time <input type="checkbox"/> None of the above <input type="checkbox"/> Other (specify) _____	
8. Sometimes, problems at the clinic make it difficult for families to give these medicines every day. Have any of these things been a problem for you: <input type="checkbox"/> There was no money to purchase medicine (if not offered at AMPATH) <input type="checkbox"/> The medicine was not available in the pharmacy. Which medicine? <input type="checkbox"/> ARVs <input type="checkbox"/> Septrin <input type="checkbox"/> Other (include abx) <input type="checkbox"/> We finished or ran out of the medicines <input type="checkbox"/> Other (specify) _____ <input type="checkbox"/> None of the above	
We are now going to ask you a few questions about missing doses. What we mean by a "dose" is any of the medicine that the child is supposed to take in the mornings or evenings. If the child took his/her medicines in the morning but missed even one medicine in the evening, then he/she would have taken one dose and missed one dose. If the child missed any of the medicines in the morning and missed again in the evening, he/she would miss two doses. If you have questions about doses, please ask as we go along.	
9. In the past week, a. On how many days did the child miss at least one dose? <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> Don't know b. On how many days did the child take a dose more than an hour late? <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> Don't know c. How many extra doses or syringes of medicine did the child take? _____ <input type="checkbox"/> Don't know	
10. How many doses of medicine has your child missed in the last month? _____ <input type="checkbox"/> Don't know	