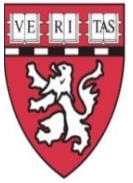




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Social Support Through Observational Trial Participation

Evidence from a Longitudinal HIV Adherence Study in Southwest Uganda

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Disclosures

- Funding from the U.S. National Institutes of Health (R21 AI108329) to conduct a study on the ethics of electronic adherence monitoring in Mbarara
- No financial conflicts of interest

Background

- Social Support: Delivery of psychological and material resources from others in one's social network
- Key factor in ART adherence
 - Bangsberg DR, Deeks SG, *Annals of Internal Medicine* 2010
 - Abimanyi-Ochom J , Lorgelly P et al. *AIDS Care* 2013
 - Takada S, Weiser S et al, *Annals of Behavioral Medicine* 2014

Motivation for Participation

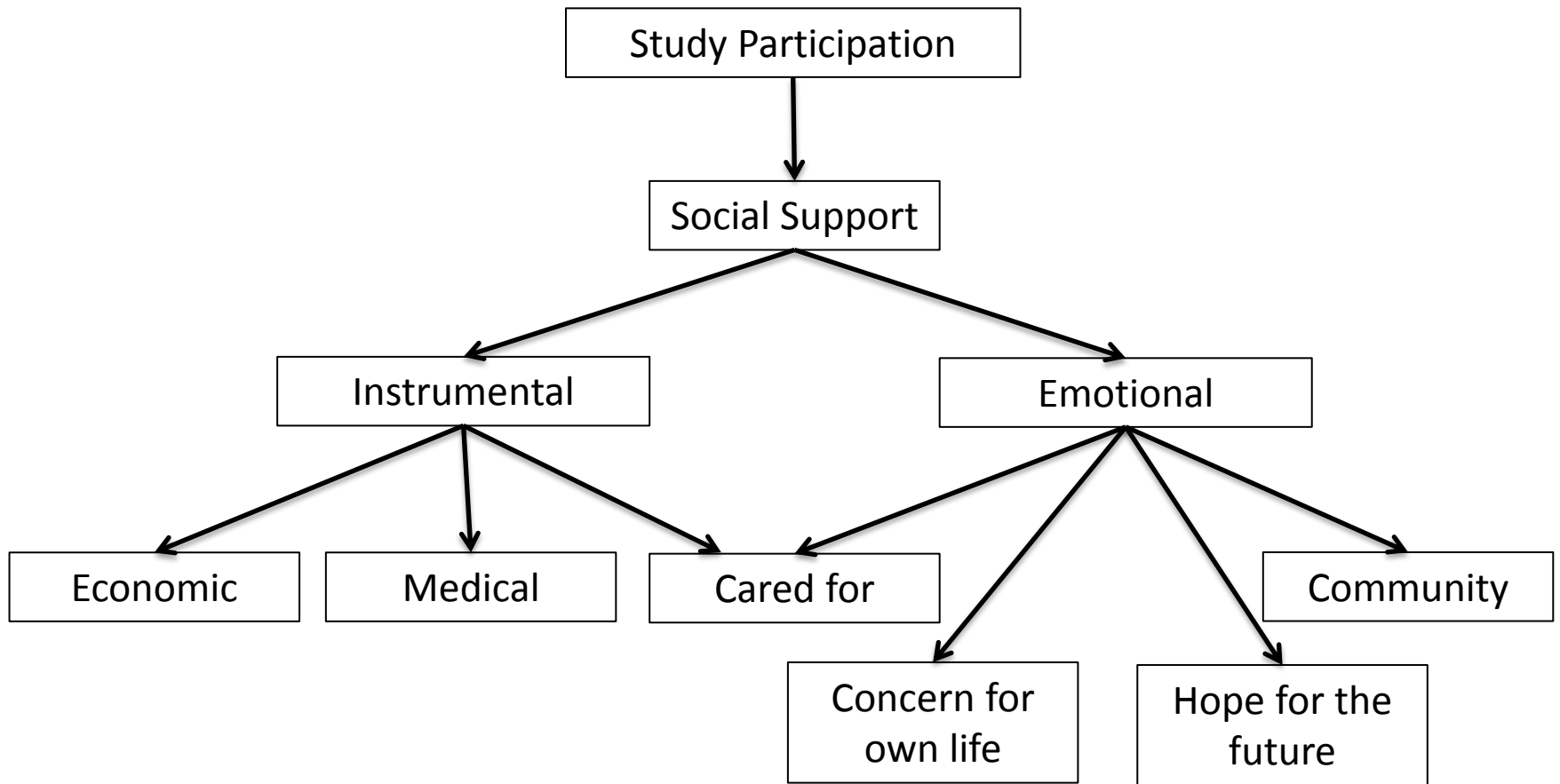
- Limited understanding of social support gained through participation in clinical trials
- Limited understanding of how this affects trial participation
- What are the motivators?
 - Altruism
 - Access to medical resources
 - Perceived improvement in quality of care

Methods

- Qualitative study about experiences of electronic monitoring
- Semi structured interviews (N=20)
 - Social support through participation in research
 - UARTO likes and dislikes
 - How social support affects adherence
- Data coded by study team
- Limitations



Overview of Findings



Instrumental Support

Incentives

- Soap
- Sugar
- Breakfast
- Transportation

Economic Support

- Collaborative savings

Medical

- Motivation to adhere
- Counsel
- Transport
- Medication Delivery

*“They give us **soap**, **transport**; they give us **breakfast** because we come early...Breakfast is something that **encourages us to come...** you will not go back worried about refunding it.”*

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*“Being involved in the study has **helped me to associate with others...** if [a study participant] has no transport we provide it from the **pool of money** that we contribute per month.”*

Instrumental Support

Incentives

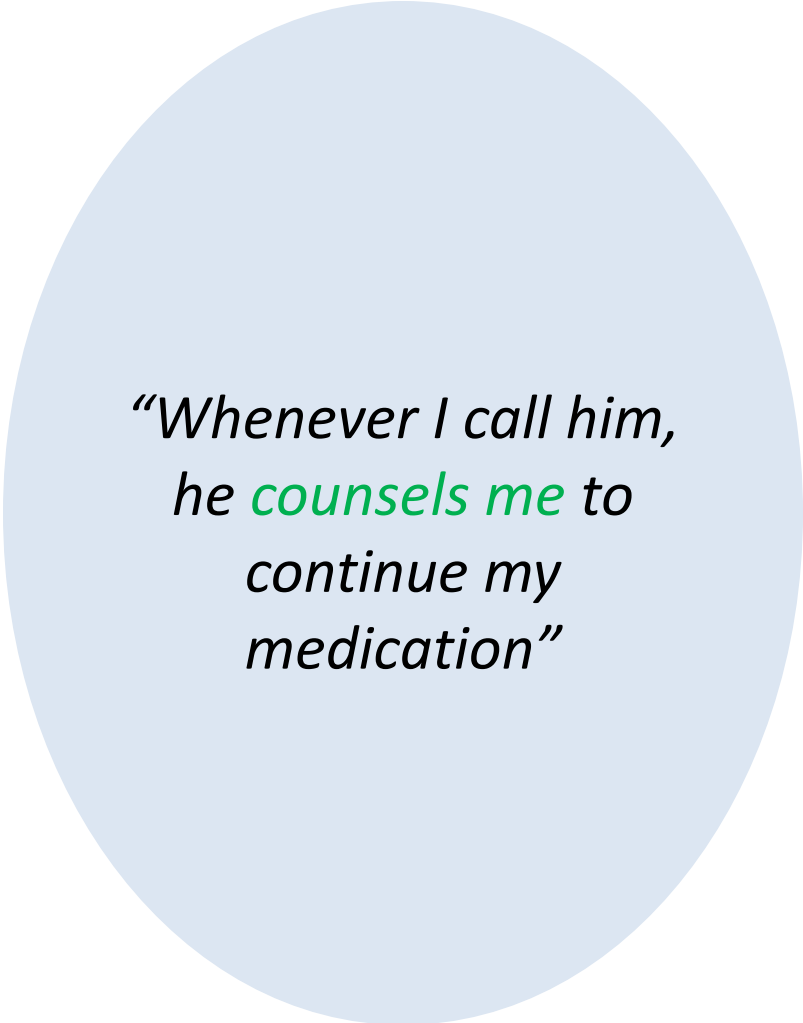
- Soap
- Sugar
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Economic Support

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*“Whenever I call him,
he **counsels me** to
continue my
medication”*

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*“He took me to the clinic... he took me back home. He told me that he would **bring me drugs and the results after.** If I had not enrolled in the study **I would not have met** someone like [research assistant].”*

Emotional Support

Community

- Remove stigma barriers
- Shared experience
- Advice and council

Self Worth


- Concern for own life
- “Courage”

Sense of importance

- “Care”
- Follow-up

Awareness

- Lack of isolation
- “Hope” for the future



“When I share my worry with other participants on the bench they encourage me and advise me on how I can increase my CD4 count”

Emotional Support

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Self Worth

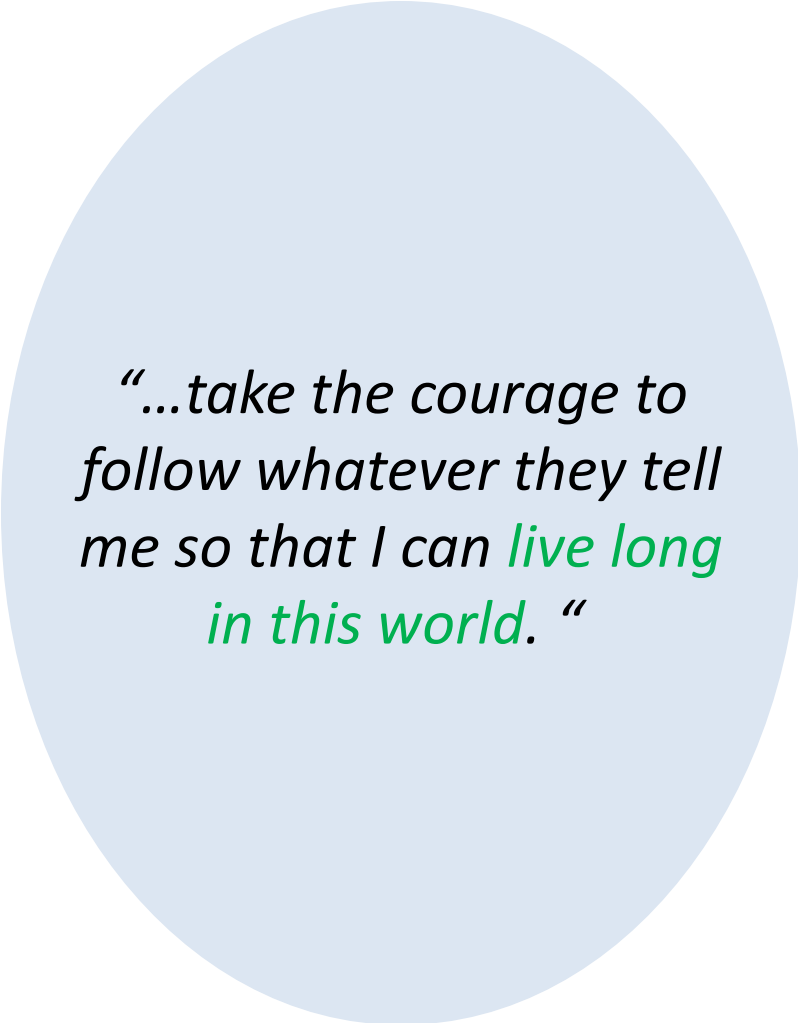
- Concern for own life
- “Courage”

Sense of importance

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Awareness

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*“...take the courage to follow whatever they tell me so that I can **live long in this world.**”*

Emotional Support

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Self Worth

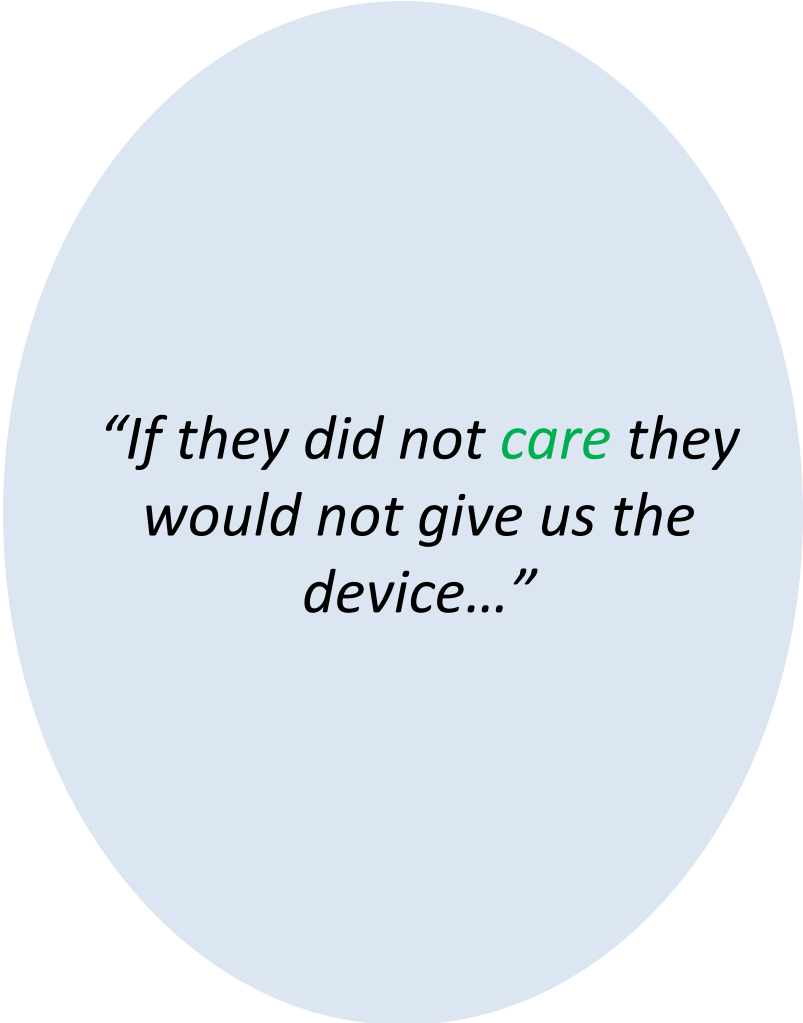
- Concern for own life
- “Courage”

Sense of importance

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Awareness

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*“If they did not **care** they would not give us the device...”*

Emotional Support

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- Advice and council

Self Worth

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- “Courage”

Sense of importance

- “Care”
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Awareness

- Lack of isolation
- “Hope” for the future

*“If you researchers do not keep us close we may feel **out of place and isolated** and this can cause us to be in self denial but if you keep us close we can have **hope for the future**”*

Feeling “Cared For”

“When someone is following up how you take your medication you see that someone really cares about your life which is a good thing.”

Conclusions

Important emotional and instrumental social support emerged through participation in a longitudinal cohort study

- Contact with staff inevitable and inherent part of study design
- Unintended relationships emerged as result of study participation
- Social support may have played important role in study participation and retention

Ethical Questions

- Should researchers strive to maintain distance from participants in order to preserve an “observational relationship” in longitudinal, observational studies?
- Does unintentional provision of social support unduly incentivize research participation?
- What are our ethical responsibilities to our research populations as we close our studies, specific to social support?

Thank You

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