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
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
UARTO

- Ugandan AIDS Rural Treatment Outcomes
- Longitudinal, observational study with a cohort of ~ 750 participants
- ART Adherence monitored electronically
- Frequent contact with research staff every 3-4 months
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

Study Participation

Social Support

Instrumental
- Economic
- Medical
- Cared for

Emotional
- Concern for own life
- Hope for the future

Community
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.”
Instrumental Support

Incentives
- Soap
- Sugar
- Breakfast
- Transportation

Economic Support
- Collaborative savings

Medical
- Motivation to adhere
- Counsel
- Transport
- Medication Delivery

“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
- Breakfast
- Transportation

Economic Support
- Collaborative savings

Medical
- Motivation to adhere
- Counsel
- Transport
- Medication Delivery

“When ever I call him, he counsels me to continue my medication”
Instrumental Support

Incentives
- Soap
- Sugar
- Breakfast
- Transportation

Economic Support
- Collaborative savings

Medical
- Motivation to adhere
- Counsel
- Transport
- Medication Delivery

“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

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

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

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• 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

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

“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”
“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

- All study participants
- UARTO Study Team
- Dan Wikler, PhD
- Norma Ware, PhD
- David Bangsberg, MD, MPH
- US NIH funding (R21AI108329 and R01MH054907)