Qualitative Analysis Of Factors Influencing Adherence Of Pediatric Patients To ARVs In Rural Uganda

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June 5, 2012

Background

- Children face more years of adherence than adults and this happens during important years of their development
  - High levels of adherence are paramount to achieve and maintain good clinical outcomes
- Studying pediatric adherence necessitates analyzing the child's social network
  - Including the caregiver, family, and community

Social Networks and Health

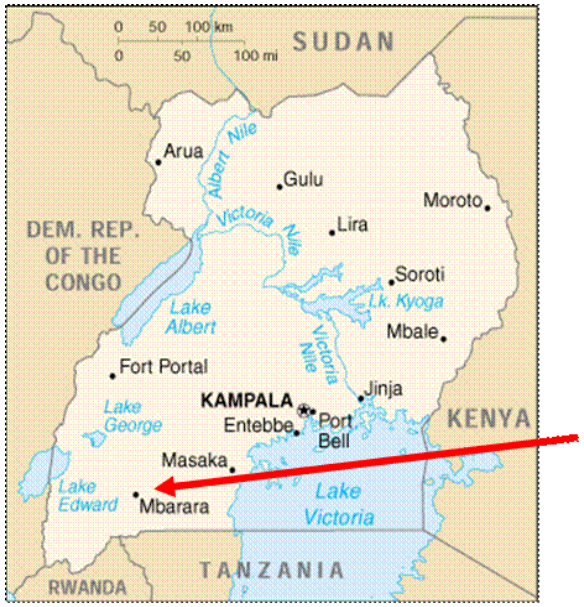
- Social networks affect health
  - Socially isolated individuals are at greater risk of negative outcomes
  - Health of caregiver can impact health of the patient
  - Disability/illness in children affects parental health
- Increased social capital is associated with better ART adherence in adult patients
  - Qualitative interviews with ~250 patients in Uganda, Nigeria and Tanzania
  - Increased social support allows patients to overcome barriers to adherence
  - Adherence seen as a social obligation to repay support

Smith, Annu. Rev. Sociol. 2008; Holtgrove, Sex Transm Infect, 2003; Pronyk, Soc Sci& Med, 2008; Ware, PLOS Med, 2009

Qualitative pediatric study

- Overview:
  - Qualitative interviews of 35 caregivers of children taking ARVs in rural Uganda in 2011
- Our hypothesis:
  - The caregiver's social networks and the nature of the caregiver-child dyad are strong determinants of ARV adherence behavior

Location of Study



- Mbarara, Uganda
  - Southwestern Uganda
  - 275 km from Kampala
  - Population ~100,000
- Immune Suppression Syndrome (ISS) Clinic
  - Mbarara University of Science and Technology
  - Children's HIV/AIDS Clinic sees several thousand children annually, with ~900 on ARVs
  - Free ART is provided through PEPFAR and the Uganda Ministry of Health

Participant characteristics

- Participants in prior cohort studies
  - CHildren's ART Adherence (CHARTA)
  - Pediatric Real-Time Adherence Monitoring (PedRAMS)
- Participants:
  - 46 children (42% female; 58% male)
  - Median age: 7 years
- Median adherence by Wisepill was high (91.7%)
- Half had detectable viremia (defined as >1000 copies/ml) and half did not (<1000 copies/ml)
- Periodic gaps in adherence were common

Haberer, PLoS, 2012

Methods

- Participants:
  - Caregivers of 35 PedRAMS participants
  - 17 children with detectable viral load (>1000 copies/ml)
  - 18 children with undetectable viral load (<1000 copies/ml)
- Interviews:
  - Qualitative, semi-structured interviews with caregivers lasting roughly 1 hour
- Interview topics: experience taking medications, social support, caregiver-patient relationship, barriers to adherence
- Inductive approach for data analysis

Results

- 8 categories of influencing factors identified:
  - Lack of resources
  - Informal support
  - Formal support
  - Coordination of efforts
  - Child takes responsibility
  - Caregiver sacrifice
  - Improvement in health after starting ARVs
  - High hopes for the child

Lack of Resources

- Lack of money and poor access to food and transportation are interrelated social determinants of health.
  - “The problem now is that the food he wants he cannot get it because I do not work and I can not afford to give him the chapattis he wants. So when I went to hospital they told me he had lost weight.”
  - “Yes I am in need, but everything comes back to money. [My child] can be sent away because of school fees if I don’t have money in the house. … I have to borrow money so that [he] has something to eat. … Even if its sugar or transport to clinic, it all revolves around money.”

Informal Support

- Caregivers receive help in the form of money, food, transportation or childcare from family, friends, or neighbors.
  - “I have only one sister and whenever I call and I tell her I am doing badly, she also says that’s also the situation at her home. … When I tell her that the child is sick and I have no money for hospital, then she is able to help me out.”
  - “My neighbors, I told them [the child’s] problem … so that when I am away and … if he gets a problem, they could rush him to hospital, tell the doctors the mother is not around and that he is on tablets.”

Formal Support

- Caregivers receive help—mostly loans—from an "institution" in the community: (a) "loan clubs," (b) banks/microfinance, (c) shops, and (d) motorcycle riders. Also includes NGO's, religious organizations, and HIV support groups.
  - "Sometimes when they are to sleep hungry it becomes that I just have to go and get a quarter of posho at the shop on credit."
  - "It is a loan club where we keep money and contribute 5000 USh (~$2) per month and you borrow in case you want to borrow and put interest. It is even registered, so it's the one that helps."

Coordination Efforts

- Coordination takes at least the following forms: (a) communication between individuals in the household about the child's medicines; (b) multiple individuals working together to give the child ARVs; (c) concurrent dosing

  - "All the family knows because I did not want to hide it from them since that would make them not give him his medication. Even when I have gone somewhere, I call and inquire whether he has taken the medication. He takes it at 7 am and 7pm."

  - "Well, sometimes we remind each other, sometimes I tell her and other times she asks if she should get for me so that we swallow at the same time, and we keep the medicine in a bag above the cupboard."

Child Who Takes Responsibility

- Children taking initiative in their own medical care by (a) reminding the caregiver of dosing times, (b) taking medication by themselves, or (c) going to clinic themselves.
  - “Even if I haven’t yet remembered to give him the medicine, for him he knows he is supposed to take the medication at that time. He calls me, ‘mummy surprise’ then I know he wants to take his medication.”
  - “No, she has no problem taking the medication, she takes it at 7;30 in the morning and in the evening. And even when I am not there, she knows the time she is supposed to take it and takes it. I give her excellent if I am to give marks.”

Caregiver Sacrifice

- The caregiver refers to the central role s/he plays in the child's treatment and the sacrifices s/he has made for the child and includes stigma.
  - "At first, there was a lot of discrimination. … Those days when I didn't know what she was suffering from, people even told me to let the child die … And I told them 'go home, and when she is dead I will bring you the body. But until then, I am going to stay with her in the hospital.'"
  - "If [the food we have] is not enough then the child has to eat first, then me I will see what to do."
  - "[Looking after the boy] has not been easy, and it still is not, but I have committed my life to it, and I cannot abandon it. … I mean that whatsoever needs to be done for the boy, I must do."

Improvement in child's health after ARV initiation motivates adherence

- Caregiver recounts the "Lazarus Effect" – the patient was sick but has dramatically improved with ARVs – and how that has positively influenced their views of the importance of ARVs.
  - "From her past I suffered a lot with her because she was doing very badly so it happened to stick in the back of my mind that at 8:00 she has to take medication, and I don't want her to go back as how she was before."
  - "Because when I tested him in 2005, he had not reached the level of taking ARVs, and then he started taking them and has lasted this long. What if he had not been taking them? I don't think he would be still alive."

High Hopes of Child

- Caregiver holds the child in high regard and has high hopes for the child's future.
  - "The only prayer I have is that I could change him to a better school with higher standards so that he can be someone of importance in future. … I worry about him a lot more than his other brothers. The good thing is he is very bright."

Conclusions

- Participants faced significant obstacles to ARV adherence and adequate care
- Obstacles were overcome with support from the family as well as community members and institutions
  - Obstacles in care often required coordination between several individuals
- The importance on which caregivers placed ARV adherence was influenced by several factors:
  - The quality of patient-caregiver relationship, Lazarus Effect, and how the caregiver viewed the child's future
- Many children take an active part in their care
  - This effect may be positive or negative depending on the child

Future Directions

- Determine if topics can be used to distinguish between the children with and without viral suppression
  - Formal support
  - Coordination of care
- Conduct additional interviews, focusing on:
  - Social support and the caregiver-child dyad
  - How children taking responsibility for their own care effects adherence
  - Mobile technology's role in coordinating care

Thanks To

- The caregivers, children, and their families
- My advisors:
  - Drs. Julius Kiwanuka, Jessica Haberer, Norma Ware, and David Bangsberg
- My research team:
  - Flavia Ninsiima, Edgar Kamusiime
- The MUST Research Collaboration personnel
- Everyone at the ISS Clinic