An SMS Support Group to Improve Adherence to PMTCT and Early Postnatal Care in a Resource-Poor Country

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Objectives

• **Background:**
  – Provide an understanding of the needs for support of women participating in programs for prevention of mother-to-child transmission (PMTCT)
  – Use of SMS in resource-poor countries

• Describe a unique “SMS support group” and our experience to date

• Plans for the future
Prevention of Mother to Child Transmission

- HIV prevalence rate among pregnant women in South Africa: 30%
- Natural HIV transmission rate from mother to child: 30% - 50%
- Transmission rate with optimal “PMTCT”: < 1%
The PMTCT cascade

Pregnancy
- Access antenatal care
- HIV testing
  - If positive, CD4
    - Return for result
      - Initiate treatment
        - Take medicines
          - Delivery
            - Mother
              +/- HAART
              At 6 weeks:
              - CD4
                - Exclusive breast feeding
                - Family planning
                - Appropriate follow up
            - Baby
              - Nevirapine
              - PCR
... and then there’s “positive” prevention

- Between 1/3 and 1/2 of male partners are HIV negative
- Risk of HIV transmission is increased in pregnancy
- Women are often unable to disclose their HIV status to their partners
  - Stigma
  - Fears of violence, accusations of infidelity, abandonment
Support Groups

Benefits
- Information and improved understanding
- Support
- Sharing of experience

Barriers
- Scheduling
- Transportation
- Staffing and space shortages
- Stigma and concern about confidentiality
Women & Health
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The Impact of Structured Support Groups for Pregnant South African Women Recently Diagnosed HIV Positive
Jonathan P. Mundell a, Maretha J. Visser b, Jennifer D. Makin a, Trace S. Kershaw c, Brian W. C. Forsyth d, Bridget Jeffery a & Kathleen J. Sikkema e
Participation in support groups

- 361 invited to participate in support group
- 144 (40%) chose to participate
- 78 (54%) attended at least half the sessions
Disclosure to partners

Significant improvement in
- active coping
- self-esteem
South Africa: Number of cell phones / 100 individuals

International telecommunications Union, 2012
In South Africa, use of cell phone technology

- Appointment reminders
- Increasing HIV testing
- Improved data management
Number of texts sent / received per day by age group (USA)

Based on adults who use text messaging on their cell phones

Mean texts per day  Median texts per day

18-24: 50  109.5
25-34: 41.8
35-44: 25.9
45-54: 14
55-64: 9.8
65+: 4.7

Pew Internet & American Life Project
Project Zumbido

Collaboration between:
- SMS Foundation (& ZygosHub)
- University of Pretoria
- Yale University

Aim:
- Evaluate the feasibility and potential benefits of a support group using SMS to:
  - Address topics relating to pregnancy, HIV and PMTCT
  - Provide support
Group SMS technology
Support Group Intervention

• Participants
  – Pregnant (18-32 weeks)
  – Comfort with English

• Clinician
  – Educate about pregnancy, HIV, PMTCT
  – Emphasize importance of adherence
  – Correct misconceptions
  – Answer questions

• Peer mentor
  – Share advice and experience
  – Provide support
Data Collection & Analysis

- Implementation notes
- Record of messages analyzed:
  - Quantitative for patterns of use
  - Qualitatively for themes
- Follow-up interviews
  - Barriers to feasibility
  - Acceptability / satisfaction
RESULTS: Patterns of Use

- 7 participants (& clinician and mentor)
- 12-week group
- 1018 messages
- Waxing and waning
- Varying participation
  - 5 active
  - 1 withdrew
  - 1 “listener”

Number of SMS Messages Sent By Week

- WEEK 1: 24
- WEEK 2: 17
- WEEK 3: 139
- WEEK 4*: 274
- WEEK 5: 80
- WEEK 6: 75
- WEEK 7: 153
- WEEK 8: 34
- WEEK 9: 56
- WEEK 10**: 14
- WEEK 11: 72
- WEEK 12: 84
Content of messages

- HIV / PMTCT
- Health and pregnancy
- Supportive interactions
- Relationships
- Other personal
## RESULTS: SMS content

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>THEME</th>
<th>%</th>
<th>TOPICS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Information</td>
<td>HIV/PMTCT</td>
<td>32.0</td>
<td>• ARVs/HAART</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• CD4</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Safe feeding</td>
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<td></td>
<td></td>
<td></td>
<td>• HIV myths</td>
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<tr>
<td>Health &amp; Pregnancy</td>
<td></td>
<td>18.6</td>
<td>• Pregnancy</td>
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<td></td>
<td></td>
<td></td>
<td>• Specific Problems</td>
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<tr>
<td>Psychosocial Dialogue</td>
<td>Supportive Interaction</td>
<td>22.5</td>
<td>• Check-ins</td>
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<td></td>
<td></td>
<td>• Prayers</td>
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<tr>
<td></td>
<td>Relationships</td>
<td>14.2</td>
<td>• Disclosure</td>
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<td></td>
<td></td>
<td></td>
<td>• Partner testing</td>
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<tr>
<td></td>
<td>Other Personal</td>
<td>9.4</td>
<td>• Reaction to diagnosis</td>
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<td></td>
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<td>• Employment</td>
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</tbody>
</table>
Medical Information: PMTCT

**Purple:**

So wen yr cd4 count is above 200 yr baby can be negative.

**Clinician:**

at any CD4 count, baby may be neg. but AZT=med to help baby stay neg. HAART=3meds to help mom get healthier/increase CD4s AND help baby stay neg.
Medical Information: Myth

Bear:
It's true dat when u a eating ice 4 da whole 9months u'l be shakeing n feeling cold.
Suzuki:

thanks guys it is so good to be in a good family like this one. Love you all
Joy:

Im not convince enough dat im positive. De last tym, me n my hubby tested negetive. So now i want de hospital to give me the results from lab. I dont trust that thngs of them dat they use. Do u trust them?
Results: Interviews

• 5 completed (4 participants + mentor)
• Overall satisfaction
• Themes
  • Connectedness
  • Increased HIV knowledge
• Stigma and time constraints
  • Would have declined traditional support group
  • Difficulty conducting focus group/interviews
Results: Other notes

- Recruitment
  - All had prior experience with mobile phones
  - Only one not eligible due to limited English
- Technology
  - Software/set-up ran smoothly
  - Problem with handsets
  - Difficult to address remotely
- Monitoring
  - Time intensive
  - Lack of control
Conclusions

• Feasible
  • Technology worked well
  • Ubiquitous use of mobile phones

• Acceptable
  • Message volumes and content
  • Participant satisfaction
Conclusions

(1) Capacity to address PMTCT
   • Medical information
   • Psychological dialogue and support

(2) Decreased social isolation

(3) Overcome typical barriers to support
   • stigma/confidentiality problems
   • transportation and time issues
   • staffing remained an issue
Next steps

• Scale-up
  • Local telecommunications partner
  • Structure / staffing alterations
• Assessment of efficacy with randomized controlled trial:
  ▪ Adherence to PMTCT and early care
  ▪ Disclosure to partners and partner testing
• Cost analysis
“While the use of mobile phones among the world’s poor is prevalent for personal and business use, its potential use for health care is hampered only by an absence of imagination and a failure to act.”

Carole Leach-Lemens

HIV & AIDS Treatment in Practice
Proportion of persons achieving at least 90% adherence with SMS reminders over one year

Q1 Q2 Q3 Q4 Overall

P<0.05

Weekly
Daily
Control