Amagugu

A family-centred, lay-counsellor driven, developmentally sensitive maternal HIV disclosure intervention for primary school-aged children

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UNICEF ECD Knowledge Building Seminar
Introduction

- Sub-Saharan Africa has one of the largest populations of HIV-infected parents globally (Hosegood et al. 2009; UNAIDS, 2013).
- As access to HIV treatment continues to increase in the region, growing numbers of HIV-infected parents are surviving to raise their predominantly HIV-uninfected children (Filteau et al. 2009; Granisch et al. 2009; McNally et al. 2006).
- HIV-infected parents need support to raise their HIV-exposed, but uninfected, children who face many risk factors associated with parental ill health and hospitalization (Qiao et al. 2011).
- Family context is often compounded by stigma, and a lack of adequate health care and support networks (Rochat et al. 2010; Vallerand et al. 2005).
- Where household burden of HIV is high children are likely to be socially exposed to HIV at much younger ages than in non-epidemic areas, and there is evidence that non-disclosure may have negative effects on them.
Benefits of HIV disclosure to children

Benefits of disclosure by HIV-infected mothers to uninfected children extend beyond the disclosure itself, including:

**Maternal Benefits:**
- Improved social support and family cohesion (Hawk, 2007)
- Less stigma and secrecy (Qiao, 2013)
- Improved parent-child relationships (Murphy, 2008)
- Lowered maternal depression and anxiety (Murphy 2011; Qiao, 2013)
- Improved compliance with health care and response to treatment (Hawk, 2007)

**Child improvements:**
- Improved custody and emergency care plans (Asander 2004)
- Less emotional and behaviour difficulties as compared to controls (Qiao, 2013)
- Further, when disclosure does not take place, or only occurs after periods of illness, children have greater emotional and behavioural difficulties
- As a result WHO guidelines released in 2012 supporting HIV disclosure to infected and uninfected children aged 6-12 years.
Problem statement

• Disclosure of one’s own HIV status, whether to partner, children or families, presents many psychosocial challenges, but also offers potential to increase support for oneself

• Despite these reported benefits, rates of disclosure remain relatively low globally and there is a paucity of interventions appropriate to low-resource, HIV endemic, settings.

• Where household burden of HIV is high children are likely to be socially exposed to HIV at much younger ages than in non-epidemic areas, and there is evidence that non-disclosure may have negative effects on them

• Primary schools years present developmental opportunities and challenges and often coincide with parental illness or initiation of treatment

• Disclosure serves as a gateway for improving/strengthening parenting support for the child
**Proposed Mechanisms**

- HIV diagnosis
- Stigma
- HIV non disclosure
- Avoidant coping
- Withdrawal isolation
- Lower family functioning
- Behavioural problems
- Parenting responses
- Mental distress
- Lower health engagement
- Child development (mental health)
- Quality of parent-child relationship
- Maternal health (HIV; mental health)

**ECD Knowledge Building Seminar 25 -26 November 2015 (© Author(s) of this presentation)**
Session 1 Positive Parenting (one-on-one counselling)
Purpose: Psycho-education on disclosure, assess readiness
Tools: Intervention steps poster and calendar

Session 2 Positive families (counsellor facilitated family meeting)
Purpose: Family awareness, family communication
Tools: Family tree with illustrated stickers

Session 3 Positive life stories (one-on-one counselling)
Purpose: Supportive counselling, emotional containment
Tools: My life/love and HIV storytelling tools

Session 4 Positive practices (one-on-one training session)
Purpose: Training on disclosure steps, prepare for child questions
Tools: HIV body map, playing cards, disclosure hand, story book

Session 5 Positive planning (one-on-one training session)
Purpose: Training on health promotion and care planning
Tools: Clinic check list, My care circle

Session 6 Positive futures (one-on-one training session)
Purpose: Training on developmental play, play for communication
Tools: “Uthando” dolls

Stage 1 – address avoidant coping, engage family support
Avoidant coping

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Stage 2 – address mothers mental distress and train for disclosure
Mental distress

Session 3 Positive life stories (one-on-one counselling)
Purpose: Supportive counselling, emotional containment
Tools: My life/love and HIV storytelling tools

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Purpose: Training on disclosure steps, prepare for child questions
Tools: HIV body map, playing cards, disclosure hand, story book

Stage 3 – Support mother driven healthy parenting behaviours (active coping)
Mother-led disclosure

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Purpose: Training on health promotion and care planning
Tools: Clinic check list, My care circle

Session 6 Positive futures (one-on-one training session)
Purpose: Training on developmental play, play for communication
Tools: “Uthando” dolls

Mother-led clinic visit

Mother-led custody plan

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5 year research programme

Design and feasibility
n=25 (2010)

Process evaluation
N=281 (2010-2012)

Randomised control trial

Maternal HIV disclosure to young HIV-infected children: an evaluation of a family-centred intervention in South Africa

Tamsen J. Rochat**, Adriane X. Arteche*, Alan Stein*, Nombulelo Dlwana** and Ruth M. Blaize*†

**Background: Sub-Saharan Africa has large populations of HIV-infected parents and is seeing a rise in these HIV-infected children. This research evaluated the ‘Amagugu intervention’ around supporting mothers to disclose their HIV status to their HIV-exposed children.

Methods: Process evaluation included semi-structured, face-to-face interviews with a subset of the 25 participating mothers who had undergone the intervention. An ethnographic approach was used to conduct 12 in-depth semi-structured interviews with the mothers, and to observe and record the events in the intervention group.

Results: Six core themes emerged from the interviews: faith and beliefs, the impact of the intervention, the support system, the social environment, the child's perspective, and the need for further support.

Conclusions: The ‘Amagugu’ intervention shows promise in helping mothers disclose their HIV status to their children. Further research is needed to evaluate the long-term effects of the intervention.

NIH clinical trial register NCT01922882

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Evaluation Results - Disclosure

• The intervention is highly acceptable, with more than 90% of mothers agreeing to participate;
• The intervention was effective with 61% of mothers disclosing 'fully' using the words 'HIV' and explaining that they have HIV or disclosing 'partially' (39%) using the word 'virus' and explaining that they have this virus.
• Mothers reported that most children reacted calmly to ‘full’ (79%) or ‘partial’ disclosure (83%).
• Compared to ‘partial’ disclosure ‘full’ disclosure was associated with more children asking questions about maternal death (18% versus 8%).
Evaluation Results:

• Post intervention, there was a significant decrease in maternal mental health problems, both for low and high cuts of depression although less significant for higher cut off; and significant decrease in parenting stress.

• Post intervention, there was a significant decrease in child mental health problems, both for internalizing and externalizing disorders, including significant decreases in Anxious-Depressed, Withdrawn-Depressed, Aggressive Behaviour and Rule Breaking syndromes. Moderate to large effect sizes were observed.

• Since the majority of children showed mental health improvements following the intervention, regardless of disclosure type, these benefits are likely accounted for, not only by the HIV disclosure itself, but also by the broader intervention with its focus on improving parenting skills and communication with children.
Trial implementation

Recruitment/follow up complete

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<th>Clinic</th>
<th>Total Recruitment</th>
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<tr>
<td>Total</td>
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<tr>
<td>KwaMsane</td>
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<tr>
<td>Sipho Zungu</td>
<td>110</td>
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<tr>
<td>Mtuba</td>
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<td>Somkele</td>
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Intervention dose

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Total randomised 235
- Never initiated: 10
- Completed to this session study close out
- Linear (Completed to this session study close out)