

# Forecasting an empowered care force that matches children's developmental needs

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# Three key components

1. Caregiver stress and mental health

2. Early years

\*First 1000 days – core caregiving capacities to enhance cognitive and emotional development, and attachment

3. Beyond early years

\*Communication which makes sense of the world they are living in

\*What is communicated matches children see

# Caregiver stress and mental health

- \* Rumination is a state of narrowed attention in which one's mind is dominated by recurrent intrusive thoughts which are difficult to dismiss and when dismissed recur. It is characteristic of depression.

# Rumination

- Recurrent intrusive negative thoughts which are difficult to dismiss
- Result in narrowed focus of attention

# Profound impact on attention and responsivity

- \* These cognitive processes form a load which affect an individual's capacity to attend and respond to the external world
- \* ↓ problem solving
- \* ↓ speed of performance

# Attentional control

- \* Co-ordinating process that directs attention
- \* Guides attention allocation to what is important
- \* Inhibition of competing stimuli (distractors)

# Enhancing caregiver capacity

- \* Three core caregiving capacities which are critical for:
- \* Cognitive Development
- \* Behaviour and emotional regulation
- \* Attachment

# Three core parenting capacities

- \* Caregiver focus of attention to child signals and associated contingent responsiveness.





# Contingent responsiveness and infant attention

- \* Caregiver contingent responsiveness to infant cues allows the infant to experience predictability of the environment that in turn guides the infant in attending and responding to environment information.
- \* The infant's ability to control attention and process information effectively is predictive of intellectual abilities.

# Infant learning

- \* Contingency important for infant development from 6 weeks
- \* By observing their parent's consistent and contingent responses to particular cues, infants learn associations between stimuli and responses

# Three core parenting capacities

- \* Emotional scaffolding, principally through warmth, consistent support, especially in stressful situations which help a child maintain emotional regulation.



# Three core parenting capacities

- \* Capacity to treat the child as a psychological agent (especially around separations)



# Each maps onto a developmental outcome

- \* Cognitive Development
- \* Behaviour
- \* Attachment

# Beyond early years

- \* Communication which makes sense of the world they are living in
- \* What they are told matches with what they see

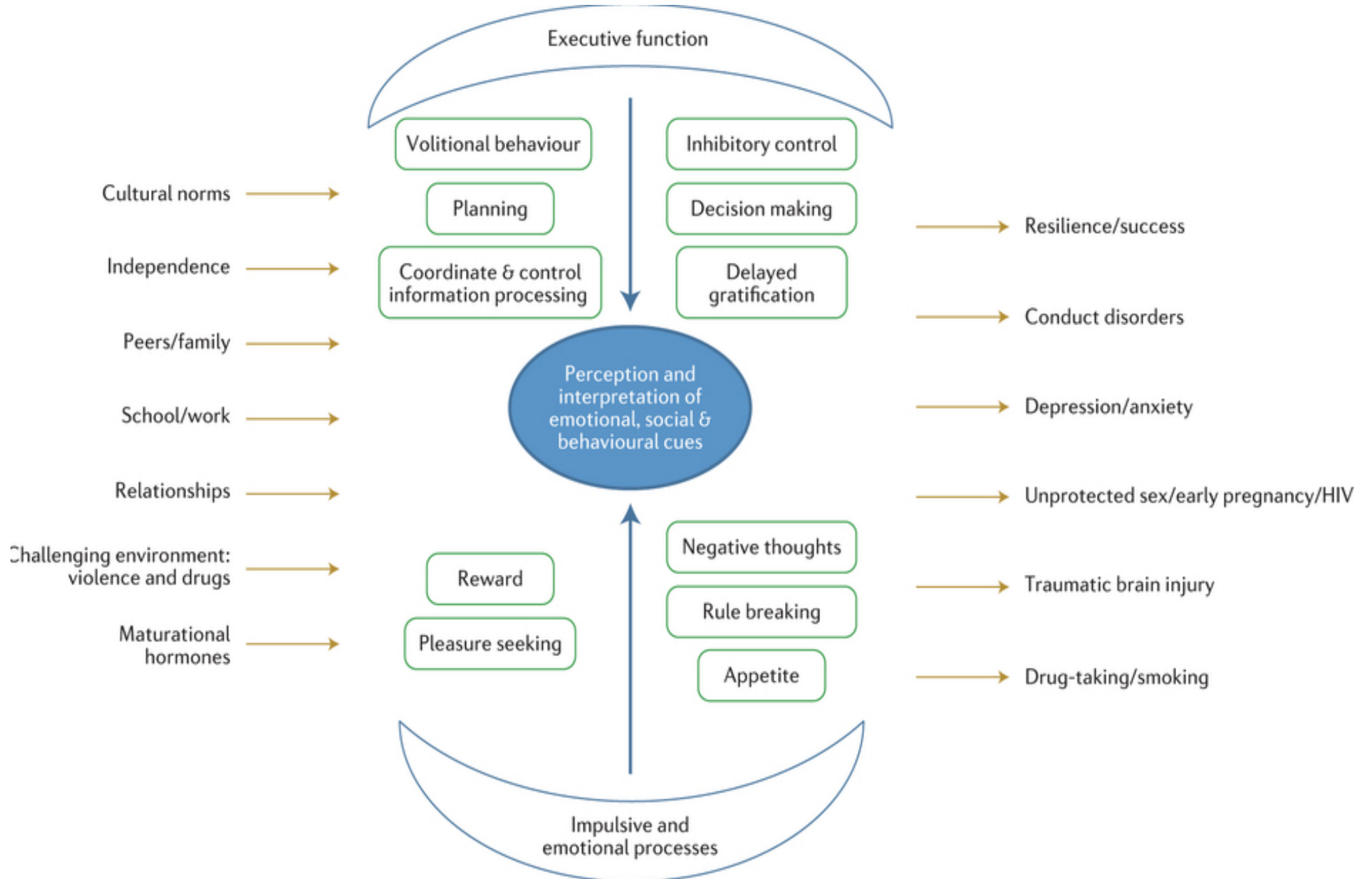
# Resilience

- \* Age appropriate support and communication is key to resilience
- \* Even young children (from 2yrs) are astute observers of things around them especially the behaviour, moods and physical state of their caregivers
- \* To build resilience children need age appropriate communication which is coherent with their observations

# Resilience

- \* This information and providing a coherent picture enables executive function, the higher order cognitive functions which allow a person to navigate their environment
- \* Importance of resilience in adversity increasingly recognised – Shonkoff et al. 2012 *Pediatrics*





## 3 to 5 year olds

- \* “Early preoperational thinking” – difficult to understand meaning of illness and death
- \* Communication through play and drawing
- \* World centres around key caregivers and children can accept substitute caregivers *especially if prepared*
- \* Eg don’t understand irreversibility of death
- \* After death need concrete details and reinforce that that the person is not coming back

# 6 to 8 year olds

- \* “Late preoperational thinking”
- \* Children understand that the caregiver will not return
- \* Develop a conscience and blame themselves
- \* E.g. an argument with a caregiver caused their death
- \* Believe that thoughts can come true
- \* Need simple explanations especially about illness or death and their absence of responsibility
- \* Engage wider network

# 9 to 11 year olds

- \* Major changes in thinking ability (concrete operational thinking)
- \* Understand cause and effect and use logical thinking
- \* Eg Understand the irreversibility of death
- \* Benefit from being involved in the care of an ill caregiver with support
- \* Need detailed information and reassurance that it's not their fault
- \* Maintain routine

# Amagugu

- \* **Investigators:** Tamsen Rochat (PI) Ruth Bland (PI) Alan Stein, Ntombizodumo Mkwanazi, Frank Tanser
- \* **Collaborators:** Mario-Cortina Borja; Adriane Arteche
- \* **Research site:** Africa Centre for Population Health
- \* **Implementation partners:** National DOH and Dlanthlani
- \* **DSMB:** Crick Lund (Chair) Nuala McGrath Conor Doherty
- \* **Donors:** Canadian International Development Agency and NIH



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# Introduction

- \* Sub-Saharan Africa has 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)

# Need for disclosure research

- \* Disclosure interventions tend to focus on *HIV-infected* children and adults, and child disclosure support often focuses on adolescents aged 12-18 years
- \* 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
- \* Increasing evidence that early adolescence may be too late to prevent risk
- \* There is a need to develop low intensity interventions suited to large scale implementation in epidemic settings

# Potential benefits of HIV disclosure to children – extends beyond disclosure itself

## **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)
- \* If 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



# Intervention aims and approach

- \* Aims of the intervention were to develop an effective HIV-disclosure intervention that:
  - \* is culturally and developmentally appropriate
  - \* is suitable for delivery by community health care workers in low-resource settings
  - \* increases disclosure among HIV-infected mothers with HIV-uninfected children aged 6-10 years
- \* Intervention approach was developed to:
  - \* be parent-driven and family-centred
  - \* allow for structure and process and provide practical tools
  - \* build a broader set of parenting skills beyond disclosure
  - \* promote and engage in HIV positive parenting
  - \* Provide a scalable training package (including manuals, materials, supervision tools, training videos)

# 5 year research programme

Design and feasibility  
N=25 (2010)

Evaluation (no controls)  
N=281 (2010-2012)

Randomised control trial  
N=465 (2013-2015)

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## Disclosure of maternal HIV status to children: considerations for research and practice in sub-Saharan Africa

Ntombizodumo B Mkwana<sup>1,2</sup>, Tamsen J Rochat<sup>1</sup>, John Imrie<sup>1,2,4</sup> & Ruth M Blend<sup>1,2,3</sup>

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Rochat et al. *BMC Public Health* 2013, 13:147  
<http://www.biomedcentral.com/1471-2868/13/147>

Spec  
Future Virology

An estimated 2.8 million children are born to HIV-infected mothers each year in sub-Saharan Africa, of whom up to 40% are likely to be HIV-exposed but uninfected. In sub-Saharan Africa up to 40% of pregnant women are HIV-infected, resulting in large numbers of HIV-uninfected children living with at least one HIV-infected parent. This article summarizes the current evidence on maternal HIV disclosure to children, explores the reported benefits of disclosure to children and mothers, highlights the gaps in knowledge and areas for future research, and discusses possible future intervention models focusing on primary school children in sub-Saharan Africa.

RESEARCH ARTICLE

Open Access

## Maternal HIV disclosure to HIV-uninfected children in rural South Africa: a pilot study of a family-based intervention

Tamsen J Rochat<sup>1</sup>, Ntombizodumo Mkwana<sup>2</sup> and Ruth M Blend<sup>1</sup>

Abstract

**Background:** As access to treatment increases, large numbers of HIV-positive parents are raising HIV-negative children. Maternal HIV disclosure has been shown to have benefits for mothers and children, however, disclosure rates remain low with between 30-45% of mothers reporting HIV disclosure to their children in both observational and intervention studies. Disclosure of HIV status by parent to an HIV-uninfected child is a complex and challenging psychological and social process. No intervention studies have been designed and tested in Southern Africa to support HIV-positive parents to disclose their status, despite this region being one of the most heavily affected by the HIV epidemic.

**Method:** This paper describes the development of a family-centred, structured intervention to support mothers to disclose their HIV status to their HIV-negative school-aged children in rural South Africa, an area with high HIV prevalence. The intervention package includes printed materials, therapeutic tools and child-friendly activities and games to support age-appropriate maternal HIV disclosure, and has three main aims: (1) to benefit family relationships by increasing maternal HIV disclosure; (2) to increase children's knowledge about HIV and health; (3) to improve the quality of custody planning for children with HIV-positive mothers. We provide the theoretical framework for the intervention design and report the results of a small pilot study undertaken to test its acceptability in the local context.

**Results:** The intervention was piloted with 24 Zulu families, all mothers were HIV-positive and had an HIV-negative child aged 6-9 years. Lay counsellors delivered the six-session intervention over a six to eight week period. Qualitative data were collected on the acceptability, feasibility and the effectiveness of the intervention in increasing disclosure, health promotion and custody planning. All mothers disclosed something to their children: 11/24 disclosed fully using the words "HIV" while 13/24 disclosed partially using the word "viral".

**Conclusion:** The pilot study found the intervention was feasible and acceptable to mothers and counsellors, and provides preliminary evidence that participation in the intervention encouraged disclosure and health promotion. The pilot methodology and small sample size has limitations and further research is required to test the potential of this intervention. A large demonstration project with 300 families is currently underway.

**Keywords:** intervention, HIV-disclosure, family-centred, Maternal HIV-disclosure

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

Tamsen J. Rochat<sup>a,b</sup>, Adriane X. Arteche<sup>c</sup>, Alan S Ntombizodumo Mkwana<sup>d,e</sup> and Ruth M. Bla

**Objectives:** Sub-Saharan Africa has large populations of HIV-infected parent need support to raise their HIV-uninfected children. This research evaluates 'Amagugu Intervention' aimed at supporting mothers to disclose their HIV diagnosis to their HIV-uninfected children.

**Design:** Uncontrolled pre- and post-intervention evaluation.

**Setting:** Africa Centre for Health and Population Studies, South Africa.

**Participants:** Two hundred and eighty-one HIV-infected women and their HIV-uninfected children aged 6-10 years.

## Maternal and child psychological outcomes of disclosure to young children in rural South Africa: the Amagugu intervention

Tamsen J. Rochat<sup>a,b,c</sup>, Adriane X. Arteche<sup>d</sup>, Joanie Mitchell<sup>e,f</sup> and Ruth M. Bla

**Objectives:** Increasingly, HIV-infected parents are surviving to raise their HIV-uninfected children, but disclosure rates to young children are low. Previously, we demonstrated that the 'Amagugu' intervention in rural South Africa, an area with high HIV prevalence. The intervention package includes printed materials, therapeutic tools and child-friendly activities and games to support age-appropriate maternal HIV disclosure, and has three main aims: (1) to benefit family relationships by increasing maternal HIV disclosure; (2) to increase children's knowledge about HIV and health; (3) to improve the quality of custody planning for children with HIV-positive mothers. We provide the theoretical framework for the intervention design and report the results of a small pilot study undertaken to test its acceptability in the local context.

**Method:** This pre-post evaluation design enrolled 281 HIV-infected HIV-uninfected children (6-10 years) at the Africa Centre for Health Studies, in rural South Africa. The intervention included six home-based sessions delivered by lay-counsellors. Psychological outcomes included: psychological functioning (General Health Questionnaire, GHQ); parenting stress (Parenting Stress Index, PSI); and child behavioural functioning (Child Behaviour Checklist, CBCL).

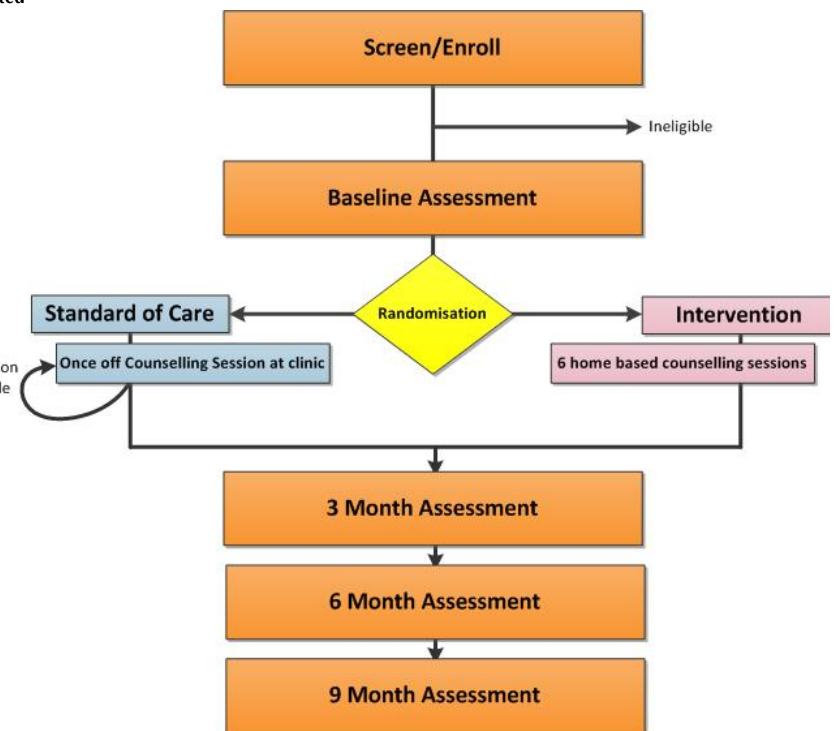
**Results:** The proportions of mothers with psychological distress (GHQ threshold at least 12) fell from 41.3 to 24.9%,  $P < 0.001$  (at least 20) fell from 17.8 to 11.7%,  $P = 0.040$ . Parenting stress scores ( $M = 79.8$ ; Post  $M = 76.2$ ,  $P < 0.001$ ) two subscales, parental distress relationship, showed significant improvement, while mothers' 'perceived difficulty' was not significantly improved. Reductions in scores were disclosure level (full/partial). There was a significant reduction in child emotional and behavioural problems (CBCL Pre  $M = 56.1$ ; Post  $M = 48.9$ ,  $P < 0.001$ ).

**Conclusion:** Amagugu led to improvements in mothers' and children's mental health and parenting stress, irrespective of disclosure level, suggesting general non-specific positive effects on family relationships. Findings require validation in a randomized control trial.

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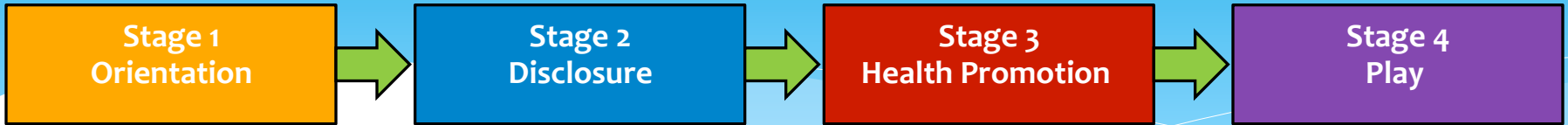
AIDS 2015, 29 (Suppl 1):S67-S79

Keywords: Africa, children, HIV disclosure, psychological, rural



NIH clinical trial register NCT01922882

# Intervention activities



Mother-led



Activity driven

# Examples of questions

Category	Questions
HIV virus related	<i>What is the “virus” exactly? Is HIV curable?</i>
Medication related	<i>Would my father still be alive if he had taken pills? Why are the baby twins taking medication, is it HIV?</i>
Transmission related	<i>Did you get HIV from other men? Will I get HIV now that you have it?</i>
Person related	<i>Is this what made my dad die? Are you going to die?</i>

# Children's questions

- \* Significant association between type of disclosure and child's question about possible death

Child's question	Full %	Partial %	OR (95%CI) p
About medication and how it works	19.3	21.8	1.17 (0.65-2.11) p=0.610
About HIV /Virus and how it works	22.8	16.4	0.66 (0.36-1.23) p=0.190
About mother's HIV/Virus transmission	15.8	15.5	0.97 (0.50-1.88) p=0.940
About mother's health care	7.6	10.0	1.35 (0.58-3.13) p=0.480
About intervention concepts	7.0	8.2	1.18 (0.48-2.90) p=0.720
About the mothers possible death	<b>18.1</b>	<b>8.2</b>	<b>0.40 (0.18-0.88) p=0.002</b>

# Amagugu Clinical Trial

- \* Funding from NIH (R01) through National Institute of Child Health and Human Development (NICHD) 2013-2015
- \* HIV positive mothers
- \* Children aged 6-10 years old

*We hypothesize that our home-based intervention, compared to the standard of care in clinic facilities, will significantly increase rates of maternal HIV disclosure and will result in improvements in health promotion, custody planning and the quality of the maternal-child relationship, emotional well-being of children and family functioning.*

# Summary of interventions

- \* **Caregiver stress/depression/anxiety**
  - \* Number of evidence based options
  - \* Behavioural activation (BA) looks promising especially in the context of HIV
- \* **Enhancing early caregiving**
  - \* Care for Child Development (UNICEF/WHO)
- \* **Combination**
  - \* Thinking Healthy Programme (Atif Rahman)
  - \* Philani Programme (Mark Tomlinson)
  - \* USAID Programmes (Lorraine Sherr Lucie Cluver)
- \* **Communicating with children from 3 onwards**
  - \* Some evidence based interventions
  - \* Gap evident

# Summary Communication

- \* Caregiver illness or family illness has a major impact on children's psychological adjustment and ability to cope
- \* Appropriate and sensitive communication is key to allow children to cope -especially meaningful explanations for the realities children observe
- \* Age appropriate communication promotes resilience and 'family' cohesion
- \* Many caregivers do this well and intuitively
- \* Principles and guidelines to support communities and healthcare workers when dealing with life threatening illness are important, where it is needed.



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