Study 1: Improving the Hospital Care of HIV+ Children

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The people at the heart of social & economic development

Child, Youth & Family Development
1. To devise a method of improving empathic care in a pediatric HIV ward, and develop a training tool for hospital staff.

2. To pilot a multi-method research approach to broaden the base of ICDP method and deepen understanding the impact of being HIV+ on child care in poor households so as to contextualising of the care niche.
1. Setting

2. Significance and project aims

3. Demonstration of ICDP

1. Background

Project 1: Points to be Covered
A Pediatric Infectious Diseases Ward in a Large Public Hospital in Durban, South Africa

Study Context:

Study 1 Background
Background: The global burden of HIV/AIDS
They are known as "dying wards" — hospitalizations under poor conditions occur — Prolonged illness and multiple breastfeeding — About 10% infected through ("mixed") Anti-Retroviral Therapy — Can be dramatically reduced with intrapartum 000 p.a.

Up to 1/3 of children vertically infected (in SA 100,000)

Background: Infected Children (SA)
Malnutrition, etc

Dermatitis

Neurological manifestations – encephalopathy

Increased metabolic rate – infections

Nutrient loss – malabsorption, diarrhoea

Reduced intake – anorexia, ulcers, thrush

Malnutrition associated with:

Diarrhoea – Rotavirus and bacteria

Background: Signs and Symptoms HIV+ child
Background: 3 Categories of Infection

Children

Category 1: Rapid progressors who die by age 1

Category 2: Children who develop symptoms (25-30%)

Category 3: Long term survivors who live beyond 8 years of life (5-25%)

Early and who die between 3-5 years of age (50%)

60%
Displaced children

Uninfected with HIV

Sick children, infected or not

Care

Children in group / institutional

Amongst others:

Very Vulnerable Children
Preparation for home 

Active feeding

Invasive procedures

Maternal preoccupation & withdrawal

Infant pain and distress

Separation

ICD-P-Informed work in hospitals

Care of sick & dying children
Children need assistance to cope

Staff distress & withdrawal

Caregiver distress, withdrawal

Painful procedures

Illness and discomfort

Strange environment

Separation from caregivers
Multiple admissions
and HIV encephalopathy
diarrhoeal disease, severe sepsis
tract infection, acute or recurrent
Failure to thrive, lower respiratory
Occupy > 60% paediatric beds
HIV infected children in Hospital
Approach to the Intervention

1. Working together to avoid blame & to
2. Create "own" solutions
3. Have a larger goal - to help other staff & caregivers while reducing risk to
4. Start from the concerns of staff

Children
Communicating and Informing

Filming in ward (+ 6 weeks)

Framing the Issues Jointly

Being frank about difficulties

Sharing expertise

Meeting to discuss issues

Working Together on the Project
Dissiminate our learning

AND

Test, describe & train

AND

Devise & discuss interventions

AND

Describe conditions, problems

Being Solution-Focused
1. Assisting from Staff Concerns
2. Reducing the pain of
   procedures
3. Active feeding
4. Preparation for return home
5. Address child distress & crying
- Can reduce pain of procedures
- Better with difficulties
- Children can be helped to cope
- Some crying is inevitable
- Caregivers
- Very distressing for staff
- Child Distress & Crying
- Touch, holding & massage
- Non-nutritive sucking
- Space/time to caregiver
- Transitional objects - comfort
- Rhythmic movement

Crying can be reduced by:
Horizotal rocking

Regular, andante (slowish)

Soothing, reduces distress

Body contact

Rhythmiccal Movement
for children

- Found to be effective soothers
- Fluffy toy
- In interventions often a doll or blanket
- At home often a soft cloth

Transitional Objects
environment

heightened attention to the

knock on benefits – better feeding

- Can reduce stress

reducing neurotransmitters

releases endorphins, other pain

nutritive

>60% of infant sucking is non-

Non-Nutritive Sucking
Massage

- Demonstrates impact on at-risk neonates, drug-addicted babies
- Decrease pain, increase alertness
- Decrease stress
- Stimulates tactile & pressure receptors
Examples - *In Situ* Solutions

1. Transitional object – the green cloth

   *A baby shows us how*

2. Massage – changing a nappy

   *A mother shows us how*
Green cloth

“Must have the green cloth”
Happy changing causes distress

Mom holds and comforts the child

Let's child put on cream (child gains some control over discomfort)

Mom rubs arms again

Wipes bottom, child protests

Mother rubs arms gently

Child has painful associations

Changing the Happy
plans
- Generates enthusiasm & leads to
- Increases motivation
- Done
- Deepens appreciation of the work
- Activates empathy for the child
- Evokes personal memories

Properties We See
Video tape

- Develop scripts, acting, complete
- Filming
- Train mothers/caregivers
- Train two nurses in massage to
- Clothes & clothing

Next Steps 1
& staff intervention-domains on children
impact of one or more of the
Set up study to evaluate the
procedures, feeding, discharge
Supporting mothers, painful
Complete all videos/audios

Next Steps
Moving toward the larger goal

- Distribute to other hospitals
- Scripted together - storytelling
- Some real sections, some accepted
- Topics of staff concerns
- Make 5 20-minute videotapes
The epidemic

Re-humanise ourselves in the face of
Promote, enable empathic care
Withdrawal

Assist caregivers & children with
Disengagement

Assist staff to cope with distress

Conclusion: The co-creation of Hope