Responsibility| Can We Leave No-One Behind?

Chair: Eunice Sinyemu, Zambia Country Director, THET

Speakers:

- Julia Downing, Professor in Palliative Care, Makerere University
- Dr Emily Padfield, A&E Clincal Fellow, Oxford Deanery
- Ruth Nalungya, Social Scientist, MRC/UVRI & LSTHM Uganda Research Unit
- Melissa Clee, Neonatal Nurse, University College London Hospital

Leaving no one behind – How knowledge of children's understanding of illness, death and dying will impact on the provision of children's palliative care in Uganda.

Downing Julia, Kemigisha Ruth, Nakayiwa Ruth, Namyeso Juliet, Ankunda Collins, Lebu Priscilla, Nabirye Liz, Ellis Judith, Namukwaya Liz, Grant Liz, Leng Mhoira

Friday 27th September 2019

Background (1)

- There is a lack of research into children's understanding of death and dying
- Important to have a deeper understanding of how children:
  - *develop their ideas;*
  - *communicate them;*
  - *act out their feelings*
- This impacts on CPC service development
- Thus improving outcomes for children and their families.

Background (2)

- Exploring children's understanding of illness, death and dying has been identified as a priority area for CPC research.

Table 4 Identified priorities for global research in children's palliative care

Order of priority	Area of research	Mean (level of importance)	% (level of consensus)
1	Children's understanding of death and dying	1.54	78.6 %
2	Managing pain in children where there is no morphine (Strong opioids)	1.61	83.1 %
3	Funding for and the cost of CPC	1.67	84.6 %
4	Training needs for CPC	1.68	82.7 %
5	Assessment of the WHO two-step analgesic ladder for pain management in children	1.72	79.4 %
5	Pain management for non-cancer children with chronic life-threatening illness	1.72	80.0 %
6	Interventions and models of care for CPC	1.76	80.5 %
6	Measuring outcomes of care	1.76	84.1 %
7	Integration of CPC into core health curriculum	1.78	79.5 %
8	Use of opioids in children	1.79	77.5 %
8	The global need for CPC	1.79	78.6 %
9	Ethical issues in CPC	1.80	75.6 %
10	Children's rights and palliative care	1.81	78.2 %
11	Understanding the needs of children and their families	1.83	79.4 %
11	Communicating with children and their families	1.83	80.2 %
11	Assessment of government support for CPC	1.83	78.2 %
12	Assessment and management of different symptoms	1.86	75.0 %
13	Models of education and training for CPC	1.89	76.2 %
14	Use of adjuvant medicines to relive pain	1.91	75.6 %
14	Non-pharmacological management of pain and other distressing symptoms	1.91	78.9 %

(Downing et al 2015)

Aim

- To explore children's understanding of illness, death and dying such that PC services in Uganda reflect this.
- To support fellows on the PC Leadership programme to undertake a national level project

Research Methods

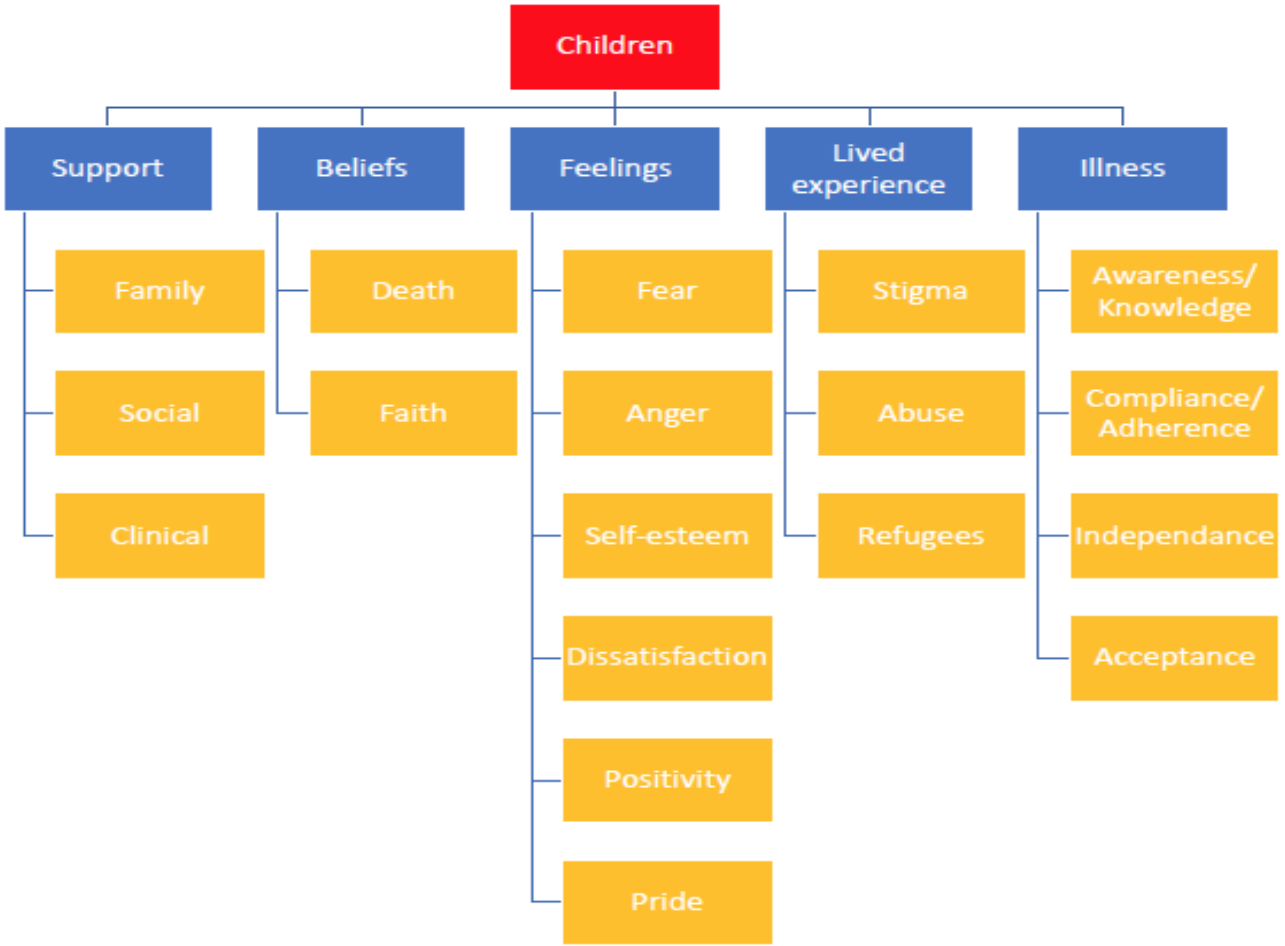
- Qualitative Research
- Semi-structured Interviews
  - *15 children*
  - *Aged 8-17 (average 13)*
  - *10 girls*
  - *3 boys*
- Language:
  - *English – 10*
  - *Madi – 5*

- Sites:
  - *Wakiso – 3*
  - *Kampala – 4 + 3*
  - *Adjumani - 5*
- Interviewers:
  - *Fluent in language*
  - *Experienced in counselling children*
- Informed consent and assent obtained
- Ethical approval was gained from HAUREC and UNCST

Analysis

- Interviews transcribed and translated as appropriate
- Themes identified and coding framework developed collaboratively by the research team
- Supported by UK and Uganda mentors and researchers from MPCU

Coding Framework



1. Support

- Family
- Social
- Clinical

"My aunt does not harass me but she gets a lot of challenges in our upkeep since we only rely on the food ration that comes on monthly basis in the refugee settlement". (C04 – 18 years)

"Am very fine am even happier than other people. I think so. As long as I have my friends around and my mum." (C10 – 12 years)

"My siblings, they have no problem, and they take care of me well" (C02 – 10 years)

2. Beliefs around Death and Faith

- Death
  - *Myths*
  - *Facts*
- Faith

"Death means very many things in someone's life. It means the person who was I your sight will never come back in your life, on earth and it's the last time you're seeing this person….. The day you bury them you let go of the memories in the brain,. Yes you might miss them but you pray they rest in peace" (C02 – 16 years)

"they don't feel pain since they are dead….. they go to heaven. I think so…. up in the sky." (C10 – 12 years)

"I fear…. I don't want to die… sometimes people die badly, accidents, and others die when they don't know what has killed them" (C06 – 13 years)

"Is it important-yes to thank God because the way I was is not the same" (C12 – 12 years)

3. Feelings

- Fear
- Anger
- Self-esteem
- Dissatisfaction
- Positivity
- Pride

"I get worried, God why is it only me with the virus, yet am still young?"
(C03 – 10 years)

"It makes me feel bad but sometimes my friends give me the work and I copy from home"
(C12 – 12 years)

"Christmas of last year was just fun. Though my father has visited me once, he gave me 200 shillings. I was still a little boy.."
(C09 – 12 years)

4. Lived Experience

- Stigma
  - *Rejection*
  - *Bullying*
- Abuse
  - *Emotional*
  - *Physical*
  - *Sexual*
- Refugees

"When I go to school children begin abusing me and telling me that I am infections and even teachers don't like me, they normally chase me away from class and even when I go for prayers I sit outside" (C05 – 9 years)

"At school, not even one tells me that I have the virus, if they knew I would feel bad" (C03 – 10 years)

"..I have spent 15 years when am well, I walk and study with it and yet many have died but me I walk with the disease. And will get more opportunities which others can't get" (C02 – 16 years)

"Sickness affects people and people do die and am in peace with them even if they abuse or use bad words for me" (C04 – 18 years)

"one time as I came to fetch water from the borehole a certain man caught me with force and that man was taken to prison… the man held my neck and I could not fight… I came and narrated the story to my mother and I was holding my underwear in my hand" (C08 – Age N/K)

"They told me when they were going to cut it off (leg), there children they don't tell so when they regain consciousness they die without knowing" *(C14 – 11 years)*

5. Issues around their illness

- Awareness/ Knowledge
- Compliance/ Adherence
- Independence
- Acceptance
- Disclosure

"My mum told me that it's for treating HIV and my mother told me that I got HIV when I was still a baby from her" see how we do. So am grateful." (C01 – 8 years)

"They tell me swallow medicine else you are gonna die. I also tell them, am gonna swallow it, I don't want to die " (C03 – 10 years)

"the doctor said that my blood vessels is like a moon shape which cannot cure… I begin feeling severe pain inside my bone and headache" (C04 – 18 years)

"No just they give me Chemo and then on Friday I go in the hospital…. Cancer ….here in the skin…. It (cancer) kills people." (C11 - 12 years)

Conclusion (1)

- Children as young as 8 are able to articulate an understanding of their life-limiting condition and its impact on them and their families.
- It is important to recognise:
  - their lived experience
  - Their need for support from different groups,
  - the impact of their own and their family's beliefs, and
  - the added stressors of being a refugee.

Recommendations/ Next Steps

CPC provision in Uganda needs to:

- take into account children's need for support from different groups;
- provide opportunities for children to explore their feelings, their lived experiences and their beliefs in a safe non-threatening environment;
- ensure age appropriate communication with children, providing information as required.

International Study

Illness Experience: 5-8yo

Akron/Haiti:

- **Medical:**
  - *The hospital is ba
  - Treatments are ha
  - Understand basics treatments
- **Emotional Expressions**
  - Half worry, the res
  - Illness makes them
  - Loss: Family vs Sch
- **Community:**
  - Hospital becomes

Experience with Death and Dying: 9-13yo

Akron/Haiti:

- **Experience:**
  - All have pet, g that has died
  - Have seen ot
  - Have attende present with
- **Processing:**
  - Worried/afra
  - Talk about co
  - Descriptive ex
  - Matter of fact
  - Belief in heav

"I am scared of dying. It's

Coping: 14-18yo

Akron/Haiti/(Both):

- **Friends/family/comm**
  - Quality time with p
- **Personal Time**
  - Think about other
- **Reassurance:**
  - Talking to people
  - Belief in heaven bu
  - Faith/Prayer
- **Encouragement**
  - From friends and f
  - To other kids*

"Well people say squeezing a ball helps. That never helps. No, not all that anger can get into that tiny ball. Or any

Differences

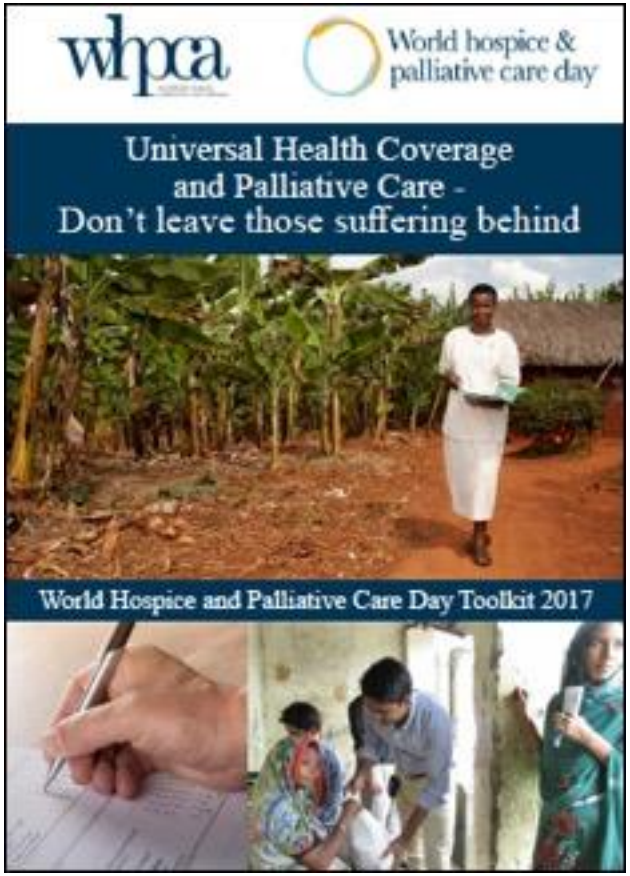
- Type of exposure to death and dying
- Avoidance of discussions about death and dying
- Community among children in the hospital setting
- Focus on faith/prayer
- Decreased knowledge of illness

Similarities

- Children worry about death and dying
- Children have experienced significant loss
- Understand death and dying
- Many do not say anything in order to protect others
- Children have a sense of responsibility to one another
- Importance of family, friends and community
- Desire to think positively
- Desire to play
- Resilience

Photo credit: Ted Stevens

- Only then can we ensure that children are ‘not left behind’ in the provision of UHC, including PC



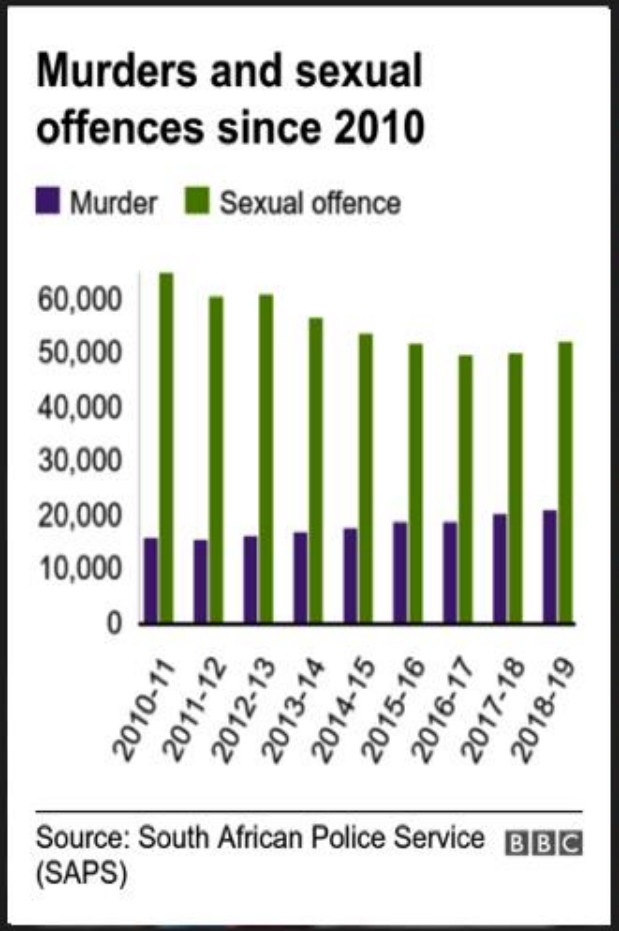
Thank You!

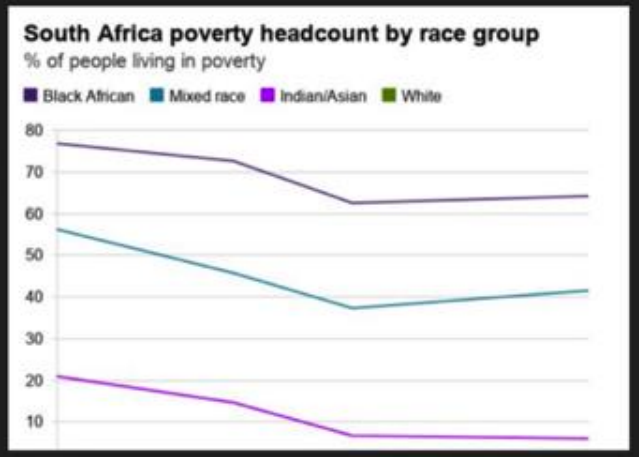
Improving Tuberculosis screening and initial management through training in the Western Cape District of South Africa

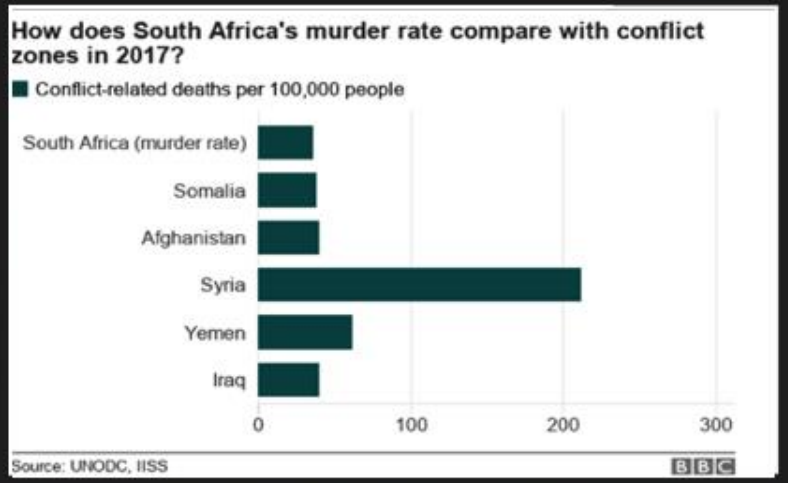
Dr Emily Padfield (A&E Clinical Fellow, Oxford Deanery)
Dr Nellis Van zyl Smit (A&E Consultant, South Africa)

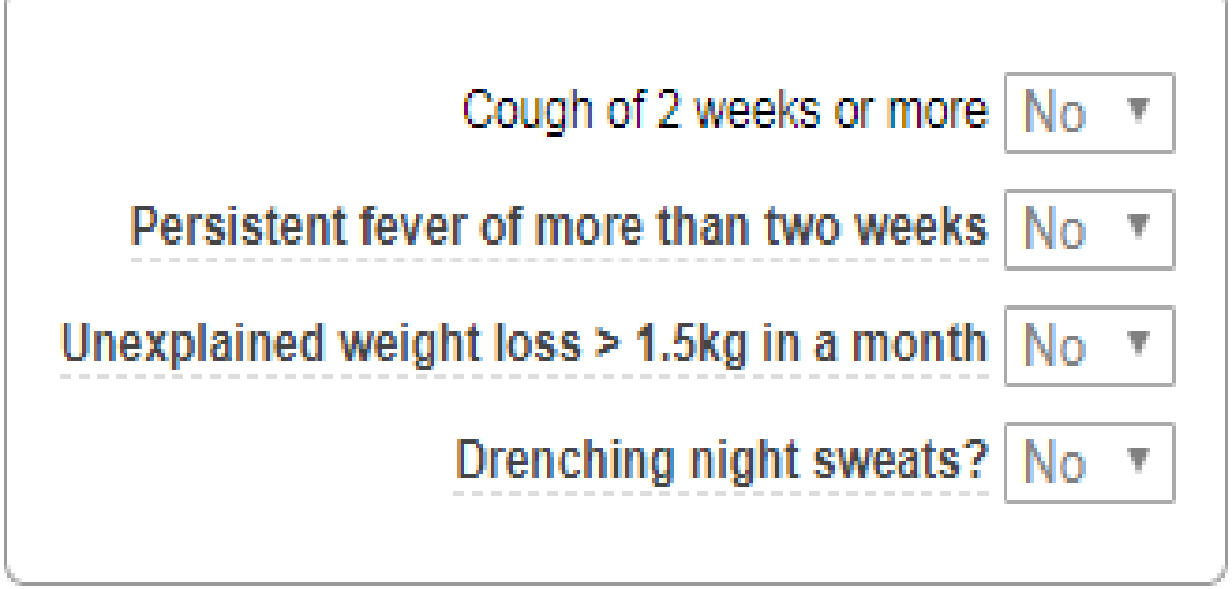
Developing people for health and healthcare
www.hee.nhs.uk

Western Cape Government
BETTER TOGETHER.









Purpose of res

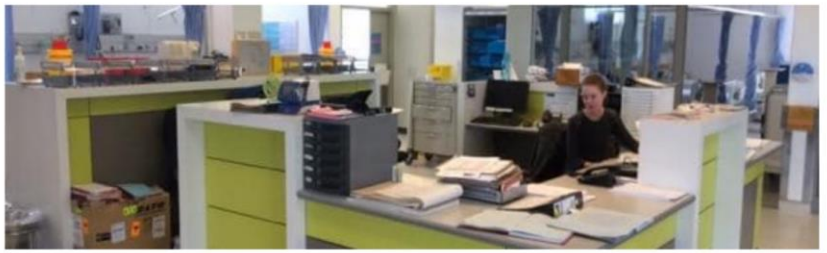
- *TB screening ra*
  - **53.5%** avera
- *Quality of screening varies*
  - **20%** of nurses were confident in screening (34/166)
  - **17%** of nurses were confident in the initial management (28/166)
- *Subop*

1. **Improve screening rates for TB**
2. **Improve initial management**
3. **Improve infection control procedures**

Health Education England

Methods

- Six facilities; two hospitals and four clinics



NHS
Health Education England

Results

- **477** staff members trained
- **4%** average increase in screening rates
- **15%** average increase in number of sputum samples sent for TB
- **19%** average increase in number of patients diagnosed with TB
- **30%** increase in TIC score

Conclusions/Reflections

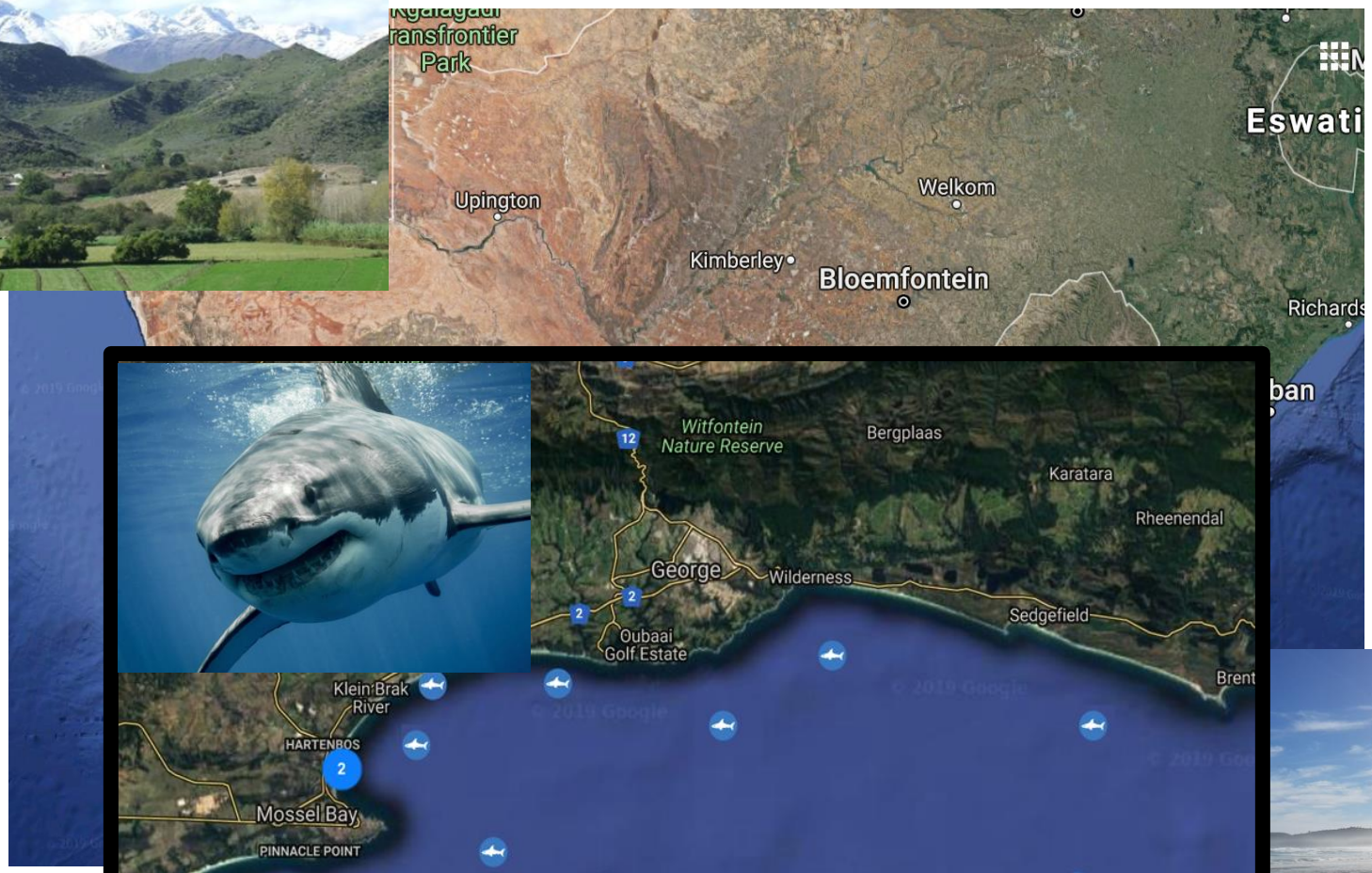
- Driving behavioural changes are challenging
- Champions offer a unique resource
- Empower and develop the capability of local staff

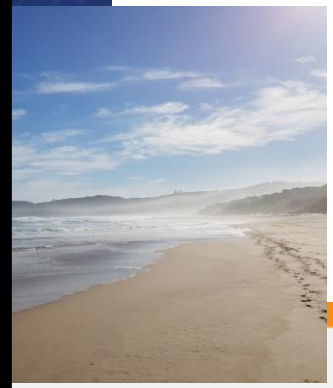
Health Education England

Any questions?

UNITE TO END TB

NHS
Health Education England





Early detection, prevention and intervention for infants at high-risk of developmental disability in Western Uganda

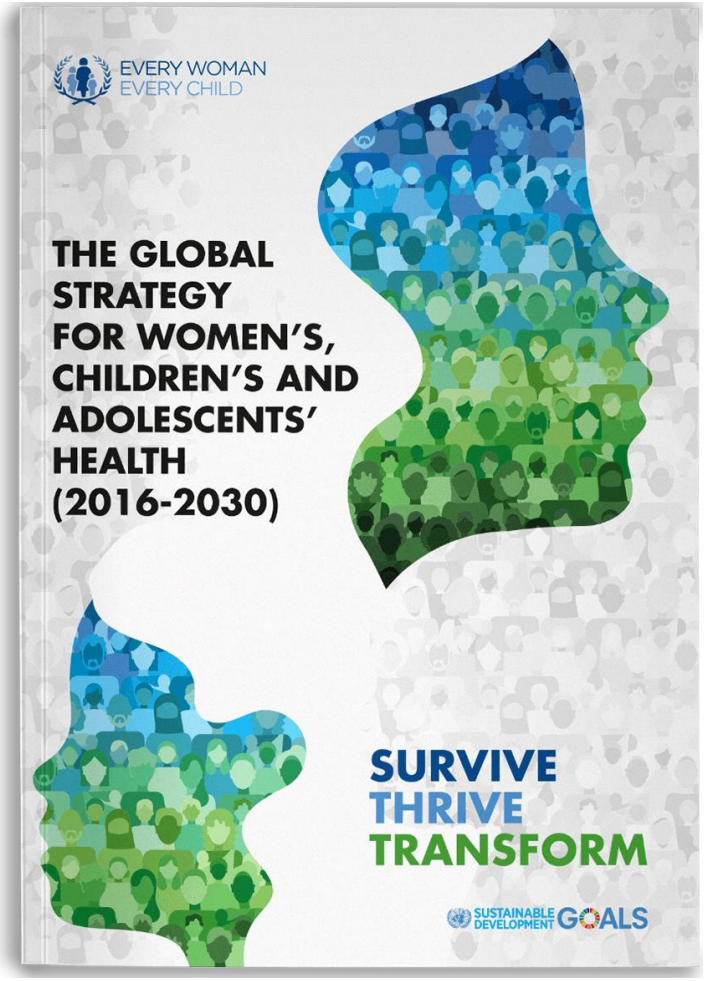
Ruth Nalugya & Melissa Clee

Transforming Global Health, THET 27th Sept 2019

Introduction

- The Global Strategy for Women's, Children's & Adolescents' Health promotes all children to survive and thrive
- Our previous research highlighted high prevalence of newborns at high-risk of disability & a lack of support services for young children and their families
- The ABAaNA Early intervention Programme (EIP) was developed to improve child and caregiver health & well-being
- 2017-18, the EIP was successfully piloted in Fort Portal in partnership with Kyaninga Child Development Centre

ABAaNA
Let hope grow...



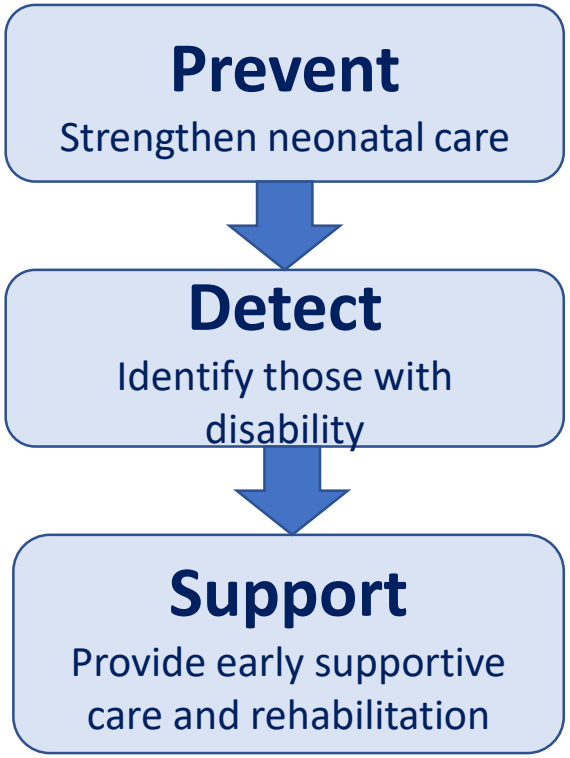
Project aims & objectives

AIM: To establish a programme of prevention, detection and support for children at high-risk of developmental disability and their families.

- PREVENT: Improve facility-based care and follow-up for small and sick newborns
- DETECT: Scale-up early identification and referral of infants at high-risk of developmental disability
- SUPPORT: Scale-up the ABAaNA Early Intervention Programme for young children with developmental disability

Activities

- Strengthening neonatal care and follow-up of high-risk infants through improved knowledge & skills in HBB & KMC
- Sensitisation and training of HCWs in early child development & establishment of high-risk neonatal follow-up clinics
- Scale-up and evaluate the ABAaNA Early Intervention Programme intervention for young children with developmental disability
- All building on existing infrastructure of child development and disability services at KCDC



global newborn network

ucl NHS

KCDC Kyaninga Child Development Centre
Helping children reach their full potential

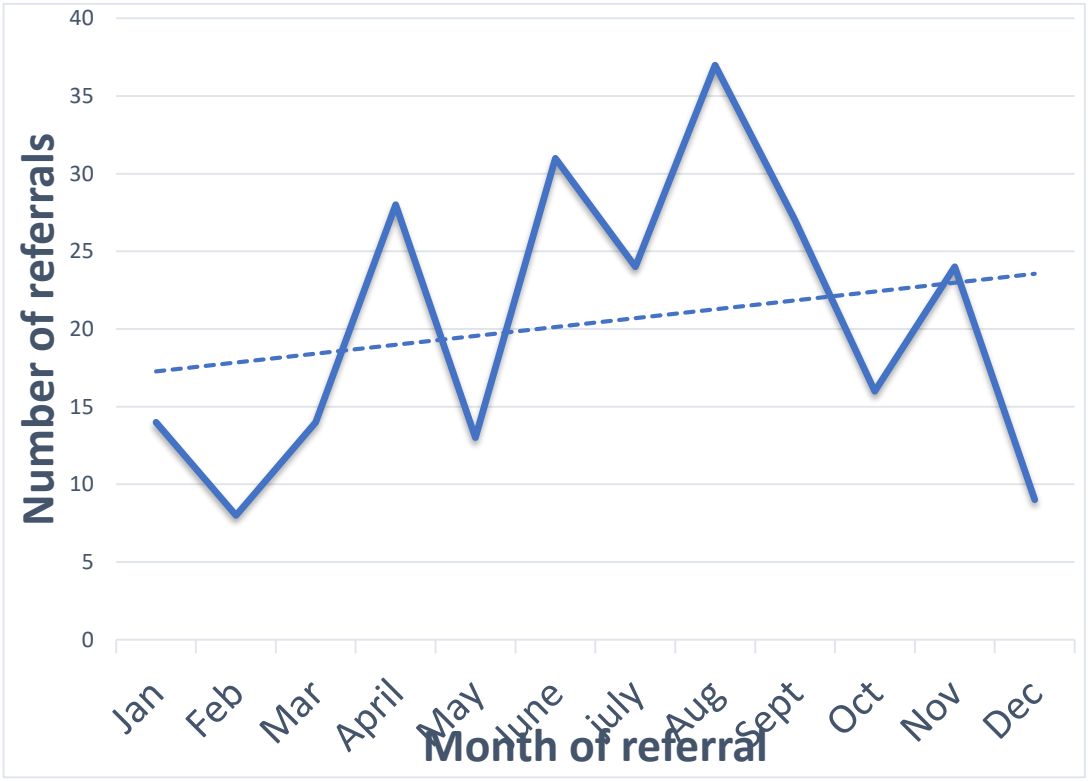
THET
PARTNERSHIPS FOR GLOBAL HEALTH

ABAaNA
Let hope grow...

PREVENT: Caring for small & sick newborns

- **Helping Babies Breathe**
  - 78% improved theory knowledge, 90% improved practical skills (N=51)
- **Kangaroo Mother Care**
  - Creation of a KMC area with reclining chairs
  - 89% improved theory knowledge (N=27)
- **Quality of neonatal care**
  - Infant feeding training by UK specialist- 10 days
  - Audits on key indicators of NICU care showed improvement over 8-months
- **Follow up of at-risk newborns**
  - Development of outpatient clinics at two new sites

DETECT: Quantitative



1. Evaluated knowledge & skills in ECD:
   - HCWs from 45 health centres trained in ECD (N=93)
   - 87% with improved knowledge, 100% improved self-confidence and attitude post-training
2. Monitored referral rates to specialist services for children <2years
   - 65% increase from 12 to 20 per month

DETECT: Qualitative

Focus group discussions (2) conducted with HCWs

Challenges in identifying and referring children:

- Pressure of work and numbers mean limited capacity to respond
- Limited knowledge of disability and restricted care provision
- Previously dismissive and turned away from services

"The training gave me an unforgettable experience… I never knew children with disabilities can make it in life and also be able to participate. We saw a video clip of a child who had cerebral palsy… It gave us hope and the strength to care … because now we understand it won't be wasted energy."

Female HCW

After training & mentorship, HCWs reported feeling empowered to care for, refer and advocate for children with disability

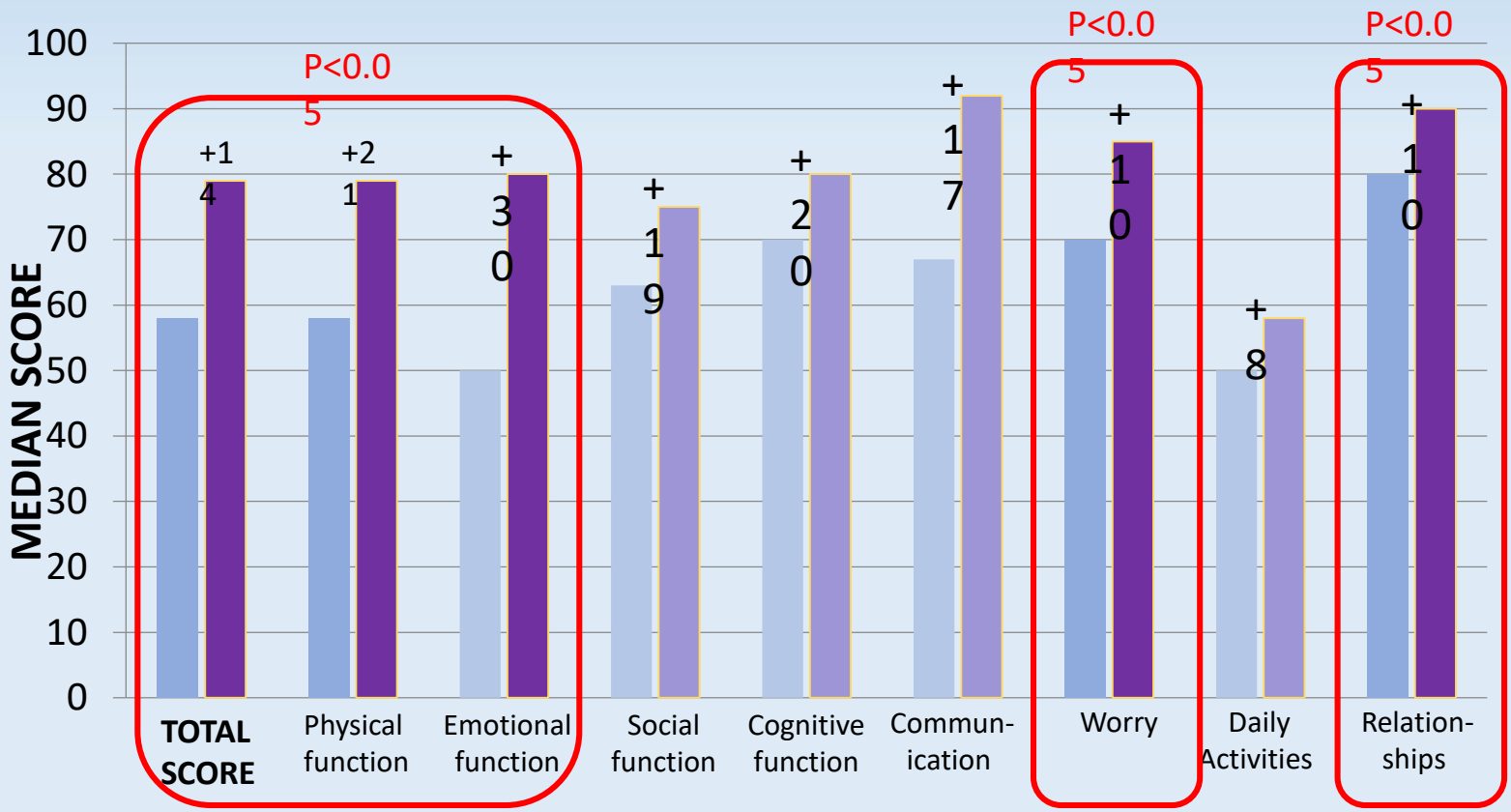
"I have learnt more tips through which I can detect disability in our community and more ways of counselling parents. I feel I am an ambassador to fight disability in my community."

SUPPORT: Evaluation

- 11 expert-parent facilitators were trained over 5 days with ongoing supervision (6 mothers, 5 fathers)
- Quantitative:
  - Pre & post programme data for 29 of 51 enrolled families using a quality of life score
- Qualitative:
  - 3 FGDs with caregivers
  - 3 IDIs & 1 FGD with expert-parent facilitators

" It gave me confidence and I got to know what happened to my child and I appreciated the fact I was not alone."

Impact: Quality of Life Score (PedsQL 2.0): 24% improvement in QoL



Impact on child health and development

Caregivers identified changes in their children's emotional, behavioural and physical health…

"I appreciate the nutrition and feeding skills they gave us because I can see a change. He has put on some weight and my mother finds it easier to feed him because she has the skills now ."

"My daughter couldn't do anything; she couldn't sit or support herself in any way, but she is somehow strong now and can sit alone in a basin and tries to hold things."

Impact on Caregivers: Knowledge, psychosocial, economic & physical health

"Before, I used to think CP was a curse and witchcraft but the training has given the understanding of what CP is and its cause. This has helped me know what to expect from the group and I can explain clearly to other caregivers."

"We had a lot of fear and used to think they were "wasted" children but meeting other mothers has taught us a lot. Fellow mothers give us hope that our children will improve, and this kept us strong."

"Whenever I would take my child to other people, they would chase me away but when we joined the group, we got to know what to tell others and they started accepting our children and that reduced the pressure on us. Some of us have reconciled with our families because they got to understand what the cause is."

Key challenges

- Geographical: Largely rural population (77%) meant transport was often challenging
- Financial: Many families living below poverty line
- Gender: Fathers often gate-keepers for maternal attendance
- HCW engagement: High staff turnover

In summary…

- Children living with disability and their families are frequently 'left behind' due to high level of stigma and exclusion
- Our three-armed approach supported affected families in accessing care and support and led to improved family quality of life
- HCWs felt empowered to care for, refer and advocate for children with disability
- Scaling-up: Feasibility RCT in central Uganda & projects ongoing in Rwanda & Kenya

Partners In Health Inshuti Mu Buzima

ADARA GROUP – BRIDGING WORLDS –

Kyaninga Child Development Centre
Helping children reach their full potential

MULAGO HOSPITAL

Imperial College London

RCPCH Royal College of Paediatrics and Child Health
Leading the way in Children's Health

wellcome trust

Cerebral Palsy ALLIANCE RESEARCH FOUNDATION

saving brains

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LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE