DEVELOPING AN EARLY INTERVENTION PROGRAMME FOR CHILDREN AT HIGH-RISK OF NEURODEVELOPMENTAL IMPAIRMENT IN UGANDA

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BACKGROUND

The global strategy for Women's Children's and Adolescent's Health supports the need for every newborn not only to 'survive' but also to 'thrive' and reach their full neurocognitive and developmental potential[1].

Globally, around 8.4 million newborns a year experience complications in the first few days and weeks after birth (accounting for 202 million disability adjusted life years) that can have life-long influence on health, development and life chances. The vast majority of this burden falls in the world's poorest countries.

Early interventions, designed to enhance a child's development in the first few years after birth, have the potential to limit and even prevent neurodevelopmental impairments following early brain injury, either directly or through their influence on the care-giving environment [2], and improve circumstances and quality of life of the child and their family.

OBJECTIVES

To develop and evaluate a modular, facilitated, participatory early intervention (EI) programme for infants at high-risk of neurodevelopmental impairment and examine its feasibility, acceptability and impact on child and family quality of life (QoL).

METHODS

A 10 modular programme was developed, adapted from an established programme for older children and supported by an expert advisory group including local parents, Disabled Persons Organisations and experts in early intervention and child development.

Term-born survivors of neonatal encephalopathy were assessed 6 months after birth using the Griffiths Mental Developmental Scales and the Hammersmith Infant Neurological Examination (HINE). Infants with moderate or severe neurodevelopmental impairment, were eligible to enter the EI programme.

A pre and post intervention mixed-methods evaluation was conducted to ensure fast-cycle learning and inform continued programme development. Pediatric QoL inventory tools (PedsQL2.0, Family Impact Module) quantitatively assessed changes in family QoL.

Wilcoxon signed-rank tests allowing for paired data were used to compare pre and post intervention scores.

Feasibility, acceptability and impact on family QoL were evaluated using small group and individual in-depth interviews amongst recruited care-givers, programme facilitators and study staff.

PROGRAMME DEVELOPMENT
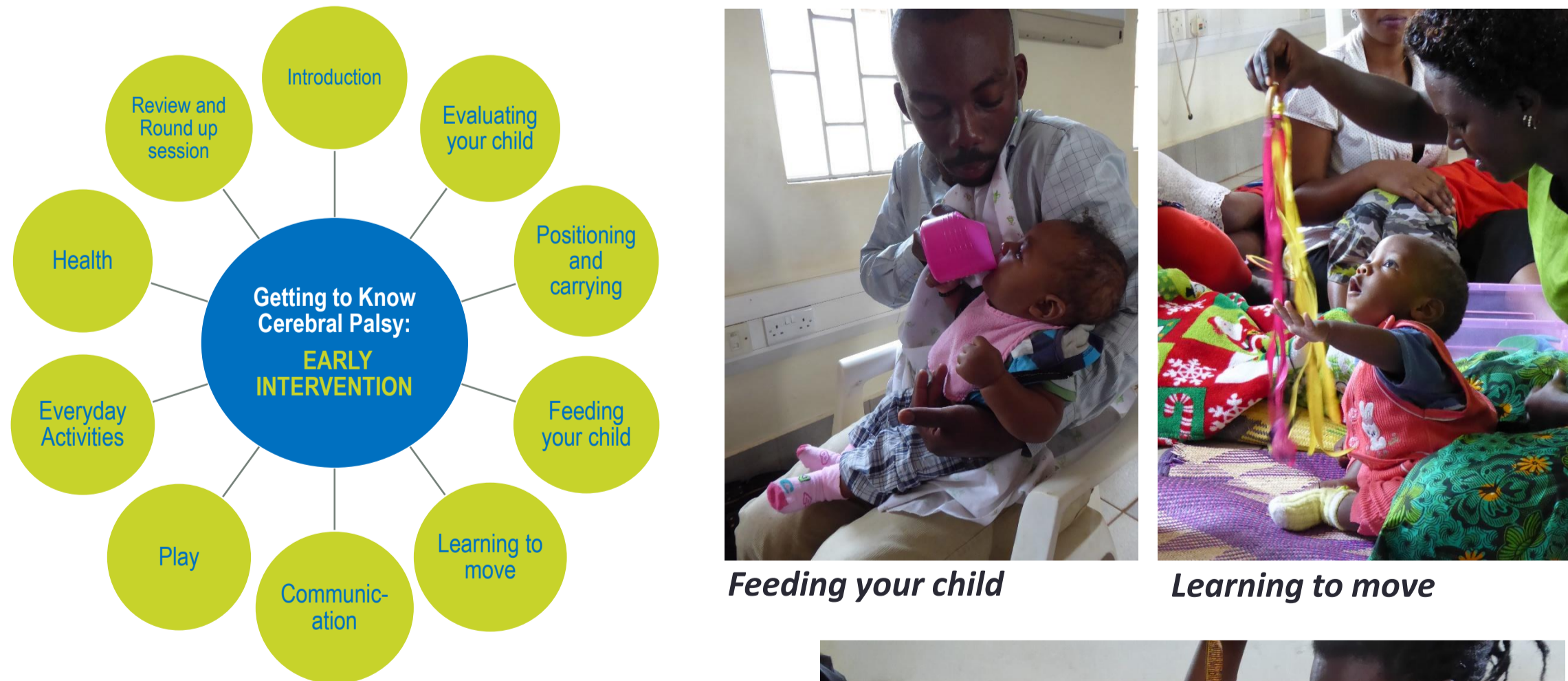
Early Intervention Programme modules

Feeding your child   **Learning to move**

Everyday activities   **Play**

Themes running throughout the programme

Promoting inclusion and participation of children with disability within the family and community

Maximising a child's developmental potential, optimising health and quality of life

Promoting empowerment of care-givers through information sharing and peer support

Sharing maternal experiences, and particularly addressing stigma

Promoting the human rights of children with disability

RESULTS: QUANTITATIVE DATA

In total 35 infants were eligible to enter the programme and 28 completed the programme and evaluation (Figure 1). Table 1 describes baseline characteristics of study infants. Total PedsQL score significantly increased post-intervention. Significant improvements in QoL were seen in emotional functioning, worry, physical functioning and communication (Table 2).
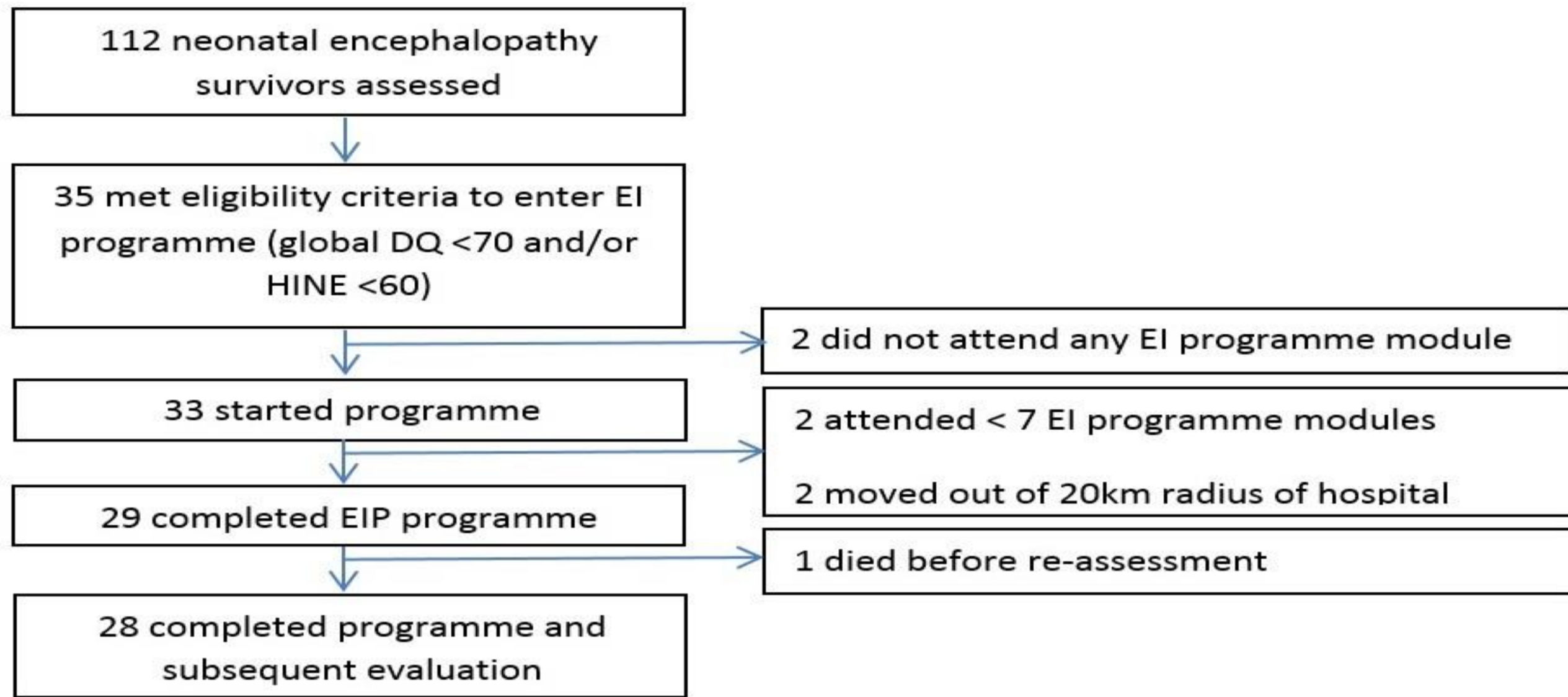
Figure 1: Flow chart of study Participants

Table 1: Basic demographics and clinical characteristics of study participants (n=28)

	Pre-EI programme, at recruitment	Post-EI programme assessment
Mean age at assessment (months) [standard deviation]	6.7 [0.66]	11.1 [1.58]
Mean attendance of programme [range]	-	8.7 modules [7-10]
Sex distribution (%)	12 female (43%), 16 male (57%)	
Median global DQ [range] {IQR}	27.25 [1.5-79.1] {12.2-52.1}	26.9 [1.2-86.9] {14.9-44.9}
HINE (range) {IQR}	37.25 [19.5-58] {28.2-44.1}	39.7 [19-78] {33.1-53.2}
Mean Haemoglobin (g/L)] [range]	114 [87-134]	109 [82-145]
Mean mid upper arm circumference (MUAC)(cm) [range]	13.9 [10.5-15.8]	14.47 [12.5-18.1]
MUAC <12.5cm, moderate acute malnutrition (%)	10.7%	0%
MUAC <11.5cm, severe acute malnutrition (%)	3.6%	0%
Mean head circumference[a] (cm) [range], centile [range]	40.99 cm [36-44.6], 1st centile [<0.4th-75th]	42.49 cm [38-46], 1st centile [<0.4th- 48th]

[a]Excludes infant with diagnosis of hydrocephalus, head circumference on 100th centile

Table 2: Comparison of total Pediatric Evaluation of Quality of Life score (PedsQL 2.0, Family Impact Module) and all subscores before and after intervention

PedsQL Family Impact Module scale	Median score (IQR) pre-EIP	Median score (IQR) post-EIP	Difference (IQR)	p-value
TOTAL PedsQL score	63.2 (50-83.7)	79.2 (72.4-94.1)	+15.6 (0.9, 30.4)	p=0.001
Subscores				
Physical functioning	65.8 (54.2-82.3)	77.1 (62.5-91.7)	+14.6 (-3.1, 29.2)	p=0.034
Emotional Functioning	37.5 (16.3-63.8)	67.5(45.0-100.0)	+30.0 (7.5, 45.0)	p=0.0002
Social functioning	75.0 (40.6-92.2)	78.1 (57.8-100)	+12.5 (-10.9, 25.0)	p=0.13
Cognitive functioning	85 (65-98.8)	97.5 (76.3-100)	0 (-8.8, 27.5)	p=0.10
Communication	66.7 (33.3-100)	83.3 (66.7-100)	+12.5 (0, 41.7)	p=0.014
Worry	57.5 (40-97.5)	87.5 (66.3-100)	+22.5 (0, 40.0)	p=0.002
Daily activities	75 (41.7-100)	95.8 (50-100)	+4.2 (0, 25.0)	p=0.07
Family relationships	77.5 (51.3-100)	100 (86.3-100)	+2.5 (0, 43.8)	p=0.015

RESULTS: QUALITATIVE DATA

Qualitatively, the programme was found to be acceptable to care-givers and facilitators. Care-givers reported increased knowledge, improved family relationships, reduced self-stigma, raised hope and enhanced emotional wellbeing.

The quotations that follow are from participating care-givers.

Some mothers describe facing stigma and social isolation:

"Even my husband abandoned us. He said that he does not give birth to such hopeless children and he does not support us."

"My neighbour told me that I delivered a ghost so I better take it to the lake and throw him in there. I refused – me, I want my baby."

Experiences of the Early Intervention Programme:

"Meeting mothers of children with the same condition comforted us. We got to know we are not alone. We got the courage to work towards the wellbeing of our children. Whenever we would see one of the children achieve a certain milestone, we would say eh, let me also put in more effort."

"We regretted the time we spent visiting witch doctors, pastors and blaming ourselves thinking we had a problem and that our children were night dancers yet the problem could easily be understood".

"It comforted us and changed our perceptions"

"She was very floppy but since now she is growing a bit more firm. Even I thought the baby was bewitched but when I was taught, then I came to know what happened. I went home and explained to my husband. Now there is hope growing"

CONCLUSIONS

Evaluation of a facilitated, participatory EI programme for infants at high-risk of neurodevelopmental impairment showed significant improvements in family QoL and was feasible and acceptable in this urban Ugandan facility-based setting. Follow up is underway to assess the longer term impact of the EI programme and a randomised control study is planned.

REFERENCES

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