



A MIXED METHODOLOGY PILOT STUDY TO EVALUATE THE IMPACT OF POSTURAL SUPPORT, CONSTRUCTED VIA APPROPRIATE PAPER-BASED TECHNOLOGY (APT), ON THE PARTICIPATION AND QUALITY OF LIFE OF YOUNG CHILDREN WITH CEREBRAL PALSY

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Introduction

The World Health Organisation (1), notes a lack of assistive devices for disabled people in low and middle income countries particularly children with Cerebral Palsy.

APT using cardboard to make bespoke chairs and standing frames has been introduced in several African countries. Such device production is potentially sustainable as the materials are cheap and available although production is labour intensive and requires training (2).

In Zambia, a group of Disabled People known as APTers have been producing devices for 24 years and a second workshop has been running for 8 years (2). A number of centres have begun production in Kenya after training courses supported by Cerebral Palsy Africa between 2009 and 2015 (3,4). Informal follow up and reports from recipients of APT devices, their carers and service providers has suggested benefits to their posture and participation but these have not been formerly evaluated or published in the scientific literature.

Aims

The Primary aim was to find out if it is possible to study the effects of APT assistive devices on the quality of life and participation of children with cerebral palsy, GMFCS levels IV and V in rural Kenya. The secondary aim was to see if APT devices are acceptable to children, families and their communities.

During an APT training workshop in Nyahururu, Kenya, a meeting with the paediatric neurologist at Aga Khan University led to scientific and ethical approval for this study six months later.

Participants

- Twelve children recruited
- Aged 1-7 years
- Diagnosis of bilateral Cerebral Palsy
- GMFCS level IV or V
- Able to tolerate and cooperate with detailed assessments
- Be brought or visited a week after fitting and then regularly to monitor usage of device and any positive or negative effects.

Exclusion criteria:

- Hemiplegic Cerebral Palsy (only one side of the body affected).
- A progressive neuromuscular disorder
- Severe uncontrolled epilepsy
- Child already using a postural support device.

References

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Methods

Both quantitative and qualitative research approaches were undertaken.

Quantitative outcome measures used were:

- The Oxford postural management tool for complex disabilities.
- The FIATS-AS parent report questionnaire to detect the impact of assistive technology device use on children with physical disabilities and their families' lives (6,7).
- The Child Engagement of Daily Life measure to assess participation in family and recreational activities, and self care for young children with cerebral palsy (8,9).
- Too few children were in the age range for the chosen Quality of Life (QoL) measure (DISABKIDS-Smiley)(5), so this was omitted from the study with QoL being assessed during individual carer interviews instead.

Qualitative family interviews were undertaken to gather subjective views and their experience of using the postural support device.

After baseline measures of gross motor function, posture (Fig 1), range of movement and participation, each child was measured for a device (Fig.2) which was then made from APT. Once complete, the devices were issued (Fig.3) with usage instructions and a recording booklet (Fig.4) to document time used and positive or negative effects. Children were visited by local therapists including follow up assessments and carer interviews six months after the devices were issued.



Figure 1. Therapist assessing posture.



Figure 2. Child measured for APT assistive device.



Fig 3. Adjustments to partially constructed chair on completing agreed by rehabilitation worker and caregiver.



Fig 4 Explanation recording booklet.

Results

The FIATS-AS 6,7 parent report questionnaire consists of 8 related dimensions which tap into aspects of child and family life that the postural support device may influence.

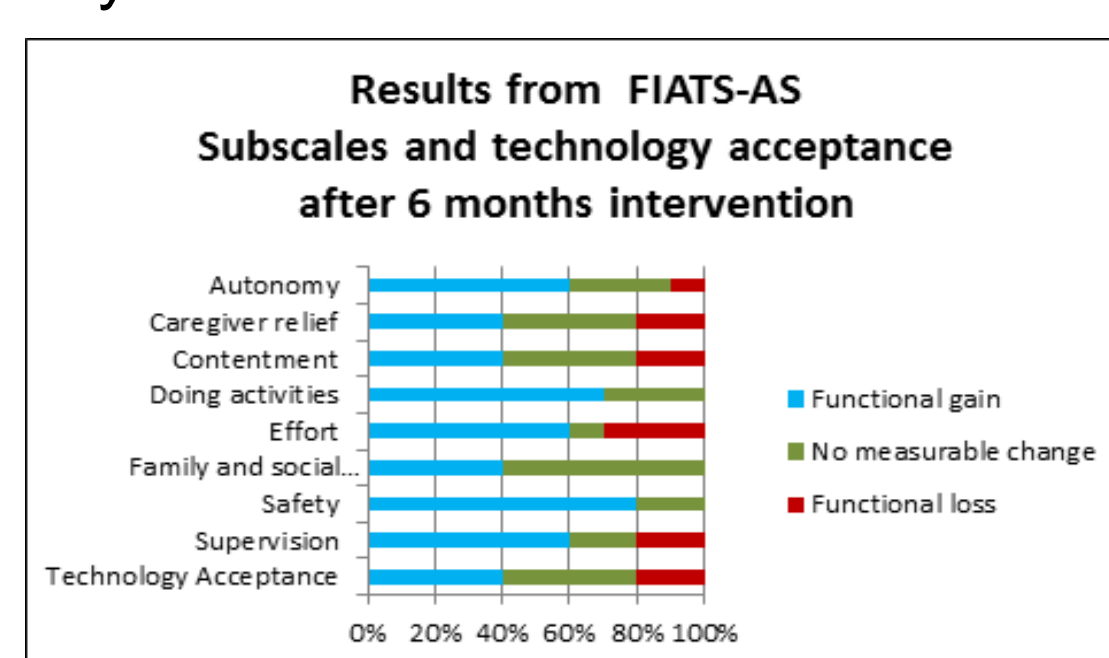


Figure 5. Change scores for the group

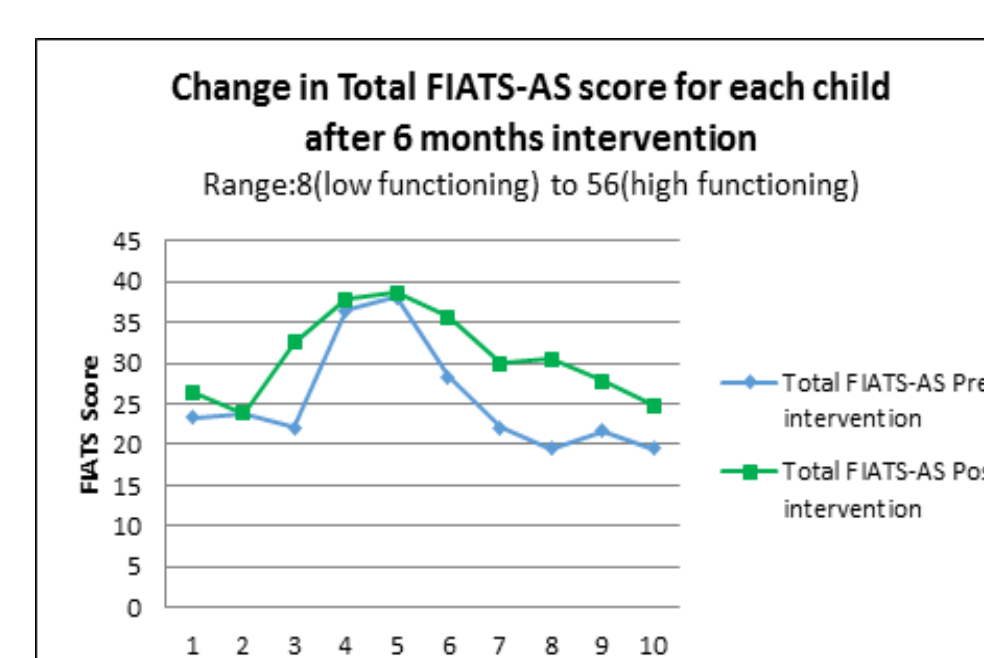


Figure 6. Change scores for the individual

70% of parents reported functional gains as measured by the FIATS-AS total score meaning the score differences exceeded the minimal detectable change at a 70% level of confidence.

The Child Engagement in Daily Life questionnaire consists of two domains, participation in family and recreational activities, 11 items, and self-care, 7 items.

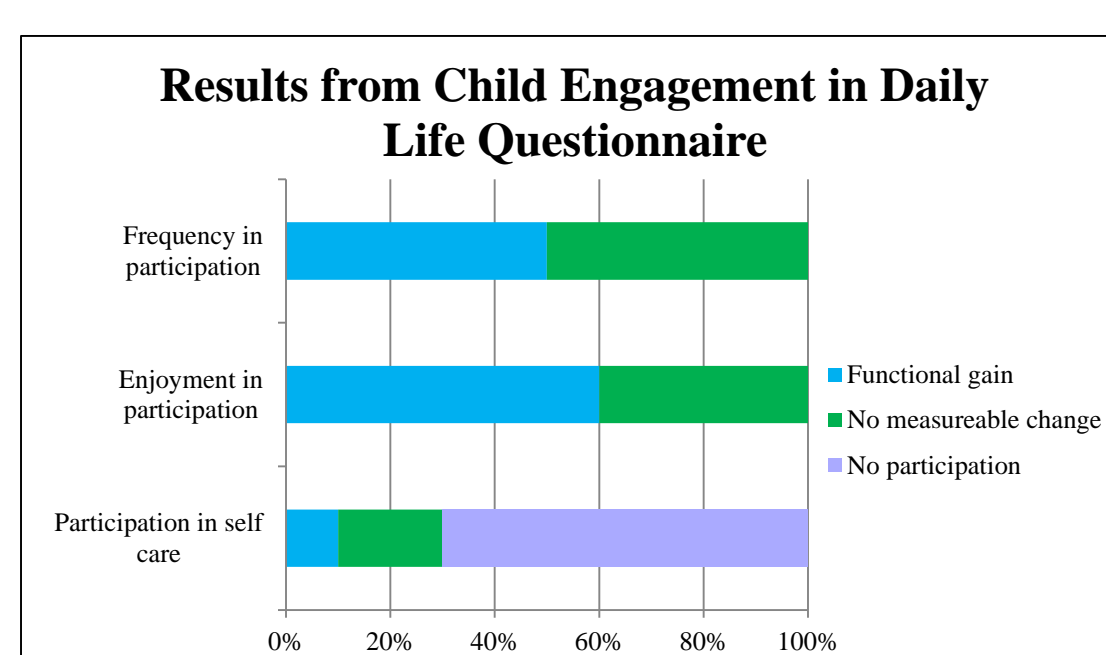


Figure 7. Change in domain scores after 6 months device use

- 9 out of 10 parents said their child's ability to do things had improved since using the device, eg. Head control, grasping objects.
- 7 out of 10 parents said that the device had enabled more social interaction, eg. Playing and/or engaging with other children

Analysis from the caregiver interviews revealed that:

8 out of 10 parents reported that the assistive device had enabled their child to be more involved in family activities at home such as play and self-care and they had more time to attend to other duties such as household chores whilst the child was in the device nearby

Conclusions

This pilot study shows that it is possible provide and study the effects of APT devices on young children with Cerebral Palsy in rural Kenya.

The introduction of a seating or standing device made from APT had a meaningful positive effect on the lives of families who have a young child with cerebral palsy of GMFCS level IV or V as measured by the FIATS-AS. The assistive device enabled half of the children in our study to participate more often in life situations such as play, family routines and self-care.

Furthermore the parent reported scores reveal that with the assistive devices over half of the children showed a measureable change in greater enjoyment of participation in these activities as measured by the child engagement in daily life tool.

Carer interviews wholeheartedly support these findings.

Larger studies are required to demonstrate significant benefits and other factors needed to support more widespread implementation.

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