

Facilitating improvement and change in services for children with Cerebral Palsy in low resourced, rural hospitals without increasing costs



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BACKGROUND

In rural, low resourced hospitals serving large communities in South Africa and Lesotho, children attending Cerebral Palsy (CP) Clinics typically are invited to attend once a month for 10 months of the year. Often due to transport difficulties or poor weather, children may not even be able to attend once a month. There are often many children to see at each CP clinic and only a small team of therapists to see them (often one or two therapists – usually Physiotherapists or Occupational Therapists – and on very rare occasions a Speech and Language therapist may be available. Children with CP thus typically receive 30 minutes of therapy monthly which translates to an average of 4 hours of therapy annually. Passive movements are the mainstay of therapy and by their own admission, many rehabilitation team therapists at hospitals feel that they lack the necessary skills to treat children with cerebral palsy and advise and support caregivers accordingly. Sessions rarely involve dialogue with caregivers or individualized goal-directed therapy programmes. Often – standardised home programmes are give out to children and caregivers.



AIM

To establish whether therapy time could be increased and a more comprehensive service offered to children with cerebral palsy and their families using the existing resources at rural hospitals, and taking into account that children with cerebral palsy are only a portion of the client caseload seen at hospitals.



METHODS

Over a two year period, teams of 3 – 4 specialist therapists spent five days at rural hospitals annually. These outreach programmes included:

- training of local therapists – through workshops and a form of clinical supervision where specialist therapists worked together with local therapists in treating children on their own caseloads using a structured, problem solving approach that could be adopted to the wider caseload;
- working with children in groups – identifying common goals in children attending the CP clinics such that therapists could spend more time working on specific goals and facilitate caregiver interaction, whilst at the same time ensure more children could be seen;
- goal-setting – the importance of good assessment and goal setting and how this helps to guide practice in busy settings is an important part of the programme;
- postural management – this is particularly important in rural caseloads where children are rarely seen and where socio-economic situations dictate priorities in family homes;
- home visits – these are particularly important in follow-up of older children and young adults with cerebral palsy who are often unable to leave their own homes due to lack of equipment and poor terrain and lack of suitable transport in the general area;
- short intensive therapy blocks – these are advocated for more complex cases or children with significant potential. Whilst this is a mainstay in many first world institutions – this is deemed a luxury in third world settings due to difficulties faced on both the part of the caregivers and their children (transport, costs, etc) as well as rehab staff (lack of manpower and resources);
- carer-to-carer training – where caregivers of children with CP are trained to run workshops for other caregivers with CP about CP and basic principles related to the condition;
- therapy protocols – are evaluated and guidelines provided based on international best practice and our experience of rural settings;
- and a database management system – caseload management systems are often paper based and difficult to track and record. Part of our programme is to set-up and supply simple Excel database sheets (hospitals lack database software and so these need to be easily applicable to any operating system).

Direct observation; a review of patient records and clinic statistics; as well as self-completed questionnaires and focus groups with therapists and caregivers were used to evaluate outcomes.



Mentoring therapists in their own setting

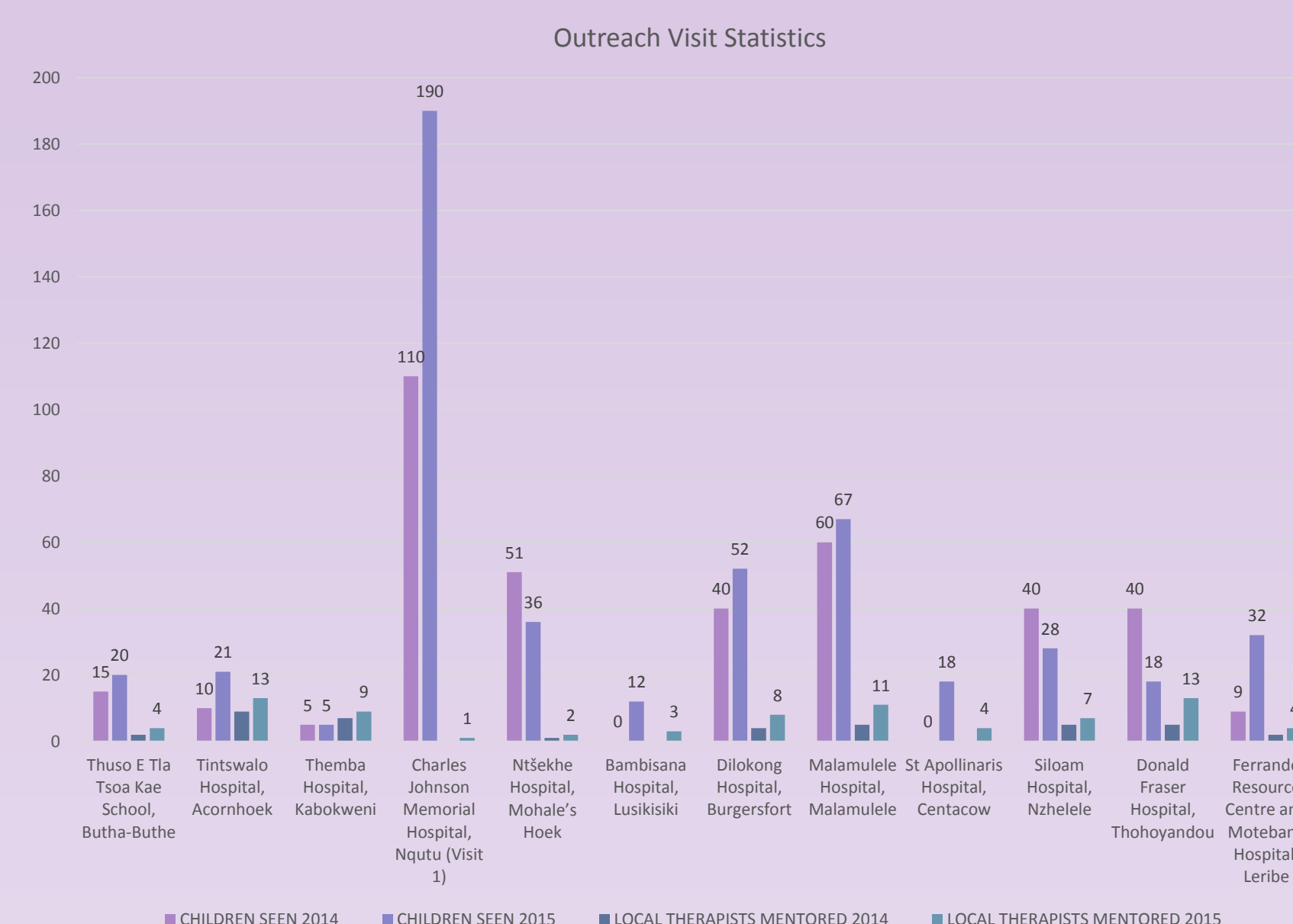


Caregiver education by a caregiver of a child with CP in groups within their own community



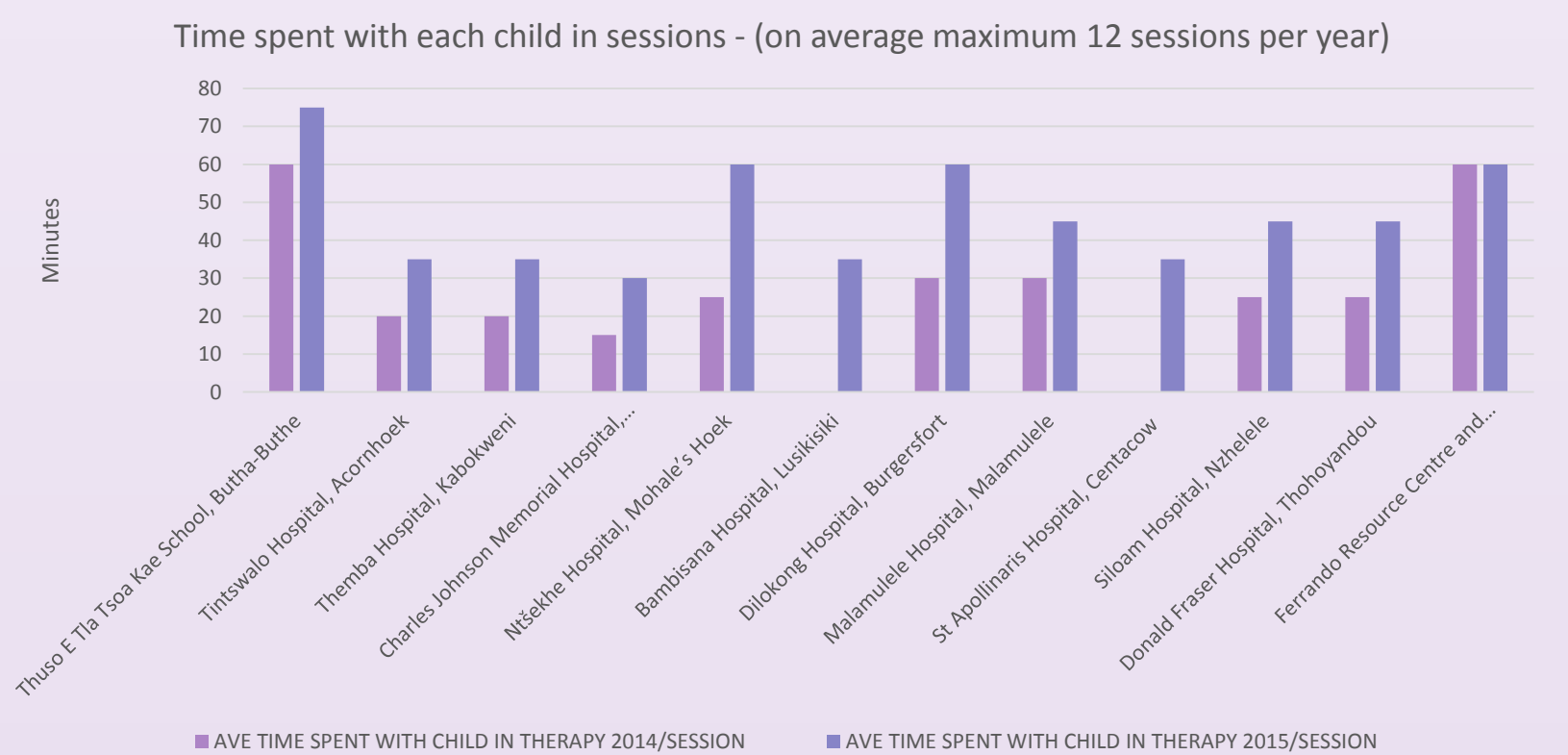
Practical skills training using what the hospital has within the hospital environment

RESULTS



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Twenty-eight outreach visits to 14 rural primary health facilities in South Africa and Lesotho involving 70 therapists and 714 children were conducted. On average, therapy contact time as well as the number of new children accessing the services doubled. Intensive therapy blocks were introduced in 4 hospitals. Structured home visits are now part of the service at 9 hospitals; whilst 4 hospitals have electronic databases. Goal setting and individualized therapy plans are offered at 5 hospitals and a carer-to-carer training programme is active at 80% of the sites. The majority of therapists (90%) felt more competent and confident.



CONCLUSIONS

Through a short focused outreach programme by a team of therapists experienced in working in rural settings, it is possible to improve quality of therapy services and care for children with CP in resource-constrained rural areas without increasing resources or costs.



Caregivers are better equipped and feel more supported in their adoption of CP as a "way of life". Children are less likely to develop significant deformities and are more functional and integrated in the family unit



Therapists

Children are seen in groups where similar goals are addresses and thus more children can be seen for longer sessions. Therapists feel better equipped with the skills necessary to manage all children on their caseload through group interventions as well as residential therapy programmes instituted at some hospitals



Therapists learn to make toys from waste products and to make APT equipment in the absence of other alternatives. Parents can get involved too!

