To evaluate the impact of parent-led training workshops on caregivers of children with cerebral palsy (CP), a parent-led training programme comprising five workshops was designed in consultation with twenty parents from rural areas representing five languages and cultures. These parents were then trained over a three-week period as workshop facilitators. Workshop topics included “What is CP,” “CP as a way of life,” “Eating and drinking,” “Communication,” and “Central Visual Impairment.”

A year later, the impact of the workshops was explored further through five focus groups with parents that had attended. This information was then transcribed, translated, and analyzed thematically.

AIM

To evaluate the impact of parent-led training workshops on caregivers of children with CP.

METHODS

During the two-year period, trained Parent Facilitators from ten rural areas in South Africa and Lesotho ran a series of five workshops for caregivers in their own communities. Caregivers completed a questionnaire after each workshop. Following translation into English, the data was analyzed thematically.

RESULTS – WORKSHOP EVALUATIONS

During the two years 564 caregivers attended all five workshops, 41 of whom participated in the focus groups. Prior to the workshops, caregivers expressed being in a state of confusion, hopelessness, and disbelief. They struggled to accept their children’s condition, believing that a child with CP “doesn’t live very long,” fell alone, and blamed themselves.

After the workshops caregivers expressed feelings of confidence, pride, and hope. “My heart is now relaxed.” Many caregivers expressed how the workshops helped them to overcome the struggle of accepting their child, which allowed them to love their child and feel confident to take them out in public.

Caregivers openly stated that two misconceptions were the root cause of non-acceptance: firstly that their child will not live a long time and secondly that therapy would “fix” the child, resulting in them not listening to what therapists tell them.

During the focus groups, the following themes emerged:

- Improved understanding of their child and of cerebral palsy
- Caring for a child with CP is a way of life (rather than a routine of exercises)
- Providing caregivers of children with CP with information in their own language, translated and analyzed thematically
- Caregivers expressed being in a state of confusion, hopelessness, and disbelief. They struggled to accept their children’s condition, believing that a child with CP “doesn’t live very long,” fell alone, and blamed themselves.
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RESULTS – FOCUS GROUPS

The workshops help parents to understand their child’s condition to the degree that not only are they able to explain CP to family, neighbours, and even strangers, but they feel comfortable and competent to do so. This greater understanding of CP has helped parents and family to accept the child, to stop blaming, to start loving the child and this then leads to the child becoming more involved and included in daily life. Parents have also gained skills and knowledge in caring for their children and this has enabled them to feel more competent as caregivers.

As a consequence of the above, parents have come to view their children in a different light – they see their children as having the potential to do things, not matter how severely disabled he or she may be. This is a really exciting step forward, because parents start to have more expectations of their children and will start to notice small improvements.

CONCLUSIONS

Providing caregivers of children with CP with information in their own language, presented in a way that is simple to understand and by a parent who has lived the same journey, is a powerful tool in dispelling misconceptions and creating a positive environment for therapy.

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