Investigating the Experiences of Informal Caregivers of Children with Cerebral Palsy in Antananarivo, Madagascar

Gemma Morgan¹, Irène Randriamampianina², M Anne Chamberlain¹, Rory J O’Connor¹

1. University of Leeds. 2. Centre Hospitalier Universitaire d’Appareillage de Madagascar

Background:
- Cerebral Palsy (CP) is the commonest cause of paediatric disability worldwide, with low-income countries, such as Madagascar, facing the largest burden.
- CP is a disorder of movement and posture, resulting in activity limitation.
- Informal caregivers play an invaluably role in the rehabilitation of children with CP.
- A link between caring for people with disabilities and caregiver burden is well established in the literature. Informal caregivers often experience 1 or more of the burdens in Figure 1.
- Despite the high prevalence of CP and burdens experienced by caregivers, no research about CP in Madagascar exists.

Objectives: explore informal caregivers’ understanding of CP, the burdens they face, their experiences of health services for children with CP and of barriers to accessing health services.

Aim: to investigate the experiences of informal caregivers of children with CP in Antananarivo, Madagascar.

Methods:
- Qualitative semi-structured interviews took place utilising a question guide.
- Purposive sampling was used to identify 13 informal caregivers at a rehabilitation centre (Centre Hospitalier Universitaire d’Appareillage de Befelatanana- CHUAM) and a public hospital (Hopital Joseph Ravoahangy Andrianavalona - HIRA), in Antananarivo, in Figure 2.
- The majority of participants were mothers, except for one father and one grandmother, who all cared for a child with CP between 1 and 19 years of age.
- A translator was used and all interviews were audio-recorded to allow verbatim transcriptions.
- Thematic content analysis was used to assign a priori codes from the objectives and question guide, then emerging codes were made from unexpected data.
- Limitations include the relatively small sample size, and the involvement only of caregivers accessing rehabilitation CHUAM or HIRA.
- Ethical approval was granted from the Universities of Leeds and Antananarivo.

Findings

CP knowledge
- Generally very poor understanding of pathophysiology
- Beliefs CP is curable, with 2 doctors offering a cure for CP
- Majority uncertain of cause
  - Recognised causes: meningitis, prematurity, asphyxia
  - Unrecognised causes: ‘Bad spirits’, ventouse delivery, mis-matched parental blood groups

Health services
- All participants accessed physiotherapy at CHUAM or HIRA.
- Limited communication with physiotherapists
- Limited speech and language and occupational therapy access
- Participants accessed alternative medicine including:
  - Osteopathy
  - Reflexology
  - Acupuncture
  - Thermal treatment
- Majority of participants utilised traditional medicine, with mixed opinions of effectiveness

Barriers to accessing health services
- Financial
  - Employment loss
  - Increased expenses
- Psychological
  - Low mood
- Social
  - Moving city
  - Relationship breakdown
  - Activity withdrawal
  - Stigma
  - Time burden
- Physical
  - Sleep disturbance
  - Limited wheelchair availability
- Relief of burden:
  - Religion
  - Seeing other children with CP

Discussion:

Knowledge:
- Caregiver education is vital as a lack of information for caregivers prevents optimal care of children with CP.
- The belief CP is curable was also found among caregivers of children with CP in Botswana, but a new finding is doctors offering a CP cure.

Health services:
- Caregiver satisfaction with a rehabilitation intervention improves compliance and reduces psychological burden, highlighting the need to improve communication with physiotherapists.
- The lack of OT and SALT is unsurprising due to there being no SALT training in Madagascar, and only a recent introduction of OT training.
- Research regarding traditional healers is necessary to establish their effectiveness.

Methods:
- Qualitative semi-structured interviews took place utilising a question guide.
- Purposive sampling was used to identify 13 informal caregivers at a rehabilitation centre (Centre Hospitalier Universitaire d’Appareillage de Befelatanana- CHUAM) and a public hospital (Hopital Joseph Ravoahangy Andrianavalona - HIRA), in Antananarivo, in Figure 2.
- The majority of participants were mothers, except for one father and one grandmother, who all cared for a child with CP between 1 and 19 years of age.
- A translator was used and all interviews were audio-recorded to allow verbatim transcriptions.
- Thematic content analysis was used to assign a priori codes from the objectives and question guide, then emerging codes were made from unexpected data.
- Limitations include the relatively small sample size, and the involvement only of caregivers accessing rehabilitation CHUAM or HIRA.
- Ethical approval was granted from the Universities of Leeds and Antananarivo.

Conclusions:
- Research gives insight into caregivers’ limited knowledge of CP and the burdens they experience as a result of caregiving. This study will inform future research for improving healthcare models for children with CP in Madagascar.

Acknowledgements
Thank you to the staff at CHUAM and HIRA, and participants who gave their time.