

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

Gemma Morgan<sup>1</sup>, Irène Randriamampianina<sup>2</sup>, M Anne Chamberlain<sup>1</sup>, Rory J O'Connor<sup>1</sup>

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



UNIVERSITY OF LEEDS

## 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 invaluable 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.

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

**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.

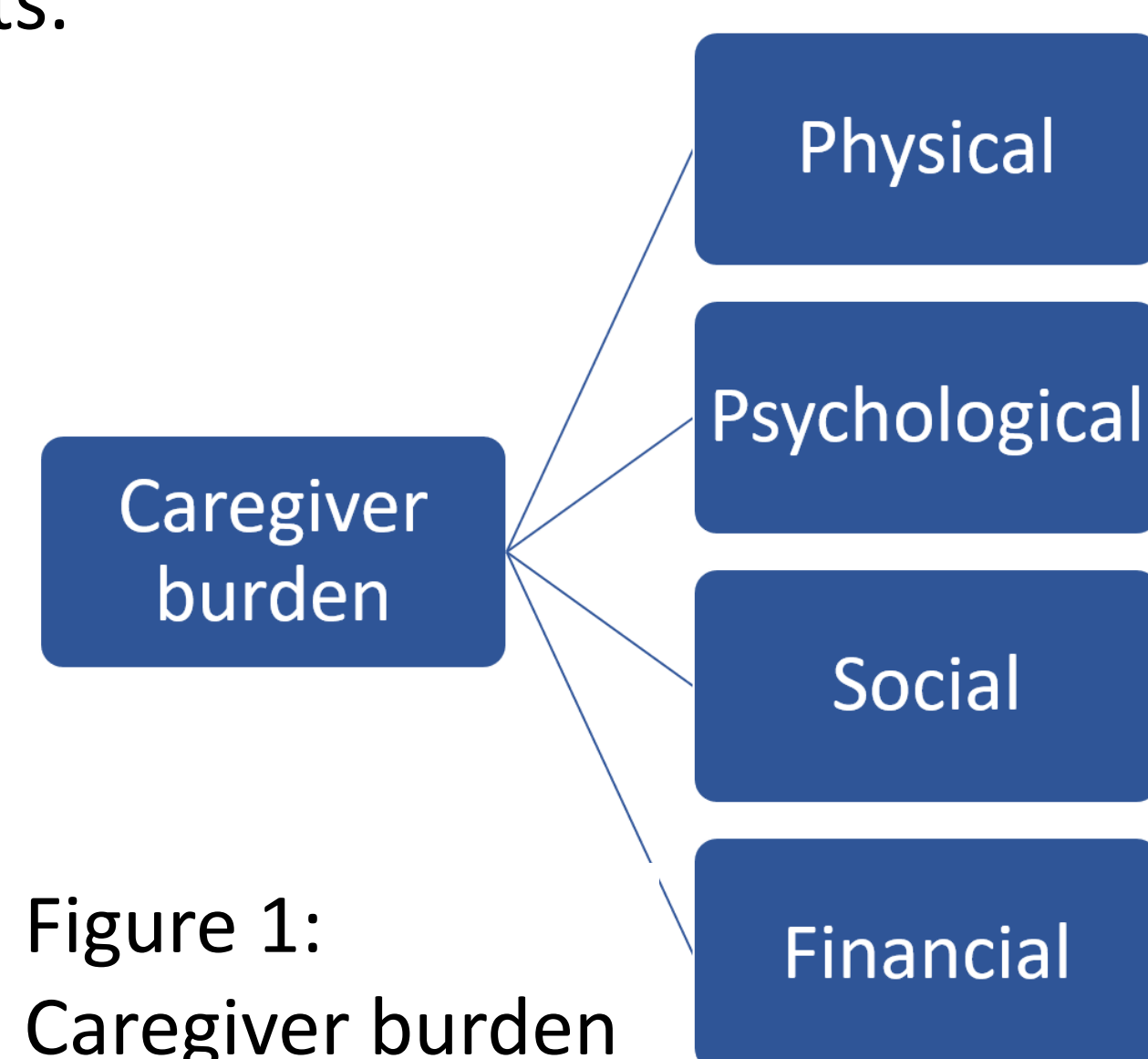


Figure 1: Caregiver burden

## 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 - HJRA), 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 HJRA.
- Ethical approval was granted from the Universities of Leeds and Antananarivo.



Figure 2: 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
  - Ideas included:
    - 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 HJRA.
- 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

### Caregiver burden

- Caregiver role:
  - Rehabilitation activities: appointments, physiotherapy exercises, medications
  - Activities of daily living
- Caregiver burden:

<b>Financial:</b> <ul style="list-style-type: none"> <li>- Employment loss</li> <li>- Increased expenses</li> </ul>	<b>Psychological:</b> <ul style="list-style-type: none"> <li>- Low mood</li> </ul>
<b>Social:</b> <ul style="list-style-type: none"> <li>- Moving city</li> <li>- Relationship breakdown</li> <li>- Activity withdrawal</li> <li>- Stigma</li> <li>- Time burden</li> </ul>	<b>Physical:</b> <ul style="list-style-type: none"> <li>- Sleep disturbance</li> <li>- Limited wheelchair availability</li> </ul>

- Relief of burden:
  - Religion
  - Seeing other children with CP

### Barriers to accessing health services

- Financial
- Travel
- Illness
- Other priorities: occupation, education

'I don't know anything about it [CP]'

'We stop the treatment because of lack of money'

'I don't go to work anywhere.. as I have to look after him all the time'

'She [traditional healer] doesn't ask for money but you just give what you want to give.. that's what we can afford'

## 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.

### Caregiver burden:

- Burdens experienced reflected other literature
- Caregivers of children with CP in Australia were also supported by social interactions at therapy sessions. This could be promoted at physiotherapy sessions in Madagascar.

### Barriers:

- The WHO recommends community-based rehabilitation in low-resource settings, which could help to reduce the financial strain and time burden experienced by caregivers.

## Conclusion:

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

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