How do low birth weight neonates fare two years after discharge from a low technology neonatal care unit in a rural district hospital in Burundi.

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Médecins Sans Frontières (MSF)
Ministry of Health Burundi
Burundi - Context

- Small country in Central Africa with ~ 10 million people
- High neonatal mortality ~ 36/1000 live births
- Main causes: prematurity, low birth weight, asphyxia and infections
- EmONC in Kabezi district hospital decreased neonatal mortality to 15% at NSCU
How well are these babies doing two years after discharge from the neonatal special care unit?
Objectives

To determine how well discharged neonates do two years after, in terms of:

- Mortality
- Screened sequelae
- Potential burden to the family in caring for impaired infants
- Nutritional status
Methods

- **Study design:** Household Survey using a structured questionnaire (August – December 2014).

- **Study population:** All discharged low birth weight (LBW) neonates in 2012 and residing in Bujumbura Rural province.

- **Ethics:** National Ethics Committee in Burundi and MSF Ethics Review Board.
Neonates included in the study

146 LBW neonates discharged

- 130
  - 11% unknown by village leader
  - 8% patient files could not be found
- 118
  - 3% migrated out of catchment area
- 113
Results – Mortality (n=113)

- Died: 6 (4%)
- Median survival after discharge in days: 183 (range: 10 – 191)
- Possible cause of death according to the mother:
  - 3 infections
  - 2 respiratory
  - 1 unknown (died while on the back of the mother)
## Baseline characteristics for those included in household survey

<table>
<thead>
<tr>
<th>Gender</th>
<th>N=107 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>57 (53%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Birth weight</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 1500 grams</td>
<td>7 (7)</td>
</tr>
<tr>
<td>&gt; 1500 grams</td>
<td>100 (93)</td>
</tr>
<tr>
<td>Median (IQR) in grams</td>
<td>2020 (1750-2250)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hospitalization Indication</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Premature/dysmature</td>
<td>59 (55)</td>
</tr>
<tr>
<td>Prenatal asphyxia</td>
<td>12 (11)</td>
</tr>
<tr>
<td>Neonatal sepsis</td>
<td>11 (10)</td>
</tr>
<tr>
<td>Risk of infection</td>
<td>19 (18)</td>
</tr>
<tr>
<td>Others</td>
<td>6 (6)</td>
</tr>
</tbody>
</table>
Sequelae screening

- 10 questions which screens childhood disability

- Questions related to: motoric, mental, speech and intellectual development and, vision and hearing impairments

- A child screened positive to at least one on ten questions is considered to be at increased risk of disability

(UNICEF’s Multiple Indicator Cluster survey)
Does sequelae cause burden to the family?

- We added 3 questions on continuous dependency which causes extra burden to the family

  - Needs always assistance (eg: can not be left alone with siblings)
  
  - Can not eat by his/herself

  - Caretaker needs to re-organize his/her daily activities
Results – Sequelae (delays in development)

1. Motor development
2. Vision
3. Hearing
4. Comprehension
5. Abnormal Movements
6. Seizures
7. Learning
8. Speech
9. Name at least one object (N = 92)
10. Intellectual impairment

0% 5% 10% 15% 20% 25%
At least one developmental impairment was found in 29 (27%) infants. 

≥ 5 impairments were observed in 9 (8%) infants.
## Results - Extra burden on the family

<table>
<thead>
<tr>
<th>Proxy Indicators</th>
<th>N=107</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs always assistance (eg: can not be left alone with sibling)</td>
<td>8</td>
</tr>
<tr>
<td>Cannot eat alone (needs always to be fed by someone)</td>
<td>5</td>
</tr>
<tr>
<td>Caretaker needs to organize life / daily activities different from before (eg: working in the field, going to the market etc.)</td>
<td>6</td>
</tr>
</tbody>
</table>
Were resuscitation at birth or very low birth-weights (<1500 gr) associated with sequelae?
Results - Sequelae (Resuscitation at birth)

There were none

(despite 30% were resuscitated at birth)
## Results - Sequelae (comparing <1500 / >1500 gr)

<table>
<thead>
<tr>
<th>Screened Disability/ Impairment</th>
<th>&lt;1500 gr N=7 (%)</th>
<th>&gt;1500 gr N=100 (%)</th>
<th>P-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor development</td>
<td>4 (57)</td>
<td>14 (14)</td>
<td>0.01</td>
</tr>
<tr>
<td>Comprehension</td>
<td>3 (43)</td>
<td>8 (8)</td>
<td>0.02</td>
</tr>
<tr>
<td>Movement</td>
<td>3 (43)</td>
<td>9 (9)</td>
<td>0.03</td>
</tr>
<tr>
<td>Learning</td>
<td>3 (43)</td>
<td>10 (10)</td>
<td>0.04</td>
</tr>
<tr>
<td>Name at least one object (n=92)</td>
<td>3 (43)</td>
<td>7 (8)</td>
<td>0.03</td>
</tr>
<tr>
<td>Intellectual impairment</td>
<td>4 (57)</td>
<td>7 (7)</td>
<td><strong>0.001</strong></td>
</tr>
</tbody>
</table>

### Burden on household

<table>
<thead>
<tr>
<th></th>
<th>&lt;1500 gr N=7 (%)</th>
<th>&gt;1500 gr N=100 (%)</th>
<th>P-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs full-time assistance</td>
<td>3 (43)</td>
<td>5 (5)</td>
<td><strong>0.009</strong></td>
</tr>
<tr>
<td>Needs to re-organize life/daily activities</td>
<td>3 (43)</td>
<td>3 (3)</td>
<td><strong>0.003</strong></td>
</tr>
</tbody>
</table>

* Fisher Exact P-values
Result - nutritional status (wasting)

Global acute malnutrition: 18%

Normal / At risk: 86; 82%

Moderate: 15 (14%)

Severe: 4; 4%
Conclusions

- Most of the infants are doing well after two years (although not all were found)
- Three in ten with developmental impairments (especially VLBWs) need continued individual and household support
- The high rate of global acute malnutrition needs focused attention
The care for a (V)LBW neonate does not end after being discharged alive from a NSCU.

Networks should be created with relevant partners providing specific services, in particular:
- feeding programs,
- NGOs involved in structural support including: education and revalidation (Handicap International),
- Ministry of solidarity for social and financial support

Community engagement should be enhanced
We thank the research team and the community health workers, without whom we would not have been able to find the participants.

We are grateful to the caretakers with their children who were willing to participate and who thanked us for showing interest even two years after.