

*“The government is responsible for our plight”*

Poor access to health care and education for people with neuro-developmental disorders and epilepsy in Malindi-Magarini region, Kilifi County

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# BACKGROUND

- Neuro-developmental disorders and epilepsy are common
- Patients and care givers suffer psychosocial distress
- Comprehensive care approach is elusive
- This study describes challenges and propose solutions

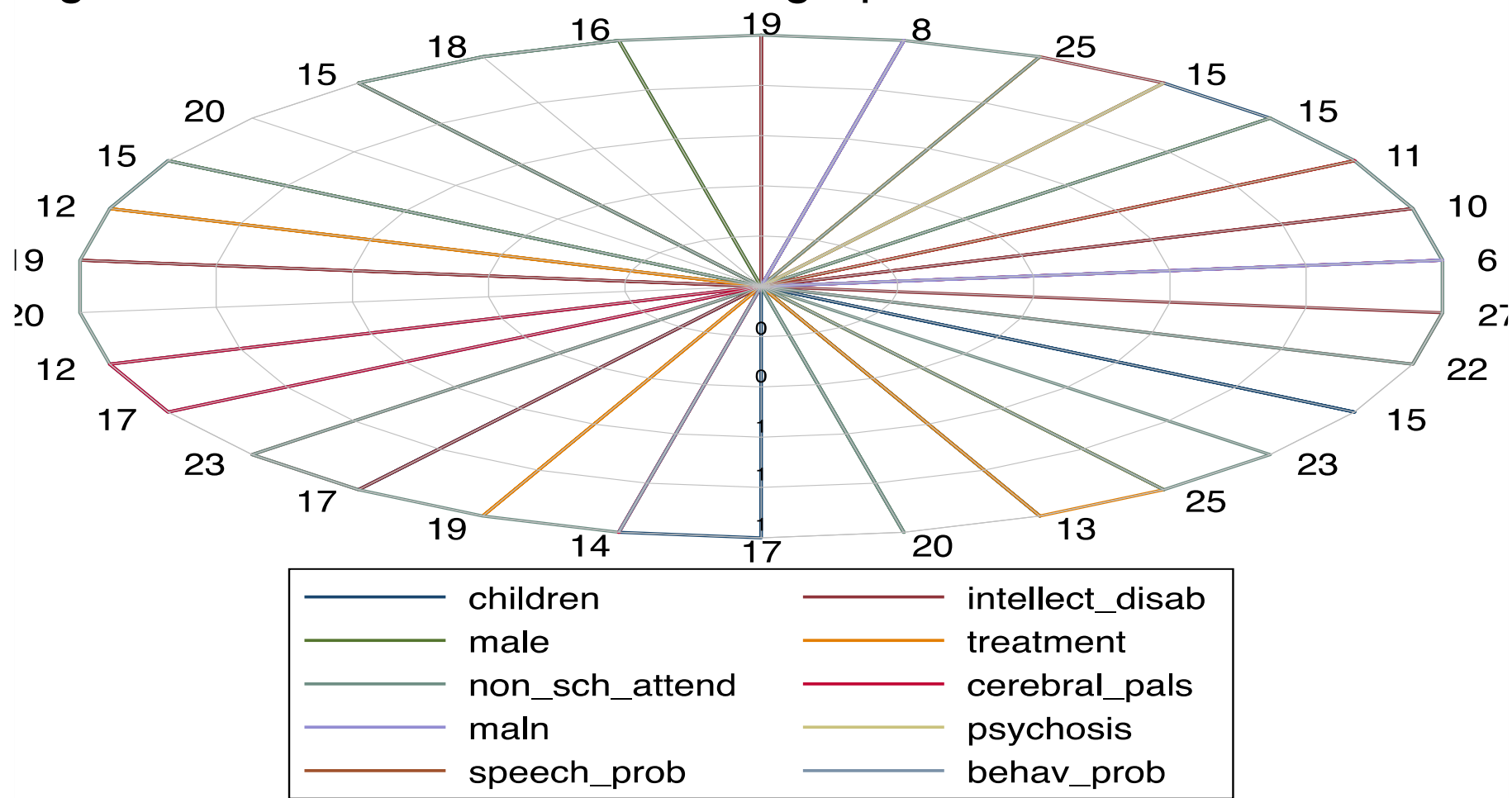
# Methodology

- A one day workshop of caregivers and patients
- Interview using a pre-defined questionnaire on general epilepsy knowledge and education
- Focus group discussion (FGD) come up with solutions regarding care, education and psychosocial support

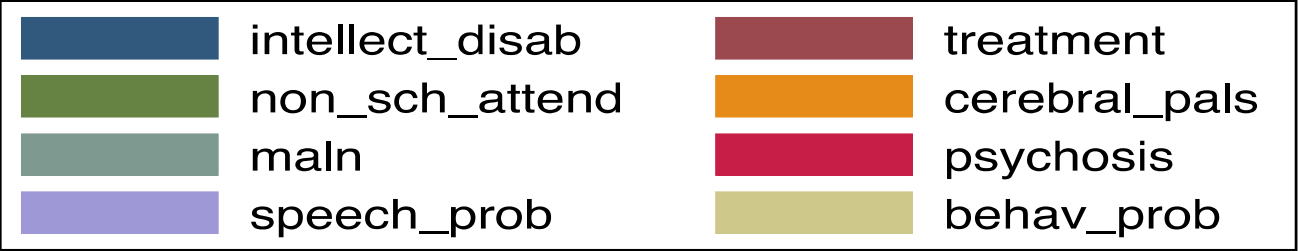
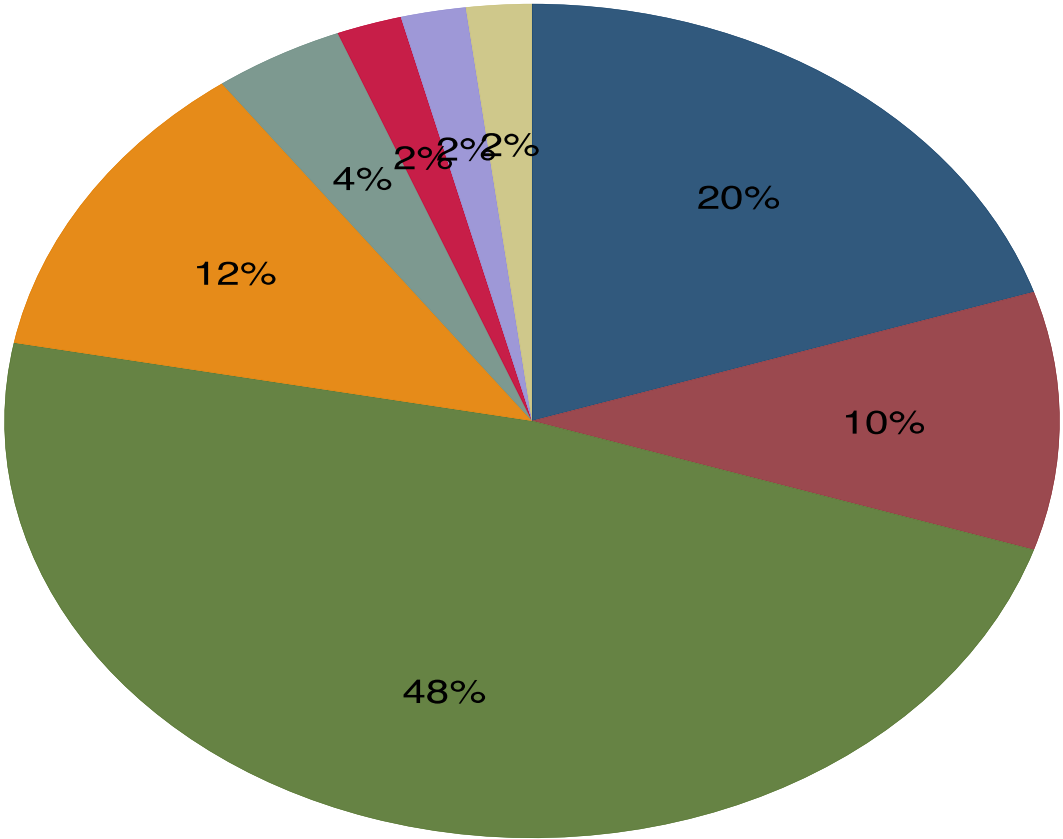
# Results

- Demographics
- Challenges
- Proposed Solutions

# Age distribution with socio-demographic and functional outcomes

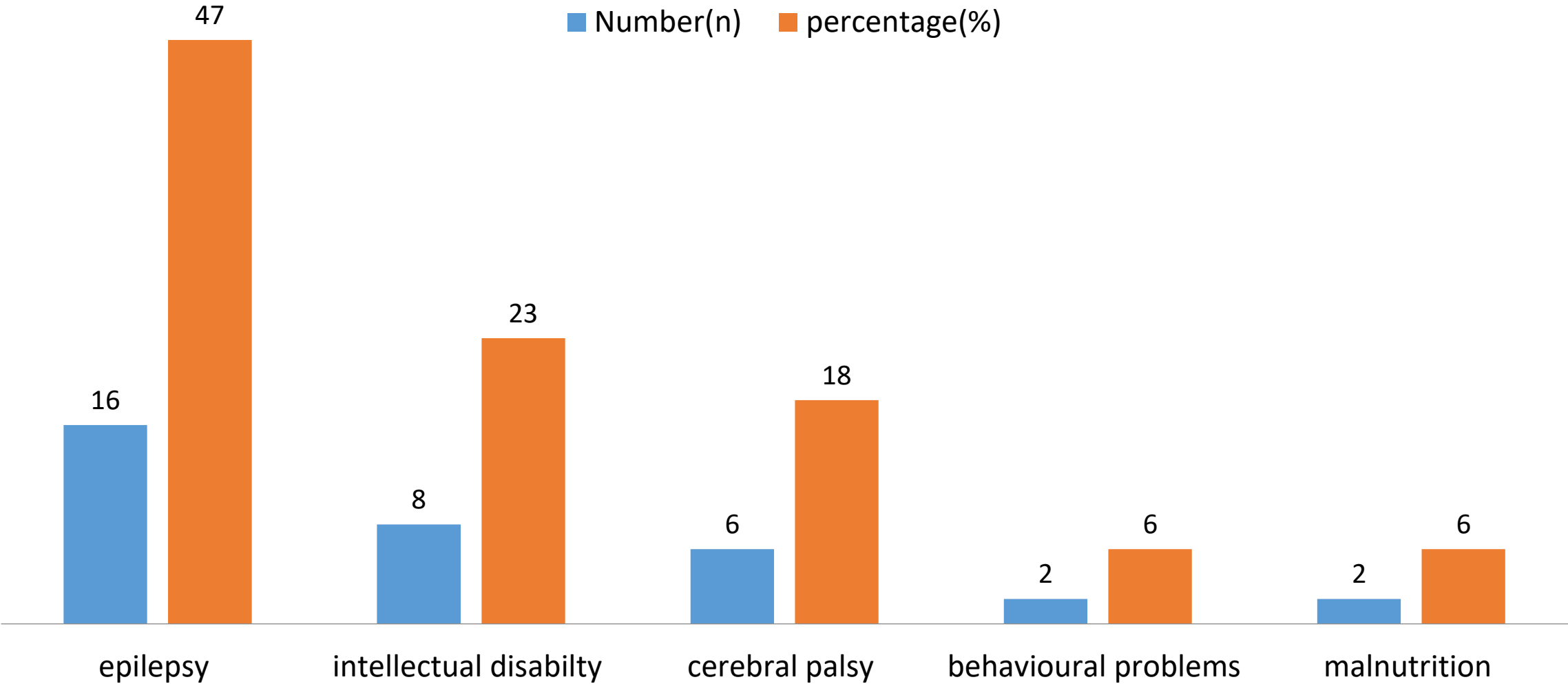


# Distribution of clinical and functional outcomes



# Clinical outcome

■ Number(n)   ■ percentage(%)



# Challenges

- Stigma and discrimination
- Lack of information
- Lack of proper nutrition
- Missed opportunities ( schooling, marriage)
- Psychological distress





Sometimes its not always what it seems!



*“my disease is not easily seen  
like other diseases but if you  
look at me closely you will see  
how it has changed my life”*

# Proposed solutions

Psychosocial support

Health care access

Economic empowerment

Education

SULUHU

- 1) Kukubali mtoto mlemavu kama Sehemu ya familia.  
- Mzazi aelezwe ili aweze kumkubali.  
- Na jamii kwa ujumla.
- 2) Wazazi wasaidiwe kiu-chumi kuwasaidia kukimu mahitaji ya watoto walemavu ya kila siku.

SULUHU YA WALEMAVU

- (1) Tunaomba mafundisho ya jamii.
- (2) Serikali izingatie elimu ya walemavu kasa wazazi dadi.
- (3) Serikali itusaidie na misaada kama madada chakula, kasa kwa watoto na uchungu.

U. TUNAOMBA SERIKALI UTULETEE MADAKITA RI WA WATOTO WALEMAVU HUKO NYANYANI.

GROUP ONE:  
Ulemavu ni nini? :- Ulemavu ni udhaifu wa vungu.  
INALETWA NA NINI: - Maumbile ama ugonjwa dhidi ya uchiwi.  
SULUHU :- Elimu ya jamii kuhusu ulemavu. Kutoa ficha watoto walemavu kupata kinga ya ulemavu.

Seizure identification and first aid education

Community awareness programs

Information provision



*“The government is responsible for our plight, we are to listen and follow but we go witchdoctors and prayers because we want help”*

*“We need information and they should also listen to us”*

*“ why should I pay more school fees for my child who is disabled”*



# Conclusion

- There is poor access to health care and formal education for children with neuro-disabilities
- Public awareness and information provision on neurodisabilities and epilepsy is key
- The government should implement policies on education, rights and entitlements of people with neurodisabilities and epilepsy

# Acknowledgement

- All the caregivers and patients who participated in the study
- FPE field team
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Thank you