Assessment of community perceptions, beliefs and societal-traditional practices toward disability that inhibit Occupational Therapy intervention and rehabilitation for children with Spina Bifida and Hydrocephalus in Northern Uganda

Isaac Odongo
AVSI Foundation Uganda,
Cavendish University Uganda
Acronyms

1) **AVSI**: International Services of Volunteers’ Association
2) **GROW**: Gulu Regional Orthopeadic Workshop
3) **SB/H**: Spina Bifida and/or Hydrocephalus
4) **IFSBH**: International Federation for Spina Bifida and Hydrocephalus
5) **PIH**: Post Infectious Hydrocephalus – Acquired Hydrocephalus
6) **FGDs**: Focus Group Discussions
7) **NIH**: National Institute of Health
8) **NPHC**: National Population and Housing Census
9) **UBOS**: Uganda Bureau of Statistics
10) **MoH**: Ministry of Health
11) **CCHU**: Cure Children Hospital of Uganda
Introduction

• Spina Bifida and/or Hydrocephalus are major global health burden and causes of disabilities (Colin Kennedy MD, Jim Stevenson PhD, Department of Psychology, University of Southampton, Southampton, UK.)

• But currently under-recognized by government healthcare systems especially in developing countries.

• They occur at a range of 0.5–10 or more in 1,000 live births worldwide

• Globally, it is estimated that approximately 300,000 babies are born each year with NTDs (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4827875/)
Prevalence estimates vary widely in the World Health Organization (WHO) regions and World Bank income classifications.

Uganda has no clear data about SB/H but it's estimated that more than 1.5/1000 births are born with Spina Bifida.

And 3-5/1,000 life births are born with or acquire Hydrocephalus (*CCHU 2016*).

10% of the total population in Uganda live with disability (*World bank and NPHC, UBOS 2014*)
Definition

Spina bifida, ‘a cleft spine’

It is a neural tube defect characterized by incomplete development of Brain, Spinal cord and/or Meninges.

The defect occur during the first trimester

It can occur at any point along the spinal column.
• **Hydrocephalus**

• Excessive accumulation of cerebrospinal fluid (CSF) in the brain ventricles.

• Not merely increased size of the head

• But accumulation of CSF which is characterized by **increased intracranial pressure** (ICP)
Background

- AVSI Foundation, is an international not for profit non-governmental organization
- Has been working in Northern Uganda since 1984 providing health care, education, social economic and development services.
- AVSI began her collaboration with IF in the year 2008, by referring 51 SBH clients for surgery
- The number has increased exponentially to currently 509 clients in the follow up program
- The mean age of clients in follow up program is 3.5 years
- Annually, AVSI refers 54 SB/H for Neurosurgery
Study approach and objectives

✓ Qualitative approach was used to:
  
  i. Assess socio-cultural practices of communities in Agago district in addressing health needs of children living with SB/H
  
  ii. Dispel myths about SB/H and scale up preventive and rehabilitative awareness
  
  iii. Dialogue with the community
Methodology

✓ Qualitative methodologies in this study include
  - Interviews with mothers during clinic visits
  - Focus Group Discussions
  - Dialogue with local leaders during a community outreaches.
  - Follow up of clients in the community
Sample size and selection criteria

✓ Convenience/purposive sampling technique was used
✓ Krejcie & Morgan (1970) Table for sample determination was used to determine sample size.

✓ Inclusion criteria:
  i. Children age 0 – 5 years, born with SB/H or acquired Hydrocephalus
  iii. Defaulted follow up for rehabilitative Occupational Therapy interventions
• SB/H is believed to be a misfortune and a punishment from god
• It is disgrace to a family
• They are kept indoor.
• they are either starved to death
• Or drawn in water
• If died, they are buried at the river bank
Follow up

- Fourteen children with Spina Bifida/or Hydrocephalus in Agago district (Northern Uganda) were followed up in two years.
- No clear evidence of the actual cause(s) of death.
- Collateral informants stated that rituals were performed.
- The rate of domestic violence and divorce is high.
- Lost to follow up could have been due to fear to disclose the demise.

Retrospective Follow up of Children with SB/H in Agago district in the years 2014/2016 respectively
Factors influencing community practices

• The nearest Neurosurgical hospital is about 336km from GROW
• GROW serves the entire region which is about 85,391 km² and has population of about 7,188,139 (NPHC, 2014)
• Majority of care givers to children living with SB/H are poor single mothers.
• Most of SB/H clients are left to be cared for by their grand mothers.
Conclusion

• Health practices of the society are greatly influenced by traditional beliefs, Culture and norms and level of literacy.
• To some extent, political and Economic factors plays a role decision making.
• Revitalization of community based health care approaches is the immediate remedy.
• Community dialogue and health education and fundamental.
Thank You