

Palliative care for the Deaf



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Brief background Of PCAU

- PCAU was established in 1999 to support and promote PC practitioners and the development of pc in Uganda
- Registered as an NGO & a professional body in 2003
- It is a membership organization with 650 individual and over twenty organizational members



PCAU's Vision:



Palliative care for all who need in Uganda



Mission statement



To increase access to culturally appropriate pc services for patients and families in need thru working in collaboration with partners to strengthen healthcare systems by means of training, capacity building, information provision and advocacy

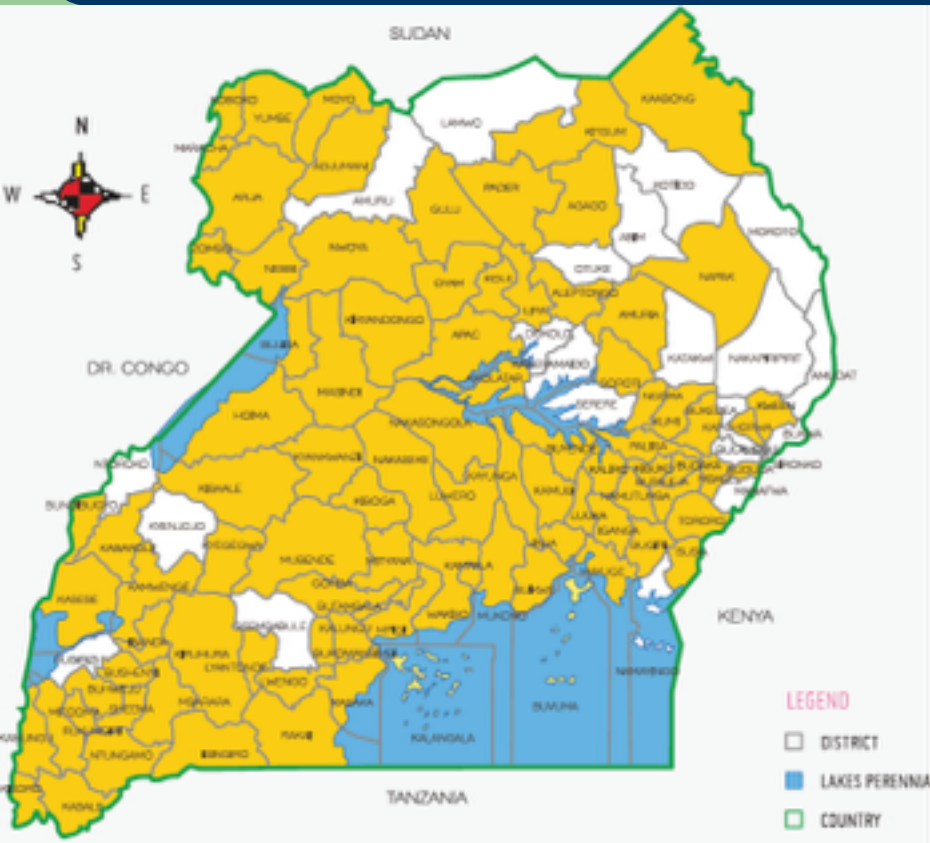


PCAU,s work

- PCAU works with different groups of people to reach as many people who need palliative care in the communities including;
 - Spiritual Leaders
 - traditional healers
 - the soldiers
 - Health care workers



Due to training and Advocacy



- PC is in 90 of the 112 districts of Uganda
- 13 RRH are now practicum sites for PC with established PC Units
- 12 Districts have stand alone Hospices / PC Programs across.
- However the deaf were brought on board in 2014



They have their own communities



They have their own communities



The Deaf in Uganda

- The National Population housing census 2014 indicated that 1,083,649 are people with hearing disability
- The Deaf face the highest communication challenge with health care workers
- They can not express themselves to be understood



The Deaf in Uganda

- Sign language is not taught in the health training Institutions of Uganda.
- Many health care workers can not use sign language to help the Deaf understand them.
- Interpreter are so few but also interfere with patients confidentiality when involve at health facilities.



Reaching out to the Deaf

- A meeting with the Executive Director of the Uganda National Association for the Deaf was held
- Sensitized him about palliative care and sought collaboration.



Reaching out to the Deaf

- The 1st ever palliative care training for the Deaf was organized and conducted.
- Presentations and group discussions were done through an interpreters





During the training.

- A lot of sharing was done and both groups learnt from each other
- They shared the pain of discrimination and Isolation by Social structure, They are called names “ Kasiru”
- A story was shared during the training: A deaf person in severe pain was referred to a mental hospital because the health care worker could not understand him.



Addressing the gap

- PCAU together with UNADS agreed to
 - Sensitize interpreters working with the deaf
 - Provide PC training to the Deaf TOTs
 - Develop a basic sign language module for training health care workers working in palliative care sites
 - Coopt a sign language trainer on the PCAU training teams.



Some of the challenges shared

- Communication barrier hinder the Deaf to seek medical services
- Communication barrier create stigma among the Deaf
- The Deaf who have life limiting illness die in excruciating pain much as they have a right to be pain free



Some recommendations.

- Sign language should be taught in the health training Institutions
- Health care workers should be sensitised about the needs of the deaf.
- The deaf must be respected and given opportunity like anybody else



Thank you all