

Engaging patients family and community for safer and higher quality care

– Experiences from Uganda

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Introduction – Key challenges (1)

- In Uganda, like elsewhere in the world, **patient Safety** has become a **well-recognized public health challenge**. Patients and their families suffer every day from preventable adverse events when receiving care.
- Uganda also faces a **double burden** of communicable and non-communicable disease, coupled with a number of healthcare challenges including.
- **Low government prioritization and spending** on health: The proportion of the national budget allocated to the health sector in 2016/17 budget was 7% below the Abuja Declaration commitment.

Introduction: Key challenges (2)

- Inadequate human resources for health;
- Poorly maintained health facilities without functioning equipment;
- Inadequate drugs and supplies;
- Weak medicine regulatory and pharmacovigilance systems;
- Weak emergency referral systems;
- Stigma and discrimination which can delay diagnosis and access to treatment;
- Low health literacy;
- These problems are compounded by widespread poverty and a lack of collaboration between and within sectors.

Why engage people and communities?

The **most effective way to address these challenges** is through **integrated and people-centred health services** that are delivered through **safe, equitable and high-quality service delivery**.

- *A people-centred health service places the values and needs of patients and families at its centre.*
- This requires for patients, families and health professionals to **work together**, to engage and empower patients to effectively **manage their own care** and **make behavioural changes**, in a non-tokenistic manner.
- Patients must be recognized as **equal partners** in their health care.



**.....When things go wrong, They are
the ones who suffer HARM!**



My work on patient safety

- My passion for patient safety dates as far as 1990's. It stems from the **experiences** I have encountered at a **personal and family level** with near miss incidents, and at the community level where I have witnessed patients being harmed, disabled and lose their lives.
- My mother **almost died due a medicine overdose** for her hypertension drug, I narrowly survived child birth.



“It was a life changing experience for me when I was selected to participate in the WHO PFPS regional workshop in Entebbe Uganda in 2011. This marked the beginning of a long journey towards patient safety advocacy! The journey has not been easy given the challenges and especially the paternalistic view of the “doctor knows best” and that the patient is merely a recipient of care, with just a body and no mind!”

CHAIN's work on patient safety

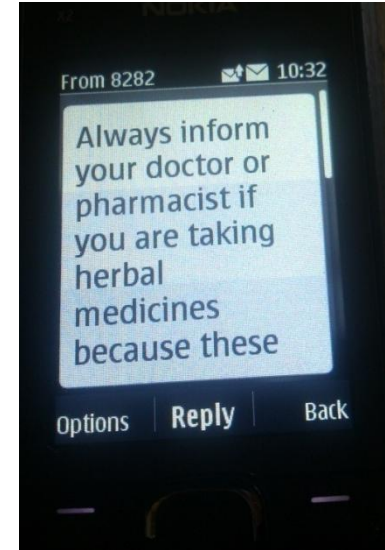


- It has spearheaded work on **promoting partnerships** between patients, family members, community, health professionals and policy makers to improve quality and safe care.
- **Target population:** Patients/patient organisations, family members, community, media, health professionals and policy makers.
- **Key healthcare stakeholders:** Ministry of Health, WHO country office, National Drug Authority.



Activities

- **Health literacy, hand hygiene, medication and injection safety campaigns.**
- **Raised awareness:** SMS messages, public hearings, media campaigns, sports, music, dance and drama community events.
- These campaigns were meant to **empower patients, families, communities and healthcare professionals** to improve safe practices i.e. safer use of medicines and injections.
- Patients accessed **appropriate information** on different patient safety issues, including appropriate prescriptions and dispensing, to **enhance adherence** and **reduce adverse drug reactions.**



Hand hygiene



Workshops

- Organised 3 day **Patients for Patient Safety** country workshop in Uganda, in partnership with MoH, WHO, NDA, AFROSAFE and UAPO;
- It was aimed at providing an opportunity to **prioritise patient safety**, concerns and issues, **train** and **orient** future advocates of patient safety;
- A **Ugandan PFPS network** of patient safety advocates coordinated by CHAIN was **formed**.



PFPS workshop participants



Empowering networks to promote patient safety

- CHAIN in partnership with IDI **trained** 5 young patients to become **patient safety advocates**: June- November 2016.
 - These were placed in 6 clinic areas where they observed practice, educated patients and documented safety incidents.
- **Trained over 200 patient safety advocates, community safe medicine advocates, village health teams**, who are currently working in health facilities and at the community level to raise awareness about issues of patient safety.

These teams are powerful in the community and health facilities for creating a critical mass of patients who will demand for higher-quality and safer care.

Patients engaged with healthcare professionals in open communication

- **Public hearings and dialogues** between patient leaders and healthcare professionals **to share knowledge** on patient safety issues that affect patients and **to discuss the patient's role** in promoting patient safety.
 - These dialogues are conducted twice a year
- **Training** of patients and health care professionals **on injection and medication safety.**



Results

- Fundamental need to educate and engage patients, patient organizations and health professionals around issues such as hand hygiene, medication safety and injection safety. Public dialogues, meetings and the media have been seen to be powerful educational tools:
- Between 2011 – 2017, CHAIN has **engaged and raised awareness with over 500,000 patients ,family and community** on the safe use of medicines, injection safety, hand hygiene and the importance of health literacy through media, sports, music, dance and drama, workshops, public hearings, dialogues and community outreach programmes.
- The innovative approaches used were not only **cost effective** in improving patient safety **in rural and hard-to-reach settings** but also **addressed issues of low health literacy**, through knowledge sharing

Key Outcomes

- Over 500,000 patients and families educated on safe use of medicines, injection safety, hand hygiene and health literacy;
- 200 patient advocates empowered to promote patient safety from cancer, epilepsy, sickle cell, HIV, Hepatitis B, and mental health organizations;
- 60 CSMAAs trained to improve adherence and reduce adverse drug reactions;
- Ugandan Patients for Patient Safety (PFPS) network formed;
- Multi-stakeholder partnership meetings held twice a year.



Contribution at the global level

- A **situational analysis** with healthcare professionals in private and public hospitals to determine the extent of the patient safety problem as perceived by healthcare professionals and to raise their awareness on the need to address the issue.
- The results **informed input in the WHO-TDR report** on Implementation Research for the control of diseases of poverty, strengthening the evidence base for the access and delivery of new and improved tools, strategies and interventions; chapter on patient safety.
- **Sitting on global patient safety committees.**

Advocacy on patient safety at the national level

- Advocated for **patient leaders** to sit on **High level Health Policy decision making bodies** at the Ministry of Health.
 - For instance, I sit on the Technical Working Group on Supervision, Monitoring Research and Evaluation – Ministry of Health and National Quality Improvement committee;
- Advocated for **integration of people-centred healthcare and patient safety into national delivery care system**
 - PCH piloted in 2 referral hospitals
 - Patient safety policy guidelines to be developed this year 2017.

Improved communication and relationship between health professionals, patients, families and the community

- Increased knowledge, improved patient and health professional relationship and **understanding of challenges faced by both parties and how to support each other.**
- Improved communication, helping to reduce medical errors.

Five young patients trained as PS advocates and placed in clinic

- The **trained advocates felt accepted by both health workers(3/5)and patients (4/5)**, taught patients hand hygiene, safe disposal of phlebotomy swabs, patient rights, directed patients to referrals and empowered them to ask questions.
- They **detected safety incidents** in the waiting area, pharmacy, laboratory, urgent care and in TB clinic these involved medicines, infection risk and a lack of patient understanding. Some resulted in referral to a clinic worker.

Collaboration



Regina with Dr. Henry Mwebesa, Director Health Services Planning and Development - MoH and Dr. Juliet Bataringaya -WHO

Joint activities with WHO, Ministry of Health, National Drug Authority and Patient Organizations



Opportunities

- Patient safety prioritized in the Health sector development plan 2015/16-2019/2020 for the coming 5 years.
- Patient safety policy guidelines to be developed and disseminated
- Global recognition of patient safety e.g. Ministerial summit on patient safety, WHO patient safety programme

Key messages

- Patients, families and communities are **powerful resources** for improving patient safety and quality.
- **Infrastructure ,equipment , training, high quality and affordable medicines** are key components of patient safety
- We need to **prioritize a research agenda to be embedded in policy** on engagement in LMICs, to understand facilitators and barriers to engagement for all stakeholders.

Listen and listen to patients, family and community!



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