Acute Rheumatic Fever/Rheumatic Heart Disease: Patients/parents and Nurses knowledge to the disease and adherence to benzathine penicillin prophylaxis

> Dr Bardley Ludawane MMed II Paediatric Symposium 31/8/17

Background

- Acute rheumatic fever (ARF) multi-system illness, cause by strep infection
- Rheumatic heart disease (RHD) is a sequelae of ARF
- Low incidence of ARF in developed countries but high in the pacific region
- Estimated prevalence of RHD in the Solomon Islands was 23/1000
- A RHD program set up in 2012

Aim of study

- Determine the level of understanding of ARF/RHD in children(patients), parents and nurses and its effect on the adherence to benzathine penicillin prophylaxis
- Determine the status of the RHD program in Honiara

Methodology

- Study design
 - Prospective follow up of a retrospective cohort.
 - Qualitative descriptive study
- Study settings



- Study sample
 - 14 children with their parents/guardians
 - 8 nurses

Methodology continue

- Data collection
 - Structured questionnaires
 - Individual interviews
 - Children and parents/guardians
 - Demographic and socio-economic characteristics
 - Knowledge of ARF/RHD and benzathine penicillin secondary prophylaxis
 - Reasons for missing injections
 - Nurses
 - Knowledge of ARF/RHD
 - Patient registration and follow up
 - Experiences with benzathine penicillin injection delivery

Methodology continue

- Data analysis
 - Audio recorded interviews
 - Translated and transcribed to English
 - Tabulation of data and common theme identification
- Ethics statement
 - Approved by Solomon Islands Research and Ethnics Review Board





Knowledge of ARF/RHD and prophylaxis	Number of patients/missed injections
8 Patients – some sort of heart problems	1 (1 injection)
4 patients responses – "I do not know"	1 (2 injections)
11 patients – highlights benefits from injections	3 (3 injections)
3 patients do not know purpose of injections	1 have missed > 3 years of injections

Examples

Question

Quote

What have you been told about ARF/RHD? Tell me your understanding of ARF/RHD? (GA), 10 years of age: "They said that I have a hole in my heart"

(JT), 11 years: "I have a heart problem...I was told that I need to drink medicine"

(RI), 12 years: "It's rheumatic heart disease, I forgot what they told me about it"

(SI), 13 years: "I do not remember...Rheumatic heart disease...I do not know"

Reasons for missing injections

- Not taken to clinic
- No nurse at clinic (village)
- Feeling lazy
- Forget injection date
- No transport (bus fare)
- Fear

Parents/guardians responses

- Parents and guardians limited knowledge
 - knew their children have some sort heart problem
- Parents viewed that treatment would make their child better
 - Showed sense of trust in doctors
 - Have fear for missing injections

Examples

Question

Quote

What have you been told about your child's condition? Tell me about the condition? Parent of AB: "I am no really sure, but I was told to keep her and prevent her from eating foods that are not good for her "

Parent of DF: "He has a sickness in his heart. He has one small hole in his heart and he has to get injections every month to prevent his sickness "

Parent of JT: "....she starts to have shortness of breath before we notice that her heart was beating fast...I do not know the name of the disease"

Reasons for missing injections

- Living with guardians
- Relocation
- Parents failure
- Nurse not responding well
- Forget injection date
- Busy



- Generally good knowledge about ARF/RHD and the treatment
- Have some difficulties with secondary prophylaxis delivery
- Report of death and shock after injection
- Not active with patient registration & case notification

Examples

>	Theme	Quote
)	Understanding of ARF/RHD and the treatment	Mataniko Nurse: "It is a one of the condition of the heart, which cause by streptococcal infection of the heart".
		Kukum nurse: "Benzathine Penicillin is an antibiotic that lasts in the body for 28 days. Protects the body from bacteria that can or commonly cause infection that will damage the heart".



Quote

Difficulties with secondary prophylaxis administration

Theme

Kukum Nurse: "Pain that is induced to the patient when giving injection shot. Client might fall into shock and blockage when giving injection to the patients"

Rove Nurse: "Benzathine penicillin injection block when injecting. Death happened straight after BPG injection given.. experienced in the clinic".

Discussion

- Patients and families
 - Limited knowledge
 - Adherence to penicillin injections were good
- Nurses
 - Have adequate knowledge
 - Needs support
- Secondary prophylaxis delivery
 - Needle and syringe blockage
 - Safety concerns
- National RHD program
 - Important program needs to be sustained

Education materials





Vodafone

Foundation

Group

Conclusion

- Patients/caregivers have limited knowledge of ARF/RHD
- Nurses have adequate knowledge of ARF/RHD
- Good adherence to secondary prophylaxis despite limited knowledge
- RHD program neglected

Recommendation

- Health Education
 - Age & Caregiver friendly
 - Community awareness of ARF/RHD
 - Refresher courses
- Revive RHD program
 - Create posts/ Capacity building of health workers
 - Improve case detection and registration and follow up
 - Set up systems for reporting adverse events
 - Review of deaths associated penicillin injections

Bigfala Tagio Tru lo..

- Prof Trevor Duke
- Dr Titus Nasi
- Prof John Vince
- Paediatrics Clinical Supervisors and colleagues at PMGH
- All the children, their families and nurses participated in this study
- Emma, Moira, Hicks and Flora for photos

Reference

- Michael D Seckeler, Tracey R Hoke. The worldwide epidemiology of acute rheumatic fever and rheumatic heart disease. Clinical Epidemiology 2011:3 67–84.
- Diagnosis and management of acute rheumatic fever and rheumatic heart disease in Australia. An evidence-based review. National Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand, 2007.
- Patience Olayinka Akinwusi, Johnson Olarewaju Peter et all. The new face of rheumatic heart disease in South West Nigeria. International Journal of General Medicine 2013:6 375-381.
- Liesl J. Zuhlke, Andrew C. Steer. Estimates of the Global Burden of Rheumatic Heart Disease. Global Heart, Vol, 2013. 189-195
- Teuila Percival. Pacific Health Review. Issue 16. 2012
- Titus Nasi, Teatao Tira et al. Insights from the Pacific Rheumatic Heart Disease Prevention and Control Programme.

Thank You

