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

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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
Results
<table>
<thead>
<tr>
<th>Knowledge of ARF/RHD and prophylaxis</th>
<th>Number of patients/missed injections</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 Patients – some sort of heart problems</td>
<td>1 (1 injection)</td>
</tr>
<tr>
<td>4 patients responses – “I do not know”</td>
<td>1 (2 injections)</td>
</tr>
<tr>
<td>11 patients – highlights benefits from injections</td>
<td>3 (3 injections)</td>
</tr>
<tr>
<td>3 patients do not know purpose of injections</td>
<td>1 have missed &gt; 3 years of injections</td>
</tr>
<tr>
<td>Question</td>
<td>Quote</td>
</tr>
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<tr>
<td>What have you been told about ARF/RHD? Tell me your understanding of ARF/RHD?</td>
<td>(GA), 10 years of age: “They said that I have a hole in my heart”</td>
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<td></td>
<td>(JT), 11 years: “I have a heart problem...I was told that I need to drink medicine”</td>
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<td></td>
<td>(RI), 12 years: “It’s rheumatic heart disease, I forgot what they told me about it”</td>
</tr>
<tr>
<td></td>
<td>(SI), 13 years: “I do not remember...Rheumatic heart disease...I do not know”</td>
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</tbody>
</table>
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

<table>
<thead>
<tr>
<th>Question</th>
<th>Quote</th>
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<tbody>
<tr>
<td>What have you been told about your child’s condition? Tell me about the condition?</td>
<td>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”</td>
</tr>
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<td></td>
<td>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”</td>
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<td></td>
<td>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”</td>
</tr>
</tbody>
</table>
Reasons for missing injections

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

• 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

<table>
<thead>
<tr>
<th>Theme</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding of ARF/RHD and the treatment</td>
<td>Mataniko Nurse: “It is a one of the condition of the heart, which cause by streptococcal infection of the heart”.</td>
</tr>
<tr>
<td></td>
<td>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”.</td>
</tr>
<tr>
<td>Theme</td>
<td>Quote</td>
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<tr>
<td>Difficulties with secondary prophylaxis administration</td>
<td><strong>Kukum Nurse:</strong> “Pain that is induced to the patient when giving injection shot. Client might fall into shock and blockage when giving injection to the patients”</td>
</tr>
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<td></td>
<td><strong>Rove Nurse:</strong> “Benzathine penicillin injection block when injecting. Death happened straight after BPG injection given.. experienced in the clinic”</td>
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</tbody>
</table>
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
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


• Titus Nasi, Teatao Tira et al. Insights from the Pacific Rheumatic Heart Disease Prevention and Control Programme.
Thank You