ARF Child Patient Interview Schedule

INTRODUCTION
(purpose of this is to make the interviewee feel comfortable)

- Introduce yourself
- Reason for interview (explain research)
- Ethics (explain consent form and any ethical issues)
- Ask the patient if they have any questions.
- Thank the interviewee for their time and willingness to participate
- Ask the interviewee about themselves (how they are feeling etc.)

Disease History/Admission to Hospital
Probe for information about the patient’s health.

There will be two possible types of patients within this group:

- Patients who have recently been diagnosed with ARF/admitted to the hospital
- Patients who were in hospital, but have since been discharged

In both instances we want to elicit information about their experiences and probe for information on the health seeking process/behaviour. Adapt questions appropriately for each type of patient i.e. pre/post hospitalisation/diagnosis.

So your child has been diagnosed with ARF, what can you tell us about his/her experience of being ill?

- Why has he/she been admitted today OR why was he/she admitted before?
- How was he/she feeling before going to the clinic/hospital?
  - How long did they have the fever before going to the clinic?
  - Do you remember your child ever having a sore throat?
  - Has he/she had previous episodes of ARF before seeking care at the clinic/hospital?
- What made you decide to seek care at the clinic/hospital at that particular moment?
- What are your child’s symptoms?
  - Probe: chorea, arthritis, skin rash, fever, shortness of breath
- What did you think it was?
  - Probe: malaria
Relationships with Health Professionals & Understanding of Disease

Understanding the patient-provider relationship aids our understanding of their decisions made in relation to health-seeking behaviour as this may or may not have an influence on their disease management/knowledge.

- When your child was admitted/diagnosed, what did the doctor/nurses tell you about their illness?
  - Probe: ARF, Sore Throat, relation to RHD, knowledge on the progression of the disease
- Do you see the same doctor/nurse each time you go to the clinic/hospital?
- Did the doctor prescribe any medication?
  - Probe: secondary prophylaxis, penicillin allergies, knowledge of treatment/disease management

Health Seeking Behaviour

Seeks to try to identify which factors made the patient decide to seek care at this particular point in time.

- What do you do when your child feels ill?
- How have you been looking after him/her until now?
  - Probe: Support Network; family and friends
- Did you use any home remedies?
- Did you see anyone else for the symptoms your child had?
  - Probe: traditional healers, stigma attached to disease/symptoms (e.g. fear of speaking out because of witchcraft)
- Do you visit the clinic/hospital with your child regularly?
  - Probe: Secondary prophylaxis

Sub-theme: Social Perceptions of Disease Characteristics

For people who described chorea-like symptoms: we want to know about the social structure of the community i.e. values, beliefs etc. factors that influence the way in which people think about disease(s). This can allow for the following probes as well as reveal further information that we did not know about prior to the interview.

- What did you think when your child experienced strange movements?
- What did other people think?
  - Probe: Chorea; Witchcraft

Impact on Daily Life

Understanding the impact of illness on the patients’ daily lives can aid the understanding of health-seeking behaviour and adherence (or lack thereof) to long term treatment.

- Is it easy to get to the hospital?
- How do you get to the hospital?
• Distance: is it far?
• Transport: is it an issue?
• Cost: can you afford to travel to the hospital?
• Probe around
  • Distance from nearest health facility that can provide care
  • Family support
  • Financial constraints
  • Current health system provisions to enable and facilitate entry into health system
• Finances:
  • How does having a child with ARF/RHD affect your work and income?
  • Can you afford treatment/medication?
  • How does the cost of treatment/medication affect the household?

Awareness
Understanding what and how much patients know about their illness and RHD awareness.

• Did you know that ARF is linked to the bug (use the culturally appropriate term) that causes a sore throat?
• Did you hear about RHD before becoming ill/your child becoming ill?
• Do you know what you can do to prevent ARF from developing into RHD?
  • Probe: penicillin; adherence to secondary prophylaxis

Thank the patient/parent for their time and participation