STOP: Lay Concepts Matter!



MY HEALTH OUR HEALTH (MHOH)



Supported by the Sexual Health and Blood-Borne Virus Program, West Australian Department of Health April 2015



Culture and health care: Lay understanding of illness, suffering and healing:

Background:

- It meant gaining better understanding of how health messages were being promoted and understood by communities especially in areas of:
- And developing methods of communications that were more compatible to target communities' understanding of viral Hepatitis

Barriers for Target population

Frequently cited Factors:

- Low levels of Literacy
- Language barriers
- Misconceptions of the virus and transmission routes
- Lack of knowledge of services and access to services



Our Experience

- The focus was on:
 - ♦ Engaging communities in the MHOH initiatives
 - Understanding how best to deliver information and communicate messages on importance of testing, treatment, and prevention
- Information sessions were held at community events and group sizes varied from 30-150
- Power point presentations/ "lecture type" approach
- Members of MHOH team part of the sessions to make observations and collect feedback.

Feedback suggested:

- Opportunity to have interactive feedback was difficult, as people came in at varying intervals throughout the session. This was especially so with the larger group
- Several distractions with large group
- Manageability a difficulty
- People from various backgrounds together with gender roles played a determining role in how information was being listened to or accepted. E.g. Women usually sat behind or arrived late and busy with children.
- ◆ There was minimal to no uptake of Brochures and information left at the back of the room on the table.
- ◆ Although having refreshments was helpful to engage people and have them stay back, it was not an effective incentive in large groups
- Feedback suggested that the communities perception was a health project run by MSCWA.
- Information about Hepatitis was perceived as another information session an seriousness as a health care message was not being effectively communicated



Objectives:

- Enhancing CaLD community engagement in prevention of Hepatitis B and C
- Enhancing interpretation of information on testing, treatment and prevention and translating it into behaviours



Methodology

- Qualitative data gathering: Group feedback discussions and observations
- Iterative-inductive approach aimed to use the data collected each time to feed into the following as part of the learning process

Note: Given the limitation of time and resources, effective information sharing had to be ensured and hence this approach.



Project based on: Explanatory Model (EM) - Arthur Kleinman

Emphasis: People's Lay beliefs/concepts influence how they make sense of their "illness"

- What causes my sickness
- Why did I become sick at this particular time
- How does sickness work inside my body
- What will happen to me
- What will this illness do to me
- How should it be treated



Expert's Model

- Formal Logic
- Explicit connections
- Driven by therapeutic imperative
- Source: Formal training and knowledge and clinical experience

Patients Model

- Informal logic
- Tacit connections
- Driven by immediate practical needs
- Source : Family, community and friends



Training Format changed to incorporate the key elements of EM

- 1. What do they call their problem? What name does it have?
- 2. What they think has caused the problem?
- 3. Why do they think it started when it
- 4. What does their sickness do to them? How does it work?
- 5. How severe is it? Will it last a long or short time?
- 6. What do they fear most about their sickness?
- 7. What are the chief problems their sickness has caused them?
- 8. What kind of treatment do they think they should receive? What are the most important results they hope to receive from the treatment?



Methodology cont.

Information sessions were held at smaller venues

Purpose of information sessions - gaining enhanced understanding of viral Hepatitis, testing and treatment

Information sharing Group: Smaller groups of between 10-15 people

Approach: Interactive, simulations, visual aids, short sentences, and simple language

Feedback collection: Interactive group discussions and members of MHOH team part of the sessions to observe and collect feedback.

Outcomes/ Results

Outcomes were measured by behavioural changes:

- Enhanced uptake of testing (350 people in 7 days)
- Enhanced uptake of treatment and follow up with GPs
- Enhanced understanding of the importance of health care



Discussion: Importance of Lay concepts:

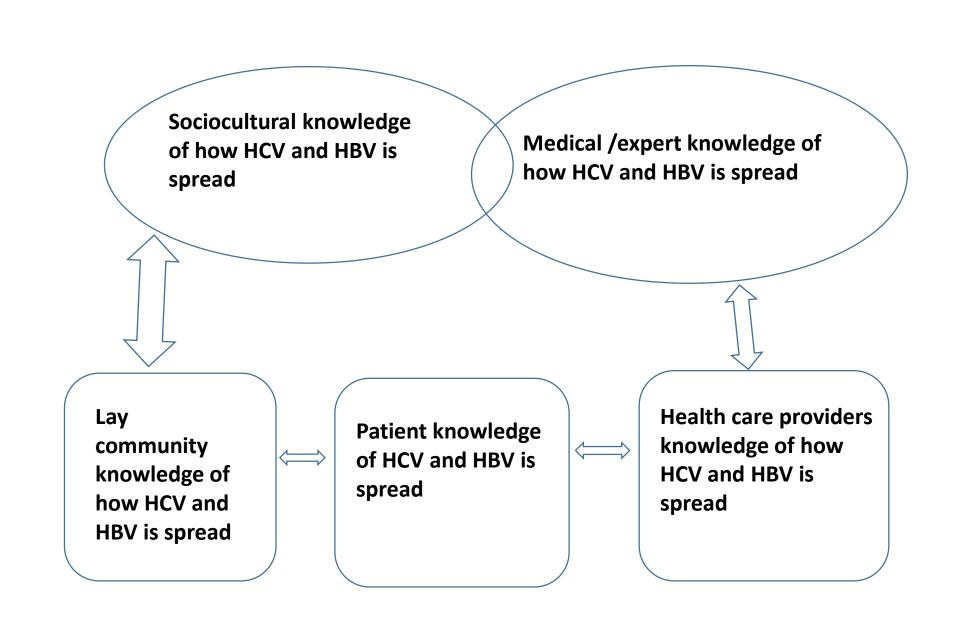
- Smaller groups and Information session format based on Kleinman's EM can be useful
- Using learning from what communities understood about Hepatitis, its transmission routes, symptoms and treatment in developing content of the information session
- Reformatting the information content and approach to suit community's literacy needs and their understanding of the Viral infection (and not that of the Expert).
- Flexibility and not "one model" suits all approach
- Breaking the viral infection in terms of symptoms and how it affects the body - as most communities understand illness though bodily symptoms



Discussion: Importance of Lay concepts:

- IMPORTANT: Recognising that Hepatitis is seen more as an illness that affects one's standing in the community and that of the family. Shame and stigma play a major role
 - Therefore the focus was not on the viral infection but on empowering communities with skills of behaviour change
 - Empowering community leaders with simple messages in accessing services (please refer to slide 10). As the core understanding of illness is "shared information within communities and not necessarily what the experts say", empowering community leaders with information is essential.





Thank you

Any Question?

