

Interpreting adherence: a social contextual perspective

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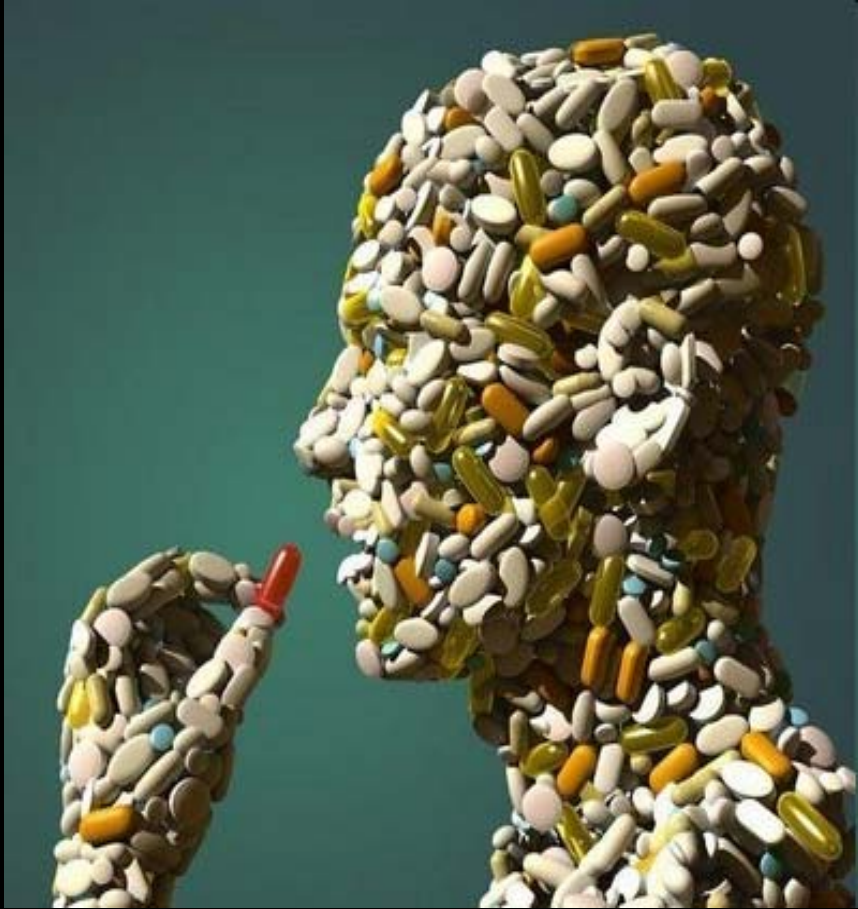


Adherence

*The biggest
single problem
in our trials!!*



Outline



- Commoditisation of illness
- Sociality
- Defiance
- Implications for interpreting adherence in trials
- How VOICE C will address these concerns

Peter, a 32-year-old patient, had been suffering from seizures ... He was now receiving a disability grant. He claimed that he was taking his medication regularly, but his records showed that he had been reporting a seizure once a month. In the consultation room, Peter was teased about the possible connection between his regular monthly seizures and his monthly disability grant. Peter joined in the joking, but was adamant that he was taking his tablets regularly.

Epilepsy, then, becomes a meal ticket and compliance the test or trial that the patient undergoes and either passes or fails.

Segar, J. (1994). Negotiating Illness: Disability Grants and the Treatment of Epilepsy. *Medical Anthropology Quarterly*, 8, 282-298.

When Lily, a nurse, threatened Jeff, a diabetic, with the amputation of his foot if he did not begin to take his medication regularly, he replied that **she could amputate the entire leg because he had no intention of being compliant.** Lily could do little more than briefly chastise Jeff before walking away dumbstruck. For several days, the story of Jeff's rebellion circulated among the Warlpiri population. Those recounting the tale often laughed as they stressed the stunned look that appeared on the Lily's face when she heard his reply.

(...) she wanted to wake up from the nightmare. But, the drug wouldn't let her. Rebecca explained: "They are giving you something that could possibly save your life, so, on one hand, why not take it and live with the side effects. On the other hand, it's like you never get out of that cancer world, because that's a reminder every day that you've got something...and maybe you don't necessarily want to do that."

Shapiro, A. (2005). Irrational Choices, Unfathomable Outcomes: Patient Ethnographies In Pharmaceutical Research. *Ethnographic Praxis In Industry Conference Proceedings*, 2005(1), 173 - 178.



Socio economic context

- Access to reimbursements?
- Access to good quality care?



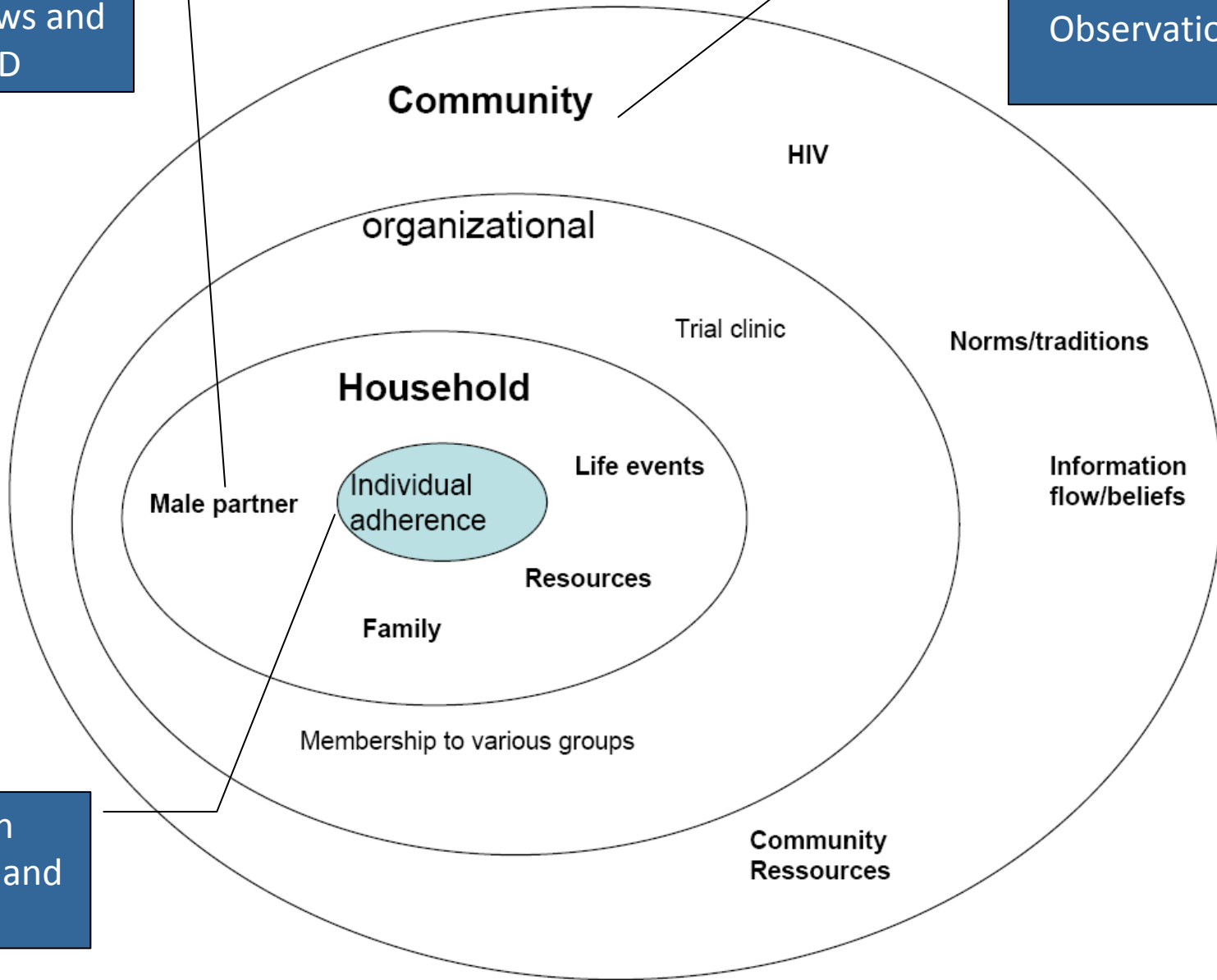
Sociality?

- Intimate relations
- Household relations
- Social relationships
- Religious
- Political
- Community



In Depth Interviews and FGD

FGD and Observations



In Depth Interviews and FGD

Activated in July 2010

Currently enrolling

1 Focus Group Discussion (FGD) with 5 Community Advisory Board (CAB) members completed on 27 July 2010

Next scheduled CAB FGD: mid-October

1 FGD with 12 Key Community Stakeholders completed on 16 September 2010



VERY preliminary findings...

- Complex social setting
- Numerous social problems 'the younger generation'
- Social group membership and networks
- Modern vs. traditional
- Intimate relations and the study product
- Public – Private domains of adherence

Conclusions

- Adherence – an issue of individual control
... but is also ... shaped by local context
- Social relations
- Materiality of everyday life
- VOICE C