Understanding the socio- cultural influences on TB prevention and management among Somali people in Sheffield.

A participatory approach

- Kate Gerrish, Mubarak Ismail, Andy Naisby
- Centre for Health and Social Care Research
- Sheffield Hallam University

Background to research

- Somali Community organisations and health care professionals confirmed that the research focus is a priority issue
- TB, diabetes, mental health and dental health consistently raised as health priorities by Somali communities
- 25-30 TB notifications in Somali community each year in Sheffield
- Challenge of growing proportion of TB patients of African origin
- Inspiration from Alberta project, Nancy Gibson

Research Aims

- To understand socio-cultural influences on the prevention, diagnosis and treatment of TB
- Identify culturally appropriate health promotion initiatives regarding the prevention of TB
    - Facilitators
    - Barriers
- Support health care professionals to provide culturally appropriate care in regard to
    - Screening, diagnosis and management of TB

Somali Community in Sheffield

- Estimated numbers between 5,000 to 10,000 people
- Second largest ethnic group in Sheffield
- First arrivals settled in Sheffield in 1950s to work in steel industry
- In 1990s during the civil war large numbers of Somalis fled Somalia to join their families members abroad.

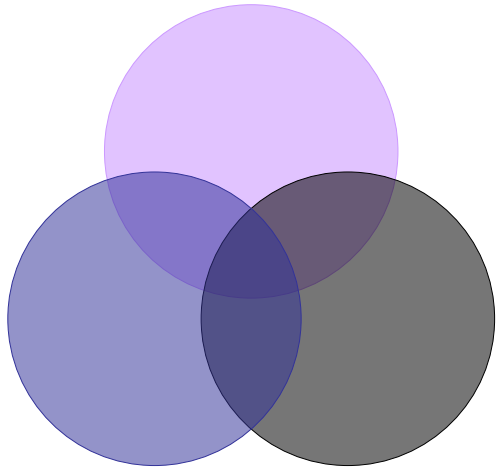
Methodology

Community participatory research approach

partnership working between researchers, community members and heath care professionals

Fieldwork

Establishing links with community organisations and opinion leaders



Interviews

Somali opinion leaders

Somali community members

Patients and ex-patients

Health care professionals

Focus groups

Somali community members

Separate groups for men and women

Use of vignettes / case studies to provide focus for discussion

Framework approach to data analysis – Ritchie and Spencer 1994

Engaging with communities

- Drawing upon expertise of Somali community
  - Advisory panel comprising community members and health care professionals
  - Somali research assistant
  - Somali community researchers Faiza, Faiza, Anab, Mohamed
  - Networks with local Somali opinion leaders and community organisations
- Capacity building
  - Developing research expertise among Somali community

Presence in the community

Traditional view of TB

- ‘In Somalia when people are walking near the TB clinic they used to cover their mouth and nose with their clothes or hats, there were no one entering the hospital even people who have family members in the hospital wouldn't go.

- Anyone who have TB will be isolated not only him but his family also will be stigmatised and that's why they don't tell anyone because they don't want to be’

- Many reported a reduction in stigmatising although still strongly expressed in young men’s focus group and community very aware of it’s influence.

- TB is strongly associated with poor living.

Understanding/knowledge of TB from focus groups

- Low levels of understanding of non pulmonary TB
- Associated with café culture
- Stigma levels felt to be improving by many but still very significant
- Variation in understanding how the disease is spread.
- Widespread association with food, drink and chewing Khat
- Hereditary nature considered a factor by some
- Most people are aware of airborne transmission

Focus group

Cafe culture

Preliminary findings: Health care professionals

- TB can be difficult to diagnose
  - "It's not diagnosed early, it can takes months to diagnose someone with TB"
- Impact of stigma associated with TB
  - Attitudes towards TB are changing – less stigma than 5 years ago
  - Contact tracing can be difficult
- Health care professionals have variable understanding of the Somali community
  - Primary care practitioners tend to be more knowledgeable than hospital practitioners
    - Need to view TB diagnosis and management within a broader context (e.g. housing, overcrowding, unemployment). view shared by Somali opinion leaders

Patient experience

- Many problems reported around diagnosis
- Multiple GP visits prior to diagnosis
- Often low levels of trust and confidence in GP system, frequently seen as barrier to hospital referral
- GPs almost set up to fail as patient wants diagnosis and cure
- Mostly high satisfaction with Hospital services and TBSN

Lack of confidence in health care system

- ‘They don't care, take the piss when I go there and say I want to see the doctor they will tell you come back next week, most people are there, I go there when I had flu and they will tell to come back’

- ‘Doctors are useless. I constantly told my GP that I had TB and want to be investigated and treated for TB and when he got tired of me he told go home you don't have anything serious ‘

- ‘ GPs don't refer you to the hospital for further investigation, people say that's the TB clinic or that's where someone's kidney has been stolen and then you get scared and tear the letter of appointment’

Reported racism

- ‘They will give more time to white patients but to people from Somalia and Bangladesh not, he treat them like shit.’
- ‘ my GP and he just do things the way is done in third world, he will give appointments to his people first and then will give you an appointment after two to three weeks.’
- ‘When you ring for an appointment they will say we don't have but when someone that they know rings they will give an appointment to them and they can tell why is ringing is it Somali or Asian.’
- Other people reported being very satisfied with GP service. ‘*Doctors in this country are very good and we thank them very much*’

Longer term psychological impact of TB diagnosis

- Some lost jobs, fell out of education, lost confidence
- Some were dropped by friends, experienced loneliness
- Some reported wariness of others persisted beyond period of infectivity/treatment
- Could harm marriage prospects
- Many expressed potential for loss of status
- Clinical psychology pilot project

Service delivery

- Often very aware of other service models in Europe and elsewhere.
- Very positive reports of being listened to, spending time.
- Appreciation of Somali health care workers
- Many requests for more thorough health checks on arrival in UK
- Appreciation of holistic model, acknowledgement of social/psychological

Key messages for future work

- Importance of TB awareness in primary care and community
- Building trust
- Value of advertising accessible service
- Value of giving time and listening
- Wealth of information for future awareness work with community

Thank You

Preliminary report available May/June 2009

Website. professor Kate Gerrish Sheffield Hallam University

For more info email: m.m.ismail@shu.ac.uk

or andynaisby@hotmail.co.uk