LIVING WITH CHRONIC ILLNESS: THE EXPERIENCES OF SUFFERERS & THEIR FAMILIES IN EAST LONDON

ENGAGING WITH GHANAIANS: BREAKING THROUGH A CULTURE OF SILENCE

Preliminary qualitative research findings: 2 ***October 2005***

Why is this research important?

East London communities are heavily affected by chronic illnesses and disabilities. These health problems have serious implications for individuals, households and society as a whole. Government and community organisations are working to support people with chronic illness, in particular by helping individuals to find jobs and to manage their health. However, we need to know more about the personal experiences and needs of sufferers and their families to ensure that such initiatives really work to improve individual lives.

Findings will be shared with government and non-government agencies with the aim of improving the services and benefits being provided to sufferers of chronic health conditions. Findings will also be shared with community participants through workshops using community languages.

What is being done in this project?

A team of university researchers is working alongside local people who have been trained to work as Community Researchers. To capture the diversity of people's experiences, the team has been working in four different locations across East London talking to men and women, younger and older people, and people from different ethnic backgrounds. The research focuses in particular on people identifying themselves as Ghanaian, Pakistani, Bangladeshi or White English. To-date there has been very little research into health among UK Ghanaians. Invariably, this group is subsumed under the broader category 'Black African' thereby concealing important diversity. This project will therefore provide valuable new information.

The project includes three phases. Phase 1 involved a 'Rapid Assessment' using interviews, informal conversations, mapping/ranking exercises and observation. The aim was to gain a broad overview of the patterns of social, economic and cultural resources available to community members and to understand how chronic illness is perceived and the prominence it has in people's everyday lives.

Phase 2 began in August 2005 and, building on the knowledge gained in Phase 1, consists of a series of detailed interviews with (i) individuals of working age who are suffering from a chronic health condition, and (ii) other family members or carers.

Phase 3, in January 2006, will involve a series of informal meetings in which emerging findings will be shared. This phase will allow community members to consider the validity and usefulness of study findings, and to comment on the ways in which they represent their community.

What has been done so far with Ghanaians?

In June 2005, an intensive period of 'Rapid Assessment' was completed over a period of seven working days in West Green Road and surrounding streets, plus Broad Water Farm in Haringey. This seven-day period of assessment followed a number of preparatory visits and contact with numerous people living and working in the area.

Six distinct data collection tools were employed by the team over the seven day period: transect walk, key informant interviews, ethnographic interviews, and two types of small group discussion. Individuals were contacted in a variety of locations including churches, shops, job centres, travel agents, cafes, hairdressers, community centres, work places, and parks.

What have we found out so far about chronic illness among Ghanaians?

We have described the preliminary findings from Phase 1 in an earlier document available on our website. Here we highlight just a few of the important themes emerging from our work with Ghanaians.

Community: complex networks and resources

The majority of individuals that we spoke to felt it made sense to speak of a 'Ghanaian community' with distinctive characteristics, including being peaceful and law-abiding, and took great pride in their 'Ghanaian culture'. However, respondents often saw their community as spanning several locations across London having Ghanaian concentrations and key resources such as community centres and churches. Furthermore, many Ghanaians appear to have complex sets of allegiances. A plethora of community organisations and associations exists established on a variety of commonalities including hometown in Ghana, school, church, clan and language group. Therefore, while most agreed that being 'Ghanaian' means something in the UK context, bringing with it certain claims and obligations, respondents also highlighted more micro-level 'communities' to which they belong. Divisions were also recognised along social class and educational lines. Most respondents had very active ties to Ghana and many live their lives between the two countries. The importance of contributing to development efforts in Ghana was a common sentiment.

Community: norms and expectations

Community-level norms and values shape the behaviour of individuals with chronic health conditions as well as their family members and carers.

We were interested to know how local people understand and talk about health. Among Ghanaians, there appeared to be a current awakening to the fact that chronic illness is a problem afflicting many people in their community. Discussions with Key Informants, such as priests and community workers, revealed their growing awareness of the significance of these issues, in particular the high prevalence of hypertension and premature death. The relative infancy of this public awareness appears to relate to the 'culture of silence' that exists.

Across all four communities, a prominent theme was the reluctance to openly discuss ill-health and the concealment of incapacity. However, these norms appear particularly extreme among the Ghanaians. Several respondents told us that even when someone dies people do not find out the cause. Respondents were afraid of being judged by the wider community. As one respondent said: *"the news even gets back to Ghana, everyone knows that your family is not functioning well!'* However, the almost complete silence around illness among Ghanaians requires further explanation. A contributory factor may be religious ideas about 'attribution' -- the notion that talking about an illness or problem will mean that the speaker will then acquire that problem. Furthermore, beliefs regarding witchcraft appear to act as obstacles to disclosure for some. In addition, the very strong priority given to income generation through work may also encourage reluctance to acknowledge illness, even to oneself and close family members.

In common with the other communities, secrecy was further heightened for mental illness and there was evidence that stigma related to mental illness presented barriers to individuals seeking and receiving support. One respondent told us, *"I have not told my family back home about this. I don't tell anyone about her [wife with severe depression]. You know Ghanaians."*

Intra-household relationships

For many living with a health condition, their support and care rests centrally with their family. However, it was also evident that such support cannot be taken for granted and is frequently a source of tension. A large proportion of our Ghanaian respondents were single, and marital breakdown was felt to be an increasing problem. The themes of isolation and loneliness were prominent in respondents' stories with many contrasting the experience of being in Ghana, where one is constantly surrounded by family members, with living in the UK where relatives are distant and one feels alone. Respondents also highlighted changing relationships between parents and children and lessening respect for elders was a concern for many.

Financial hardship

In all four locations, the link between chronic illness and financial hardship was a prominent one, particularly among male respondents. However, among Ghanaians there was a strong reluctance to discuss financial issues, and it appears that external expressions of wealth are an important element of social status for many Ghanaians. Social pressure makes being able to consume conspicuously, both here and in Ghana, a priority for many.

Waged work and barriers to employment

Phase 1 fieldwork suggests a complex set of factors that affect whether or not someone with a chronic illness is economically inactive. Community and family-level norms regarding the position of formal employment in people's lives appear to be significant. Among Ghanaians, there is a strong focus on the importance of earning an income through work for both men and women. Individuals were found to be working long hours, often in multiple jobs and to express a definite preference for working over claiming state benefits. This was true even though many appear to be employed in unskilled, manual jobs and those with qualifications are often under-employed. The image of someone coming home tired after a hard day's work was a positive one for many Ghanaians. This strong 'work ethic' reduces the likelihood that sick individuals will withdraw from work (or even take time off to consult a doctor).

Social and religious participation

The importance of social participation to people's sense of well-being was a common theme. Respondents linked financial and other impacts of chronic health conditions to a reduced ability to maintain social contact. For many Ghanaians, 'coping' with chronic illness means being able to socialise, go to church, attend funeral services and interact with family and friends without people being aware of the problem. Religion plays an important role in coping with illness for many, both on a personal level, and also via church groups that may provide emotional and financial support in times of need.

Formal support: disparity and dissatisfaction

In relation to health and social services, we found huge variation in people's levels of satisfaction and personal experiences. However, among Ghanaians there appears to be in general a lower level of awareness of entitlements and 'how to play the system' plus a reluctance to depend upon state support compared to the other ethnic groups.

Immigration and residential status issues

Immigration issues were a prominent theme among Ghanaians. Chronic illness complicates matters for those with temporary (or restricted) rights of residence in the UK in various ways. Illness may affect people's reasons for being in the UK and their options for leaving the country. It may prevent individuals from pursuing proper immigration channels, and may mean that other family members are forced to give up work and in some cases overstay. Also, becoming sick without residential rights seriously compromises well-being as individuals are unable to access health or social care.

Key findings from Phase 1

Growing awareness of need to understand and address health needs of community:

- Concern about premature deaths
- Overwork believed to contribute to poor health
- Insecure jobs mean people ignore ill-health and continue to work

Culture of silence:

- Fearful to share experiences
- 'Not in our culture' to talk of illness
- Ignorance of causes and stigma make illness a taboo subject

Utilization of health services:

- Poor uptake of services
- Delayed health-seeking & not taking medications worsens health further

Reluctance to claim state benefits:

- Unfamiliar with system
- Preferring to work if at all possible

Living alone:

- Many live alone – families back home or marital breakdown
- Many single mothers

Immigration status is a concern for many.
Religion as a way of coping.

Engaging with Ghanaians: breaking through the culture of silence

Above we have presented some of the preliminary findings from Phase 1. Much of the discussion has been descriptive, and we are cautious regarding some of our conclusions. However, what is clear so far is that Ghanaians are more reluctant than individuals from the other ethnic groups to participate in the research project. A number of factors seem to converge to create this situation including: a strong tendency not to reveal health problems to others; an active ‘gossip culture’ and associated distrust of other community members; a strong work ethic and extremely busy working lives; and in some cases, beliefs regarding illness causation that encourage secrecy.

In response to these concerns the research team has been active in identifying multiple, trusted individuals within the Ghanaian community who can refer potential respondents to us. In addition, wherever possible, interviews are being conducted by non-Ghanaian researchers to reassure respondents of a confidential and non-judgemental environment. We have also expanded our geographical focus to include other parts of London aside from Haringey.

Importantly, those Ghanaians who have come forward to be interviewed have proved to be very valuable respondents. Furthermore, many have said how much they enjoyed the experience. The opportunity to ‘open-up’ about their lives in a confidential setting with a sympathetic listener has been very useful for most of our respondents. Nevertheless, our target for recruiting Ghanaians, both sufferers and other family members, is still well behind those for the other ethnic groups, particularly for men.

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Where can I find out more?

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How can I get involved?

Fieldwork will continue until December 2005. If you would like to be included as a respondent or if you know someone else who would be interested to participate, please contact us. **We are particularly keen to hear from people identifying themselves as Ghanaian, especially men, since they are currently under-represented in our research sample.** Alternatively, if you would like to attend one of our dissemination workshops in January 2006, please get in touch so that your details can be added to our mailing list.