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Project Synopsis

Quality of Life and Healthcare Communication in a Global Community

HIV/AIDS Strand

The Health Communication Research Centre (HCRC), as an interdisciplinary initiative within Cardiff University, co-ordinates communication and discourse based research in areas of health and social care. In association with the Centre for Language and Communication Research, we are part of a 5-year research programme in *Language and Global Communication* (funded by The Leverhulme Trust, 2001-2006, amounting to over 1 million pounds).

The strand in HIV/AIDS is devoted to exploring the Quality of Life (QoL) issues that surround the biomedical and socio-political dimensions of HIV/AIDS. What constitutes Quality of Life (QoL) - whether medically, socially or individually - is as problematic for people living with AIDS and for those who support them as it is for discourse and communication researchers. Within the increasingly institutionalised healthcare sphere, QoL remains a robust outcome measure as can be seen from the development and administration of context- and disease-specific QoL questionnaires. Beginning with a definition of QoL as the relationship between experiences and expectations of various stakeholders, we wish to explore how QoL issues are differentially realised in governmental and non-governmental literature. More specifically, we will focus on the tensions between notions of prevention, treatment and therapeutic support when it comes to specific actions and decision-making about life style choices. One of our assumptions is that current understandings of causes/sources of HIV partly determine how people normalise their experiences and expectations. Hence, having access to HIV/AIDS-related information in a globalised community may not necessarily lead to informed decision-making and changes in risk behaviour.

One important aspect of the project is to compare QoL issues concerning HIV/AIDS in different local and cultural settings. Based on the vast amount of work carried out in Europe, USA and Africa, we will focus on the Asian scene, and in particular undertake a case study in the Indian context, where HIV/AIDS is nearly becoming an epidemic.

This project will involve continued collaboration with NGOs such as ActionAid with reference to the cultural manifestation of educational programmes, including community-led peer education, as is the case with Stepping Stones.

The key research questions are:

- What are the tensions between health status and Quality of Life more generally and how are these weighted in the experiences of people living with HIV/AIDS? How are the discourses of diagnosis, treatment and therapeutic support managed in the individual and public spheres?
- How do different governmental and non-governmental organisations address issues of prevention and education and who do they regard as their main targets of attention? How does their actions (constituted in their communicative practices, e.g., use of metaphors, rhetorical devices) lead to particular conceptualisations of HIV/AIDS?
- To what extent cultural and social taboos shape people's understanding of HIV/AIDS and consequently, their attitudes towards HIV testing, risk behaviour etc? In what ways do QoL measurement instruments align with these complex social, cultural and interpersonal dimensions? How do various HIV/AIDS prevention campaigns accommodate cultural differences while also attending to social, economic, ethical and bio-medical issues?
- In what ways HIV/AIDS is symptomatic of other social and political ills, e.g., poverty, illiteracy, delinquency, sexual behaviour, gender inequality?

We aim to liaise with various public and private-sector agencies (e.g., WHO, UNAIDS, ActionAid, NACO) for whom our research findings will have practical relevance.

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