

Inaugural Lecture of Gillian Lewando Hundt, Professor of Social Sciences in Health

Given at the Launch of the Institute of Health 10.9.02

Local Voices on Global Health Issues

Colleagues, Guests, Friends and Family,

Thank you for this opportunity to address you today. It has been a pleasure to welcome you to this launch of the Institute of Health, which has only been made possible by the hard work and enthusiastic participation of so many colleagues within the Faculty of Social Studies. In particular I would like to thank the core team - Dr Maria Stuttaford, Dr John Moorhouse, and Nihid Iqbal for their commitment.

I hope you have had an opportunity to hear and take in the range of

- Multi-disciplinary social sciences research that is going on within the Faculty within the different departments and research centres
- Postgraduate awards in professional development in health and medicine, which are on offer from all the faculties.

Today 36 people presented on their research and teaching and these were just tasters, providing a tantalising glimpse of the variety of activity, reflection, debate and practice going on within the University.

The ethos of the Institute of Health is **inclusive, exciting and working at smooth interfacing between research policy and practice, and between medicine and the social sciences. Its aims are to:**

- **Profile externally the extensive but fragmented social science research in the area of health within the University**
- **Facilitate internal networking and the development of interdisciplinary and multidisciplinary research with external and internal partners**
- **Provide a gateway to flexible continuing professional development courses in health and medicine at the University**
- **Co – ordinate social science teaching within LWMS**

I am continually amazed by the talented researchers that I discover within the Faculty and across the University - it is a case of 'watch this space!'

In the tradition of an inaugural lecture or keynote address, one has to be

- brief,
- entertaining,
- not too erudite,
- give some indications of academic finesse,
- be both personal and scholarly,
- indicate how one's own work links to that of others.

A tall order for a short person, one might say. However, let's give it a go!

General Issues

Talking today about local voices on global health issues, I will be focusing on:

- **The role of social science research in public and international health.**

In particular, I will address issues of the impact of poverty on health and barriers to accessing care due to class, gender, ethnicity disability, age, region and religion.

- **The relevance and importance of local voices on these global issues.**

This is a plea for **eliciting local opinion, recognising and using local wisdom and knowledge, of both users in the communities we work with and health professionals.**

I will focus on **the importance of context**, whether this is a clinic, a village or a particular country.

There are **battlefields of knowledge in every setting, a variety of notions of expertise and experience** (Long & Long 1992). It is vital that local views based on daily, lived experience are not overlooked.

I am trained in both anthropology and sociology at Edinburgh and Warwick and have worked as a member of Faculty at Ben Gurion University of the Negev, the University of Birmingham, the London School of Hygiene & Tropical Medicine and for the last two years here at the University of Warwick. I work collaboratively with other social scientists, clinicians and epidemiologists (Lewando Hundt & Forman 1993). I am an unashamed hybrid who uses theory and method eclectically. Since Social Anthropology is a subject that is not well represented here at Warwick, I will spend a few words on its scope and approach. Social Anthropology focuses on learning about the lives of other people by:

- listening to words
- observing actions
- placing these within the wider social, economic and political context

The method of **ethnographic participant observation** means that it is not only about **what people say they do, but what they do.**

In addition, it means that you could look at anything in a small scale setting - households in a village or encampment, a hospital ward, the activities of a pharmacy:

‘Anthropologists provide rich descriptions of how people live and why they act as they do...a holistic approach to daily life’

Cynthia Myntti – The Anthropologist as Storyteller: Picking Up Where Others Leave Off in Public Health Research pp227- 236 in The Health Transition – Methods and Measures Eds. J. Cleland & A.G. Hill

We use a wide range of research methods including: participant observation, individual and group interviews, participatory appraisal techniques, surveys, document analysis, social biography or life histories, secondary analysis of data, narrative collection and analysis, taping and analysis of conversations;

- **The interfacing of research policy and practice through collaborative and multidisciplinary endeavour, involving partnerships between researchers and practitioners, policymakers and users from different levels, disciplines and fields of practice.**

My own view is that partnerships are crucial both for multi-disciplinary research and the development of policy and practice. This is not just about combining **different types of expertise**, but concerns **issues of mutual respect, developing individual and institutional capacity and adequate dissemination.**

So, in this talk I will use examples from my own work and lay to rest, I hope, the suspicion that I only choose research topics by their location in terms of tourist appeal rather than by their content or relevance!

Globalisation and Health

This is not another peroration on globalisation. I think it is a given that the process of globalisation has economic, political, social, cultural, technological and environmental aspects. This has been underlined by the debates at the recent Earth summit, which have focused on environmental issues. I would agree with Anthony Giddens in his Reith lectures of 1999 on globalisation that

‘Along with ecological risk, to which it is related, expanding inequality is the most serious problem affecting world society’

(Giddens, 2002: 16)

Health is part of both the global and the local. It is an important part of both public and private expenditure, of public policy and private decision-

making, affecting both populations and individuals (Lee, Buse, Fustukian 2002).

Practitioners of **clinical medicine explore the health of the individual**, whereas practitioners of **epidemiology and public health scrutinise the health of populations**. **Social scientists work in partnership with both** clinicians and epidemiologists in local, national and international settings. Our work reflects the **local and the global nature of health**.

Particular topics

The issues that I will be focusing on today to illustrate these three key themes will be drawn from my own research over the last thirty years. They are

- **Poverty & health – focusing on the example of water**
- **Access to drugs, both legal and illegal**
- **Communication between health professionals and their patients**

Of necessity, this will be a whirlwind tour delivered with broad brushstrokes.

I will be using vignettes from my own research, which will be based around the views and voices of the local people in the settings within which I have worked. This talk will focus on hearing their voices and on taking notice of their views.

These **local voices** will be those of people involved in studies in the Middle East, (parents - Negev Bedouin Palestinian Israelis and Palestinians in Gaza), in Kenya (health professionals on the Swahili coast) and in South Africa (villagers in Limpopo Province). I have learnt so much from their generosity and experiences.

Health and Poverty – a Policy Imperative

The impact of poverty on health is well researched and well documented. Addressing this issue is one of the priorities of current global, national and local policies.

The World Bank, whilst pursuing structural adjustment policies, also espouses **poverty reduction strategies** (Review of the Poverty Reduction Strategy Paper (PRSP) Approach: Main Findings 2001 World Bank)

The Department for International Development has, in the last few years, issued a number of policy papers addressing poverty. In 2000 they published '**Human Rights for Poor People**' and in 2001 '**Better Health for Poor People**'. Recently, they also have addressed the issue of water and its links

with poverty with a paper: '**Addressing the Water Crisis: Healthier and More Productive Lives for Poor People.**'

At the national level, the **Independent Inquiry into Inequalities in Health**, chaired by **Professor Sir Donald Acheson**, summarised and updated the evidence on inequalities in health in England (previously summarised by the Black Report of 1980 and the Health Divide of 1987). It made 39 recommendations of which only 3 were specifically aimed at the NHS and many were concerned with addressing the impact of poverty on health.

The later **White Paper on Saving Lives: Our Healthier Nation** (1999) targeted particular conditions such as cancer, coronary heart disease and stroke, accidents and mental illness. Its overall aim was linked to social justice, specifically, '**to improve the health of everyone and the health of the worst off in particular**' (DoH 1999 xiii)

At the local level, Health Action Zones and Healthy Living Centres are addressing issues of social exclusion and health. Locally, there are two Healthy Living Centres being set up in Coventry and one in Leamington Spa. There is a widespread recognition that poverty causes ill health and premature death.

At the same time as these policies addressing poverty, there have been moves of late to recognise the voices of the poor, the expertise of patients and to democratise professional – lay relations.

The groundbreaking work of **Robert Chambers** in his classic book 'Putting the Last First' (Chambers, 1983) has been taken on by the World Bank, and they have issued a report on the '**Voices of the Poor**' (World Bank 2001). Within England, the Department of Health report on the **Expert Patient** (DoH 2001) has emphasised the importance of hearing patients' views. The impact of consumerism, self help groups and lobbies and the availability of the information on the World Wide Web have facilitated this sea change.

Participatory methods are becoming more widely used. There are opportunities for new ways of researching, formulating and implementing policy and of providing health care.

There has been much research which supports attention to **lay concepts of health and illness** (Curren & Stacey 1986, Kleinman 1980); there is also a body of work on **illness narratives** and **health seeking behaviour** which has been growing over the last half-century.

There is a large amount of research on health inequalities – issues of differential access and experience of health and health care, depending on one's class, ethnicity, gender, age and region. Research at Warwick has focused particularly on gender, poverty and disability. Much of it has been done in partnership with users – both lay and professional.

Recently, more attention has been given to suffering, risk and the body. For example, Pierre Bourdieu's work 'La Misere du Monde' (Bourdieu *et al* 1993) became a best seller in France – and in England has sold reasonably as 'The Weight of the World – Social Suffering in Contemporary Society' (Bourdieu *et al*, 1999). Within anthropology, there has been more of a focus on **suffering and conflict** (Davis 1992, Hastrup 1993), whilst in sociology there has been increasing interest in **sociology of the body and of emotions** (Williams & Bendelow 1998, Williams 2001). The theoretical approach that I shall be adopting in this lecture is that of a political economy perspective, which will also be concerned with structure and agency and the 'room for manoeuvre' (Davis 1994) that people have.

So, to return to health inequalities and the impact of poverty on health. There has been much attention given in the recent Earth Summit to **water**. I am choosing to use the example of water as an aspect of the effects of poverty on health from my own work.

Water in Southern Africa

I am currently working with colleagues from Warwick, the London School of Hygiene and Tropical Medicine and the University of Witwaterstrand on a **Southern Africa Stroke Prevention Study**. This study is funded by the Wellcome Trust and is led by Dr Margaret Thorogood, a leading epidemiologist in this area, who is the Principal Investigator. The other co-applicants are: myself, as an anthropologist, Dr Connor, a neurologist and Professor Tollman, a specialist in public health.

Cardiovascular disease is beginning in rural Africa and the second most common cause of death after the age of 45 in these villages in the northeastern corner of South Africa, is stroke. There are many components to this study – epidemiological, neurological and anthropological.

In the latter, we are trying to learn about lay ideas of health and illness and household health-seeking behaviour. Stroke sufferers rarely go to the clinics or hospitals – they visit healers and prophets. The clinics have few drugs, can do little and there is a widespread belief that the reason one has a stroke is related to sorcery or witchcraft.

As one part of this study, we have a team of three local graduates and a study co-ordinator, who have been conducting rapid ethnographic assessments of villages using participatory techniques. During village community meetings, group and individual interviews, the topic of water constantly heads the list when people are asked about what are the health problems in their village. Here are some examples of what they say from a small village of Mozambican refugees:

Physically we are all right. Our only problem is water and electricity. We get water from ML, which is very far. It take us about 30 minutes to get there.

If I fetch water at ML using a wheelbarrow I go once or twice a day. Sometimes we go from one to five weeks without any water at this pipe. When this happens we pay cars to get water for us from nearby villages. We pay R1 per 25-liter container. However if I am paying a car it all depends on how much money I have at that moment but I pay from R2, 00 to R10.

The water that we use today we buy from a certain man who has made a borehole in his back yard. We pay 2: 50 for a 100 litres of water. The place where we get water is not very far; it is about ten minutes walk.

Our main problem is shortage of water in our village.

Water is very important such that now that we have to buy it is a serious problem. What if you do not have money to buy water while you desperately need it to cook? People who do not have money to buy water get water to drink from the river down there (pointing to the south) and it is bad because it will cause cholera for them.

The fetching of water takes up a large part of the day – using wheelbarrows with 25 litre containers, or hippo rolls. Although water pipes have been laid and the situation is much improved, access varies owing to where you live, whom you have available in your house to get water and how well maintained the local supply is. This is women or children's' work. Women complain of aching backs and legs. This is unpaid health work – and unclean water takes its toll.

Interestingly, the men are very ignorant about water. In this same village, one man declared that his children fetched water from taps and that there was no problem. At the community meeting in this village, a group of men with much debate, drew a map of the village and did not mark the correct water tap which the women and children accessed several times a day. This only emerged from watching and talking with women and children. A real example of the gendered division of labour!

The division of labour in the household means that men are often absent and that, owing to the gendered division of labour, women and children fetch water and wash clothes. Women's unpaid health work includes many hours of fetching water. Their concern is not only with the time, or the backache, but also with the clear health consequences of not having clean water easily available for domestic use.

Structure and Agency in this setting

These villagers have difficulty with access to water because of the historical and current structure of South African society. They live in what was, under apartheid prior to 1994, the homeland of Gazankulu. Their villages, like all the villages and towns of former Bantustans, are not on any map you buy over the counter. Some were displaced from the cities, the Kruger National Park, or

white farming areas and given infertile land to live on. Many of them are Mozambican refugees who have settled in South Africa over the last forty years. Their dependence on migrant labour, lack of access to water, electricity, schools and clinics, and their high unemployment (80%) is a consequence of the social structure of the society they live in. This is improving rapidly, but they still remain amongst the poorest in the country. They live close to the Kruger National Park, which has many private game lodges within it. The contrasts are stark.

In terms of ways to work within this social structure at the village level, people find ways to express their agency and find room for manoeuvre. There are winners and losers. A winner here is the man in the village who built a borehole in his backyard and charges his fellow villagers for the water R2.50 for 100 litres. The losers are: the Community Development Forum (CDF). They are trying to get a public pump constructed but are making no progress since the borehole owner is a member of the CDF.

Continuing the theme of water we move to the Middle East and look at aspects of shantytown living, in a vignette, which I will call:

Water, Rubbish and Rats

When there is no central supply of running water, there is also no drainage, sanitation infrastructure and no organised rubbish disposal. These are the classic conditions of peri-urban shantytowns throughout the southern hemisphere.

My early work was amongst the Bedouin of the Negev who were in transition from semi-nomadism to sedentarisation in planned urban towns. Some lived in encampments of tents, others in shantytowns of huts and tents and others in planned towns.

Like all Bedouin in the Middle East and indigenous peoples elsewhere, they are under pressure from the State to settle and vacate land, which once was 'useless' but is now valuable for development. This land is being sought for use as nature reserves, army manoeuvre areas, industrial centres, intensively irrigated farms or as areas for new towns.

These people are Palestinian citizens of Israel. They are the forgotten Palestinians who remained in Israel; they are offered urban settlement but no irrigated agricultural land, for that is only available to Jewish Israelis within collective villages – kibbutzim or moshavim. They live between rocks and hard places – but that is another lecture.

The lack of access to water when living in a tent or hut has consequences in terms of sanitation and the health of children, but in order to understand the social processes involved and to plan the interventions, social science is needed.

During the late 1980s I was approached by a colleague at Ben Gurion University of the Negev, who told me that several Bedouin men had complained to him about being plagued by rats in their homes. He approached me since I had a history of health-related research amongst the Bedouin and, in the early 1980s, had set up and managed a Bedouin Mobile Follow Up Service.

I contacted the vet based at the District Office of the Ministry of Health, who told me that the solution was for all families living in shantytowns without rubbish disposal or sanitation (40,000 approximately in 1989) to dig holes and bury their household rubbish in them. Dissatisfied with this answer and uncertain about the size of the problem, I set out to visit this particular shantytown with a sanitarian from the MoH and the Professor of Infectious Disease Control.

We arrived and asked some women who came out of their homes to see us, if they had a problem with rats. We were met with a torrent of information: the rats bit their children while they were sleeping, they ate baby chicks, and they gnawed holes in clothes. We were ushered into spotless homes and shown the rat holes in the walls, floors, cupboards and clothes. We saw the nesting boxes for the chickens on the top of poles so that the rats had a harder time reaching the eggs. My colleagues went to the wadi (dried up riverbed,) where the rubbish was thrown and visited the two local shops. Meanwhile, I sat in a spotless kitchen courtyard drinking tea, being told how the biggest rats lived down the latrines and scabbled around trying to bite you when you were squatting defecating.

The epidemiologist declared 'Never have I seen such proximity between the host and the parasite!' He showed us the two shops set close to each other by the main road. Both were constructed from sheets of asbestos. In the one on the left, you could put your hand under the asbestos from outside the shop and there were rat droppings in all the sacks of sugar, flour and rice. The other shop owner had cemented the asbestos to the ground and his goods were uncontaminated.

A community meeting was held in the kindergarten. It was well attended by men who sat on the small, red, plastic pre-school chairs. The spokesman kicked off by saying 'In most places the cats eat the rats, but here the rats eat the cats'. Poisoning them was proving ineffective since they would leave the poison and eat the food that it was scattered amongst. Also, the poison was a hazard for children and domestic livestock.

The sanitarian explained that rats could live without food but not without water so that the challenge facing the community was to make the whole place dry so that the rats would dehydrate and die. This sounded fine in theory but in practice the latrines were wet and the plastic water pipes were laid above ground from the outlet of the central water pipe on the main road some 100 metres away. There were also outdoor taps and bowls of water for livestock. No wonder the rats lived well!

The epidemiologist explained that all food could be stored in rat proof dustbins and containers and that the community could organise to dig the rubbish in the wadi into the desert with a bulldozer.

The anthropologist was concerned with both micro and macro issues concerning social structure. Drying out the latrines with a chemical spray would require a person from each family group to be trained so that they could work with the men and women in their extended family group. In addition, on enquiry it emerged that as this was an unrecognised village along with many other Arab villages in Israel, the Ministry of Health was responsible for rubbish disposal. They were outside the mandate of a regional council who would only provide central drainage and rubbish disposal services to recognised, planned towns.

We conducted a rat census, distributing cages at dusk and collecting them at dawn the next day and found that the returned cages only contained young rats. The Ministry had no cages big enough for these fat rats and we caught no full grown ones. The rats were proven to be carrying no infectious disease.

The immediate problem was addressed locally by the community in a piecemeal way. Subsequently, a few years later, a Palestinian Israeli NGO, Adalla, petitioned the High Court concerning the responsibilities of the Ministry of Health to unrecognised villages (Lewando Hundt 1999)

Structure and Agency

The lack of sanitation, rubbish disposal and running water were a direct consequence of being Bedouin Palestinians in Israel subject to State policies of displacement and sedentarisation. When nomadic, tents would be moved regularly to prevent the accumulation of rubbish or parasites and to find new water and pasture. Once in towns, the infrastructure of services was available, but whilst living in transition in shantytowns, living conditions were worse and the health of children suffered.

The women living in these huts had kitchens that were cleaner than mine, despite the rats, the sandstorms and the lack of paved floors, running water, sanitation or electricity. They were doggedly keeping their homes and their families well, despite terrible constraints. The decisions to take individual action in the home, community-level action to dry out the latrines and to contact an NGO to prepare a court case were all different levels of expressions of agency.

Bottle-feeding and the Growth of Children

One of the areas of health that were clearly affected by the lack of running water there – and indeed worldwide – was child health. Young children had repeated diarrhoea, in particular when being bottle-fed with milk formula. This impacted on their growth with high levels of stunting. This, as we know, was and is an international problem. The dehydration that accompanies

gastroenteritis makes it a killer disease and a cause of child mortality and morbidity.

In this setting of the Negev, it caused high rates of hospital morbidity since, relatively speaking, nutrition was good and there was free accessible health care in the clinics and hospital. But, in the 1980s hospitalisation was frequent and in the summer, two thirds of the children in the Paediatric Wards were Bedouin. The adoption of oral rehydration solution, there as elsewhere in the world, has lessened the mortality and morbidity, but it is still present as a problem.

Oral rehydration solution or treatment – placing small quantities of sugar and salt in boiled water and feeding it to a child with diarrhoea in order to rehydrate them – was marketed worldwide as a vertical programme by UNICEF, WHO and PAHO. This programme gave work to many medical anthropologist who explored lay beliefs on GE and established in Nicaragua (Scrimshaw & Hurtado 1988), Zimbabwe (De Zoysa 1984) and that local people in these settings had explanatory models of illness (Kleinman 1980) which identified many different types and causes of GE. In each of these settings parents considered that only in 2-3 out of the 6-8 types of GE would it be considered appropriate to attend a clinic. But in addition to ideas of causation of illness there are issues of access and patterns of decision-making in households, which are to do with gender and resources.

One case I remember from my fieldwork in the 1970s. I was living with a family in a tent, which was static, and near taps. I was working part time as a teacher. I came home to find the four months old baby girl quite sick for the fourth day in a row. She had been having diarrhoea but she was vomiting repeatedly. Her mother had been breastfeeding her and giving her one bottle made up from milk powder at bedtime. This was a common pattern in this society that was moving from prolonged breast feeding to a breast and bottle pattern. The mother was feeding her rice water, which was the traditional gruel for children with diarrhoea and indeed is very effective as a home made oral rehydration liquid. The baby seemed very apathetic, quiet and shrivelled.

The father was absent, working as a bulldozer driver on a construction site, where he also slept. When I asked about seeking help, the wife said, 'the clinic is closed. I can't go to the doctor or the hospital without my husband being here. I have no money. I am waiting for him to come home and doing what I can' The mother in law who was also a healer said 'What we need in this family are boys like your first born, not weak girls like her.'

What happened, you may ask?

Well, I was faced with the choice of observing a baby getting sicker and sicker and maybe dying; of writing this up as data or of intervening and 'contaminating' the data. I went to the hospital with the mother and the baby was admitted and given an infusion. The family then had a debt since they had no insurance, but the hospital never charged. The baby got a secondary infection, but survived and now is favoured second wife of one of her cousins,

and a mother of 8 children. The family took out insurance and I became a medical anthropologist rather than a social anthropologist with a continuing interest in health seeking behaviour at the household and community level and barriers to health care (Lewando Hundt et al 2000, 2001)

Subsequent research that I undertook with Professor Naggan and with support from the National Institute of Health Bethesda in collaboration with Dr Heinz Berendes and Dr Michele Forman revealed a high level of stunting of normal birth-weight children amongst the Negev Bedouin. This means being below the 2nd percentile in height for age. In a 1981-2 cohort of all normal birth weight babies born in the Negev, the level of stunting was 12% at 6 months, 19% at 12 months and 33% at 18 months. This was higher than the average rates of stunting being reported at that time in Bangladesh. It was a combination of poor living conditions, the use of milk formula and weaning, which took place when a baby was hospitalised (Forman *et al*, 1990 & 1995). Stunting is of course a global and historical health issue. Rowntree observed that children in York were shorter if they were from poorer families. Baird (1952) analysed the correlation between social class and occupation and height in Aberdeen.

So ends the section on Water and now we are going to move onto voices about drugs – prescribed and non prescribed, legal and illegal.

Drugs

The supply of and demand for pharmaceuticals is a global health issue. They are manufactured and distributed by multinationals, sold and consumed locally, within public sector clinics and hospitals and private pharmacies.

Pharmaceuticals are the topic of novels such as John Le Carre's *The Constant Gardener*. Companies such as Glaxo Smith Kline, Solvay or Bayer are key players in the financial markets and global private public partnerships are being set up to make drugs available for malaria, AIDS and TB (Buse and Walt 2000a, 2000b)

The WHO Action Programme on essential drugs was established in 1975 and there have been increasing moves to review national drug policies and make safe low cost drugs available to the entire population (WHO 1988).

Globally there are considerable sales of over the counter (OTC) drugs. Although these made up only 10.2% of sales globally in 1997, (Davies 1997) the proportion of OTC sales as compared to prescription drugs is much higher in developing countries since fewer drugs are regulated by prescription and private drug sellers are an important point of care.

Here, in England, NICE is reviewing evidence on the effectiveness of drugs and making decisions concerning whether they will be available within the National Health Service. These are important policy decisions affecting the quality of care and the financing of care.

Social scientists have studied a variety of topics:

- the history of multinational drug companies,
- the prescribing practices of the medical profession,
- the supply of essential drugs,
- the patterns of drug use in different settings by patients,
- the meaning and significance of drugs within specific cultural settings (van de Geest & Reynolds Whyte 1988, Nichter 1996, Hardon 1994).

Nichter argues that the popularity of pharmaceuticals points to the 'commodification of health' (Nichter, 1996). We consume medicines to feel better. One could surmise that in difficult economic and political situations over which people have little control, such as prolonged conflict medicines are viewed as a powerful short-term solution – something one can do – providing a quick fix or a magic bullet. Globally, self-medication is more common and in developing countries a wider range of pharmaceuticals are available OTC to do this with.

Drug shortages in Gaza

I carried out research in Gaza with Dr Susan Beckerleg and members of the Gaza Health Services Research Centre led by Dr Yehia Abed, Dr Ragda Shawa and Dr Ayoub El Alem, between 1994 and 1999. This was a study to evaluate and improve maternal and child preventive health services funded by the EC through the Avicenne Initiative in both the Negev and Gaza. (Lewando Hundt et al 1997, 1998, Beckerleg et al 1999, Lewando Hundt 1996, 2000).

We asked women and men: what were their experiences with antenatal childbirth and post natal and child health services? To our surprise, people kept on raising the issue of drugs.

They reported a problem of availability drugs within the UNRWA and Ministry of Health clinics. Drugs were free to all refugees and their descendants at the UNRWA clinics and within the MoH clinics the drugs were free to all pregnant women, children under 3 and those with insurance both refugees and residents. This is what they said in 1995 –6:

'Most of the time we don't find drugs in the clinic by the end of the month and they tell us to come on the first of the months but can the disease realise that It's not the first of the month when it decides to come? For this reason, I go to a private doctor'.

I come to the clinic first and if there is no medication I go to the private doctor

'Usually the patient carries this big list which contains a heavy antibiotic and a strong analgesic and asks for such drugs which I judge medically to be too

much for his condition. If you refuse to prescribe them, yet you cannot, you will have an inevitable quarrel. Some fight, like our fight for Jerusalem.'
(Doctor in MoH clinic)

Additional data were gathered in private pharmacies. We established that men bought drugs on behalf of family members, that there was a wide range of OTC drugs being sold and that both private doctors and pharmacists were benefiting from the shortages and erratic supplies at the primary care clinics. The poorer people were more likely to buy OTC drugs with advice being obtained from the pharmacist rather than prescribed drugs obtained through a visit to a doctor. There was a lot of multiple prescribing and people could not afford to purchase what was prescribed for them. So that there was also poor prescribing practice and a demand for drugs which was 'medically unnecessary' on the part of the consumer.

The study led subsequently to a locally led intervention, which addressed the erratic supply of drugs in government primary care clinics. A primary care drug store was set up in the Northern Gaza Strip for the clinics in that area to hold three months supply. This stood empty at first, as the MoH had no money to pay their bills. However, once the political situation worsened, there were donations and drugs arrived. The three month's supply was stored and then distributed to the clinics at regular fortnightly intervals, rather than monthly. This enabled the primary care sector to retain control over their drugs, rather than having to negotiate constantly with the Central Pharmacy, which also supplied the hospital.

This was successfully piloted and then replicated in other areas of the Gaza Strip and proved its worth during the recent Intifada al Aqsa when so many children were being wounded.

The local voices raising the issue of the lack of steady supply of drugs were the catalyst for this aspect of the study. Further work on prescribing, patient demands and pharmacy practices remains to be done.

Issues of drug supply and demand are part and parcel of health sector reform and health services research. Here at Warwick, we have others doing such research - on India the health economist Dr Anil Gumber, on Pakistan, Dr Shaheen Ali. In addition there are of course a multitude of projects that are ongoing in the UK based mostly within the Centre for Health Services Studies (CHESS) and the Centre for Primary Health Care Studies.

Now I would like to turn to another setting in on the Swahili coast of Kenya, in order to profile global health issues relating to **illegal** drug use.

Illegal Drugs in a Kenyan Coastal Town – Heroin

This is a beautiful setting, a paradise lost to tourist development that has brought sex tourism and heroin. This is a small town that was developed intensively by Italian investment in terms of the building of hotels. There is

high unemployment, the economy is one of feast and famine and is dependent on the tourist trade with a declining fishing industry. The coast is underdeveloped compared to other parts of Kenya. I suspect there may be people here who have been on holiday there. It is a sought after destination.

With the rise of tourism has come a rise in heroin use and commercial sex work amongst the young people. This has particularly affected the Muslim Swahili population.

The research profiled here was carried out in partnership with the Omari project a rehabilitation project for heroin users, which is the only free residential centre in Sub Saharan Africa. The movers and shakers of setting this up were Dr Susan Beckerleg and her husband. It is funded by the National Lottery and the British Council and is linked to the Bristol Drugs Project. Project management had noticed that women were less likely to come to the Centre and were more invisible as users. The research was funded by the ESRC to look at the health needs of female heroin users and the knowledge and practice of health professionals and practitioners.

I carried out interviews with health staff including nurses and doctors from the public and private sectors, Traditional Birth Attendants, and indigenous healers in the summers of 2000 and 2001. The first set of interviews revealed that

- The health personnel knew little about the size of the heroin problem in the town
- Nor how to treat the users for illnesses or for detoxification when they wanted to stop using.

Estimates of the numbers of users ranged widely. Ideas about what people did with heroin varied. Protocols for 'detoxing' revealed the use of a lot of medications. The users were not able to apprise the health personnel of their needs since this was a criminalised activity. The health personnel had no one to ask. The ethnographic fieldwork, which Susan Beckerleg carried out, enabled us to estimate accurately the number of users and their practices in the town. In order to access and understand the behaviour and practices of these young people, ethnographic fieldwork was necessary. Interviews or surveys would have been inappropriate and inadequate (Beckerleg & Lewando Hundt in press).

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During 2001-2, the community has mobilised together with the Omari Project to tackle this issue. The Muslim elders have asked the police to arrest dealers and have worked at entrapping them. They have also begun to offer work to young people who have spent 6 months at the Centre. Whilst I was there last summer, the imams from the coast met in the town to discuss what they could do. As part of the research study, three workshops were held for health

personnel to give additional information and training on how to meet the health needs of heroin users.

As one private doctor said

'These are our children and grandchildren. We cannot abandon them.'

LEGAL Drugs in Kenya – Highly Active Anti Retroviral Therapy (HAART) for HIV/AIDS

In 2001, the Kenyan Attorney General announced that a task force was to be established to review AIDS-related laws having regard to human rights standards and public health efficacy (Mwaniki, 2001a). The task force was set up against a background of high HIV infection rates nationally.

In 2000, sentinel surveys of antenatal women found HIV infection rates of up to 35% in urban sites, up to 31% in rural areas and that the overall estimated prevalence rate for adults aged 15 to 49 was 13.5% in 2000 (Republic of Kenya, 2001).

In June 2001 the price of HAART in Kenya fell to just under \$140 per month. Health officials and other observers widely believe that the price will fall again. Clearly, the price of HAART still disqualifies many from its benefits. Nevertheless, the lower prices enable many Kenyans, who until recently could not even consider HAART, to be treated for AIDS and not just for opportunistic infections associated with the disease.

It is not yet known how the availability of cheaper HAART will affect policy and practice relating to HIV within Kenya, or how local communities will respond to changes in HIV testing and the increased availability of treatment. However, the Kenyan Ministry of Health has adopted a cautious approach and outlines the limitations of treatment with HAART. They advise that the following should be considered before prescribing:

- Possible side effects
- The need for careful medical supervision
- The need for back up laboratory testing
- The costs of about US\$1000-2000 a year (Republic of Kenya, 2001).

Last week GlaxoSmithKline announced that they were dropping the price of HAART further so that, at last, these patented drugs will be cheaper and more readily available. Another global issue - pharmaceuticals: patenting, access for people in developing countries to these patented drugs.

This is what the health practitioners had to say in the summer of 2001:

'If the HIV test is positive, I discuss the result with patient. There is no cure, but there is treatment which manages the condition and is now cheaper and within reach of the middle classes. The triple therapy can give 5-6 years of life. The fact that the treatment is cheaper makes it easier to tell the patient

the result. It used to cost 70,000 Shillings (\$1000) a month. It went down in price two months ago. One sort costs 6,504 Shillings and the other 7,294 shillings. The drugs are not available here – you need to go to Mombasa. The follow up is costly due to the need for blood tests. I have a small lab for liver function tests. The viral load is done in Nairobi and the CD4 in Mombasa and that costs 2,900 Shillings.'

(Private doctor)

'I think that treatment for AIDS with HAART remains a high-class privilege, not a middle class privilege. I expect the price to fall again next month.'

(HIV prevention programme co-ordinator)

'HAART is very expensive. The price dropped in May or June. I use the cheapest combination of ART. It costs 12,000 a month. I only prescribe to families who have the means to continue with the treatment.'

(Private doctor)

Also at the same time during that summer of 2001, rapid testing kits along with voluntary testing and counselling arrived in this small town.

In many African countries Voluntary Counselling and Testing (VCT) centres are being promoted and funded by international donors. The approach is premised upon the use of rapid HIV tests, which necessitate only one visit on the part of the client. In a matter of 30 to 45 minutes the client can:

- 1) Obtain pre-test counselling on whether he or she should undergo the test, as well as the medical and social ramifications of doing so.
- 2) Have a blood sample taken and tested.
- 3) Receive the result of the test and obtain post-test counselling tailored to whether the result was positive or negative.

This new technology means that health professionals have to be able to communicate complicated information on risk that is emotionally loaded in a very short time.

This is a dilemma that is a common problem within clinical medicine today. As technology speeds up, screening tests at the point of care are becoming more common – Rapid Testing for HIV and antenatal genetic screening based on nuchal folds and biochemical analysis of blood are two cases in point. Other technologies are under development. The challenge of informing and communicating the results gets tougher and more complex for health professionals and users have to absorb and digest information on the statistical, clinical and social risks in a short period of time which then lead to having to make decisions about treatment.

To add to this challenge, there are dilemmas about confidentiality. The VCT model, developed internationally, is based on individual counselling and confidentiality and is being used in a setting where there is some confusion amongst health professionals concerning who should know the result, how should they be told and how to keep confidentiality in a very small town.



Here are some examples of what they said to me last summer.

'I had one patient who had repeated chest infections. I tested him for HIV without telling him. When his wife came to ask why her husband was not getting better, I told her. I could tell her once she had asked for information. I told her that instead of treating symptoms I thought the HIV should be treated.' (private doctor)

'I have a patient who has had malaria and TB, both of which she is resistant to treatment. She has fever and weight loss and a rash. I am going to call the husband and suggest an HIV test be done. The husband is the victim. I will then call the lady.' (private practitioner – uncertain qualifications)

'There was one woman who came with a European man to get tested. She came back alone and asked for her result, and asked us to tell the man that she was negative, even if she was positive. We refused to do this and refused to give her the result without the man being present. But he had gone away. In fact, he was negative and she was positive. It was as if she had been tested before and knew the results. So the results have not been given.' (Nurse in private clinic)

Meanwhile, Ministry of Health staff were trying to improve practice.

I held a meeting for clinical doctors – public and private – some months ago. I presented on maternal-foetal transmission and someone else presented on chemotherapy for TB. There was some discussion at that meeting of diagnostic testing for suspicious cases and the need to discuss the issue and get consent.' (Senior staff, MoH)

'Confidentiality is a big problem within the hospital and in a small place like this. I am not sure that the VCT team will be able to deal with it.' (Senior staff, MoH)

Here in this small town on the Swahili coast, the local effects of the global practice of drug patenting meant that treatment for AIDs was out of the reach of most individuals. The views of health workers reported here highlight important outstanding issues concerning the effective and ethical use of HIV testing and HAART as strategies to combat AIDS in Kenya and other African countries and highlight these issues in a particular local context.

Doctor-Patient Communication

I have to say that all the local voices of patients and health professionals, wherever I have worked, have wanted one and the same thing. The patients want to be treated with respect by health professionals and to be listened to. The health professionals have wanted to have the time and resources to do just that and would like the public to respect them. Sadly in many settings, this is lacking.

Drugs are not available throughout the month. Sometimes there is a heavy load of work because of the great number of patients which reaches 120 at the beginning of the month. This load makes the doctor unable to render adequate care to his patients. What physician in the whole world is capable of seeing more than 50-60 patients per shift? (Gaza - Doctor MoH clinic)

“Sometimes they treat us patiently; sometimes they don’t because of the stress and the crowding. It depends on the circumstances” (Negev - Woman about nurses in Well Baby clinics)

In the Negev 22% of the women interviewed wanted the nurses to be more patient and respectful and for there to be more staff so that waiting times would be reduced (Lewando Hundt et al 1997, 1998,).

Here at LWMS (Warwick), patients and carers from deprived communities participate in teaching medical students, by being interviewees in a semester long course called ‘Health in the Community’ - a community based course, looking at inequalities in health. These patients or carers agree to be interviewed at home and to share their experience and expertise with the students. A recent evaluation by Dr Jackson and Dr Blaxter (Jackson *et al*, forthcoming) explored their views on participating in teaching and here are some of their voices:

Well actually I’m pleased that somebody did come and listen to me. Because I couldn’t get no one to listen to me....Well I think they would learn more because they sit and listen to you more than what they’d listen down the hospital (13).

And it should have been done years ago.... It won’t help these doctors already in there but, er... it will certainly help the ones that’s coming in... (17)

Sometimes you do get doctors that will listen, and it is so much easier if they will listen to what the parents have got to say and not just take it as what’s written in the notes, you know. I found it very rewarding and I thought that if they (the medical students) go on and do take to heart what parents have said, it’ll be very worthwhile. (1)

Learning Partnerships for Doctors of Tomorrow

We stand at a point, here at the University of Warwick, with the LWMS (Warwick) accepting its third intake of 136 students, who begin their induction next week. The 136 students in the second year are doing Medical Ethics this week and the 67 third-year students are in their clinical placements. They will be graduating in less than 24 months. The Leicester Warwick Medical Schools are a federal teaching partnership with a currently jointly validated

medical degree. The biological science graduates at Warwick have a curriculum that is front-loaded with social science.

A leading surgeon, Andrew Rafferty, who sits on the governing body of the Royal College of Surgeons, was interviewed on the Today programme this morning concerning the 'dumbing-down of medical education through the new fast track courses'. This fast track course is hard work and rigorously assessed. It only takes in biological science graduates. The students use cadavers sharing the anatomy facilities at Leicester, and are taught alongside the Leicester students from the middle of the second year, sitting the same exams as the five year cohorts during the whole of Phase 11. This is no easy option as I am sure Professor Lauder both as the Dean of LWMS and as an esteemed pathologist will concur.

The social scientists here at Warwick are harnessing their expertise to further enhance and develop an innovative curriculum, built on the solid foundation of the work of colleagues at the Leicester Medical School led by Professor Stewart Peterson.

Medical Ethics is being delivered in Leicester and Warwick by a combined group of philosophers, lawyers and sociologists led by the Professor of Philosophy, Bill Fulford whose work in this area is groundbreaking both here and at the University of Oxford (Dickenson & Fulford 2000). Further teaching in social science is being developed within Phase 11 or what is generally called the **clinical phase** of the curriculum in complementary therapies and progress is being made in shared learning with plans for the opening of a training ward at the Walsgrave Hospital in the near future.

The curriculum outline for all medical schools in the UK is set out by the GMC and over the last decade more emphasis has been placed on the place of the patient in society, on the social context of health. This is in line with international developments in Medical Education. The Leicester Medical School led the way with the last revision of the Medical School curricula as set out in the Tomorrows Doctors document (GMC 1994). There is now a new one out for consultation and LWMS both at Warwick and Leicester are once again at the cutting edge. Whereas once the emphasis was on clinical knowledge, now there is a recognition that along with sound clinical knowledge, contextual understanding is necessary.

Without the communication skills to take a good history and without trust between health professionals and users, a clinician is just a technician. The ability to integrate different kinds of knowledge, to problem solve, to place the individual experience of the local patient within the social context and global clinical developments are essentials today.

Sir Donald Irvine, whilst President of the General Medical Council, gave decisive leadership concerning the need for doctors to respond to the public's changing expectations, both through his position and his paper in the Lancet (Irvine 1999). Work in this area within continuing medical education is ongoing here at Warwick (Barnett 2002).

So too did Professor Emerita Meg Stacey in her book on 'Regulating British Medicine' on the workings of the GMC (1992). In addition she has done so much to further the agenda of users in the public arena and to develop research in the sociology of health within this university.

Thank you both for your support at this point when there is such energy and commitment to develop a particular distinctive ethos and flavour to health and medicine within this University in collaboration with the Trusts in the area.

It seems clear to me that the only way forward in tackling these global health issues is through local partnerships between the academy and users, whether they be patients, carers, health professionals or policymakers and administrators. These partnerships need to build capacity at the institutional and individual level and should be mutually rewarding.

And so we come full circle to this picture of a carpet, as a visual metaphor. Each thread of this carpet on its own is unremarkable and only a fragment although carefully spun. The different threads together make a durable carpet of many colours, which can transform a space. The whole is greater than the sum of its parts. But creating it requires hard graft and tenacity that is often both physical social and intellectual.

I would like to conclude by thanking the many people who have helped me and been so generous with their time, friendship and support over the years - Some of them are here today but many are absent. Some have died, some live in distant places, are unable to travel, or are too frail to attend. They have been part of the earlier stages of my professional and personal journey and have provided the stepping stones and building blocks.

We stand today both globally and locally at a staging post in a never ending journey, chasing a mirage of perfect health and equity of health care delivery as an aspect of social justice (Dubos). By working together in partnerships across many boundaries – intellectual, national, and sectoral, we can progress and we must ensure that we continue to hear and honour local voices so that they too can make a difference.

Thank you for coming along today and sharing in this endeavour.
Gillian Hundt 10.9.2002

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