Saturday the 27 September 2003 at 16.55 - 17.25

Abbott, P., Beck, M.

Glasgow Caledonian University

HEALTH AND TRANSITION: THE CASE OF THE FORMER SOVIET UNION

The decline in life expectancy especially amongst middle aged men in the former Soviet Union since 1991 has been widely reported. There is significant epidemiological evidence that lifestyle - especially diet, alcohol and tobacco consumption play a major role in explaining the difference in mortality patterns between Western Europe and the countries of the former Soviet Union. However the development of sociological explanations for the health impact of the transition have only just began to be developed and have tended to be based on an analysis of data for the Russian Federation failing to take account of the significant differences in the impact of the transition on the health of the populations of the countries of the former Soviet Union. Mortality data indicates that life expectancy for both men and women differs considerably between the countries, as does the difference between in average life expectancy for men and women. Furthermore the reduction in life expectancy varies between the countries.

This paper will develop a sociological explanation for the health impact of the Transition on the population of the former Soviet Union using both primary and secondary data for eight of the countries. Specifically the paper will argue that health outcomes depend on the resources which social groups are able to utilise in responding to the transition and the coping strategies they are able to adopt.

Saturday the 27 September 2003 at 10.10 - 10.40

Abbott, S., Bryar, R., Caraher, M., Carter, Y., Chapman, J., Kessel, A., Petchey, R., Shaw, S.

City University

A TYPOLOGY OF PUBLIC HEALTH NETWORKS: FACT OR ARTEFACT?

Background

The shifting of many NHS resources to Primary Care Trusts (PCTs) has meant the fragmentation of former health authority departments of public health. Public health networks (PHNs) are intended to ensure that small public health teams in PCTs can share resources and skills.

Aim of study

To explore the development of PHNs, and to identify a typology of networks.

Methods

Semi-structured telephone interviews with key players (27) in PHNs (13) in three government office regions of England, February - April 2003. Documentary analysis.

Findings

Many differences between PHNs appear to reflect different developmental stages rather than different visions of what a PHN should be. Two types could be identified: a "hub" model, and a matrix model. In the first, the PHN centres on a hub consisting either of shared services co-located with the PHN administration, or of a significant commitment by PCT Directors of Public Health to work for a specified time each week for the PHN, or both. In the matrix model, PHN members are helped to link with each other by structures such as a co-ordinator or web-site, but linkages are likely to be ad hoc rather than regular and formal.

Discussion

It appears that apparent differences between PHNs are less likely to arise from organisational differences than from differences in vocabulary and interpretation. It seems likely that a majority of PHNs will come to resemble each other in the medium term.

Abstract Book prepared 18th July 2003

1

Saturday the 27 September 2003 at 16.20 - 16.50

Abraham, J., Davis, C.

University of Sussex

REGULATION MATTERS: EXPLAINING THE WITHDRAWAL OF PRESCRIPTION DRUGS FROM THE MARKET IN THE UK AND US

Between 1971 and 1992 there were twice as many drugs withdrawn from the market in the UK because of safety problems as there were in the US. Over the last 25 years, drug policy researchers, government regulators and industry-funded researchers have put forward five possible explanations for why there were more drug safety withdrawals in the UK than the US in this period, but until now no systematic research had been conducted to test them authoritatively. They are: (1) simply because the UK approved more drugs than the US (2) because of an industrial corporate strategy to seek approval of 'less safe' drugs in the UK early, but not to seek approval, or to seek approval later, for such drugs in the US (3) because British regulators were more vigilant in spotting safety problems with drugs after entering the market than their American counterparts (4) because the slow and overly bureaucratic US regulatory system lagged behind the UK in making decisions to approve new drugs which meant that the US could see safety problems which emerged in the markets of the UK and/or Europe before having to decide on marketing approval in the US (5) because regulators' safety standards for drug approval were more stringent in the US than in the UK. By analysing the regulatory case histories of each drug we demonstrate that by far the most important explanation is the greater stringency of regulators' safety standards in the US in this period.

Saturday the 27 September 2003 at 15.10 - 15.40

Airey, L., McKie, L., Backett-Milburn, K.

Glasgow Caledonian University/CRFR Edinburgh University

WOMEN, WELL-BEING AND MID-LIFE

Over the past decade, concern about ageing Western societies has led to an increase in research and theorising of later adulthood. However, in the UK, less attention has been paid to mid-life, which represents a strategically important period in the lifecourse, structurally, culturally, physically and psychologically. In particular, little is known about the diverse experiences of women in their fifties with regard to well-being, ageing and the anticipation of ageing. This paper reports on a qualitative study designed to explore how women aged 50-59, in differing socio-economic circumstances, perceive, manage and construct the cultural, economic and health intersections of ageing.

The paper focuses firstly upon methodological issues. The study, undertaken in Glasgow, was designed to pilot strategies for recruiting 20 women from a diverse range of circumstances into discussion groups and one-to-one interviews. Here, we describe our response to the methodological challenges associated with recruiting women who may be relatively isolated in addition to those involved in varied forms of cultural expression/consumption. We reflect upon the effectiveness of recruitment strategies used in this project, and discuss how the lessons learned from piloting may be applied in future research.

The paper then draws on empirical data to illuminate some ways in which women's experiences of health and well-being at mid-life are shaped by structural and cultural influences operating at this stage in the lifecourse. In particular, we explore how the gendered nature of women's work and family commitments might influence the well-being of mid-life women in differing social circumstances.

Saturday the 27 September 2003 at 16.55 - 17.25

Alner, M.A., Jenkings, K.N.

University of Newcastle

VARIATIONS IN THE ORGANISATIONAL PROVISION OF ACUTE AND REPEAT PRESCRIPTIONS IN GENERAL PRACTICE: AN ETHNOGRAPHIC STUDY

With 587 million prescription items reported dispensed in primary care in England in 2001, the use of medicines as the most common therapeutic intervention continues to rise. The Department of Health plans to implement a National Prescription Service (including Electronic Transmission of Prescriptions - ETP) in all primary care organisations by 2004, which aims to facilitate this therapeutic intervention. Recent accounts of the management of prescribing in current practice are sparse. This paper reports ethnographic investigations of prescribing processes from 12 GP practices across England. These practices were part of the ETP pilot evaluation project which partly assessed changes to current work practices and social interactions as a result of ETP.

Focusing upon the practical work activities of the production and delivery of prescriptions six key 'generic stages' in acute and repeat prescribing processes were identified: Request, Processing, Authorisation, Query management, Signing and Issue of prescription. Within these, various locally situated activities involving the use of computer and paper systems and staff and patient interaction were observed. Each of these 'generic stages', and their local production, will, by varying degrees, be affected by ETP when it becomes operational. It is suggested that administrative staff are important 'actors' throughout the repeat prescribing process with more management control responsibility during the prescribing processes than currently recognised. Consequently any ETP system which does not consider these locally accountable activities and which keeps administrative staff 'out of the prescribing loop' may prove detrimental to prescribing work practices and result in an 'inappropriate' system when implemented.

Saturday the 27 September 2003 at 10.45 - 11.15

Arber, A.

University of Surrey

"WHICHEVER WAY YOU WANT TO PLAY IT": DOING INTERPROFESSIONAL WORK IN PALLIATIVE CARE

This paper explores how the boundaries between different professional groups are made and unmade through talk-in-action. The data discussed is based on ethnographic observations and audio recordings of 8 multidisciplinary team meetings in hospice, hospital and community palliative care. I am interested in how the palliative care team constructs interprofessional work in their talk. I have undertaken a linguistic analysis, which explores how the boundaries of palliative care are jointly constructed by use of questions, gate keeping, challenges to non-specialist practitioners and explicit and implicit negotiations and agreements. I conclude by suggesting that the impact of 'specialist' nurses is disrupting the boundary between the specialist and non-specialist practitioner. The specialist nurse and general practitioner boundary is becoming a fragile space for evaluative and political action.

Friday the 26 September 2003 at 14.00 - 14.30

Armstrong, N.

University of Nottingham

AGE AND WOMEN'S EXPERIENCES OF CERVICAL SCREENING

Current NHS policy is that all women between 20 and 64 years of age should have a cervical smear test every 3 to 5 years, depending on the policy of their local area. This is a test to check the health of the cervix, the neck of the womb, and identify any abnormal cells that may go on to develop into invasive cervical cancer if left untreated. With a few exceptions, all women within this age group are routinely invited for screening and automatically receive an invitation letter and information leaflet when their next test is due.

This paper will draw on qualitative interview data to suggest that the ways in which women view cervical screening and their experiences of the smear test itself are influenced by their age and position in the life course. The importance of factors such as perceived vulnerability, sexual behaviour, other health concerns and issues around the nature of the menopausal female body will be examined and the ways in which these can influence how women think about and experience cervical screening will be discussed.

The paper will conclude by arguing that women can have very different experiences of cervical screening at different stages in their lives and that they are critical of the cervical screening programme's tendency to treat women as a homogenous group.

Friday the 26 September 2003 at 14.40 - 15.10

Aveyard, P., Markham, W.A., Lancashire, E., Bullock, A., Macarthur, C., Cheng, K.K., Daniels, H.

University of Birmingham

THE INFLUENCE OF SCHOOL CULTURE ON SMOKING AMONG PUPILS

We propose a hypothesis to explain schools' influence on pupils' smoking and test this using a cross-sectional survey of 23, 282 pupils from 166 West Midlands secondary schools. We hypothesise school-level educational achievement scores would not be associated with smoking prevalence, but schools providing value-added education given the social background of pupils (authoritative schools) would provide effective support and control, have a relatively strong influence on pupils lives and be associated with lower than average smoking prevalence. Schools providing value-denuded education (laissez-faire schools) would have a relatively weak influence on pupils lives and be associated with higher than average smoking prevalence. The school achievement measures were proportion of pupils achieving five A-C GCSEs and the proportion of half days lost to truancy. Value-added/denuded terms were created by regressing five A-Cs and truancy on five markers of the social profile of pupils at the school. Authoritative schools achieved better than expected rates on both measures. Laissez-faire schools achieved worse than expected rates on both measures. All other schools were classed as indeterminate. Multilevel logistic regression related the risk of regular smoking to school culture in both achievement and authoritative/laissez-faire terms, both with and without adjustment for pupil-level risk factors for smoking. Schools achievement measures were unrelated to pupils' smoking. The odds ratios (95% confidence intervals) for smoking in authoritative and laissez-faire schools relative to indeterminate schools were 0.80 (0.70-0.91) and 1.16 (1.07-1.27) respectively. Adjustment for pupil-level smoking risk factors had little effect. School culture is an independent risk factor for adolescent smoking.

Sunday the 28 September 2003 at 09.40 - 10.10

Baldwin, C.

Ethox

THE SEAMY SIDE OF NARRATIVE: THE CASE OF P C & S V UNITED KINGDOM

In July 2002 the European Court of Human Rights ruled that Rochdale Social Services had failed to provide 'relevant or sufficient reason' for removing a child from her mother at birth and that their actions were not necessary to protect the child. At the hearing the UK government repeated the arguments that the domestic courts had found convincing, focusing on the dangerous mother. The ECtHR was not, however, persuaded and ruled that the human rights of the parents and the child had been violated by the actions of the authority and the domestic courts, under Justice Nicholas Wall. The injustice perpetrated cannot simply be explained by bad practice or conspiracy. Rather it should be seen as the outworking of the injustice inherent in the conceptualisation of abuse and the investigatory process. These two aspects combined to allow such things as fabrication, selective investigation, conceptual confusion and cognitive dissonance to go unnoticed and/or not worthy of note or criticism within the current child protection system. This paper will attempt to explain the official acceptability of such actions and the nature of this injustice by drawing on narrative theory and the sociology of stories. It will conclude with some suggestions for greater reflexivity and transparency in the investigation of alleged child abuse.

Sunday the 28 September 2003 at 09.00 - 09.30

Bancroft, A., Wilson, S., Cunningham-Burley, S., Backett-Milburn, K., Masters, H.

University of Edinburgh

CONCEPTIONS OF THE FAMILY AND SELF AMONG OLDER CHILDREN OF SUBSTANCE MISUSING PARENTS

Drug and alcohol (substance) use often takes place in a family context and has a profound effect on family life, family dynamics and roles. Most research into substance misuse in a family context examines how parents with a substance misusing child manage. However, many substance misusers are parents themselves, and there is very little research into the experiences of their children. The Joseph Rowntree Foundation project "Surviving Parental Drug and Alcohol Use" investigates the experiences of older children (16-21 years) of substance using parents. This age group is of interest because it is a time of transition and is poorly provided for by services. Respondents will be in transition to work or higher education, setting up a new home, and forming relationships themselves. Concepts of the family take on a particular importance for them. This paper presents some findings from the project. Experiences of neglect were common in respondents' accounts, in addition to experiences of physical violence and being forced to witness domestic violence. Role reversal was also common, where children take on caring and parenting roles for themselves. Respondents reported a sense of loss and shame, of having had a happy family life denied to them. It was common to deal with this by remaining distant from others and being reluctant to form close ties. Family history was important to their own concept of risk to themselves and problems they might face in adulthood. Their family situation was important to their concepts of the self and their future direction.

6

Sunday the 28 September 2003 at 09.00 - 09.30

Barbour, R.S., Cawley, M., Eborall, H.

University of Dundee, University of Glasgow & University of Edinburgh

REDEEMING SCRIPTS: MAKING DECISIONS ABOUT MEDICATION IN THE CONTEXT OF PRESCRIPTION CHARGES

This paper reports on a study commissioned by a local consortium of health care professionals concerned about the impact of prescription charges on those on low incomes within one deprived locality. Seven focus groups were held with purposive sampling ensuring coverage of the views and experiences of people of differing ages, genders, socio-economic circumstances and health status. Participants shared a perception of sharp price increases with entitlement having been systematically eroded. Cost also affected decisions to consult the GP, with anticipation of prescription charges sometimes being invoked as a cause for delay. Although participants in all groups admitted to strategies such as hoarding medication, 'eeking out' drugs and, occasionally, using other family members' prescribed medication, most accepted the need to redeem prescriptions in full and did not question GPs' prescribing decisions. The study identified a lack of knowledge about pre-payment certificates and lengthy waits to qualify for exemption also caused considerable hardship. Specific issues arose for post-MI patients, as they negotiated a transitional period when several drugs, or drug combinations, might be tried out, with some wastage, additional costs, and potentially powerful disincentives with regard to reporting of side-effects. Interim measures might be usefully introduced in both cases.

Sunday the 28 September 2003 at 10.50 - 11.20

Bellaby, P., Flynn, R.

University of Salford

'SUBSTITUTING H FOR C': MIGHT IT REDUCE INEQUALITIES IN HEALTH?

Public health started with water and sewerage. Overall improvements by distribution of health care and primary and secondary prevention latterly have tended to favour the rich more then the poor. The radical remedy by redistribution of wealth tends to be a losing battle of plan with market. Does the unglamorous infrastructure again hold the key? Carbon (C) fuel has direct impact on respiratory health where there are high levels of energy consumption. It is a diffuse effect, but it impacts the urban poor most. This is only a small part of its link to health inequalities. High C consumers contribute heavily to global warming, with impact on environment and indirectly on human health. They have an especially marked effect in the tropics, where there is much poverty. Apart from removing the ill-effects of C on health, and notably on health inequalities, Hydrogen (H) promises to put otherwise scarce and expensive energy in the hands of developing countries that do not have oil/natural gas/coal. Most have some energy source for sustainable generation of H: geothermal, biomass, solar, wind or wave, and could reduce their dependence on C by inserting H as energy store in the cycle of production and consumption. But the H future is not a new idea. The technology still has far to go. There is a resurgence of political interest: new investment in H in UK, following that in other developed countries. The paper concludes by asking how realistic the promised future is, technologically, economically and politically.

Saturday the 27 September 2003 at 15.45 - 16.15

Bendelow, G., Griffiths, F., Green, E.

University of Warwick

THE TRANSMISSION OF 'EXPERT' ADVICE AND ITS RELOCATION WITHIN WOMEN'S 'LOCAL BIOLOGY': HEALTH TECHNOLOGY AND MIDLIFE WOMEN

In this paper we report on findings from a national ESRC funded study on the use of health technologies at women's midlife. This study explores lay and health professional accounts of using hormone replacement therapy (HRT), screening for breast cancer and screening for osteoporosis. Data was collected from interviews with 93 women recruited via health care sites and from community groups and interviews with 62 health professionals. In addition, over 100 consultations between women and health professionals were recorded. In this presentation we explore issues around the balancing of health and social risk, focusing particularly on the transmission of 'expert' advice and its relocation within women's 'local biology'.

Sunday the 28 September 2003 at 10.20 - 10.40

Blackburn, C., Dolan, A.

University of Warwick

<u>NEW FATHERHOOD: MOTIVATOR OR INHIBITOR FOR SMOKING BEHAVIOUR</u> CHANGE?

Although mothers' smoking has been shown to be the most harmful to the health of unborn and young children, fathers' smoking has also shown to be linked to adverse health outcomes. Estimates suggest that a large majority of smoking households with infants contain fathers who smoke. Fathers however, are a neglected target group for health promotion smoking programmes. They are neither targeted directly, nor to any great extent indirectly, through their partners. Little is known about fathers and smoking. Although men's smoking has received some attention, men as fathers have been neglected in the literature on smoking. Little is known about whether fathers change or attempt to change their smoking status and habits during their partner's pregnancy or after the birth of their child.

This paper draws on data from a cross-section study of 339 fathers of new infants in England and examines whether the experience of new fatherhood acts as a motivator or inhibitor for smoking behaviour change. It suggests that over half of current smokers reported smoking the same or more cigarettes than usual during their partner's pregnancy and after their baby's birth. Active attempts to reduce cigarette consumption and to quit smoking were commonly reported, although successful reductions in cigarette consumption and successful quit attempts were less common, especially after the baby's birth. This paper will draw on the literatures on fatherhood and inequalities in men's home and work lives to theorise these findings.

Saturday the 27 September 2003 at 16.55 - 17.25

Bloor, M.

Cardiff University

PROBLEMS OF ENFORCEMENT OF INTERNATIONAL REGULATIONS ON WORKERS' HEALTH AND SAFETY IN A GLOBALISED INDUSTRY: AN ETHNOGRAPHIC ACCOUNT

This is an early report of a continuing ESRC-funded comparative study of port-state control inspectors in UK, Russian and Indian ports. This paper will concentrate on the UK data, gathered through ethnographic observation and depth interviews.

Seafarers' living and working conditions and health and safety are extensively regulated by two UN agencies, IMO and ILO. But, as with other globalised industries, there is extensive regulatory avoidance and problems of regulatory enforcement. The burden of regulatory enforcement rests largely with national inspectorates visiting foreign-flagged ships berthing in their national ports.

- · Clearly, national inspection systems can, in principle, police global industries if there is cross-national co-ordination. Some progress towards this has been made by the adoption of common inspection manuals. However, this study shows that the discretionary character of the manual allows very substantial variation in inspection practice even within national jurisdictions.
- · Inspection resources are limited the UK, for example, only commits itself to inspecting 25% of visiting foreign-flagged ships so effective enforcement depends on good targeting of resources. However, this study shows that current targeting practice is only partly effective and needs further development.
- · Inspectors are comfortable with inspecting the technical adequacy of physical plant (such as fire fighting equipment), but less comfortable with the monitoring of those living and working conditions (such as excessive working hours) leading to new occupational health and safety hazards.

These data are related to existing ethnographic literature on workplace health and safety and to criminological studies of regulatory intervention

Paper/Poster Abstracts - listed in alphabetical order of first author

Friday the 26 September 2003 at 14.40 - 15.10

Bolam, B. Gleeson, K. Murphy, S.

Queen's Medical Centre

THE RESEARCHER INTERVIEW AS REFLEXIVE PRACTICE IN QUALITATIVE LAY HEALTH BELIEFS RESEARCH

Researching lay health beliefs necessarily highlights the researchers' own embodied concerns and problematises the traditional distinction between lay person and health expert. In this paper, we describe the rationale and use of a reflexive interview in which the primary researcher was interviewed using the same schedule as with research participants. This data, transcribed and analysed alongside that of research participants, enhanced critical reflection on the positions of researcher as both lay person and health expert. In conclusion, the limitations of this strategy are outlined and we argue that the reflexive praxis needs to be both clear and sensitive to specific research interests.

Friday the 26 September 2003 at 15.20 - 15.50

Bourgeault, I.

McMaster University, Canada

GENDER, LOCATION AND HEALTH LABOUR: A VIEW FROM CANADA AND THE U.S.

Two key factors are absent from the literature on the rationalization of the health care division of labour: gender and location. When we take a closer look at the move toward the lowest cost/most flexible care provider, it is often one with a greater proportion of women.

Rural/remote areas are also noted for their propensity toward substitute labour. Seldom are these critical factors examined explicitly and comparatively in the development, implementation and evaluation of health human resources policy. I report here on the first phase of an ongoing research program of the influence of gender and location on the rationalization of the health care division of labour within three health care arenas - maternity, primary and mental health care - in Canada and the U.S. The data include key policy documents and position statements from the various provider groups and secondary source documents [i.e., the published literature] and a preliminary analysis of key informant interviews being conducted in Ontario and New York. What is revealed from this analysis is that:

- 1) there is much more substitute health labour in the U.S. as evidenced by the greater number of different kinds of care providers;
- 2) in particular, there is a greater use of specialty nursing labour nurse-midwives, nurse practitioners, psychiatric nurses in the U.S.; and
- 3) the main impetus for the shift in health human resources in Canada tend to be shortages and maldistribution of services, whereas in the U.S. the shifts occur largely due to cost concerns.

Paper/Poster Abstracts - listed in alphabetical order of lirst autr

Saturday the 27 September 2003 at 09.35 - 10.05

Brindle, L.

University of Bristol

CONSTRUCTIONS OF KNOWING AND UNCERTAINTY IN TALK ABOUT 'THE RIGHT TREATMENT' FOR PROSTATE CANCER AMONGST MEN IN THE PROTECT STUDY

This study explored how risk, benefit, knowing and uncertainty were constructed within interviews and clinical consultations which span men's progression within the ProtecT Study from being at population risk to receiving treatment for localised prostate cancer. The ProtecT Study involved case-finding within the community. Those men identified with localised prostate cancer were then asked to participate in a randomised trial of three major treatments: surgery, radiotherapy and monitoring. Diagnostic appointments with urologists and information appointments with trained nurses were tape-recorded and fully transcribed. In-depth interviews were conducted with men prior to detection and then following diagnosis, treatment decision-making and every twelve months following treatment. Case studies included men who had been interviewed one year following treatment and who had chosen or were randomly allocated treatments. Transcripts were examined for instances in which the potential outcomes of treatments were formulated. Discourse analysis was used to explore how variable constructions of uncertainty, risks and potential benefits of treatments are located and achieve social action within clinical encounters in which treatments are discussed and within research interviews about participants' experiences of case-finding, treatment decision-making and treatment. The analyses demonstrate how health and threats to health are formulated within talk about treatment for prostate cancer and how acceptable levels of risk and uncertainty are achieved discursively. The constitution of experiences of 'possibly having' and then being diagnosed with prostate cancer within 'risk' and 'knowing' talk are explored and implications for the theorisation of the experience of 'living at risk' are discussed.

Sunday the 28 September 2003 at 10.20 - 10.40

Brindle, S., Douglas, F, van Teijlingen, E., Fearn, P., Mackinnon, D.

University of Aberdeen

EVALUATION OF A HEALTH PROMOTION INTERVENTION DELIVERED THROUGH UNIVERSITY COMPUTERS AND AIMED AT STUDENTS

Background

Students are regarded as one of the healthiest groups. At the same time becoming a student is often a major life change, a transition moving from school to university, moving out of the parental home into a (shared) flat, hall of residence, etc. It is also recognised that students (like many young people) are more likely to engage in risk taking behaviour. The Health Education Board for Scotland together with You(th) Scotland therefore developed a health promotion intervention aimed an students at Scottish universities. This intervention consisted of a series of short video clips which ran automatically when students logged on their university computer.

Mixed methods

Questionnaire survey and focus groups.

Participants

Students at two universities in Scotland

Data Collection

- (1) questionnaire to assess students' attitudes towards health and health promotion and their knowledge and experience of the Student Desktop Health Resource;
- (2) six focus groups at same universities exploring some of the issue in more detail The length of the groups was about 45 minutes. Data analysis. SPSS was used to analyse the questionnaires and a thematic analysis was used for the focus groups.

Findings

The intervention had been noticed by 63% students. Most (82%) considered the video clip topics a good idea, and generally the issues covered were regarded as 'clear and understandable' (58%). In the focus groups most had seen clips, some said they didn't immediately know what it was nor associated it with health. Almost all thought that universities were right to participate in this initiative.

Friday the 26 September 2003 at 16.40 - 17.10

Brooks, F., Lomax, H.

CRIPACC, University of Hertfordshire

CONTESTED KNOWLEDGE: PATIENT AND PUBLIC INVOLVEMENT IN HEALTH CARE DECISION MAKING

Incorporating service users' perspectives in health care decision-making is currently one of the ways policy-makers and professionals are seeking to resolve contested areas of health care provision. However, initiatives that have attempted to move beyond rhetoric to actual practice remain comparatively rare. This paper presents findings from a two-year ethnographic study of an attempt by an acute hospital to involve the local community in health care decision-making, through the creation of a patient council. Discussion focuses on the impact of this form of public participation on the culture of the health care organisation. Drawing on observation and interview data, the paper will explore how the patients' situated knowledge has provided a direct and largely unanticipated challenge to the agendas promoted by the health care workers. The discussion will then focus on ways by which service users and providers negotiated and managed this process including the effect of acceptance by professionals and healthcare managers of the council members' right to generate change. The paper concludes by outlining how far progress has been made towards creating a shared set of values between the patients and professionals involved.

Sunday the 28 September 2003 at 09.40 - 10.10

Broom, A.

La Trobe University

VIRTUALLY HEALTHY: A STUDY OF THE IMPACT OF INTERNET USAGE BY AUSTRALIAN MEN WITH PROSTATE CANCER ON PATIENT/MEDICAL SPECIALIST INTERACTION AND DISEASE EXPERIENCE

This paper reports on an investigation into the effects of Internet use (for information and support) on experiences of disease and encounters with medical professionals. Drawing on a study of the Internet usage of Australian men with prostate cancer, this paper examines how access to information and online support affects men's experiences of prostate cancer, and in particular, the possible implications of 'Internet informed patients' for doctor-patient interactions. The study involved in-depth interviews with 33 Australian men with prostate cancer and 15 prostate cancer specialists.

Results of this study show that accessing information and/or support online can have a profound affect on men's experiences of prostate cancer, empowering them within the treatment process, and providing a method of taking some control over their disease. Furthermore, for some men, online support groups provide a unique and potentially liberating source of support and information that allows for sharing and intimacy by limiting inhibitions felt in face-to-face encounters.

However, it is shown that for some medical specialists, Internet-informed patients challenge their power within the medical encounter, a challenge that may result in specialists employing strategies that reinforce traditional patient roles and alienate patients who use the Internet. This paper examines how 'desperation', 'irrationality' and 'vulnerability' are used rhetorically to justify discourses of patient incompetency and thus denigrate the ability of patients to retrieve and assess Internet material. It is argued that these strategies present as methods of reproducing medical dominance and the consolidation of the expert/lay divide.

Saturday the 27 September 2003 at 14.00 - 14.30

Brunt, E.

University Of Bristol

"I'D LIKE TO SEE THAT DAY ARRIVE, PERHAPS, COME THE REVOLUTION": COMPLEMENTARY THERAPIES IN NHS CANCER CARE

The United Kingdom has recently witnessed a substantial growth in the popularity of complementary and alternative medicine and cancer patients have increasingly used complementary therapies to mitigate the side effects of orthodox treatment.

In the past decade there has been a significant increase in access to complementary therapies via the NHS, but service provision is uneven with a wide range of methods of service delivery.

This paper draws on an on-going PhD study on the use of complementary therapies in cancer services in seven NHS Trusts in the South West. Research methods included a short postal survey of service providers and semi-structured qualitative interviews with doctors, nurses, managers and complementary therapists, examining the attitudes of healthcare professionals and decision-makers towards the use of complementary therapies for people with cancer.

The research considers how the social construction, or social production, of medical knowledge and medical discourse, both orthodox and complementary, impacts upon the possible integration of complementary approaches to healthcare into the dominant biomedical paradigm.

Sunday the 28 September 2003 at 09.00 - 09.30

Budge, F., Harris, C.

University of Plymouth

THE SOCIAL IMPACT OF RARE DISORDERS: THE EXAMPLE OF CONGENITAL NYSTAGMUS

There are many rare disorders, which have received little attention in medical sociology. Although only few individuals may be affected by any single disorder, collectively large numbers are affected. Congenital nystagmus (CN) is an example. CN is a continuous spontaneous oscillation of the eyes affecting 1 in 3000. The condition has onset around birth, non-progressive but life-long, with no meaningful treatment. CN is usually presumed to be a 'typical' visual impairment. However, the existence of features specific to CN lead to a range of educational and social difficulties, not seen in other conditions and often unrecognised by care-givers and educators. We investigated the social impact of CN by conducting a number of in-depth interviews with affected children and adults.

We first discuss the specific features of this disorder, and how it differs from other types of 'visual impairment'. We then discuss the results of the qualitative interviews, and indicate some of the emerging themes including coping strategies, experiences of the medical system, educational difficulties, and the impact of 'rarity' itself.

We draw two conclusions of relevance to medical sociology. First, the use of 'umbrella' terms such as 'visual impairment' glosses over the details that impact on affected lives. This results in misunderstanding of the disorder, leading to unmet needs for those affected. Second, social researchers often neglect relatively rare disorders. It is important to not underestimate the total social burden and impact of these disorders, whilst at the same time it is crucial to understand their specific features without over-generalisation.

Saturday the 27 September 2003 at 16.20 - 16.50

Cameron, E., Mathers, J., Parry, J.

University of Wolverhampton

<u>PEOPLE EXPERTS AND PROFESSIONAL EXPERTS: HOW DO THEIR CONCEPTS</u> <u>OF HEALTH AND THEIR PERCEPTIONS OF INFLUENCES ON HEALTH COMPARE?</u>

Research in progress is exploring whether there is any common ground between people in communities and those working in the statutory and voluntary and community service sectors as to how health and its influences are perceived. This is a central part of a two year study, funded by the Department of Health under its Health Inequalities Programme, which focuses mainly on disadvantaged groups within communities and is seeking to find new shared ways to measure health, illness and well-being, via non-medical indicators. Other parts of the project involve participants in assessing routinely collected and wide-ranging measures and indicators, reflecting their choices and views.

The project is being carried out across the Black Country and Shropshire by a collaborative multi-disciplinary research team from the Universities of Birmingham and Wolverhampton. The methodology incorporates both quantitative and qualitative approaches. Some of the initial findings from 29 two-stage focus groups and 20 informal intervviews with people experts and professional experts will be presented and key themes and suggested sociological frameworks discussed.

Friday the 26 September 2003 at 15.20 - 15.50

Cawley, M., Barbour, R.S.

University of Glasgow

"I'M NOT OVERWEIGHT AT ALL, I'M JUST THREE FEET UNDER HEIGHT" COPING WITH THE STIGMA OF OBESITY

Obesity has become a stigma in contemporary post-industrial societies as both medical and social norms dictate that the "ideal body" should be slender in order to be healthy. Fifty percent of the population are classified as overweight and therefore do not meet medical or cultural ideals. Medical research has consistently highlighted the physical health risks associated with excess weight, however the psychosocial aspects have been neglected in comparison. Although there is a lack of consensus about what causes obesity, individuals are often stigmatised by claims that obesity is due to their sloth and gluttony. Teasing, negative comments and discrimination perpetuate the stigma and make it harder for individuals to cope with not being "normal."

This paper is based upon an on-going PhD study, investigating the psychosocial aspects of obesity. Men and women (aged 30-60, all BMI groups) living in deprived and affluent areas northwest of Glasgow completed a community health survey. In addition, 20 semi-structured interviews were conducted with a purposive sample of obese respondents. The survey results confirmed that obese males and females report the greatest body dissatisfaction and lowest levels of self-esteem. The semi-structured interviews have explored lay understandings of health and well-being and have generated in-depth accounts about weight gain and comfort eating. They have also provided insights into the ways in which individuals construct their identities to deal with the stigma that they face on a day-to-day basis.

Saturday the 27 September 2003 at 16.00 - 17.00

Chalder, M.J.E., Coombes, L.J., Moore, L.A.R.

Cardiff University

TEENAGE ALCOHOL PROJECT - A SCHOOLS-BASED, PEER-LED INTERVENTION TO REDUCE PROBLEM DRINKING IN THE UNDER 15S IN SOUTH WALES

There appears to be no reliable evidence of effectiveness for any programmes previously aimed at preventing alcohol misuse with young people of school age. By developing a peer-led, schools-based intervention to reduce pupil problem drinking and conducting an exploratory trial of this intervention, the Teenage Alcohol Project (TAP) attempts to re-apply an approach which has already demonstrated some success in the related fields of smoking prevention and sexual health.

Primarily, the study is designed as a cluster randomised controlled trial, with school as the unit of randomisation. There are three separate study arms - three schools have been randomly allocated to have the intervention delivered to pupils in Year 8; three more have been randomly allocated to have the intervention delivered to pupils in Year 9; and a further three schools have been randomly assigned to a control condition across both Years 8 and Year 9. Running contemporaneously is a process evaluation to explore the strengths and weaknesses of the prescribed intervention.

Primary outcome measures include (i) self-reported frequency of feeling the effects of alcohol and (ii) self-reported frequency of drunkenness. Secondary outcome measures include (i) self-reported consumption of alcohol in the past week, (ii) attitudes and beliefs concerning alcohol and alcohol consumption, (iii) perceived norms concerning alcohol consumption and (iv) future intentions regarding alcohol consumption.

Sunday the 28 September 2003 at 09.40 - 10.10

Chandola, T., Clarke, P., Marmot, M.

University College London

PATHWAYS BETWEEN EDUCATION AND HEALTH: A CAUSAL MODELLING APPROACH

There has been considerable debate over the mechanisms underlying social inequalities in health. Differences in health between people of different educational levels have been one of the main indicators of health inequalities. However, there has been little research that has investigated all the mechanisms, or pathways, postulated to underlie the association. The association between education and health could arise from a number of pathways - from childhood social position, social class in adulthood, background personality and intelligence factors, healthy lifestyle behaviours and childhood illness. The analysis of all these hypothesised pathways between education and health is crucial in order to formulate effective policies aimed at reducing health inequalities.

Data from the Whitehall II study (a cohort of British civil servants) were analysed using structural equation models and graphical models. While each of the pathways were associated with education and health, among men, the association between education and health was explained (statistically) by the effect of education on adult social class and the effect of social class on smoking and health. Among women, the pathways between education and health include adult social class and intelligence. Policies aimed at reducing health inequalities may need to take account of these pathways between education and health for effective policies.

Saturday the 27 September 2003 at 09.35 - 10.05

Chapman, J.L., Abbott, S., Carter, Y.H., Shaw, S., Congdon, P. Petchey, R., Bryer, R.

Barts & The London Queen Mary's School of Medicine & Dentistry

JOINT WORKING IN PUBLIC HEALTH: A PREREQUISITE FOR SUCCESS OR A SUGAR-COATED NIGHTMARE?

Introduction

The recent restructuring of the NHS following the publication of 'Shifting the Balance of Power' drastically changed the organisational structure of Public Health and the ways in which the public health function is delivered. With the emergence of smaller public health teams based in PCTs and StHAs, specialists are increasingly reliant on partnerships and networks to fulfil their public health roles. This presentation will convey findings from a recent Department of Health funded study researching the capacity and development needs of Specialists and Consultants in Public Health post-restructuring. Particularly, this discussion will focus on the role of devolved organisational structures and inter and intra-organisational integration in the successful deliverance of public health.

Methods

Questionnaire to all identified Specialists and Consultants in Public Health working in PCTs, StHAs and the HPA in England

Expected Results

An assessment of learning and skills gaps among specialists, the degree of inter and intra-organisational working and consequent professional isolation and the extent to which current public health infrastructure is acceptable to specialists will be presented. The links between these data will be analysed with the view of understanding why and when joined up working occurs in public health and what form it takes, and the pros and cons of such working. This data will be mapped across England highlighting geographical differences. The presentation will also shed light on whether there is sufficient capacity within the specialist public health workforce, taking into account current inter and intra-organisational arrangements, to tackle the public health agenda.

Saturday the 27 September 2003 at 15.45 - 16.15

Charles-Jones, H.

University of Manchester

RE-DEFINING THE THRESHOLD OF PATIENT-HOOD IN PRIMARY CARE: AN ORGANISATIONAL DEVICE TO CONTROL ACCESS

This paper comes from an ethnographic study of general practice organisation set in the north west of England. It focuses on the redistribution of medical work within primary health care teams.

The paper explores how primary care professionals talk about the redistribution of medical work in general practice. In particular, it examines how primary health care team (PHCT) members' draw on the available discourses to categorise and classify patients. The categories create hierarchies of work and patients, which assist the PHCT in organising the patient's interaction with the practice. Drawing on Foucault's notion of 'dividing practices' this paper examines how the PHCT members set the threshold for patient-hood and in doing this what they accomplish.

The paper shows how PHCT members, especially those nurses involved in telephone triage, draw on a discourse of patient-education to operate the threshold of patient-hood. Patients are taught how to manage certain illnesses themselves and are therefore kept 'out of the system'. They are also taught the correct way to access the practice and the criteria they need to meet to do so appropriately. The degree to which patients are forced back onto themselves and the correct route into the practice varies between practices and within each practice at different times. The unpredictability of the threshold makes it harder for patients to negotiate access and strengthens the PHCT's control of it. The threshold for patient-hood therefore acts as an organisational device to manage the practice resources and deliver external policy requirements especially those of access.

15

Saturday the 27 September 2003 at 14.00 - 14.30

Clarke, K.D.

King's College London

BECOMING A BODYBUILDER: AN ETHNOGRAPHIC EXPLORATION OF THE SOCIALISATION PROCESSES INVOLVED IN CONSTRUCTING AND CONFIRMING A BODYBUILDING IDENTITY

Whilst men with muscles are perhaps more commonplace than they used to be, the more muscular physiques associated with being a bodybuilder are not such everyday occurrences. Even though bodybuilding has globally recognised competitions and champions and its participants consider bodybuilding to be a serious recreational and health enhancing sport, it is still viewed by outsiders as an undesirable and even deviant underground activity. Using an interactionist inspired model of sports socialisation this paper uses an ethnographic methods approach to explore how men become bodybuilders and how they enter the world of bodybuilding. Using data from 17 ethnographic interviews with participants from two bodybuilding gyms, this paper will demonstrate that becoming a serious bodybuilder, and attaining a bodybuilding identity, involves more than one event or making a single decision, and more than the influence of society. Instead it involves extended interactive processes through which individual men come to identify themselves as athletes or bodybuilders. It involves long-term complex processes through which individuals; acquire knowledge about their sport, become associated with a group of recognised athletes in their sport, learn the norms and expectations shared by group members, earn the acceptance of group members and experience repeated confirmation and reconfirmation of their identities as bodybuilders. In conclusion, the process of bodybuilder identity construction and confirmation is gradually formed as participants become knowledgeable and accepted members of their bodybuilding gyms and the bodybuilding world.

Sunday the 28 September 2003 at 10.50 - 11.20

Coe, C., Dolan, A.

University of Warwick

MEN'S TRANSITION TO FATHERHOOD AS SEEN THROUGH THE EXPERIENCES OF MATERNITY SERVICES: AN EXPLORATION OF ROLES, EXPECTATIONS AND REALITY

Fatherhood is now an area of policy concern, often cast in terms of 'crisis', and is the subject of much academic, professional and media attention. Against a backdrop of increasingly insecure male employment and changing family forms it appears that the traditional 'certainties' of fatherhood have given way to an increasingly disputed terrain and somewhat contradictory experience. On the one hand, men are encouraged to express their nurturing feelings and to take an active role in parenting. On the other, men are still expected to participate fully in the workplace and act as providers, constructing their identities as men through their work role. This paper presents the findings of a small preliminary study that sets out to explore some of these tensions and to better understand the perceptions and experiences of first time fathers and in particular men's perceptions and experiences around child birth and maternity services. This study also explores the perceptions and experiences of those health professionals who engage with fathers and the factors that shape the way in which maternity services meet, or fail to meet, the needs and expectations of fathers. Presenting data from a series of in-depth semi-structured interviews the authors begin to delineate the different experiences of fathering in modern society. They suggest that whilst men's assigned role as 'supporter' to their partner legitimises men's presence at the birth, it may also enable health professionals to 'side-step' the issue of addressing fathers' individual needs.

Saturday the 27 September 2003 at 16.20 - 16.50

Collett, T., Dodgeon, B., Chandler, J., Maconachie, M., Williams, M.

The University of Plymouth

HOW LONG TERM IS LONG-TERM ILLNESS?

Is 'permanent sickness' permanent and is it related to reportage of 'limiting long term illness'? In this paper, we examine whether adults of working age who report long-term illness at one census point do so at other census points. Using longitudinally-linked census data from the Office for National Statistics Longitudinal Study (LS), our study follows three age cohorts (15 - 24, 25 - 34, and 35 - 44 years old) from 1971 through 1981 to 1991. The LS is based on just over one percent of the population of England and Wales, and our sample comprises 155,000 adults of working age who were between the ages of 15 - 44 years old in 1971 (and still members of the LS at the 1981 and 1991 Censuses).

This longitudinal study will allow us to examine patterns of reporting long-term illness over time and to contribute our findings to broader discussions and debates within medical sociology about measures of 'self-reported' health status. Following each of the three age cohorts over time also allows us to assess the advantages of lifecourse perspectives based on longitudinal as opposed to cross-sectional data. In addition to age, we will explore gender, education, and class differences in patterns of reporting illness over the lifecourse.

Friday the 26 September 2003 at 16.00 - 16.30

Corbett, K.

St George's Hospital Medical School

CONTESTING AIDS/HIV: THE LAY RECEPTION OF BIOMEDICAL KNOWLEDGE

This paper is based a doctoral study of lay responses to the medical screening and testing technologies used in HIV and AIDS. These technologies (namely, HIV antibody-tests, T cell counts and Viral Load tests) are used in the clinical surveillance and monitoring of the health of diagnosed people. The paper develops a conceptual framework from within the sociology of scientific knowledge using the work of Bijker and Foucault. It is argued that HIV/AIDS screening and testing technologies embody degrees of certainty over diagnosis, prognosis and treatment. It is further argued that lay theorising and global activism over such technological indeterminacies has helped to foster diverse meanings for these health technologies. The paper draws on a discourse analysis of interview data drawn from a U.K. sample of diagnosed people. This analysis showed a spectrum of articulated affinity with various propositions and presuppositions about the nature of HIV/AIDS and the associated screening and testing technologies. The paper analyses how individuals actively engage with various technological frames when speaking, thinking and acting in relation to HIV, AIDS and their response to the results of HIV technologies. The paper argues that the latter response to these health technologies constitutes a lay epistemology of HIV and AIDS characterised by uncertainty and resistance underpinning a continuum of responses ('response-styles') for living with a diagnosis of HIV and AIDS.

Abstract Book prepared 18th July 2003

16

Saturday the 27 September 2003 at 10.45 - 11.15

Cotton, A.

St Martin's College of Higher Education

CHRONICLING NARRATIVES OF HEROIN STIGMA: SOME NOTES ON LIES, SECRETS AND SILENCES. KEEPING FACE AND BEING A GOOD ENOUGH WOMAN

Use of heroin and other illicit drugs is deeply imbued with symbolic meanings within contemporary Western culture. Women's use of heroin raises particular responses, issues and tensions. These are perhaps mirrored within contemporary mental health practice - societal concerns about morality, social roles of women and considerable ambivalence about addressing complex meanings find their way into substance use care settings. Practitioners, and researchers are thus faced with significant dilemmas when listening to women's stories and accounts of their drug use. A particular anxiety may relate to believing women's accounts - especially those that may be contradictory, found unlikely, and/or deeply distressing.

Consideration will be given to the complex facets of identity, layers of meaning that women allude to in accounting for their heroin and other drug use. The impact of the identity of the listener will be explored, as will the connections between women, as friends, sharing drugs and experiences. Connections as fragile and uncertain, relying upon assumed shared notions of what friendships are about, together with the ambivalencies women feel towards each other will be considered. The discussion will draw upon Adrienne Rich's notions of lying as survival - and explore some implications for women surviving stigmatising discourses of being morally and socially suspect, whilst attempting to present themselves as good enough women.

Saturday the 27 September 2003 at 11.55 - 12.25

Cresswell, M.

University of Manchester

TWO KNOWLEDGES OF DELIBERATE SELF-HARM

Deliberate self-harm (DSH) - which broadly refers to non-fatal acts of self-harm such as self-poisoning and self-laceration - is a controversial psychiatric concept. It has been the subject of epidemiological research in the UK since Erwin Stengel's pioneering inquiries in the 1950's. Specifically, the nature of the link between non-fatal acts of self-harm and fatal acts (suicide) has been hotly debated, as has the place of DSH within developing systems of formal diagnosis and classification.

The concept itself came under attack from the mid-1980's onwards from the emerging "psychiatric survivor" movement. This movement emphasised self-harm as an adaptive response, often to traumatic early experiences, and was sharply critical of psychiatry's understanding and treatment of self-harmers. Specifically, "survivor" groups have fundamentally challenged the existence of any substantive link between DSH and suicide and have also advanced alternative interpretive frameworks for its understanding.

This paper compares and contrasts the two knowledges - that of psychiatric epidemiology and psychiatric survivors -located in two historical archives:

- 1. The body of work of five major post WWII UK epidemiologists: Erwin Stengel, Neil Kessel, Norman Kreitman, Gethin Morgan, and Keith Hawton
- 2. Psychiatric Survivor texts self-help books, collections of personal accounts, journal articles, internet resources -emanating from UK survivor groups, from the mid 1980's onwards.

The aims are twofold:

- 1. Demonstrate the main cognitive features of these contrasting knowledges
- 2. Discuss the extent to which such knowledges may be compared.

Friday the 26 September 2003 at 15.20 - 15.50

Crinson, I.

St George's Medical School

IDEOLOGY AND PROFESSIONAL PRACTICE: NURSING IN THE MODERNISED NHS

In its first annual report published in 2002, the NHS Modernisation Board which has the responsibility for overseeing the implementation of The NHS Plan, claimed that nurses were failing to embrace 'modernisation' because of old-fashioned 'working practices and attitudes, some unchanged since 1948'. This view reflects a well established pattern of governmental criticism, both Conservative and New Labour, directed at the perceived intransigence of the health professions in the drive towards rationalising the NHS. Whilst the medical profession has been the primary target of such criticism, nursing has not been immune to the accusation that it is holding onto an outdated ideology of professional practice. Drawing on the results of research undertaken for a PhD, this paper is concerned with the ways in which the transformational relationship existing between the organisational structure of health care and the material practice of nursing, serves to shape the discourses that nurses draw upon to inform their practice. Utilising a positive rather than a negative conceptualisation of ideology (conceived as a structural mediator of our shared representations of reality), these discourses can be seen as being both stratified and dynamic. Stratified in the sense that nursing practice is influenced by a wide range of often disparate ideas, many of which have their origins in very different sets of historical and social circumstances. Yet dynamic in the sense of reflecting the active response of nurses to the demands made upon their labour within the ever changing structural and organisational relations that characterise the modernised NHS.

Friday the 26 September 2003 at 16.00 - 16.30

Dhar, R.

Institute of Applied Manpower Research

<u>DISASTER AND DOCTOR-PATIENT INTERACTION: SOME METHODOLOGICAL</u> ISSUES

Medical Sociologists have limited their studies on doctor-patient interaction to an institutionalised and formal setting (a hospital or a referral clinic). In these types of settings both the role players are aware of their role expectations and the interaction is more or less dictated by these roles. The field of study has however, remained oblivious to doctor-patient interaction in a setting which is both unfamiliar to doctor and the patient, as in the case of disasters.

A large number of people are physically and psychologically affected by disasters and require medical attention. The treatment that is given to them is in a makeshift set up where both the doctor and patient are in distress, the doctor because of limited resources available with him and the patients who not only suffer physical injuries but also loss of near and dear ones. A sociological interrogation-which may cast light on doctor-patient interaction in such a setting needs to be made to study the Psycho-social consequences of such interactions on both the role players. But before that one needs to address a number of issues like what aspects of doctor patient interaction to focus on (communication, decision-making), what techniques of investigation to adopt (interview, observation) and how to apply (if possible) the existing models of doctor-patient interaction to such a complex situation. To seek answers to these questions and to demonstrate whether the place and the situation where the treatment takes place has any bearing on doctor-patient interaction is the focus of this paper.

Sunday the 28 September 2003 at 10.20 - 10.40

Dingwall, R.

University of Nottingham

THE POWER OF INSTINCT? BIOLOGICAL DETERMINISM AND THE SOCIAL SCIENCES

This paper considers the debates between sociology, psychology and biology in the early years of the 20th Century and their implications for contemporary responses to the resurgence of biological determinism, particularly from behavioral genetics and evolutionary psychology. It will, in particular, be argued that the debate over the role of instinct in explaining human social behaviour, involving scholars like Mead, McDougall, Faris and Bernard, offers important resources for a debate that social scientists have been reluctant to take up. Social scientists need to re-engage with biology and to spell out the limitations of its determinism rather than simply denouncing this or standing to one side of the arguments between biologists. Particular attention will be given to the explanation of forms of social deviance, such as crime and illness, and to the problems created by the idealist turn in contemporary sociology with its naïve rejection of realism.

Saturday the 27 September 2003 at 15.10 - 15.40

Dolan, A.

University of Warwick

EXPLORING THE MATERIAL AND PSYCHOSOCIAL INFLUENCES ON THE HEALTH OF WORKING CLASS MEN: A CASE STUDY OF TWO CONTRASTING URBAN AREAS

This paper presents the findings of a qualitative study that set out to explore the effects of material and psychosocial influences on men's health. This study has been informed by recent debates from within a materialist/structural perspective on health inequalities. These have contested the extent to which the main effect of inequalities in income and other material goods is not directly material, but psychosocial, associated with the subjective appraisal of one's 'relative' position in an unequal society, which make it more difficult to maintain social networks and self-esteem. However, neo-materialist analysis counter these arguments with evidence showing the continuing significance of the lack of material resources held by individuals and the systematic under-investment across a wide range of community infrastructure, which result in greater social fragmentation and lower social cohesion. In exploring some of the mechanisms and processes by which material and psychosocial environments impact on individual health, it places 'real' men and their views and experiences at the forefront of the investigative process. The findings highlight the complexity of ways that working class men make sense of, and develop personal strategies for dealing with, the relative effects of indirect psychosocial and direct material circumstances.

It also shows the ways in which material circumstances and 'relative deprivation', together with dimensions of gender, interact to affect social cohesion within neighbourhoods and men's ability to maintain social networks and supportive relationships. It shows that the impact on health may vary according to variations in social and material circumstances.

Sunday the 28 September 2003 at 09.40 - 10.10

Doran, N.

Rusholme Health Centre

CHRONIC BACK PAIN - A MATTER OF SEMANTICS?

'The point that I realised it was chronic pain urm was the point when I realised it wasn't actually stopping......the pain was with me all day long and all night long.....every waking, breathing, moving moment of my life'. (Extract from interview as part of PhD project).

According to the International Association for the Study of Pain (IASP), pain is considered to be chronic once it has exceeded three months. However a thorough search of the literature has revealed that in the case of chronic back pain, the term 'chronic' has come to take on more than a straightforward time dimension. While definitions of pain are manifold and culture specific, differences in meaning ascribed to key words such as 'chronic' may not be an issue of confined semantics, but rather, may actually predict attitudes, therapies and subsequent outcomes. Drawing on both the current literature, as well as some preliminary findings from fieldwork carried out as part of my PhD project amongst those attending a self management in pain group in central Manchester and a spinal clinic in Liverpool, this paper aims to explore how chronic back pain is currently classified and understood in research and practice and how this affects those living with long term pain.

Sunday the 28 September 2003 at 10.20 - 10.40

Dyson, S.E., Cochran, F., Kennefick, A., Kirkham, M., Morris, P., Squire, P., Sutton, F., Dyson, S.M.

De Montfort University

SCREENING SELECTIVELY BY ETHNICITY FOR HAEMOGLOBIN DISORDERS: THE CURRENT STATE OF COMMUNITY MIDWIFERY

As part of the NHS Plan, the NHS Haemoglobinopathy Screening Committee has commissioned projects to examine the issue of selecting women deemed to be at risk of carrying genes associated with sickle cell/thalassaemia by means of an ethnicity screening question. Around 160 observations of midwifery practice and about 100 short interviews with mothers and midwives in four contrasting areas of England have been conducted. The observations and interviews sought to shed light on the actual practices of asking an ethnicity question in clinical practice in the NHS. In this paper we report on the wider contextual features of current community midwifery that suggest reasons why community midwifery will be a very fragile platform upon which to try to impose screening programmes. From the observations made, it appears that there are numerous contextual issues that are likely to be playing a part in the possibility of asking an ethnicity question successfully as part of selective antenatal screening for sickle cell/thalassaemia. The lack of sufficient staff and the pressures under which community midwives currently operate have been well documented. In addition to these we report on other factors we were made aware of in the course of the research. These include the current state of midwifery; the pressures on, and priorities of midwifery managers; the contradiction between labour-intensive emotion work and the proceduralization of midwifery practice, and the uncertainty engendered by the particular topic of sickle cell/thalassaemia.

Saturday the 27 September 2003 at 11.20 - 11.50

Dyson, S.M., Culley, L.

De Montfort University

NEGOTIATING ETHNIC/FAMILY ORIGINS: PERSPECTIVES OF HAEMOGLOBINOPATHY NURSE COUNSELLORS

Fourteen depth interviews were tape recorded with 22 specialist sickle cell/thalassaemia nurse counsellors as part of a broader project examining selective antenatal screening by ethnicity for sickle cell/thalassaemia. Respondents recounted instances where attempts to target screening by ethnic selection had failed because of poor design of categories, lack of awareness on the part of midwives initiating the screening, unease with issues of ethnicity on the part of the midwife, client resistance to categories based on prior experience of racism, dual or complex ethnic identities on the part of the client and issues in ethnic identification following adoption. A minority of clients seen for counselling when identified by laboratory tests as carriers of genes associated with variant haemoglobins or thalassaemias describe themselves as 'White English'. In such cases clients are positioned in such a way as to require them to problematise their 'white' ethnicity. Counsellors (mainly of Black British: African/Caribbean descent) recount how they sometimes manage the emotion work of negotiating the client's ethnic/family origins.

This is achieved by a selective emphasis on those aspects of British history relevant to mixing of gene pools felt to pose the least possible threat to the self-image of the client.

Friday the 26 September 2003 at 16.00 - 16.30

Eborall, H., Cunningham-Burley, S., Fowkes, F.G.R.

University of Edinburgh

IS PREVENTION BETTER THAN CURE? LAY MEANINGS OF SCREENING, PREVENTION AND PREVENTIVE MEDICATION FOR HEART DISEASE

Purpose

The present study aims to understand lay perceptions and meanings of the prevention of heart disease within the context of population screening and preventive medication.

Methods

Participants were members of a healthy population invited to attend screening for asymptomatic atherosclerosis, some of whom had subsequently been invited to participate in a large randomised control trial assessing the efficacy of low-dose aspirin in preventing cardiovascular events. Semi-structured qualitative individual interviews and focus groups were conducted with a range of participants. The interviews were fully transcribed and the transcripts analysed inductively and interpretatively for emerging themes.

Findings

A range of themes emerged from participants' accounts. Salient issues centred around the screening experience and preventive health practice, all relating to an underlying personal risk perception. For example, interpretations of the screening result were made in light of individuals' prior beliefs about their health. "Risk status" as ddefined by a 'novel' clinical measurement was interpreted differently to standard clinical measures, and both were interpreted differently to risk from lifestyle behaviours or family history of disease. Beliefs about aspirin as preventive medication were rooted in attitudes towards medication in general, aspirin-specific attributes, and doctor-patient relationships. Study participants often held contradictory beliefs and practices about prevention.

Conclusions

Qualitative research can complement results of larger RCTs; the success of preventive methods will depend on their perception and interpretation by the target population. This study suggests that screening for asymptomatic conditions may be difficult in the light of people's pre-existing beliefs.

Friday the 26 September 2003 at 16.40 - 17.10

Edgely, A., James, N., Murphy, E., MAUPH.

University of Nottingham

CONFLICT AND CONSENSUS BETWEEN PROFESSIONS AND STATE: THE CASE OF NURSE PRESCRIBING IN AUSTRALIA, BRITAIN, SWEDEN AND THE USA

Nurse prescribing offers an interesting case study for examining the question of what conditions are conducive to enhancing professional collaboration in health service delivery. In the United States, nurse prescribing has generated considerable antagonism from physicians (Webb 1992), whereas in Britain the development has been largely welcomed by doctors (Luker et al 1997). This paper will begin by exploring the history of nurse prescribing in terms of patient access. It will then make a comparative analysis of the development of the ways in which policy initiatives have been framed by health care professions and management (Australia, Britain, Sweden and the US). In Britain and the United States the policy has been firmly framed in terms of the benefits to patient care, although in Britain the case has also been made for reducing workloads of highly qualified medical staff at the same time as throughput is increased. Alternative interpretations suggest Government and particularly fiscal interests offer a more powerful explanation for the policy development. Finally, the paper will compare the British and US experience within the context of their different health economies. We note the difference between regulatory regimes in unitary and federal state systems: highlight the different imperatives for deregulating professional boundaries: and identify the possibilities for consensus and conflict between professions, and between professions and the state.

Saturday the 27 September 2003 at 15.45 - 16.15

Ellins, J.

University of Sussex

THE POLITICS OF SICKNESS: ANALYSING THE POLITICAL ECONOMY OF MEDICALISATION

The concept of medicalisation has been used by medical sociologists to explain the enlargement of the patient population. It describes the expansion of medicine's sphere of authority and the medical profession's motives within this expansion. This paper argues that the recent growth in the prescribing and consumption of medicines cannot be accounted for by the existing medicalisation literature. While recent research has pointed towards the pharmaceutical industry as an active participant in medicalisation, it has not fully integrated the process of medicalisation with the political economy of medicines development, marketing and regulation. The paper presents findings from documentary and empirical research examining the growth in the prescribing of three prominent pharmaceutical drugs: Prozac, Ritalin and Viagra, in the UK and USA. It outlines the role played by the pharmaceutical industry, and institutions of the state (principally drug regulatory agencies), in the process of medicalisation. In addition, analysis demonstrates how the corporate interests of pharmaceutical manufacturers can be subtly promoted through professional and patient organisations and actors. Finally the implications for the regulation and prescribing of medicines are considered.

Sunday the 28 September 2003 at 09.40 - 10.10

Flynn, R., Bellaby, P.

University of Salford

KNOWING THE UNKNOWN: ISSUES IN THE PUBLIC PERCEPTION OF RISK

The debate about risk society and trust in abstract systems has intensified scrutiny of the relationship between lay and expert knowledge. There are important parallels between ideas about this relationship in the sociology of health and illness, and critiques of the public understanding of science and technology.

This paper explores some of these parallels and illustrates the problems of investigating public perceptions of risk in the development of the 'Hydrogen economy' (Rifkin) - a radically new energy system which could potentially transform economic and social structures. The paper reviews two different but related literatures: about lay or folk beliefs in health and medicine, the 'problem' of patient compliance and power of medical professionals (Bury; Gabe; Popay & Williams); and about the sociology of scientific knowledge and social studies of technology, particularly the 'problem' (or 'deficit model') of the public understanding of science (Irwin; Wynne). The latter suggests we must move beyond a realist versus constructivist dualism, and acknowledge the socially constructed character of scientific knowledge itself and the contextualised interpretation of risks. These approaches are used to address the question of how to investigate public awareness of, and attitudes to, the Hydrogen economy when it is largely 'unknown'.

Saturday the 27 September 2003 at 16.20 - 16.50

Gabbay, J., le May, A.C.

Wessex Institute for Health Research & Development

FROM EVIDENCE-BASED MEDICINE TO THE SOCIAL CONSTRUCTION OF KNOWLEDGE-IN-PRACTICE: AN ETHNOGRAPHIC STUDY OF PRIMARY CARE

Evidence-Based Healthcare (EBHC) has been promoted for a decade as a model for improving clinical practice. Its proponents advocate importing explicit knowledge from the world of research and incorporating it into practice. This contrasts with the parallel vogue for Knowledge Management (KM), whose main aim in the industrial sector is to elicit and promulgate practitioners' tacit knowledge. Neither the EBHC nor the KM movements have addressed the need to understand the processes of collective sensemaking by which knowledge from whatever sources is negotiated, constructed and routinised in clinical practice. What are the social processes by which evidence/ information/ knowledge - tacit or explicit - becomes transformed into knowledge-in-practice?

In this study we explored how practitioners in a highly-regarded 8-partner GP practice use various sources of knowledge to shape their individual and collective healthcare decisions both at policy and at individual patient level. We employed standard ethnographic methods intermittently over one year and tested our emerging model, presented here, with the research subjects.

Clinicians rarely accessed and used explicit evidence directly, but relied what we have called "mindlines" - internalized, tacit guidelines - that were informed by brief reading, but mainly by their own experience, their interactions with each other and with opinion leaders, patients, pharmaceutical reps, and other sources of largely tacit knowledge, mediated by organizational demands and constraints,. Mindlines were iteratively negotiated with a variety of key actors, often via a range of informal interactions in fluid "communities of practice", resulting in routinised practice based on socially constituted knowledge.

24

Sunday the 28 September 2003 at 09.40 - 10.10

Gibbon, S.

University College London

BEYOND GENETICISATION: THE 'TRAFFIC' OF KNOWLEDGE TRANSMISSION IN CLINICAL BREAST CANCER GENETICS

This paper is based on ethnographic research carried out in two cancer genetic clinics in the UK. It examines how new genetic knowledge associated with 'BRCA' genetics is transmitted at the interface between practitioners and patients. I suggest that such practices are constituted by a certain degree of multi-directional 'traffic'. For instance I show how a discourse of 'visibility and voice' among predominantly female patients, in part a product of gendered health activism around breast cancer, is also an important component of clinical practice. At the same time, for practitioners, this entails a degree of sometimes uncomfortable 'code switching'. In a similar way the ethical value and morality of a notion of 'nurturance' towards others, itself a dimension of such gendered health activism, is an essential 'tool' and 'technology' for knowledge transmission in the clinic. Nevertheless this can have equally uneasy consequences for patients and practitioners. These complex entanglements raise questions about how the social impacts of new genetic knowledge are to be defined and investigated.

Saturday the 27 September 2003 at 16.55 - 17.25

Glover, G.R

University of Durham

MAPS OF MENTAL HEALTH CARE: NEW DATA, NEW POSSIBILITIES

National statistics about mental health care in England have advanced substantially in the last few years. Two new major data sources are now available which allow a far more detailed perspective of facilities available and the work that they do.

The Annual Mental Health Service Mapping collates an internet based inventory of all types of mental health facilities with relevant details concerning targeting, staffing and volumes. These data can be mapped to local government, primary care trust and national service framework implementation team boundaries.

The Mental Health Minimum Data Set is a patient based record of the care received by individuals from specialist mental health services. It is assembled by NHS Trusts, largely from data that has been collected for a number of years and returned quarterly to the Department of Health. Patient records include details of the individuals problem and sufficient keys to map them to general practices, primary care trusts, local authority electoral wards and, subject to restrictions relating to confidentiality, their exact residential location.

These data sources open a wide range of possibilities for geographical analysis of patterns of mental health problems and the way they are addressed by available services. The paper will present data from some selected areas and discuss the opportunities for research arising from the new data sets.

Saturday the 27 September 2003 at 14.00 - 14.30

_ .. _ _ _

Godin, P., Davies, J., Heyman, B.

City University

UNDERSTANDING THE MANAGEMENT OF RISK AND DISORDERLY BEHAVIOUR WITHIN A FORENSIC MENTAL HEALTH CARE UNIT: A STRUCTURALIST APPROACH

This paper is based on a qualitative research study of a forensic mental health care unit involving over 50 interviews with staff, 10 interviews with service users, fieldwork observations, staff feedback groups and workshops. In the course of the study we increasingly became aware of how differently people in different positions within the organisation understood and attempted to manage risk. We also became intrigued by the way certain risky and disruptive behaviour, identified as violence, manipulation, incontinence and promiscuity, provoked various responses attempting to maintain or re-establish order within the unit.

In this paper we explore how Mary Douglas's structuralist approach to understanding risk and blame, and purity and danger can be used to offer a reasonable explanation of these phenomena. Drawing on the work of Steve Rayner, we consider how Douglas's grid-group model of stratification and integration may be used to understand four cultural locations that give rise to different perceptions of and attitudes towards risk within one organisation. We also use Douglas's structuralist approach to consider why deviant behaviour that the staff could not easily associated with mental illness, as well as the incontinent and promiscuous behaviour of women service users, were regarded by staff as particularly threatening to what they believed to be the purpose of the unit.

Saturday the 27 September 2003 at 15.10 - 15.40

Goenka, S., Seeberg, J., Ammini, A.C., Patel, T., Dwivedi, S.N., Reddy, K.S., Sood, A., Sell, H., Shah, P.

Initiative for Cardiovascular Health Research in Developing Countries

THE MAKING OF AN ACUTE DISEASE: DIABETES AND HYPERTENSION MANAGEMENT IN PRIVATE GENERAL PRACTICE

In India, 60-80% of all health care is sought through the private general practitioners. India has the largest number of type 2 diabetes patients in the world. Diabetes and hypertension are chronic diseases where regular control of risk factors, co-morbidities and prevention of complications of the disease is an essential component of treatment and management.

Aims:

To describe the diabetes and hypertension related health care delivery in private general practice and factors that influence these practices.

Methods:

Ethnography (n=15) and ethnographically guided semi-structured interviews (n=70) with private general practitioners in south Delhi. Semi-structured interviews with 20 doctors representing different types of practices (specialists and general) in Delhi.

Results:

Tests for diabetes, its complications and co-morbidities were either rarely prescribed or prescribed much later than clinically desired. The GP's clinics were more like check stations for a service, which the patient (based on his/her own perception) bought, across the table, whether it is a blood pressure check or a blood glucose check etc.

The GPs were professionally isolated and operated amongst stiff competition in a commmodified health care market. This environment over time tended to wear away their scientific knowledge and hindered application and further acquisition of scientific knowledge. This was in a background where the GPs, to start with, felt inadequately trained on the practical aspects of diabetes and hypertension.

Conclusions:

The environment and the conditions of the GPs' practice were such that, over time, for all practical purposes, chronic disease like diabetes and hypertension had been systematically reduced to acute diseases.

26

Sunday the 28 September 2003 at 10.20 - 10.40

Goode, S.

King Alfreds College

BEING A SUBSTANCE-DEPENDENT MOTHER: RELATIONSHIPS WITH CHILDREN

This paper will examine the everyday routines of being a substance-dependent mother, particularly a mother dependent on illegal substances such as heroin, crack-cocaine, and amphetamines. Life when substance-dependent can often be viewed as a constant negotiation of a chronic series of crises, in particular the daily round of obtaining first money and then drugs, in order to stave off withdrawals, while also evading detection and arrest. In many ways these endless minor crises do constitute the fabric of everyday life. Nevertheless, the mundane and unexceptional routines of life must also still be conducted - people must still eat, sleep, do housework, maintain a family life, and children must go to school, and be kept clean, clothed, and entertained. It is these everyday routines which this paper will bring to the fore, with a focus on how, given the constraints of substance-dependency, women do manage to raise their children, often well and often without assistance from any formal (or informal) support networks.

In order to illustrate this, the paper draws on a series of interviews with fifty substance-using women, conducted in the West Midlands area between 1994 and 1997. The specific areas that this paper will briefly cover will include:

- The concept of 'powerless responsibility'
- The general impact of substance-use on the mother-child relationship
- Children aware of drug-dealing
- Children aware of shoplifting
- Issues of gender
- Sexual abuse of the respondents' children
- The mothers' fears for their children in the future

Saturday the 27 September 2003 at 11.55 - 12.25

Greenhalgh, J., Flynn, R., Long, A.F.

University of Salford

Abstract Book prepared 18th July 2003

THE IMPACT OF STANDARDISED HEALTH STATUS MEASURES ON CLINICAL DECISION MAKING: LACKING AN EFFECT OR LACKING A THEORY?

Systematic reviews have concluded that the use of standardised health status measures within routine clinical practice has little impact on the clinical management of the patient or on patient outcomes. However, the rationale and mechanism of any effect of this intervention have been left implicit or seemingly taken for granted. This paper aims to critically examine the empirical explanations for the lack of effect and provide a critique of the theoretical basis of the evaluations of this intervention. This draws on a comprehensive literature search of randomised and non-randomised studies of the impact of health status measures in clinical practice and of clinicians actual use of, and attitudes to, such measures. Two main conclusions can be drawn.

Firstly, the role that standardised health status measurement can play within clinical decision making is uncertain. Their influence depends on the aims of treatment, the particular domain of health status measured, patient characteristics and clinicians' attitudes to health status measures.

Secondly, the theoretical basis of the intervention within randomised controlled trials is often poorly defined. Its impact has been assessed using a number of disparate outcomes and no overall theoretical framework to delineate the relationships between these outcomes has been developed. The trials have focused on an assessment of whether the intervention 'works' but have paid less attention to understanding 'how it works'.

The paper ends by presenting an outline theoretical framework of how the use of health status measures could influence clinical decision making to guide future research in this area.

Paper/Poster Abstracts - listed in alphabetical order of first author

Saturday the 27 September 2003 at 11.55 - 12.25

Gulbrandsen, P., Aasland, O.G., Hofoss, D.

Centre for Health Services Research - HELTEF Norway

<u>THE DOCTOR AS GATEKEEPER - RELATION TO PERSONALITY, PATERNALISM, AND JOB SATISFACTION</u>

Background

In an era of rising expectations to health services and limited resources available, higher pressure has been put on doctors to act as gatekeepers. The gatekeeper role is one of potential conflict with the traditional medical role. We hypothesized that there could be an association between the doctor's gatekeeper style and his personality, degree of paternalism, and job satisfaction.

Objective

To assess the relation between gatekeeper style and personality (Eysenck & Eysenck 1971), degree of paternalism (Falkum & Forde 2001), and job satisfaction (Job satisfaction scale, Warr, Cook & Wall 1979).

Material and methods

Questionnaire survey to a representative sample of Norwegian physicians in 2002, with 967 responders. Five groups of doctors with different gatekeeper styles were identified: Doubters that did not feel the role as a burden (95), doubters that did feel the role as a burden (118), no-doubters of conservative (restrictive) attitude (90), no-doubters of liberal (permissive) attitude (76), and those that did not fit clearly into one of these categories (588). The relation between the described inventories and these subgroups were explored by standard bi- and multivariate (logistic) regression analyses.

Preliminary results

None of the gatekeeper styles were significantly associated with personality (extroversion, neuroticism), degree of paternalism, or job satisfaction.

Interpretation

When doctors complain about the burden laid on them in the rationing of limited resources, this does not seem to be related to important characteristics of the doctor. Possibly, the difficult part of the gatekeeper role is related to characteristics of the individual patient.

Saturday the 27 September 2003 at 16.20 - 16.50

Gundersen, T.

SINTEF Unimed

FEMALE SURGEONS - UNDER THE KNIFE? EXPERIENCES OF HOW GENDER IS MADE RELEVANT IN WORK SITUATIONS

Studies show that fewer women than men complete specialist training in surgery. One common explanation is that working conditions make it difficult for women to combine home and job responsibilities. On the other hand studies also indicate that this factor is not sufficient to explain the loss of women in the course of specialist training. The main focus of this presentation is to give a broader understanding to those conditions that seem to influence a woman's choice to either complete her specialist training in surgery or consider abandoning the field.

The analyses are based on a qualitative study (combined observation and interview) of 6 female and 3 male physicians in junior positions in a surgical unit at a large Norwegian hospital.

Results will illustrate the various ways that women experience the relevance of the gender issue in the workplace. First by showing how the organisation of duties in a surgical unit can influence work opportunities differently for female and male surgeons. Secondly by assessing the role of gender (for women) in different types of interactions; with senior physicians, patients and nurses.

The way the women in this study interpret gender at work shows that surgeons are most often associated with being male. Women react to this in different ways, e.g. some develop strategies to neutralise the role of gender in work situations, while others consider leaving the field.

Abstract Book prepared 18th July 2003

27

Friday the 26 September 2003 at 16.00 - 16.30

Harris, F., van Teijlingen, E., Bryers, H., Caldow, J., Farmer. J., Hundley, V., Ireland, J., Kiger, A., Tucker, J.

University of Aberdeen

<u>DELIVER US FROM 'RURALITY': MATERNITY CARE PROVISION IN 'RURAL' SCOTLAND</u>

This paper explores the impact of 'rural' versus 'urban' representations on the provision of maternity care in 'rural' Scotland. While the terms 'rural' and 'urban' are often used to denote particular locations and demographic 'types', in fact these labels are associated with a discourse of centre and periphery; marginality and power.

This paper is based on a project funded by NHS Education for Scotland. We conducted 70 face to face interviews in ten different areas of rural Scotland selected by purposive sampling. We explored the provision of sustainable maternity services in these areas with a particular emphasis on skill maintenance and best practice in the development and maintenance of these skills. Several key themes emerged, these included problems of maintaining skills in areas where there are low numbers of deliveries and problems around appropriate training for rural practitioners.

Interviews with maternity care providers in 'rural' locations also revealed some core ambiguities based on the gap between representation and practice. While rural health practitioners are often regarded as being less skilled than their urban, hospital-based counterparts, in practice they are highly skilled professionals with training needs which are specific to their rural practice.

Saturday the 27 September 2003 at 14.35 - 15.05

Hawkey, M.

Florence Nightingale School of Nursing and Midwifery,

GENETIC KNOWLEDGE; BURDEN OR OPPORTUNITY FOR HEALTHCARE CLINICIAN

Along with advances in biology and medicine, the mapping of the Human Genome has led to an awareness that an individual's genetic information may have ramifications not only for themselves but also for their next-of-kin. As a result, traditional values in nursing and medicine, attuned to the needs of the individual patient, are increasingly tested by the tension between a duty to protect the confidentiality of such information and the desire to make it available to those within the wider family for whom it may have profound implications.

Even where patients are willing to consent to such disclosure, the problem posed for the health professional is whether family members who have not requested the information may actually want to receive it. This difficulty is further compounded in situations where patients refuse to consent to disclosure of their genetic information, even though such information - in the opinion of the clinician - will be of benefit to the patient's next-of-kin. In such a situation, not only does the clinician break faith with their patient, they are also at risk of doing more harm than good to the person to whom they feel obligated to pass the information.

My paper is a presentation of findings from PhD work in progress on the responses of both specialist and generalist clinicians to a series of vignettes which illustrated pertinent ethical dilemmas regarding the confidentiality of genetic information. What Andrews (1997) refers to as "the potential eugenic symbolism of breaching confidentiality" will be discussed.

Paper/Poster Abstracts - listed in alphabetical order of first author

Sunday the 28 September 2003 at 10.20 - 10.40

Hayter, M.

University of Sheffield

FOUCAULT IN THE FAMILY PLANNING CLINIC: DISCIPLINARY PRACTICES WITHIN THE NURSE/CLIENT CONTRACEPTIVE CONSULTATION

Background

Family planning clinics provide contraceptive care and advice to thousands of women each year. Using contraception is part of many women's lives yet little research has been done into the way in which contraception is discussed with women in the clinical setting. This paper presents the findings of research undertaken in five family planning clinics in the north of England to explore the power relations operating within the nurse/client consultation.

Method

A grounded theory methodology was used. Data collection and analysis utilised the constant comparative approach. 52 nurse/client consultations were audiotaped and 15 semi-structured interviews with family planning nurses conducted.

Findings

Nurses utilised several discursive techniques to encourage women to effectively use and comply with a contraceptive regimen. This included teaching the woman about reproductive anatomy whilst utilising the discourse of risk. Women were subsequently encouraged to perform self-surveillance and occasionally self-examination as part of using contraception. Additionally nurses undertook direct surveillance of the woman's body and contraceptive practices. Nurses also instructed women in the compliance with a contraceptive regimen.

Discussion

This process illustrates a clear example of the notion of productive power (Foucault 1984) operating within in the health care consultation. It provides an interesting example of the 'Foucault paradox' (Turner 1995) in that in order to enjoy control over fertility women are required to engage with medical discourse around reproduction and police their bodies closely. It also provides an illustration of the development of body techniques that are simultaneously enabling and constricting (Frank 1991).

Friday the 26 September 2003 at 15.20 - 15.50

Heaton, J., Sloper, P., Noyes, J., Shah, R.

University of York

THE EXPERIENCES OF SLEEP DISRUPTION IN FAMILIES OF TECHNOLOGY-DEPENDENT CHILDREN LIVING AT HOME

This paper focuses on one of the key findings from a wider study of the temporal organisation and effects of the home care regimes for technology-dependent children and their families.

The experiences of a purposive sample of 36 families were examined using a variety of qualitative methods, including semi-structured interviews and time-line drawings. All the children in the sample used (or had recently used) one or more medical devices (such as artificial feeding, assisted ventilation and dialysis machines) on a daily basis.

In this paper we focus on the families' experiences of sleep disruption. We outline the extent to which family members' sleep was disrupted, the reasons for this and the impact on those concerned. We conclude by looking at the implications for policy and practice for this group.

Saturday the 27 September 2003 at 09.35 - 10.05

Heaven, B., Murtagh, M., Rapley, T., Kaner, E., May, C., Thomson, R.

University of Newcastle upon Tyne University of Newcastle upon Tyne

"YOU GO AND SEE A DOCTOR AT THE SURGERY, NOT AT RESEARCH": HOW 'PATIENTS' IN AN RCT UNDERSTAND THEMSELVES AS EXPERIMENTAL SUBJECTS

The randomised controlled trial (RCT) is the 'gold standard' for the production of clinical evidence. Results from RCT's are commonly understood as providing definitive evidence for the efficacy of medications, therapies, clinical interventions, and form the basis of new evidence-based guidelines of practice. However the premise underlying such trials is that, intervention aside, the remaining system is a good proxy for real clinical encounters.

In this paper we explore accounts of older people included in an RCT of the efficacy of decision support tools intended for people with atrial fibrillation. Whilst the design of the RCT assumed a controlled study of patient behaviour, preliminary findings from this study suggest that participants (n=20) viewed their involvement quite differently, and often defined themselves as co-operative 'experimental subjects'.

Qualitative and quantitative techniques were used to examine both behaviours occurring within the trial's GP/patient interactions, and patients' post-clinic accounts. Qualitative techniques involved semi-structured face-to-face interviews in participants' homes, whilst the quantitative component of the study comprised content analysis of doctor-patient interactions.

Individuals participating viewed themselves as either patients, experimental subjects, or a combination of these roles varying in their patient/subject emphasis. In addition, subjects often changed their orientation at different points within their interaction with GPs.

Through this paper we demonstrate the value of linked qualitative work in understanding the experiences, motivations and overt behaviours expressed by participants within the setting of an RCT. We also point to the problems of interpretation posed by the hybrid identity of subjects within RCT's of 'complex interventions'.

Saturday the 27 September 2003 at 15.45 - 16.15

Hedgecoe, A.

University of Sussex

DISAPPOINTMENT AND DISCLOSURE IN THE PHARMACOGENETIC CLINIC

This paper explores some of the issues for patients and doctors raised by the introduction of a new genetic technology, pharmacogenetics, into the clinic. Pharmacogenetics is the use of genetic tests to decide how to prescribe drugs, allowing doctors to focus treatments on those who will gain the most benefit, and avoiding unfortunate, and possibly lethal side effects. The pharmaceutical industry is currently showing a great deal of interest in pharmacogenetics, as are regulators, bioethicists and other commentators; unfortunately there are very few examples of this technology actually being used in the clinic.

This paper presents results from an empirical study of one of the few examples of pharmacogenetics currently in clinical practice; the drug Herceptin, used to treat the ~30% of women with metastatic breast cancer whose tumours over-express a gene called HER2. Using interviews with clinicians applying this technology, this paper shows how doctors limit disclosure about the nature of Herceptin and whether patients are being tested for their eligibility for treatment to avoid 'disappointment' about not being able to receive this new drug. This in turn raises issues about the duties of clinicians to provide information to patients, informed consent and broader issues about public awareness of new medical technologies.

31

Saturday the 27 September 2003 at 10.10 - 10.40

Hewison, A.

University of Birmingham

EVIDENCE-BASED MANAGEMENT IN HEALTH CARE AND THE ADVANCE OF RATIONALITY

The rise of evidence-based medicine and more recently evidence-based policy reflect the enduring influence of rationality on the organization and delivery of health care. The latest manifestation of this process of rationalization is the emergence of evidence-based management in health care.

This paper examines the development of evidence-based approaches in health care. Recent reviews in the sociological literature (Davies 2003, Griffiths 2003) identified a relative neglect of the study of the organization and management of health care. It is suggested that recourse to the ideal type of rationality provides a useful means of addressing this imbalance. It provides an organizing schema which can inform the study of a range of related issues inherent in this development. These include the problematic nature of evidence, the social processes involved in the implementation of change on the basis of evidence, and the assumptions from which accepted definitions of management arise.

Evidence-based practice is central to the 'modernization' of health care in current UK policy. Sociological analysis of the origins and enactment of this dimension of the modernization agenda can provide insights on the policy implementation process, the contested nature of knowledge, and the use of evidence as an element in strategies for professionalization. It will be demonstrated that the work of Weber and Ritzer in particular can contribute to the development of a more complete understanding of the management and organization of health care.

Saturday the 27 September 2003 at 09.00 - 09.30

Hibbert, D., Mair, F., May, C., Boland, A., Angus, R.M., Capewell, S., Haycox, A., Roberts. C.

University of Liverpool

SCIENCE AND SENSIBILITY: HIDDEN TECHNOLOGIES IN THE CONDUCT OF A RANDOMISED CONTROLLED TRIAL

Our paper presents findings from an ethnography of a randomised controlled trial (RCT). The RCT was set up to compare a new telenursing service with an existing specialist nurse service offering home care for patients with acute respiratory illness. After running for eight months, the trial was halted due to disappointing recruitment.

The technical performance of the telecare equipment offers only a partial means to understand this apparent 'failure'. Rather, it is necessary to consider the interplay of various technologies performed in the trial setting, including those of the RCT and of nursing practice. The latter incorporates the specific protocols of the specialist service as well as the 'softer' technologies of nurse-patient relations.

The RCT constituted grounds for re-negotiating the meanings and importance of each technology within and between the actor groups. We illustrate this with two examples. One concerns a 'standard' measure of breathlessness used in the study (the Borg Score), and the attempts made to re-stabilise its content and meaning. The other is the issue of trial recruitment, where the debate between the science of the RCT and professional sensibilities was especially intense. Nuances in the responses (such as 'resistance') to the technologies are explained partly by the multi-faceted or 'hybrid' nature of actor roles and identities in the research setting.

Sunday the 28 September 2003 at 09.40 - 10.10

Hilton, S., Hunt, K., Petticrew, M.

Medical Research Council Social and Public Health Sciences Unit

COLLECTIVE ACTION VERSES SELF: PARENTAL ATTITUDES TO IMMUNISATION WITHIN THE CONTEXT OF THE MMR CONTROVERSY

The past century has witnessed a huge decline in the mortality and morbidity from childhood infectious diseases. Whilst clean water and improvements in sanitation and living conditions have played a significant role in this major public health achievement, mass immunisation is widely credited as having eliminated the threat of many of these once-common diseases.

However, recent speculation about a possible causal association between the Measles, Mumps, and Rubella vaccine (MMR) and autism and bowel disease, coupled with a growing mistrust of public policy on immunisation, has led many parents to re-examine their once-unchallenged decisions to vaccinate. Parents' reactions to the controversy have led in some places to a drop in immunisation uptake, which has fuelled speculation about an impending measles epidemic.

Understanding parents' attitudes and experiences of childhood immunisation is of paramount importance if confidence is to be returned to the Childhood Immunisation Programme. However, very little published work to date has used a qualitative approach to examine parents' feelings about immunisation and perceptions about infectious diseases, within the context of the current MMR safety debate. This paper presents some of the findings from a qualitative study involving 15 focus groups, carried out with a range of parents living in Glasgow and the surrounding areas. The paper explores some of the issues that parents consider as part of the vaccine decision-making process, and examines how parents' perceptions on other high profile health debates have affected attitudes to immunisation.

Saturday the 27 September 2003 at 14.35 - 15.05

Hirschkorn, K.A., Bourgeault, I.L.

McMaster University, Canada

REGULATING HERBAL MEDICINE AND ITS PRACTITIONERS: A COMPARATIVE LENS ON HEALTH POLICY AND PROFESSIONAL PERSPECTIVES

The challenges that the rapid growth in the use of natural health products (NHPs) poses for both "alternative" and "conventional" health care professionals in Western nations is the focal point of this paper. Of particular interest are the roles that practitioners play in mitigating the risks associated with medicinal herbs, in ensuring accessibility, in bridging or resolving the discrepancies of knowledge between conventional and alternative medicine, and in fostering an informed public. With this in mind, I will report on interview and documentary data regarding the practices and regulation of herbalists in the Canadian context. This will be contrasted with data of the roles and views of mainstream health care providers -- namely pharmacists, physicians and nurses -- in regards to herbal medicine. The second part of this paper involves a comparative lens on health policy and professional perspectives in the United Kingdom and Germany. Particular attention will be given to trends and models that inform the integration of herbal medicine into the provision of mainstream health care services.

Paper/Poster Abstracts - listed in alphabetical order of first author

Saturday the 27 September 2003 at 14.00 - 14.30

Holland, P., Whitehead, M.M.

University of Liverpool

SOCIAL AND ECONOMIC CONSEQUENCES OF CHRONIC ILLNESS: HOW DO THEY VARY BY GENDER AND SOCIAL CLASS?

Reducing inequalities in health is a key priority in public health strategies at local, national and international levels. To devise effective policies and interventions, however, a better understanding is needed of the mechanisms which produce inequalities in health. Research has shown that adverse social circumstances create inequalities in health but little is known about the impact of ill health on socio-economic circumstances. Ill health itself may lead to poverty and other health risks, leading to more severe illness and disability for poorer groups and exacerbating existing social inequalities in health.

In our study we examine the impact of limiting longstanding illness and specific chronic diseases on employment and income. Using data from the British Household Panel Survey, we investigate whether, and how, individuals' employment and financial circumstances are altered after the onset of a chronic illness. We also examine whether employment and financial circumstances post-onset of illness vary by age, gender, and social class.

Understanding the nature and pattern of social and economic consequences of chronic illness will provide a starting point for future analyses of policies and interventions to address these adverse consequences.

Saturday the 27 September 2003 at 15.10 - 15.40

Hollenberg, D.

University of Toronto

A CRITICAL ANALYSIS OF INTEGRATIVE HEALTH CARE (IHC) IN CANADA: A MULTI-CASE STUDY EVALUATION

Background/Rationale

This paper reports and critically discusses preliminary research findings from a multi-case study evaluation of three IHC sites in Canada. IHC is a worldwide phenomenon involving the coordination of care amongst culturally diverse healing traditions and practices (e.g. Western biomedicine and traditional Chinese medicine). The main purpose of the study was to understand how integrative health care delivery models are developing in Western-based health care settings. According to the WHO (2002), IHC occurs at various levels in 25 WHO member states. To date there have been few in-depth studies evaluating IHC as it pertains to health services and policy in Canada or elsewhere, leaving the "sociology" of IHC virtually unexplored.

Methods

Qualitative interviews, ethnographic observation, and document analysis were conducted with patients, practitioners and administrators at a cancer clinic; a pain clinic within an urban hospital; and a proposed hospital-based traditional Chinese medicine clinic. A "critical social science perspective" that views ideology and power as crucial to health care contexts was used to theoretically ground the research.

Preliminary Research Findings

- 1) Canadian IHC settings do not reflect proposed theoretical models of IHC (e.g. clear clinical guidelines and communication).
- 2) Privatization of "non-biomedical" healing practices is posing barriers to the development of IHC (e.g. restricting patient accessibility).
- 3) Biomedical institutions view non-biomedical health services as a revenue generating mechanism to address deficit reduction in health budgets.
- 4) Particular biomedical practitioners are appropriating non-biomedical philosophy and practice. Additional findings will also be discussed, forming the main body of this presentation.

Abstract Book prepared 18th July 2003

33

Friday the 26 September 2003 at 14.00 - 14.30

Hooper, H., Ong, B.N., Dunn, K.M., Croft, P.R.

Keele University

WHEN HARRY MET BARRY, AND OTHER STORIES: A FOCUS ON RELATIONSHIPS IN BACK PAIN CARE

This qualitative study forms part of a longitudinal investigation of pain, disability and healthcare use in primary care low back pain consulters. Sixteen purposively sampled patients and their healthcare professionals were interviewed about experiences with back pain and their therapeutic relationships. This case study draws on the accounts of one patient, his wife, and 3 matched healthcare professionals.

The interview with Barry and his wife Angela highlights the dynamics of a co-constructed narrative of back pain. Barry appears comfortable with Angela's control of the story-telling and usually defers to his wife's interpretations of events. The joint narrative is fundamentally supportive of Barry's condition and Angela is careful to portray Barry's suffering as genuine. Yet, her preference for a proactive approach to healthcare is undermined by Barry's unquestioning respect for health professionals-"he's worked hard [to] be in that job". Angela and Clare (physiotherapist) perceive that Barry's limited expression-of his suffering, his agenda, and his feelings regarding care received-result in less beneficial care where opportunities remain unfulfilled and problems unresolved. Yet, ambivalent feelings are shown towards Angela's role as narrator of Barry's pain. Analysis reveals a positive and mediating role for informal carers within the total provision of healthcare. However, the construction of Barry's limited expression in opposition to Angela as an expert patient raises issues around these roles in the therapeutic encounter that require further exploration.

Saturday the 27 September 2003 at 11.20 - 11.50

Humphrey, C.

King's College London

PLACE, SPACE AND REPUTATION: THE CHANGING ROLE OF HARLEY STREET IN ENGLISH HEALTH CARE

By 1948 when the NHS began, Harley Street already had long-established iconic status as an elite environment where aristocratic patients received individual attention from the 'great names' in English medicine. Subsequently the street came to symbolise the continuing availability of private, personal medical care and all that represented - a haven of traditional values and relationships or an undesirable and dangerous anachronism, depending on your point of view. In the present day, the term 'Harley Street' remains a convenient cipher for private medicine, used by the media, in academic texts, House of Commons debates and commercial adverts and often tilted by context to imply either high quality or inferior care. But over the century since its fame/notoriety began, what actually happens in Harley Street (who does what for whom behind its fine Georgian facades) has changed considerably, as has its role in the wider health economy.

Starting with a brief account of Harley Street in the early 20th century, this paper will use data from three sources (recent interviews with doctors in private practice, documents in the Wellcome History of Medicine library and a search of current internet sites) to map its development until now. Analysis of the identity of its occupants, their patterns of practice and patient/client groups will be used as a focus to explore continuity and change in the nature of, and relationships between, public and private health care, orthodox medicine and complementary health care, medical knowledge, health policy and wider social change.

Saturday the 27 September 2003 at 10.10 - 10.40

Hunter, B.

University of Wales Swansea

CONFLICTING IDEOLOGIES AS A SOURCE OF EMOTION WORK IN MIDWIFERY

This completed doctoral study explored how midwives in an area of Wales experience and manage emotion at work. A multi-method ethnographic approach was used, incorporating focus groups, participant observation and interviews. A purposive sample of student and qualified midwives (n = 67) was accessed, representing a broad range of clinical locations, length of experience and occupational status. Transcribed data and field notes were analysed thematically.

Findings indicate that community and hospital environments present midwives with fundamentally different work settings that have diverse values and perspectives. The result is two primary occupational identities and ideologies, which are in conflict. Hospital midwifery is dominated by meeting service needs, via a universalistic and medicalised approach to care; the ideology must by necessity be 'with institution'. Community-based midwifery is more able to provide an individualised, natural model of childbirth reflecting a 'with woman' ideology. This ideology is officially supported, both professionally and academically. However, there is no clear match between ideology and context. This is problematic for occupational identity, resulting in the need for emotion work. This is particularly significant for integrated midwives, who work in both institutional and community settings. A theoretical framework is proposed, which identifies relationships between context, occupational identity, occupational ideology and emotion management.

This study extends our knowledge of emotion work in health care. Whereas past studies have located emotion work primarily within practitioner/client relationships, these findings suggest that a more open-minded approach to investigation is needed in order for other sources of emotion work to be identified.

Saturday the 27 September 2003 at 11.20 - 11.50

James, V., Williams, J., Hampshire, M., Whynes, D.

University of Nottingham

TENSIONS OF TRADITIONAL BUREAUCRACY AND ENTREPRENEURIAL GOVERNANCE: A CASE STUDY IN PRIMARY CARE

From traditional bureaucracy to entrepreneurial governance, primary health care delivery in the UK provides insight into the changing mores of public sector management. It exemplifies modernisation strategies designed to meet consumer expectations for a health service of the 21st century, and illustrates impacts felt by professionals, managers and consumers.

Intra- and inter- professional tensions between positive, caring, individuals (nurses, doctors, managers, patients), and between new and established primary care delivery systems, were revealed by a case study of an innovative primary care PMS (Primary Medical Services) project. Many of those involved reporting feelings of marginalisation and unjust treatment as the project continued, with the Health Authority required to assist the new (PMS) project while continuing with the established GMS (General Medical Services) systems. It is argued in this paper that re-evaluations of the relevance of Weber's work on bureaucracy, with a focus on substantive rationality and emotion in organisations, helps explain how those involved appealed to different rule systems - traditional bureaucracy and entrepreneurial governance - as the pressures of competing norms were personally experienced. In comparing the two approaches, Du Gay (2002) contrasts the benefits of empowerment, customer focus, decentralisation, organisational vision and market mechanisms of entrepreneurial governance, but also notes the fragmentation, loss of accountability, loss of common patterns (e.g. recruitment, rules of procedure), and the institution of personality brought about.

Friday the 26 September 2003 at 16.40 - 17.10

Kanaris, A., Kelly, M.P., Speller, V.

Health Development Agency

MOVING TOWARDS EVIDENCE BASED PRACTICE: THE WORK OF THE HEALTH DEVELOPMENT AGENCY

In April 2001 the DH published its Research and Development Strategy (DH, 2001), which endorsed the HDA's role as laid out in the White Paper, Saving Lives: Our Healthier Nation, (DH, 1999), of 'maintaining an up to date map of the evidence base of public health and health improvement.. and effective and authoritative dissemination of evidence to practitioners'.

This paper will present an overview of the objectives of the HDA's Evidence into Practice activities and will also discuss the three distinct phenomena involved in moving towards evidence based practice, namely building the public health evidence base, the process of which involves addressing a range of epistemologies and the legitimacy of various types of learning and of finding ways of synthesising them and turning them into agents for change; developing guidance and resources; and bringing about changes in practice. It will also confront some of the practicalities involved in applying the evidence into practice, the complexities involved in the process and the ways of working with the different logics involved.

Saturday the 27 September 2003 at 09.35 - 10.05

Karlsen, S., Nazroo, J., McKenzie, K., Bhui, K., Weich, S.

University College London Medical School

RELATIONSHIP BETWEEN PSYCHOSIS, COMMON MENTAL DISORDERS AND RACISM AMONG ETHNIC MINORITY GROUPS IN THE UK

Several studies of treated populations have found higher rates of psychosis among people from ethnic minority groups in the UK. Speculative explanations for these ethnic differences suggest that the stress associated with living in, in this case, England promotes the development of psychosis and potentially other mental health problems among people from ethnic minority groups. One possible cause of such stress that has remained largely unexplored is the impact of racism outside mental health services: whether the experience of racism in everyday life may predispose an individual towards mental health problems.

This paper presents findings from secondary multivariate analyses of the Ethnic Minority Psychiatric Illness Rates in the Community (EMPIRIC) study. EMPIRIC is a population-based study developed to explore differences in mental and physical health and other indicators among Caribbean, Indian, Bangladeshi, Pakistani, Irish and 'white' people in England. These analyses explored the impact of experienced interpersonal (verbal, physical and work-related) racism, perceptions of racism in wider society and socio-economic status on the likelihood of reaching the case threshold for common mental disorders and psychosis. The findings suggested that each measure of racism had an independent effect on health. There was some consistency, and also some variation, in the findings when the different ethnic minority and gender groups were explored separately. These findings suggest that a comprehensive understanding of the relationship between ethnicity and health requires an appreciation of the influence of racism.

Saturday the 27 September 2003 at 16.20 - 16.50

Kennedy, A., Gask, L., Nelson, E., Reeves, D., Richardson, G., Roberts, C., Robinson, A., Rogers, A., Sculpher, M., Thompson, D.G.

National Primary Care Research and Development Centre, Nottingham

TRAINING SPECIALISTS IN GASTROENTEROLOGY TO CONSULT IN A PATIENT-CENTRED STYLE

We have investigated an approach to improve patients' ability to self-manage chronic illness. We believe such patients need to work in partnership with their doctor; patient-centred consultations are one way to achieve this. Patients are experts in the experience of living with their illness, this is complementary to the professional's knowledge about disease. This report describes our experience of training specialists in gastroenterology to consult in a patient-centred style. The training session aimed to recruit specialists for an RCT of an intervention to promote shared care in inflammatory bowel disease and provide them with the basic skills to carry out the intervention. The training sessions lasted for two hours and included: use of a champion; details of the research; the skills necessary for patient-centred working; demonstration video; role-play and video feedback training. The two major components of a patient-centred consultation for IBD were taken to be: Addressing the impact of the disease on the patient; and Establishing with the patient what treatment works. These were demonstrated using a video of a model consultation. The participants then took part in a role-play, using a patient-centred consultation to introduce specified changes in management. One pair's role-play was recorded on a video and utilised in a video feedback session. All participants remained fully signed up to the trial. It is unusual to introduce this type of training to a senior group of consultants. Presenting the package as part of a research programme may have made the procedure more acceptable.

Saturday the 27 September 2003 at 11.20 - 11.50

Kent, J., Faulkner, A., Geesink, I., FitzPatrick, D.

University of the West of England, Bristol

THE SOCIAL SHAPING OF REGULATORY POLICY RELATING TO HUMAN TISSUE ENGINEERED PRODUCTS

This paper describes emerging regulatory policy relating to innovation in human tissue engineered technologies (HTEPs). It outlines the development of a growing number of healthcare products that apply cell and tissue technologies in novel ways. The emergence of these technologies, situated in the context of wider debates around the governance of biotechnology, raises important issues. It has been suggested that we are witnessing changes in the political culture of 'red' biotechnology governance in the EU and that relationships between EU institutions may be characterised by competitiveness. Suggestions that we are moving away from a model of technocratic decision-making based on regulatory science towards 'a participative ethos' have identified changing relationships between science, industry and state regulation and growing attention to ethical concerns. In the area of pharmaceutical regulation despite consumers' growing activism it has been argued that there is minimal decline in producer power or medical authority and Europeanisation of regulation has led to a form of highly organised neo-liberal corporatism. We may be witnessing a more user-oriented approach to medical device regulation. Thus it may be that different forms of governance and participation are associated with different types of technology. We analyse current initiatives at the EU level to develop new legislation that aims to protect public health and regulate the market for HTEPs. We report on preliminary data from a research project that is part of the ESRC Innovative Health Technologies Programme.

Friday the 26 September 2003 at 16.40 - 17.10

Killen, M.M., Alderson, P.A., Hawthorn, J., Warren, I.

Institute of Education, University of London

RESEARCHING INTERPRETATIONS OF CARE IN NEONATAL UNITS

Researching interpretations of care in neonatal units `Foretelling futures: dilemmas in neonatal neurology' is a current study in four neonatal intensive care units (NICU). We are investigating how staff and parents share information about the babies' care and development, and their uncertain futures (funded by the Wellcome Trust 2002-2004). The care for these babies is complicated in severral ways: by the setting, and by the relationships that parents, nurses and doctors have with the babies. NICUs can be more like science labs than nurseries. Parents' access to their child is limited, and many feel fraught and anxious. The staff perform frequent painful interventions as well as caring ones. Medical care of babies with brain injury is largely limited to efforts to relieve and control problems that occurred before admission to the NICU, and to predict uncertain futures. This paper presents the reported views and interpretations, and the observed experiences, of those involved in these complications of care. It will briefly review connections between the ways that staff and parents share in the practical care of the babies and how they share information about the babies' potential futures.

(Research in progress)

Sunday the 28 September 2003 at 10.50 - 11.20

Lankshear, G., Ettorre, E., Mason, D.

University of Plymouth

<u>PROFESSIONAL PERCEPTIONS OF RISK AND ACCOUNTABILITY IN A MATERNITY</u> DELIVERY SUITE

Introduction

Using the results of a study to investigate the implementation of a computerised decision support system in a maternity delivery suite, this article explores decision making, uncertainty and professional perceptions of risk and accountability.

Methods

Qualitative research techniques were used in three NHS sites. Data was gathered during set weeks over two years (1999-2000) in the first site; during one month (2000) in the second site and for four weeks (2002) in the third site. Field notes and interview tapes were transcribed and analysed through the use of Atlas.ti.

Findings

Although professionals, in interviews, said that 'risk' and 'thoughts of litigation' were not a worry to them, remarks and comments made during their work communications with colleagues, showed that these thoughts were present, and that they sometimes impacted on their behaviour and practice. There was also evidence that discerning who was actually responsible and accountable for decisions made was not always easy. Repeatedly, all levels of staff thought themselves accountable for decisions made about any patient with whose care they were involved.

Conclusions

The hospital setting, which is publicly presented as a 'safe' and controlled environment where technology and expertise can give a definitive answer to all problems, by these very claims, opened up professionals to risk. The reality was that in spite of technology, uncertainty continues to surround decision making related to the birthing process. The research has relevance for academic debates around risk, professional accountability and responsibility, professional boundaries and decision-making.

Paper/Poster Abstracts - listed in alphabetical order of first author

Saturday the 27 September 2003 at 14.35 - 15.05

Larsen, J.A.

University of Surrey

SCIENCE AS A SOCIAL MYTH: SYMBOLIC HEALING IN CONTEMPORARY DANISH MENTAL HEALTH TREATMENT

The paper discusses how the theories and language of science is used in contemporary mental health treatment and it examines individuals' attempts to generate meaning following their experiences with psychosis. The enquiry is based on an ethnographic study of a Danish early intervention community program in mental health and it involves longitudinal interviews with fifteen of its users. This paper directs attention to the social dynamics of the intervention and it analyses the symbolic meaning involved in the healing process. Anthropologists have demonstrated how symbolic healing operate in various cultural contexts to influence processes of recovery from illness by the means of language, ritual and the manipulation of powerful cultural symbols. For example, shamanism in 'primitive societies' and psychoanalysis in modern societies. Generally, instances of symbolic healing have represented alternatives to modern, scientific and medical based treatment techniques. However, recent mental health treatment for people suffering from severe mental illnesses, such as schizophrenia, is combining therapeutic approaches with biomedical theories and, thus, integrates biomedicine and symbolic healing. This paper examines 'psychoeducation' in the Danish community mental health early intervention programme for young people diagnosed within the 'schizophrenic spectrum'. It is demonstrated how symbolic healing operates in this context by means of scientific language and theories.

Sunday the 28 September 2003 at 10.50 - 11.20

Lawler, D.

Coombe Women's Hospital

"GRIEVING FOR MYSELF": WOMEN'S LIVED EXPERIENCES OF POSTNATAL DEPRESSION

Aim of the Study

To investigate women's subjective experiences of living through postnatal depression.

Objectives of the study

Gain an insight into women's lived experiences' of postnatal depression.

Gain entry into their world and gain an understanding of the basic social processes that illuminate human health and illness.

Methodology

A qualitative hermeneutic approach was chosen to conduct the study.

A purposive sample of 7 - 5 primiparous and 2 multiparous women participated in the study. Data collection consisted of audio-taped unstructured interviews conducted by the researcher in participant's own homes over a four-month timeframe. Thematic analysis of transcribed text began once the first interview was completed. The hermeneutic circle, dialogue and the fusion of horizons were used as metaphors to understand informants' experiences of postnatal depression and were adapted from that of Diekleman et al (1989). Findings of the study were presented within the framework of the four existential life worlds - lived space (spatiality), lived body (corporeality), lived relations (relationality) and lived time (temporality).

Findings

The core finding to emerge from this research was that all the women experienced a sense of self-loss after the birth of their baby. It is hypothesised that this loss of self-concept propelled the women consciously or subconsciously into a process of grieving. Postnatal depression was a stage in their grieving process that was influenced by extraneous variables. Viewing postnatal depression in this way may also help reduce the stigma surrounding the concept.

Saturday the 27 September 2003 at 14.35 - 15.05

Lawrie, T., Matheson, C., Bond, C., Roberts, K.

University of Aberdeen

PHARMACY CUSTOMERS' EXPERIENCES AND VIEWS OF USING PHARMACIES WHICH PROVIDE DRUG MISUSE SERVICES

Background

In Scotland community pharmacy services to this client group are advanced and well developed. However, some pharmacists are concerned that drug misuse services might discourage other customers particularly needle exchange services and do not offer drug misuse services for this reason. The purpose of this study was to examine the views of pharmacy customers to the provision of drug misuse services by community pharmacies.

Methods

The study was qualitative in nature. Ten pharmacies participated: 5 in Aberdeen and 5 in Glasgow, both cities with large drug misusing populations. 8 pharmacy customers were interviewed in each pharmacy. Interviews were conducted in pharmacies with high involvement with drug misusers and low/no involvement with drug misusers and pharmacies were located in city centre, suburban and rural locations. This purposive sample was intended to cover a range of different factors, which might affect the views of customers.

Results

The vast majority of customers were supportive of pharmacies offering these services although many would prefer methadone to be consumed in a private area of the pharmacy. Customers were more knowledgeable and supportive of needle exchange services than they were of methadone services. People tended to be supportive of these services regardless of age, gender, social class or location.

Conclusion

Concern was not as high as many pharmacists perceived. Customers were very supportive of needle exchanges services. A private area would address customer concerns. These findings should ally the fears of pharmacists and encourage more of them to offer drug misuse services particularly needle exchange, which is currently under provided.

Saturday the 27 September 2003 at 09.00 - 09.30

Lees, S., Papadopoulos, I., Ridge, M.

Middlesex University

BELIEF AND EXPERIENCES IN RELATION TO CANCER OF THE CHINESE LIVING IN SOHO, LONDON

There is very little known about the cancer information needs of the Chinese community who live and work in Soho, London. This is particularly the case with asylum seekers and refugees who often lack social networks and support and have poor access to health services. The Chinese are an established and significant ethnic group in England making up approximately 220,000 (0.45%) of the population in 2001. There are a large number of Chinese people resident within Westminster (7,740) and Soho and West End has the largest concentration of Chinese people within Westminster. There is no information about the cancer needs and problems accessing cancer information and services of this Chinese population. In the light of this the Research Centre for Transcultural Studies in Health, Middlesex University in collaboration with Macmillan Cancer Relief have conducted a study to explore Chinese cultural-based beliefs about cancer and Chinese experiences of cancer in order to develop culturally sensitive cancer information, particularly for the diverse and heterogeneous Chinese community who live and work in Soho. Focus groups were conducted with Chinese health experts, young Chinese, older Chinese, asylum seekers and 'below stairs' workers living or working in Soho in order to elicit their meanings and experiences of cancer with the context of their every day lives. The presentation will discuss the findings from this study and issues around accessing hard to reach communities for research.

Saturday the 27 September 2003 at 14.00 - 14.30

Levitt, M., Weldon, S.

University of Central Lancashire

GENETIC DATABASES: PUBLIC PERCEPTIONS OF PRIVACY AND TRUST

An EC funded project has been planned to provide knowledge about the Ethical, Legal and Social Aspects of population-based human GENetic databases (ELSAGEN 2002-2005). Part of the project involves a programme of qualitative and quantitative research, on public views and perceptions of privacy and trust in relation to personal medical and genetic data. This has been carried out in UK, Estonia, Iceland and Sweden. The paper will briefly examine the existing UK research on public perceptions of biobanks, justify the need for further qualitative research and present findings from focus groups held in different parts of the UK. As opposed to questions more tightly framed in answers to specific questions on biobanks, that exclude ambivalence and wider concerns about privacy and trust in institutions governing databases, in the focus group discussions participants were able to provide a context for their views in personal stories and to raise broader issues. We will be drawing on the findings from our focus groups to explore what appears to be a relative lack of public trust in the frameworks for governance of genetic databases in the UK, in comparison with results from the (quantitative) sociological data from Estonia, Iceland and Sweden.

Saturday the 27 September 2003 at 11.20 - 11.50

Li, S.

Kingston University and St. George's Hospital Medical School

'CENSORED TALK'

This paper examines how palliative care nurses manage interactional difficulties in their daily practices in three palliative care settings in the UK. Accounts of trouble-talk are produced which constitute patients as not 'nice' individuals who are 'undeserving' of nurses' niceness. Examination of nurses' talk reveals that 'undeserving' individuals can destroy opportunities for nurses to produce a feeling of themselves as 'nice' and competent professionals. The data analysis identifies an instance of talk which is 'censored' by nurses when they actually became very critical of their patients in one setting. 'Censored talk' refers to parts of talk which are 'edited out' from the parts that are 'edited in' or 'approved'. The significance of this 'censored' talk is discussed reflectively. This paper suggests that 'censored talk' in my data serves as a self-preservation device for palliative care nurses to prevent disclosure by other sources such as researchers from exposing their embarrassment because of its serious nature. It serves to protect and preserve their professional image from being harmed and to re-constitute themselves as 'professionals' who are morally accountable and responsible people in their talk. This paper argues that 'censored' data is as valid as 'approved' data.

Saturday the 27 September 2003 at 11.55 - 12.25

Lian, O.S.

University of Tromsoe, Norway

CONVERGENCE OR DIVERGENCE? A CROSS-NATIONAL STUDY OF PRIMARY HEALTH CARE IN NORWAY, BRITAIN AND THE CZECH REPUBLIC

We are said to live in the age of globalization. In a globalized world there will be a single society and culture occupying the planet. This perception of contemporary society is also reflected in the area of health service research. The dominating theory is as follows: Many countries are currently reorganizing their health services in response to cultural, economic, and technological changes. Because the changes are global, and because ideologies are global, different countries are drawn toward similar reform programs. This is the convergence thesis. It implies that different countries are moving from different positions toward some common point. The alternative thesis is that each country has unique cultural, economic, political and historical traditions that are likely to override global changes, and thus create patterns of divergence. In this paper I discuss the convergence/divergence theses by comparing recent changes in primary health care in Norway, Britain and the Czech Republic (the period from 1990 to 2003). The empirical data consists of political documents, as well as scientific articles and reports. To understand the dynamics of change, recent developments in each country are compared and discussed in relation to their economic, cultural, political and historical context (i.e. an institutional approach). The main purpose is to understand and explain rather than to evaluate or advise.

Paper/Poster Abstracts - listed in alphabetical order of first author

Saturday the 27 September 2003 at 11.20 - 11.50

Lillrank, A.

University of Helsinki, Finland

IS INTERSUBJEKTIVE UNDERSTANDING POSSIBLE?

My recent analysis shows how diagnosing back pain is an uncertain process that ranges from several years, up to twenty years. This process profoundly challenges the individual identity and both the doctor-patient relationship and employer- employee relationships.

Intersubjectivity is defined as the interplay between subject and object. Social interaction, shared experience and empathic understanding are not synonyms for intersubjectivity. Instead, intersubjectivity is ambiguous because the interplay may allow both constructive and destructive interaction.

My data consists of 165 individually written autobiographical narratives, obtained in Finland in 1999 through an autobiographic writing competition called "The Back Bone in Your Life". To illustrate my points I use one woman's narrative as an example of the complex interaction between patient trust and medical misdiagnosis.

Since back pain is a baffling problem and challenges the central biomedical epistemology - objective knowledge and measurable findings separate from subjective experience, - it allows doctors to show a disrespectful attitude toward back pain sufferers. Back pain sufferers with a medically invisible disability face ongoing demands to establish trust between the body, the self and the health care professional.

Hence, it has motivated me to continue further with my research into key issues relating to individual, social and moral problems impacting on back pain sufferers: how do they make efforts to reach intersubjectivity in the social interaction between patient trust and medical misdiagnosis?

Saturday the 27 September 2003 at 09.00 - 09.30

Litva, A., Canvin, K., Gabbay, M., Bell, P., Jacoby, A.

University of Liverpool

"IT'S BETTER IF PATIENTS DO COMPLAIN": LAY INVOLVEMENT IN THE QUALITY OF HEALTHCARE DELIVERY

Currently the NHS is undergoing changes that affect how Primary Care is monitored and delivered. These changes aim to make the healthcare system trustworthier by increasing accountability and responsiveness to local healthcare needs. Initially Primary Care Groups (PCGs) were created but these have evolved into Primary Care Trusts (PCTs) who are now responsible for the purchasing primary healthcare services and monitoring them including a framework called Clinical Governance. The Government has stated that the public are to participate in Clinical Governance particularly with regards to identifying which services need to be improved and how to improve them.

The aim of this study was to explore and compare lay and professional perceptions of public involvement in clinical governance. The informants were drawn from 5 PCGs located in the North-west of England. In-depth interviews were used to explore 32 PCG board members (professionals) perceptions while 10 focus groups with conducted with different types of lay informants (n=60).

Lay and professional differ in their ideas about who the 'public' are and what their role should be. Neither supported a 'public' representation, with professionals referring to patients and users and lay informants preferring the concept of lay representatives to act as overseers. Whilst there was a recognised need for cultural change amongst healthcare professionals to involve users in healthcare decision-making, the findings show a need for 'society' to shift from being consumers of their own healthcare to becoming producers of collective healthcare.

Saturday the 27 September 2003 at 09.35 - 10.05

Lyons, S., Clarke, A.T.

University College Dublin

CEAD MILE FAILTE* OR NOT? PERCEPTIONS OF HEALTH WORKERS TO ETHNIC MINORITY WOMEN IN IRISH MATERNITY SERVICES.(*100,000 welcomes)

Ireland has experienced a massive increase in the numbers of new immigrants to the country in the past 10 years, notably the number of asylum seekers has risen from merely a handful in the early nineties to well over 10,000 per year by 2002. Unlike our other European neighbours, Ireland has always been a homogenous nation and the country has struggled to accept, and provide for, multi-culturalism, especially within the health services. The maternity services have appeared to be particularly under pressure. Non-national births made up 13% of all births in the city for 2002 and it is estimated that over half of asylum seekers arriving into Dublin are already pregnant. In the largest qualitative study to date in the capital, focus groups and semi-structured interviews were conducted with service providers within the maternity services in relation to their experiences caring for this new population. One of the major themes to emerge was that of difficulties of language and communication. Other problems, perceptions and solutions to caring for ethnic minority women in the maternity services are explored from an Irish perspective.

Saturday the 27 September 2003 at 09.00 - 09.30

Macnaghten, E.

Lancaster University

THE IMPERATIVE OF WELLBEING: A CRITICAL ANALYSIS OF CHANGING DISCOURSES OF WELLBEING

Wellbeing is a quality in demand in today's society. It is a virtue that is much desired, much promoted, and much debated. Yet, wellbeing is not a concept set in stone. Rather, conceptualisations and experiences of wellbeing are produced in and through wider social perceptions and practices. This paper highlights prevalent contemporary conceptualisations of wellbeing and suggests that present day quests for wellbeing reflect emergent and immensely important shifts in social perceptions of individual agency and responsibility. In particular, dominant discourses of wellbeing appear to be related to changes in subjectivity; they manifest a move from subjects as citizens to subjects as consumers. Simultaneously, prevailing ideas of wellbeing are increasingly drawing on wider social discourses of interconnectedness and networks as wellbeing comes to be explicitly described as contentment through well-functioning connections. The discussion in this paper is informed by a media analysis of newspaper reports from 1984 to 2003 and by qualitative interviews with practitioners and users of alternative health practices.

Madden, S., Sim, J.

Oxford Brookes University

THE RELATIONSHIP BETWEEN THEORY AND DATA IN QUALITATIVE DATA ANALYSIS: THE EXAMPLE OF INDUCTION-ABDUCTION ANALYSIS

The traditional assumption within qualitative research is that it is an inductive process. However, it has been argued that researchers always bring their own thoughts, concepts and theories to the research process, which is thus necessarily driven and informed by previously-held theoretical constructs. However, few data analysis approaches deal specifically with the relationship between previously-held theoretical concepts and those that emerge from the data. The aim of this paper is to present our experiences of using a relatively unknown approach which addresses such issues: the induction-abduction method, originally described by the philosopher Peirce. Drawing on a study of the diagnostic process in fibromyalgia syndrome, data analysis was facilitated by heuristic categories: a priori categories, first order constructs and second order constructs. This process is evolutionary, which ensures the coding is informed by theory, and as the analysis continues, the data informs and refines the hierarchical coding. The paper will argue that such an approach allowed previously developed theories, which in the case of diagnosis included labelling theory and negotiated order, to provide a framework to the study. However, data-driven themes allowed such theories to be refined, with new theoretical concepts emerging. We believe that such an approach should be considered when exploring complex issues, such as diagnosis, within an existing theoretical context.

Saturday the 27 September 2003 at 14.00 - 14.30

Brooks, F., Magnusson, J., Kendall, S., Smith, H., Bell, J., Coggins, A., Oakley, L.

University of Hertfordshire

PHYSICAL ACTIVITY AND ADOLESCENTS: WHY A WINNING TEAM ISN'T HEALTHY

Although the detrimental impacts on health status of low levels of exercise in young people are recognised few exercise promotion interventions for this age group have been implemented or evaluated in the UK. This paper reports on a qualitative component of a larger intervention study concerned with assessing ways of getting teenagers to become more active. Focus groups were undertaken with young people aged 13-17 to obtain their perceptions and experiences of taking part in physical activity.

This paper sets out to explore the motivators and barriers for young people to engaging in physical activity. The discussion will focus on the meaning and value of physical activity as perceived by adolescents and on gender differences. The discussion will identify how the social aspect of engaging in physical activity is highly important as a motivator for both boys and girls. While embodied discourses relating to weight maintenance is also a particularly strong motivator and conversely also a barrier amongst girls. The discussion will then explore how school based sports are perceived by young people as being detrimental to both the continued pursuance of physical activity and also their emotional well being and self-esteem. In particular the relationship of the discourse of 'competitiveness' to the cultural norms of school based physical activity will be examined.

Finally the attention will be given to the implications of the findings for schools as sites of health promotion and for the implementation of the core principles of the forthcoming NSF.

Markham, W.A., Aveyard, P., Bullock, A., Thomas. H.

University of Warwick

A PRELIMINARY INVESTIGATION INTO FACTORS THAT INFLUENCE LIMITING LONGSTANDING ILLNESS AMONGST UK GRADUATES USING A RETROSPECTIVE COHORT STUDY

This investigation paper focuses on self-rated limiting longstanding illness amongst UK graduates and was driven by two hypotheses. Hypothesis 1 was that childhood social class influences adult health independently of educational attainment and adult income. Hypothesis 2 was that typical committed graduates would enjoy better health than atypical middle class detached graduates, typical working class detached graduates and atypical working class detached graduates independently of educational attainment and adult income. Hypothesis 2 is based on the belief that whereas the values of committed graduates facilitate good human functioning and good health, the values of the three types of detached graduates do not. Commitment and detachment were identified through childhood social class and typical/atypical life choices.

Graduates in 1985 (n=5093) and 1990 (n=8147) were recruited from 20 UK higher education institutions in 1996. The influence of childhood social class was examined as a linear trend in a binary logistic regression equation predicting the outcome in 1996 after adjustment for age and adult income. This process was repeated replacing childhood social class with childhood social class, atypical graduate status and their interaction.

Hypothesis 1 was not confirmed. As predicted by Hypothesis 2, typical middle class committed graduates enjoyed better health than atypical middle class detached graduates and typical working class detached graduates independently of educational attainment and adult income. Contrary to Hypothesis 2, atypical working class detached graduates enjoyed the best health in early adulthood but this advantage over typical middle class committed graduates may not continue throughout adulthood.

Saturday the 27 September 2003 at 14.35 - 15.05

McCarthy, J.

Trinity Collge, Dublin

THE POLITICS OF DISABILITY- A POLITICS FOR ALL?

Within the last four decades the field of disability research has undergone significant changes. Both in Ireland and abroad the issue of disability is no longer conceptualised as an individual tragedy, but rather presented as a discourse of social exclusion. According to this critical approach 'disability' is a product of economic, material and social inequality. Within this framework the individual experience of disability in itself becomes political, offering a critique of social barriers that deny people with impairments full integration into the social world.

This paper examines the implications this contemporary discourse has on the lives of Irish people with disabilities. Specifically, this work considers the tensions created in the interface between this new political discourse and the traditional practices of disability management. Conventionally, people with disabilities were either cared for in the home or provided for within State institutions. According to such responses, people with impairments were segregated from 'the normals' in the areas of education, employment and social life. Predicated on the ideology of individualism disabled people were viewed as dependent and tragic. By drawing on data generated from interviews with participants from a sheltered workshop program this paper questions how the politics of social exclusion has effected the lives of people with impairments within these remaining traditional enclaves of the disability community.

McCourt, C., Morgan P., Youll, P.

Thames Valley University

OPENING ACCESS TO DECISION MAKING ABOUT HEALTH RESEARCH FUNDING? A CASE STUDY OF SOCIO-TECHNICAL TENSION IN 'VIRTUAL' GROUPS

This paper will report the findings of a DoH funded project that aimed to increase the open-ness, transparency and effectiveness of the health research funding process, through from setting priorities to awarding research funds. The DoH, particularly through its London Regional Office, has experimented with innovative approaches to research commissioning in recent years with the twin aims of improving the inclusiveness and quality of the process. One such experiment piloted the use of a 'virtual' rather than face-to-face decision-making process, using a bespoke website. Our evaluation utilised the quasi-experimental nature of the project to compare the experiences of participants and outcomes of the process in both 'virtual' and face-to-face commissioning groups within a single funding programme. Action research principles were also utilised to feed learning back into the process, and to benefit fully from the insights of participants. A range of methods, including non-participant observation, interviews, documentary analysis, questionnaires and collaborative enquiry groups were used to track the process. The study showed that using novel technologies had the potential to meet the aims of increasing access to participation that was not fully realised in practice. Our findings indicate that while novel technologies may have a role to play in facilitating the desired outcomes - such as inclusion - technical solutions are not sufficient, and attention must be paid to the wider structures and relationships within which the uses of technology are embedded. We develop the concept of socio-technical tension as a means to describe the complexity of social relationships surrounding uses of technology.

Saturday the 27 September 2003 at 15.45 - 16.15

McGowan, F.

University College London

SHAPING THE MALE BODY: THE ROLE OF SPORT AND MILITARY EXPERIENCE IN THE DEVELOPMENT OF A 'PHYSICAL' MASCULINITY

This paper presents findings taken from a larger qualitative study which explores perspectives of health and experiences of embodiment among Dutch men at different stages of the life course. In depth interviews with twenty men whose ages ranged from 20 - 40 revealed the importance of sport in the construction of masculine identity and show how involvement and ability in sport is unquestionably accepted and endorsed as a measure of manhood. Although the importance and role of sport changes and/or lessens over the life course, it is shown to be a central and determining characteristic of growing up, as an important expression of male physicality socialising boys to be men. As National Service remained compulsory in the Netherlands until 1996, some interviewees also recounted time spent in military service, where physical exercise and endurance featured prominently in the daily regime. Both the organised culture of the military and the institution of organised sport serve to produce and endorse Connell's (1995) notion of hegemonic masculinity defined as "the culturally idealised form of the masculine character". The findings are further related to the defining characteristics of this ideal and dominant form of masculinity as the accounts of the respondents show how this representation continues to shape and discipline both masculine identities and male bodies.

McKie, L., Hughes, B., Hopkins, D., Watson, N.

Glasgow Caledonian University

THE REVOLT OF THE PATHOLOGICAL: MEDICAL KNOWLEDGE AND THE CHALLENGE OF NEW SOCIAL MOVEMENTS

Professions, in general, and the medical profession, in particular, were described by George Bernard Shaw as a, 'conspiracy against the laity'. If this is the case, then one can argue that the new social movements that champion the cause of women and disabled people specialize in bringing the laity together in order to expose the conspiracy and to challenge the negative representations about the laity which are embedded in medical knowledge.

This paper has as its objective the clarification of the different ways in which new social movements have contributed to the de-professionalization of knowledge. It will address, through a comparative analysis, the different ways in which the Disability Movement and the Women's Movement have contributed to this epistemological revolution. For early second wave feminism, medicine was a player among many in an oppressive partriarchal web which could be detected in the organisation of family life, welfare policy, the labour market, educational opportunities and so on (McKie et al., 2003). For disabled people medical surveillance was far more ubiquitous, more central to their experience of oppression and exclusion, pivotal in their construction as dependents in need of care (Watson et al 2002: Hopkins et al 2002) and most significant in both their representation and 'invalidation' (Hughes 2000). These histories are important to the different ways in which the revolts of the pathological have developed.

Saturday the 27 September 2003 at 16.55 - 17.25

McMunn, A., Kuh, D., Bartley, M.

University College London

SOCIAL ROLES AND WOMEN'S HEALTH: NEED SATISFACTION OR NORMATIVE SATISFACTION?

Women's increased labour force participation in the 1970s triggered debate into the relationship between women's social roles and their health, leading researchers to role quality as a potential explanatory concept. Three main gaps in this research have been identified. First, only subjective measures have been used as physical health outcomes. Second, work has mainly been limited to cross-sectional data sets. Third, the concept of role quality remains undeveloped and a-theoretical. This thesis uses longitudinal prospective data on women from the MRC National Study of Health and Development, a cohort of people who were born in 1946 and have been followed since that time. This paper examines:

- 1. whether social role patterns in adulthood vary between subjective health and an objective measure of health, namely obesity.
- 2. whether educational attainment or poor health in early adulthood account for the relationship between social roles and adult health.
- 3. whether social roles act as a marker for adult socio-economic circumstances.
- 4. and whether a theory of role quality based on need satisfaction or normative satisfaction appears to be useful in explaining relationships between social role patterns and adult health outcomes among women in this cohort.

Meetoo, V., Papadopoulos, I., Lees, S.

Middlesex University

THE ROLE OF THE ETHNIC MINORITY VOLUNTARY SECTOR IN PROMOTING SOCIAL CAPITAL: A CASE STUDY OF THE LONDON BOROUGH OF ENFIELD

There is a paucity of research on the role of the voluntary sector in countering social exclusion, poor health and quality of life, in particular the black and minority ethnic (BME) voluntary sector, which tends to include smaller, less established and poorer organisations than the wider voluntary sector. In light of this The Research Centre for Transcultural Studies in Health (RCTSH), in collaboration with Enfield Voluntary Action (EVA) and Enfield Racial Equality Council (EREC), have undertaken a study to explore the role and scope of the black and minority ethnic (BME) voluntary sector in Enfield in promoting social capital with its subsequent impact on quality of life and health.

A sample of voluntary organisations providing services for BME communities in Enfield were selected in order to explore how the organisations promoted participation, trust and safety, social networks, co-operation, as well as regeneration, health improvement and quality of life. Data was collected by conducting: i) documentary analysis of organisational materials; ii) semi-structured interviews with key informants from each organisation; iii) focus groups with service users and iv) an extensive literature. This presentation will discuss the findings of this study.

Friday the 26 September 2003 at 16.00 - 16.30

Melia, K.M.

University of Edinburgh

NHS MODERNISING AND THE NURSING PROFESSION

The central concern of this work is the place of nursing within the new NHS. This paper presents work in progress in the form of the main themes from empirical work undertaken as an ESRC Research Fellow. The overall aim of the project was to contribute to the understanding of the place of nursing in the new NHS, through an examination of the NHS modernisation process from the various perspectives of service provision, higher education and professional regulation.

The work has entailed examining discussion documents, proposals and reports on government consultations on health service modernisation. The data comprise transcripts from interviews with key people in the service and education sectors, the Scottish Executive and bodies concerned with quality assurance and professional regulation.

Emerging from the work are a number of issues for the nursing profession. These concern shaping of the nursing agenda by the demands of medicine and service managers nursing's position in Higher Education, control of the curriculum and so on issues for professional regulation (post Kennedy, Redfern) team-working, extended roles and professional boundary blurring

Concluding remarks: few would dispute the benefits of modernising, but from nursing's viewpoint the possibilities are mixed. Nursing is the largest group in healthcare and only recently fully established in higher education. Funding issues for postgraduate education in health care cast the old medical dominance arguments in a different light. What kind of change is this - Everett Hughes revisited?

Miers, M., Pollard, K., Clarke, B., Means, R., Ross, K., Thomas, J.

University of the West of England Bristol

INTERPROFESSIONAL EDUCATION IN HEALTH AND SOCIAL CARE: LEARNING FROM A REALISTIC EVALUATION

In 2000 the Faculty of Health and Social Care, UWE, Bristol, introduced a pre-qualifying curriculum which provided interprofessional learning opportunities for all its ten professional programmes. An evaluation of the curriculum, utilising Pawson and Tilley's (1997) model of 'realistic evaluation' began in September 2001. The evaluation programme comprises a series of linked studies collecting data concerning outcomes, mechanisms and context through a longitudinal study of two student cohorts (n=852), case studies of learning groups and observation and documentary sources concerning faculty and placement environments. Initial assumptions about learning, teamwork and collaboration, change management and about professional practice and relationships contributed to the design of the curriculum and the evaluation. These are being tested and reformulated during the course of the research.

This paper identifies the initial assumptions about professional practice and relationships that informed hypotheses at the start of the research, outlines relevant preliminary findings and explains the refinement of the researchers' assumptions and the reformulated hypotheses. The findings come from the longitudinal study of student cohorts, which has shown that students on some professional programmes have pessimistic views of interprofessional working on entry to pre-qualifying programmes, from case studies of learning groups and from pilot work studying student learning in placement settings.

The paper reflects on the contribution of a realist approach to evaluation of interprofessional education and on the significance of diverse discourses about professional and interprofessional practice for all contributing to the education of health and social care professionals.

Saturday the 27 September 2003 at 16.55 - 17.25

Milton, B., Whitehead, M.

University of Liverpool

SOCIAL AND ECONOMIC CONSEQUENCES OF CHILDHOOD ASTHMA ACROSS THE LIFECOURSE: A SYSTEMATIC REVIEW OF THE EVIDENCE

There is a socio-economic gradient in the prevalence of many childhood conditions, and two mechanisms have been identified which generate this social inequality in health. Firstly, disadvantaged socio-economic conditions may have an adverse impact on health. Secondly, ill health may have an impact on subsequent socio-economic circumstances to exacerbate the experience of ill health across the lifecourse. This paper presents the findings of a systematic review that examines the second of these mechanisms.

The review describes and explains the socio-economic consequences of childhood-onset respiratory disease by synthesising existing evidence on the effects of asthma on children's life trajectories. The synthesis maps the ways in which asthma affects academic attainment and experiences of education, labour market participation, occupational trajectories and income. The review also examines the differential consequences of asthma for different social groups, and the impact of this social patterning on the pathways that lead to health and social inequalities at the adolescent transition and beyond into adulthood.

A comprehensive search strategy was used to identify primary studies from the medical and social science literature. The review found that the existing literature is dominated by cross-sectional studies that focus on children's experiences of education, particularly on the effects of school absence on academic achievement. Although the review took an inclusive approach that aimed to locate studies with a variety of research designs, few qualitative studies were identified. The paper will outline the principal findings of the review, together with recommendations for further research on the social outcomes of childhood asthma.

Mobasheri, M., Teijlingen, E., Smith, W.C.S.

Medical School, Aberdeen

TO WHAT EXTEND DO SOCIODEMOGRAPHIC FACTORS EXPLAIN DIFFERENCES IN THE TREND OF OBESITY IN THE UK

Introduction

Obesity is an increasing medical and social problem, which affects all ages, both genders and all socioeconomic groups in both developing and developed countries. WHO has reported (2002) that it is one of the top health priorities. It leads to adverse metabolic changes, raises the risk of heart disease, stroke, diabetes and many forms of cancer.

Aim

To establish the contribution of sociodemographic factors as explanation for the increase in Body Mass Index (BMI) in England (1991-2000) and Scotland (1995 & 1998).

Method

Statistical analysis of the above data sets, using Chi squared and regression analysis.

Results

The percentage of people with BMI who are overweight and those who are obese has increased between 1991 and 2000 in England and between 1995 and 1998 in Scotland. This increase is greater in women compared to men. The age groups 65-74 and 55-64 for both genders have the highest proportion of overweight and obese people. Chi squared test shows a relationship between BMI and sociodemographic and social class. Linear regression between BMI and age, gender and social class explains only some of the differences.

Discussion

In all of these surveys gender, age and social class only account for a small component of the BMI trends. Further investigations are required to access the impact of other lifestyle factors.

Friday the 26 September 2003 at 15.20 - 15.50

Monaghan, L.

Newcastle University

<u>DOORWORK, VIOLENCE AND RISK: EMBODYING HEALTH AND ILLNESS IN THE NEW NIGHT-TIME ECONOMY</u>

Work impacts upon the body, health and illness in a myriad of ways. Correspondingly, medical sociologists have explored many work-related issues, including: the patterning of morbidity and mortality by occupation; lay epidemiology among workers; gendered risk-taking and risk management; macro-economic and organisational level constraints on health-related practices; and, the relation between work, lifestyle and identity. Contributing to the sociology of health, illness and work, this paper provides an overview of a recently completed ethnography of doorwork, violence and risk. Using an embodied sociological perspective, which is attentive to the flesh and blood dimensions of social life, it provides an empirically grounded knowledge of nightclub and pub security work in Britain's new night-time leisure economy.

Doorwork is a masculinist, working-class practice that deals with and in physical violence; it is undertaken in an alcohol-fuelled domain that must be surveyed and controlled by workers who place their 'disposable' bodies in the front line of danger. Doorwork therefore represents an interesting case for exploring, among other things, the embodiment and enactment of plural workplace masculinities in a risk environment; the significance of gendered bodily capital (body build and acquired techniques of the body) in attenuating, minimising or amplifying physical risk to self and others; and, the impact of intra-group relations on dealing with occupational danger. Finally, in recognising that work, leisure and pleasure are blurred in the new night-time economy, sociological attention is briefly directed at workplace sexual opportunity, pleasure and risk.

Moore, R.

University College Dublin

LAMBEGS AND BODHRANS: RELIGION, IDENTITY AND HEALTH IN NORTHERN IRELAND

Northern Ireland is held by current Western world leaders (perhaps prematurely) as an exemplar of how peace can work. Since 1969 the Province has been synonymous with extreme social division. The basis of this lies in religious affiliation. A striking feature of Northern Irish society is that while religion may be seen as the generic cause of segregation and conflict, it is also tied in to lifestyle, beliefs and wider notions of identity. While in a general sense Catholics and Protestants have a common culture in terms of sharing many of the basic features of modern living in the West, historic beliefs and practices operate to divide this small society. In addition there are other important nuances. Ethnic culture, hinged around religious identity, influences social organisation and everyday life in profound ways. Importantly it can affect potential for assistance from family and friends and the willingness and ability to tap into important resources and information networks. This paper draws on ethnographic research conducted in 1996 and discusses how this significantly influences health and health chances.

Friday the 26 September 2003 at 15.20 - 15.50

Moore, L., Campbell, R., Starkey, F., Sidaway, M., Holliday, J., Audrey, S., Parry-Langdon, N., Bloor, M.

Cardiff University School of Social Sciences

MRC CLUSTER RANDOMISED TRIAL OF A SCHOOL-BASED, PEER-LED, ANTI-SMOKING INTERVENTION (ASSIST PROJECT)

Intervention

The peer-led intervention is based on a diffusion of innovation approach, in which the most popular and influential pupils in Year 8 are identified, and given training to provide them with the knowledge and skills to intervene with their peers in everyday situations to discourage them from taking up smoking.

Methods

59 participating secondary schools were randomly allocated whether or not to receive the intervention in addition to normal smoking education. All 10889 pupils in these schools were asked to complete a baseline questionnaire and to provide a saliva sample. Follow-ups are being undertaken immediately post-intervention, and at one and two years post- intervention.

Results

Response rates at baseline and first post-intervention follow-up were 93.7% and 91.0% respectively. 27% of pupils in intervention schools reported that they had had a conversation with a peer supporter. The proportion of pupils reporting at first follow-up that they smoked at least one cigarette per week was 6.5% in intervention schools and 8.8% in control schools. Among pupils experimenting with smoking at baseline, 8.5% were weekly smokers at first follow-up in intervention schools and 9.7% in control schools. The paper will also present the results of analyses of data on smoking attitudes, norms and future intentions.

Conclusions

Results from the first post-intervention follow-up suggest that the intervention has had some effect on the rate of smoking uptake by Year 8 pupils. However, the longer term follow-ups will be the true test of the potential of this approach to reduce smoking uptake in adolescence.

Moreira, T.

National Guidelines Research and Support Unit, University of Newcastle

COMBINING REPERTOIRES OF EVALUATION IN THE CONSTRUCTION OF CLINICAL GUIDANCE: AN ETHNOGRAPHIC STUDY

This paper aims to describe and understand the social organisation of knowledge within clinical practice guideline development processes through ethnographic research. It focuses on the types of judgments used by members of guideline development teams.

Ethnographic observation focused on three main sites: two multidisciplinary guideline development groups - composed of consultants, GPs, nurse practitioners, pharmacists, patient representatives and a guideline methodologist - and the everyday work of the guideline research and support team - methodologist, statistician, systematic reviewers and secretarial support. The 'social career' of guidelines was followed from the moment when the disease/condition was, as the methodologist put it, "possibly connected to everything" to it becoming a bounded set of relationships, flows and exchanges between different actors relevant for the disease's management.

The paper argues that guidelines groups articulate clinical guidance by working in four different repertoires of collaborative evaluation - agonism, contingency, politics and process - which they constantly confront and combine in the construction of the document. It is argued furthermore that to understand the practices of combination of repertoires it is necessary to observe how group members construct boundary relations between these different forms of judgement.

Friday the 26 September 2003 at 14.40 - 15.10

Murphy, E.

University of Nottingham

ANTICIPATORY ACCOUNTS: VOCABULARIES OF MOTIVE AND THE ANTICIPATION OF FUTURE HEALTH-RELATED CONDUCT

C. Wright Mills's called for a truly sociological analysis of actors' 'motive talk', which de-couples the commonsense link between reasons actors give for their actions and their mental state prior to those actions (Mills 1940). Previous theoretical and empirical work in this field has been restricted to just one part of Mills's agenda - the reasons that actors give for untoward acts they have already committed. However, Mills was equally concerned with the reasons which actors offer for potentially untoward future conduct. He hypothesized that the availability of an acceptable 'vocabulary of motive' for future, potentially untoward, conduct might be a determinant of its enactment. In this paper I seek to rehabilitate this lost dimension of Mills's program through an analysis of the talk that women produced during a longitudinal, qualitative interview study of their infant feeding choices. The mundane activity of infant feeding offers an excellent opportunity to examine how actors anticipate and account for possible future untoward action and how such accounts are related to future conduct. The analysis confirms Mills's claim that justifications and excuses may precede as well as follow action, and shows that such anticipatory accounts bear a strong resemblance, in form and content, to the post hoc repair work that actors engage in as they defend untoward action that has already been carried out. It also offers empirical support for the Mills's claim that the ability to generate anticipatory accounts of this nature is a determinant of the enactment of potentially untoward conduct.

Nathoo, T., Shoveller, J.A.

University of British Columbia

BUILDING STABILITY: MOTHERING, MENTAL ILLNESS, AND THE RESPONSE OF THE PROFESSIONAL SYSTEM

Mothers with mental illness are often involved in numerous professional systems, including mental health, health care, child protection, welfare, and family services. Drawing upon in-depth interviews with mothers with chronic and persistent mental illness, this paper describes women's experiences of mothering and mental illness and the ways in which the professional system responds to women, their children, and broader families. Women described the ways in which they attempted to build a stable environment in which they felt supported in managing their mental health and in their parenting. However, many mothers in this study experienced numerous challenges to the process of building stability, including stigma, single parenthood, poverty, and illness-related disruptions such as child apprehension and hospitalisation.

This paper also examines how the professional system influences outcomes for women. As women come into contact with a number of different areas of the professional system, have different experiences and social locations, possess a range of abilities to function, and require different kinds and levels of support, mothers with mental illness present numerous complexities to the professional system. In order to manage these complexities, the system uses the strategies of adapting, decontextualising, and simplifying. As well, women's experiences are shaped by the broader socio-cultural context, including societal views on mothering and mental illness. Although mothers with mental illness can present challenges to the professional system, the system can support women as they strive to develop stability for themselves, their children, and families.

Friday the 26 September 2003 at 14.00 - 14.30

Nazroo, J., McCaffrey, K., Waller, J.

University College London

BEING CONFRONTED BY THE SEXUALLY TRANSMITTED NATURE OF CERVICAL CANCER: THE IMPACT OF SCREENING POSITIVE FOR HUMAN PAPILLOMAVIRUS

Human papillomavirus (HPV), a sexually transmitted infection, is accepted to be the primary cause of cervical cancer. Clinical trials are now underway in the UK to evaluate the effectiveness of using HPV testing in routine cervical cancer screening, amid a growing demand to include it in the national cervical screening programme. The research on which this paper is based set out to investigate: how HPV testing and testing positive for HPV influenced perceptions of cervical cancer, how the meanings attached to cervical cancer change if it is conceived as a sexually transmitted infection, perceptions of risk of HPV and cervical cancer, and the consequences of being identified as 'at risk'.

This study uses qualitative methods to explore the beliefs and feelings of women testing positive for HPV in the context of cervical cancer screening. In-depth interviews were conducted with women participating in clinical trials of HPV testing. Purposive sampling was used to ensure that the sample was heterogeneous in terms of age, ethnicity, socio-economic position, marital status, and cytology screening result. Verbatim transcripts were analysed using the framework approach.

Findings reported on here will focus on how and in what ways women acknowledged the sexually transmitted nature of HPV and their status as HPV positive, and how this both shifted their perceptions of cervical cancer and impacted on their identities and biographies.

54

Nettleton, S., O'Malley, L., Watt, I.

University of York

"I JUST WANT PERMISSION TO BE ILL": A NARRATIVE ANALYSIS OF PEOPLE LIVING WITH MEDICALLY UNEXPLAINED SYMPTOMS

How do people make sense of, and learn to live with, symptoms of illness which are medically unexplained or remain undiagnosed? This paper reports on an ongoing analysis of the narrative accounts provided by neurology outpatients in England who have long endured profound illness symptoms and yet are living in 'diagnostic limbo'. In common with other chronic conditions, the data reveal that these patients experience 'uncertainty', 'meanings at risk', stigma and so on. However, these dimensions of their experience appear to be intensified by their lack of 'categorical identity'. The stories told by the men and women in this study are perhaps, best typified as ' chaos narratives' (cf Franks) in that they have no clear cut genesis, progression, prognosis or plot. Furthermore the discursive and cultural resources available to them to try and make sense of their symptoms are limited, because symptoms that are not perceived to have a legitimate physical basis tend to be regarded as psychological in origin. Thus those who live in 'diagnostic limbo' hover precariously between partial and provisional psychological and physical explanations for their illness. Maintaining or resurrecting one's sense of self and one's social identity is extremely difficult within the context of the discursive and diagnostic limbo.

Friday the 26 September 2003 at 16.00 - 16.30

Northrop, M.

Anglia Polytechnic University

REPORTING RISK; NEWSPAPER COVERAGE OF OBESITY

The concept of risk and the formation of the new public health approach have been widely discussed. The role of the media in risk amplification is also a recurrent theme.

This article examines the above issues in relation to newspaper coverage of obesity. Using the "fishing expedition" approach to content analysis, (Krippendorf 1980), Articles from three newspapers were collected for a period of one month, (February 1999). They were then analysed in relation to what information was included and how this was presented.

The analysis was carried out initially by the author and then checked for reliability by colleagues reading the original newspaper articles and comparing their interpretation with that of the author.

Saturday the 27 September 2003 at 09.00 - 09.30

O'Farrell, B.

Trinity College Dublin

RECOVERING FROM EATING DISORDERS, ESTABLISHING A TRUST BOND WITH AN EMBODIED SELF

This paper explores the embodied strategies, which are used in recovery from eating disorders. Critically evaluating the available discourses of recovery, including its theorisation, this paper will argue for an embodied understanding of eating disorder, oppositional to medically sanctioned understandings. I will argue that an embodied understanding of Eating Disorder must be the foundation from which to formulate strategies and frameworks for recovery.

My contention is that mistrust, especially the mistrust of the body, which intensifies in modern contexts, is fundamental to eating disorder. Conversely, recovery is contingent upon the development of a trust bond with the body, a trust bond with an embodied self.

I will argue that this approach to eating disorder demands a critique of conventional medical treatment options. Employing the theories of Foucault (1990), Turner (1987) and Hepworth (1991) to point up conventional medicines involvement in the maintenance of social order with respect to the controlling of bodies, I will argue that conventional medicine consolidates mistrust of the body and that furthermore that the "lines of force" operating discursively through the institution of conventional medicine perpetuate this mistrust. Since establishing a "recovered" self is contingent upon the formation of a trust bond with an embodied self I propose that the Natural/Alternative Medical perspective provides a more suitable foundation for the formulation of strategies to help people with eating disorders.

Sunday the 28 September 2003 at 09.00 - 09.30

O'Malley, L., Nettleton, S., Burrows, R., Leader, B., Watt, I., Muncer, S.

University of York

TECHNOLOGY, INEQUALITY AND HEALTH: THE EXPERIENCES OF PARENTS AND CHILDREN IN THE MANAGEMENT OF CHRONIC ILLNESS

This paper draws on data derived from qualitative interviews with parents who are involved with the daily management of childhood asthma, eczema and diabetes to explore the meanings and use of e-health information. The paper examines whether having access to the internet makes a difference to the day to day management and lived experiences of these chronic conditions. The study was carried out in three localities in the UK which differ in terms of their social deprivation and the proportions of households which have internet access. The findings contribute to ongoing debates regarding inequalities arising from the 'digital divide'. These arguments resonate with the notion that 'digital exclusion' is not just a

function of access, but perhaps one of the 'better equipped' being able to engage with these technologies in ways that may advantage them further. Such assertions add weight to the assumption that the 'information rich' will invariably achieve better health and welfare outcomes than the 'information poor'. The data presented in this paper enable us to throw light on what it means to be information rich or poor. It reveals the ways in which people use, access, and interpret information and the extent to which they act upon it. It becomes apparent that the relative merits and demerits of being able to access on-line health information are not straightforward and consequently we can begin to question the extent to which the internet places patients in an advantageous position when it comes to the everyday, routine management of chronic illness.

O'Neill, M., Williams, G.

Cardiff University

METHODOLOGY IN PARTICIPATORY ACTION RESEARCH: ANYTHING GOES?

One of the defining attributes of participatory action research (PAR) is that it involves turning "lay" people into researchers. The ethos that informs this approach is that people learn or understand best, and more willingly apply what they have learned, when they do it themselves. However, an integral part of the PAR approach, as in any other research, is the collection of data. Social science data collection principles and methods are often alien to lay people who lack specialist expertise. If people are to take ownership of "doing it themselves" there is a need to utilise and develop indigenous forms of knowledge collection in partnership between academics and lay people in order that all participants can contribute to the PAR process. As in most other areas of this type of research this approach can challenge established ways of doing things and so, in relation to data collection methods, the process may contest what have traditionally been characterised, by academics, as 'rigorous', 'robust' and 'validated ' forms of data collection. This paper discusses the development of new, innovative and reciprocal action research models and methodologies, which have transcended the inherent tensions in the action research process. Theses issues are illustrated with reference to PAR with 'hard to reach' populations in South Wales.

Sunday the 28 September 2003 at 09.00 - 09.30

Owen, C.

University of Derby

RISK, MORALITY AND PLEASURE IN PRACTICE: THE CONSTITUTION OF NARRATIVES OF RISK IN PUBLIC AND IN PRIVATE

This empirical study uses a discussion group and in-depth semi-structured interviews to explore how discourses around the concept and management of risk are taken up, internalised and interpreted by a sample of health promotion professionals and how narratives of risk are constituted and operationalised within the reflexive project of self-construction. This endeavour, the research suggests is not so much driven by the imperatives of discourse, expert knowledges and threats but by the imperatives of self-construction. An explanatory insight is offered into the ways in which the power relations between the reproducers of institutional health risk imperatives and the individuals who are also produced by them are managed in the same body; that is a phenomenology of power relations and risk narrative.

Saturday the 27 September 2003 at 16.00 - 17.00

Panagos, M., Haimes, E., Richardson, D.

University of Newcastle upon Tyne

PARENTAL RIGHTS OF WOMEN WITH HIV SEROPOSITIVE STATUS

This poster draws on empirical research undertaken on women affected and infected by HIV/Aids in relation to their perception of reproduction within an HIV testing context. The primary objective is to address how decision-making is socially constructed, to report some findings of the study undertaken throughout different parts of the UK and to conclude with a discussion of psychosocial and ethical implications raised on a family social policy level relating rights of 'informed consent', 'privacy and confidentiality', and 'public order' to that of the 'principle of finitude' while living in a 'risk' society to male and female reproductive rights, such as that of knowing of one's HIV status as opposed to not, and that of HIV parenting. The sample was drawn from a variety of settings, including an academic setting, self-help groups and governmental and non-governmental organisations throughout the country. Data was drawn from a questionnaire evaluated by SPSS and twenty-four in-depth semi-structured qualitative interviews in the UK among women of an unknown or a known positive or negative HIV serostatus. The method of membership categorization device {MCD} was employed to analyse women's responses and to examine the way in which they make sense of daily phenomena and interpretations of notions of 'reproduction', 'rights' and 'HIV testing' by attaching to categories assumptions about their characteristics. Grounded theory and phenomenology were adopted into my data analysis. Women linked HIV infection with notions of 'stigma' and 'risk' in relation to reproductive choices in both everyday life and an HIV testing context.

Saturday the 27 September 2003 at 14.35 - 15.05

Papadopoulos, I., Lees, S., Tilki, M.

Middlesex University

CHALLENGES TO CULTURAL COMPETENCE TRAINING WITH HEALTH CARE WORKERS

The authors have conducted training courses with health care workers in a variety of settings and disciplines. Drawing on their experiences and a research study this presentation will discuss the barriers and enablers to conducting such training. Whilst the research study focused on providing cultural competence training to mental health care workers, training has also been provided to a range of teams from physiotherapists, to transcultural community mental health workers who specialise in providing services to refugees and people from minority ethnic groups and to student nurses from different European countries. The training is based on the Papadopoulos, Tilki, Taylor and Lees model for developing cultural competencies. Cultural competence is now considered essential for all health care professionals; however, despite the considerable effort being invested in this currently up and down the country, there is no common agreement as to its definition, or the best ways to promote it. The presentation will outline the approaches used by the authors and will discuss the impact of variables such as context, professional background, years of professional experience, nature of clients, peer influence, etc in order to highlight the challenges which such training may pose.

Abstract Book prepared 18th July 2003

Paper/Poster Abstracts - listed in alphabetical order of first author

Saturday the 27 September 2003 at 16.00 - 17.00

Ali, A., Kinsella, F., Merrell, J., Murphy, F., Philpin, S.

University of Wales, Swansea

IDENTIFYING THE HEALTH AND SOCIAL CARE NEEDS OF INFORMAL CARERS WITHIN A BANGLADESHI COMMUNITY IN SOUTH WALES

Objective

To identify the health and social care needs of informal carers caring for an adult dependant within a Bangladeshi community in South Wales.

Method

A qualitative study was conducted using focused interviews with a sample of 20 Bangladeshi informal carers, who were caring for an adult dependant. A combination of purposive and snowball sampling was utilised. Interviews were conducted in the carers' preferred language and were audiotaped, transcribed and translated into English. Verification of the translated transcripts was conducted. Thematic analysis was used to analyse the data.

Findings

The findings indicate the complexity of informal carers' needs and the following key themes were identified: carers' perceptions and experiences of their role, including carers' understanding of their dependants' conditions; the influence of cultural factors on informal carers' needs and carers' experiences of health and social care provision.

Carers reported that caring for their dependants was an 'honour and aprivilege'. The caring experience was mediated through a number of cultural elements including religious beliefs, caring obligations, language and isolation as a result of migration. The carers demonstrated limited knowledge regarding health and social services available and a perceived lack of understanding of the Bangladeshi culture by service providers was identified. Material issues related to socio-economic status, housing and social exclusion compounded carers' experiences.

Conclusion

Health and social care needs of the Bangladeshi informal carers interviewed are not being met.

Recommendations to improve the accessibility, acceptability and appropriateness of health and social services to improve future provision are proposed.

Saturday the 27 September 2003 at 11.55 - 12.25

Pitson, L., Williams, C., Hundt, G., Spencer, K., Heyman, B., Sandall, J.

James Clerk Maxwell Building,

PERCEPTIONS AND KNOWLEDGE OF DOWN'S SYNDROME, AND DECISIONS ABOUT SCREENING IN PREGNANCY

Following the publication of national guidelines for antenatal screening, most expectant parents in the UK can expect to be offered a screening test to determine the probability of the foetus having Down's Syndrome. If they choose to have this test and the foetus is found to be at 'increased risk' of having Down's Syndrome, invasive diagnostic testing is offered. If this offer is accepted and the foetus is diagnosed as having Down's Syndrome, parents then face the choice of continuing or terminating the pregnancy.

Decisions by prospective parents about screening, invasive testing and termination for Down's Syndrome are shaped by personal and social circumstances, together with an often complex set of moral beliefs, perceptions and attitudes. In this paper, I will focus on and explore the particular influence of perceptions of the nature and implications of Down's Syndrome itself. I will link this discussion with wider sociological debates about the social meaning and perception of disability, as recently explored in similar contexts by thinkers such as Priscilla Alderson.

I will draw on data from a study of innovations in prenatal screening, funded by the MRC and the ESRC under the Innovative Health Technologies Programme and carried out in two NHS Trusts. Data include in-depth interviews with pregnant women and their partners, and a postal survey of 1,000 pregnant women receiving maternity care across both Trusts.

Saturday the 27 September 2003 at 09.00 - 09.30

Pope, C., Goodwin, D., Mort, M., Smith, A.

University of Bristol

<u>DOGS THAT DON'T BARK IN THE NIGHT - ANAESTHETIC MANTRAS AND WHAT HAPPENS IF THEY ARE NOT SAID</u>

As part of a large qualitative study of expertise in anaesthesia we gathered data relating to the induction of, and emergence from, general anaesthesia. The data presented in this paper are taken from observations of, and interviews with, anaesthesia personnel, supplemented by other material drawn from the personal experience of the authors. What anaesthetists say to their patients as they go to sleep and wake up again and the functions of this talk has not, to our knowledge, been explored. From our observational work, we noted distinct patterns of speech that were often repeated in a soft, rhythmical manner. We called these 'anaesthetic mantras' and delineated three broad categories of mantra: functional, descriptive and metaphorical. Mantras appear to serve many purposes, for example they reassure the patient whilst also signalling to others that induction is taking place, thus helping to ensure that it is accomplished successfully. Some of the interview data suggested that a failure to deliver the appropriate mantra during induction disrupts the smooth, predictable sequence of events. Our question is, given the important differences between interview and observational data, do these interview accounts provide a negative case (like Sherlock Holmes' "dog that did not bark") or should they be treated as stories that anaesthetists tell?

Saturday the 27 September 2003 at 10.45 - 11.15

Porter, M., van Teijlingen, E., Bhattacharya, S., Campbell, D., Hall, M., Mollison, J., Templeton, A.

University of Aberdeen

CHOOSING TO HAVE ONE CHILD: DEFENDING THE INDEFENSIBLE

Falling birth rates throughout the developed world including the U.K., have prompted media interest in women who choose to be childless or to have only one child. Only children are widely perceived as selfish, spoilt and lonely and their parents as selfish and irresponsible. Existing research does not support these views of only children or of their parents.

This paper is based on tape-recorded interviews with 49 women who had only one child or who had left a gap of five or more years before having another child. They were a representative sample of a wider cohort of 1117 women giving birth by caesarean section in Aberdeen between 1980 and 1995 who responded to a postal questionnaire about their experiences.

The paper discusses respondents' reasons for having only one child and their views of the advantages and disadvantages of being an only child. It shows that where women deliberately chose this course of action they tend to be defensive, possibly because of others' reactions to this non-normative choice. Most women in stable relationships had experienced some social and/or medical pressure to have more children. Those who had a large gap between children also tended to be defensive, arguing that the gap was not an issue. When there were problems, however, they often attributed them to the larger than average age gap.

Friday the 26 September 2003 at 14.40 - 15.10

Potts, L.K.

York St John College

<u>'HARNESS THE POWER OF A NUMBER OF BRAINS': RETHINKING AETIOLOGY OF BREAST CANCER</u>

Recent research (part of the ESRC 'Science in Society' programme) considers the legitimate/authoritative understandings of breast cancer aetiology, from health policy makers and epidemiologists, alongside women's perceptions of local environmental risks. The project combined a collective mapping exercise with individual life-narrative recounting, by inviting stories of participants' lived environment around times of life believed to be of particular vulnerability to environmental hazards. Interviews with the 'professional experts' revealed the normative paradigm of breast cancer aetiology, and a diffuse, disembodied knowledge of local environmental hazards. Local women's perceptions of hazards were more specific, and informed by a different discourse of risk; there were also marked differences between women who had had breast cancer, and those who had not, suggesting how issues of trust and embodied knowledge are significant here. The potential for dialogue between these different knowledge discourses, generates, I suggest, a substantive epistemological challenge to current epidemiological thinking and practice. This work also demonstrates the usefulness of a technological tool, GIS-P (geographical information systems for participation), as a means for community engagement in scientific decision making, and so to a dynamic citizen engagement with governance. As a participatory approach to public health, the tool could usefully be applied more extensively, and in relation to many other health issues. And since the approach demands a broad, holistic understanding of health determinants in a community, it has the potential, too, to re-frame traditional policy paradigms and to yield a deeper ecology of health.

Sunday the 28 September 2003 at 09.00 - 09.30

Prout, H., Evans, M., Prior, L., Tapper-Jones, L., Butler, C.

Health Centre, Maelfa Cardiff

BARRIERS TO INFLUENZA IMMUNISATION IN OLDER PEOPLE (PRELIMINARY FINDINGS)

Influenza in older people is a major cause of hospitalisation and mortality during winter months. In spite of studies, which show that influenza vaccine is both safe and effective, vaccine uptake in older people still remains sub-optimal. This study investigated beliefs regarding flu and the flu jab of older people and primary care staff in the Bro Taf area of South Wales to promote flu vaccine uptake in older people.

Stage one of this study used in-depth interviewing with 54 people aged 65 years and over, while stage two used in-depth interviewing with 27 primary care staff; 9 GPs, 9 Practice Nurses and 9 receptionists.

Results of stage one identified that the majority of those interviewed did not feel at risk from flu whilst potential and actual side effects of the flu jab were reasons for low uptake. Preliminary results of stage two indicated that many staff felt that flu is serious for older people although not a major problem for healthy older people. Moreover, many staff felt that if flu jab payments to practices were terminated, then flu jab uptake would decrease.

To conclude, clear communication of the risks of flu, particularly to healthy older people are an important determinant of flu vaccine uptake. Health professionals can promote immunisation both by personalising the risk of catching flu and by tackling misconceptions about side effects. Primary care staff need also recognise the risks of flu to healthy older people, while financial reimbursement for flu jab administration should still be prioritised.

Saturday the 27 September 2003 at 09.35 - 10.05

Rapley, T., Finch, T., May, C., Moreira, T., Heaven, B.

University of Newcastle upon Tyne

HYBRID MEDICINES: TECHNOLOGIES AND SUBJECTS IN PRIMARY CARE

Technological solutions to problems of knowledge and practice in health care are routinely advocated. Drawing on a series of empirical studies of new technologies of practice, this paper explores the ways that these new systems of practice are being deployed as intermediaries in interactions between clinicians and their patients.

Central to this analysis is the apparent conflict between two important ways of organising ideas about practice in primary care. First, a shift away from the medical objectification of the patient, towards patient-centred clinical practice in which patients' heterogeneous experiences and narratives of ill-health are qualitatively engaged and enrolled in decisions about the management of illness trajectories. Second. the mobilisation of evidence about large populations of experimental subjects revealed through an impetus towards evidence-based medicine, in which quantitative knowledge is engaged and enrolled to guide the management of illness, and is mediated through clinical guidelines.

The tension between these two ways of organising ideas about clinical practice is a strong one, but both impulses are embodied in new 'technological' solutions to the management of heterogeneity in the clinical encounter. Technological solutions themselves, we argue, embody and enact these tensions, but may also be opening up a new array of hybrid practices * technogovernance * in which the heterogeneous narratives of the patient-centred encounter can be resituated and guided.

Saturday the 27 September 2003 at 10.10 - 10.40

Redley, M.

The University of Edinburgh

DELIBERATE SELF-HARM THE PATIENT AND PSYCHIATRIST ENCOUNTER

The presentation is based upon 2 data sets, 31 qualitative interviews with hospital based psychiatrically trained medical personnel and 50 qualitative interviews with non-psychotic self-harm patients (by overdose). The psychiatrically trained medical personnel have assessed the non-psychotic self-harm patients and in both data sets the reasons why the overdose was taken are discussed.

Using a social constructivist methodology that enables the patients' and the psychiatrically trained medical personnels' accounts to be given equal ontological status the analysis discusses some striking parallels between how these lay and professional accounts explain why an overdose was taken: both psychiatrically trained medical personnel and patients see self-harm as environmentally determined. Both psychiatrically trained medical personnel and patients see themselves as powerless to change the determinating environment.

Both psychiatrically trained medical personnel and patients see the other as morally deficient: medical personnel don't listen and self-harm patients are not motivated to take medical advice. Self-harm patients seek to avoid moral responsibility for self-harm (putting the responsibility else where) and psychiatrically trained medical personnel do not hold self-harm patients morally accountable for taking an overdose (though they do hold them morally responsible should they cause 'trouble' on the hospital ward).

The paper discusses these parallels by considering why psychiatrically trained medical personnel do not appear to credit self-harm patients as theoretic actors (morally responsible agents) and how this might explain the absence of empathy in these patient-psychiatric encounters: listening out for risk factor but not listening to the patients.

Friday the 26 September 2003 at 14.00 - 14.30

Regan de Bere, S., Britten, N., Petersen, A.

University of Plymouth,

OUT OF THE DISSECTING ROOM: IMAGES OF THE BODY, LIFE AND DEATH IN MEDIA DEBATES ABOUT THE NON-USE OF CADAVERS IN MEDICAL EDUCATION

Using dissection to understand anatomy has long separated medicine from other established sciences, and provided it with a distinct sense of professional identity. However, recent high profile and controversial media coverage (e.g. the 'Alder Hey affair', unethical organ bio-banks and alleged trafficking of body parts, diseased corpses and so on) has questioned the autonomy of the medical profession in using cadavers for dissection, prompting more public debate about anatomy teaching. At the same time, moves towards using new technologies to simulate or replicate living bodies have also come under harsh media criticism, this being most often based on cultural, (rather than purely pedagogic) arguments. These dissection/non-dissection debates emphasise the ways in which our bodies, even in their inanimate states, have significant cultural relevance in human societies.

This paper considers the use and non-use of cadavers in the teaching of anatomy and relates this to cultural interpretations of bodies, health and illness. It considers recent media coverage in terms of: i) the ways in which the various media present certain definitions and meanings relating to the use or non-use of cadavers; ii) their use of cultural and historical references to the dissection room, the medical profession and ethical traditions, and; iii) what we can learn from media analyses about people's changing constructions of the body, life and death.

Saturday the 27 September 2003 at 11.20 - 11.50

Rivers, C.

South Bank University

INTERROGATING PATHOLOGY: AN EXPLORATION OF THE EXPERIENCES OF LESBIAN, GAY AND BISEXUAL PEOPLE WITH EXPERIENCE OF MENTAL DISTRESS

The last thirty years have witnessed significant cultural changes in perceptions of lesbian, gay and bisexual sexuality as an illness. For most of the twentieth century, medical theories viewed lesbian, gay and bisexual sexuality as inherently pathological. Viewed by psychiatry as individuals in whom desire had been directed towards the 'wrong' object, lesbian, gay and bisexual people have been prescribed medication, psychosurgery and aversion therapy in attempts to alter their sexual desires. Subsequent political struggles have reworked and reclaimed lesbian, gay and bisexual sexualities as alternative, equal and healthy lifestyles.

However, the experience of mental distress re-engages the vulnerable lesbian, gay or bisexual self with discourses of illness and mental pathology. This paper will explore the contemporary interface between mental distress and lesbian, gay and bisexual sexuality, and will explore the negotiation of lesbian, gay and bisexual identities with mental health professionals, family members and heterosexual mental health service users.

This paper is based on a study using semi-structured interviews with lesbian, gay and bisexual people who have experience of mental distress (n=23) and with mental health service providers (n=25).

Abstract Book prepared 18th July 2003

Saturday the 27 September 2003 at 11.55 - 12.25

Roberts, R., Pfeffer, N.

London Metropolitan University

EXTENDING THE CLINICAL GAZE: THE JOURNEY(S) OF A HOSPITAL SAMPLE

This paper explores laboratory technicians' understandings of hospital samples. It focuses on pregnancy related material. It draws on participant-observation and focus group data collected during a two-year project exploring ethical and social issues in the collection, use, storage and disposal of pregnancy-related tissue samples. Collection, exploitation and disposal of pregnancy related material is highly controversial: for different related reasons, why and how it is acquired, the ways in which it is handled, its storage and disposal, provoke strong feelings. There have been a limited number of explorations into how people directly concerned with its collection, that is, medical professionals and women in the clinic, understand this material. Much of this research is polemical. What people in the hidden 'backstage' of NHS hospitals think about it has largely remained unexplored. Yet laboratory and mortuary technicians, porters, people working in refuse collection, and manufacturers of laboratory consumables routinely handle, process, transform, investigate, store and dispose it. This paper will suggest some ways in which their relationship to the material is structured socially, legally, physically and symbolically.

Saturday the 27 September 2003 at 15.10 - 15.40

Robertson, S.

Lancaster University

"I'VE BEEN LIKE A COILED SPRING THIS LAST WEEK": EMBODIED MASCULINITY AND HEALTH

This paper presents a critical exploration of the relationship between masculinity, embodiment and health by reporting part of the findings from a qualitative study on lay men's and health professionals' beliefs about masculinity and preventative health care.

Following an historical 'absent presence' in sociology, there has been a current surge of popular and academic interest in 'the body' moving it from this place of implicit invisibility to a place requiring explicit consideration. In these considerations embodiment has become politicised and what constitutes the body, whether physical or social, material or cultural, experiential or representational, has become hotly contested. Empirical studies of health and illness have provided fertile terrain for helping ground such debates about the nature and function of embodiment. Yet, whilst much 'men's health' writing has focused discussions on male bodies, particularly how men take an instrumental approach to body maintenance, little empirical work has been carried out in exploring a more fully embodied approach to understanding masculinity and health.

A series of focus groups and interviews with health professionals and lay men, including gay and disabled men, were undertaken and, through a process of narrative analysis, the gendered nature of the lived body in everyday life and its relationship to health emerged as a major theme. Both socially constructed and objectively real elements to embodiment were apparent in the empirical data and the integrated nature of these elements, and their implications for health promotion work with men, form the basis of this paper.

Abstract Book prepared 18th July 2003

Friday the 26 September 2003 at 16.40 - 17.10

Robling, M.

University of Wales College of Medicine

THE IMPACT OF KNEE PROBLEMS UPON QUALITY OF LIFE: CHANGE AND ACCOMODATION WITHIN THE PATIENT 'BIOGRAPHY'

An ongoing trial of patients with internal derangement of the knee (i.e. meniscal and ligament damage) is evaluating the impact of different management strategies upon quality of life. Quantitative assessment of change assumes stability over time of the construct under consideration. However, a recent theoretical model of response shift describes how self-evaluation of quality of life may change due to changes in patient evaluation of the importance of component domains and redefinition of the target construct.

A purposive sample of patients (stratified by age, gender and stage of management) were interviewed. The interview followed a semi-structured schedule, incorporating an individualised quality of life assessment (SEIQOL) which allows patients to describe areas of life important to them. The second half of the interview explored in-depth, patient understanding of disease causation, its affect on their daily life, their expectations for the future and their experience of the health care system.

39 patients were interviewed and are currently being followed up after six months with a second interview. On both occasions a quantitative assessment of quality-of-life will also be conducted (EQ-5D). Analysis of the SEIQOL data will primarily compare changes in elicited quality-of-life domains and patients' evaluation of such changes. The analysis of the second half of the interview will use a grounded theoretical approach to identify recurrent emerging themes. The paper will describe the role of the knee problem within the individual patient 'biography' as they accommodate to their knee problem and its potential impact upon quantitative assessment of quality-of-life.

Saturday the 27 September 2003 at 16.20 - 16.50

Rowley, E.

University of Nottingham

"THEY'RE TIMEBOMBS STUCK TO THE MIDDLE OF YOUR CHEST". THE MEDICALISATION OF WOMEN'S HEALTHY BREASTS

Women's bodies have become increasingly medicalised (Kohler Riessman, 1983). Normal processes such as childbirth, menstruation and menopause have arguably been taken away from the individual woman's control (Kaufert and Lock, 1997), and placed into the hands of doctors. Consequently, women and normal life events have been constructed as diseased and in need of medical management.

The medicalisation of women's bodies has recently amplified. Women at risk of hereditary breast and ovarian cancer can decide whether or not they wish to know if they have a mutated gene. Upon receipt of a positive test result, women are routinely offered screening in the form of annual mammograms or prophylactic surgery (oophorectomy and/or mastectomy). These two prevention strategies are radically different. Each have their own implications for the women involved, and these procedures may potentially contribute to the extended medicalised gaze that has fallen upon women's bodies. For instance, women's healthy, non-cancerous breasts are being subjected to mammography or radical surgery even though no cancerous cells are likely to be found.

This paper offers preliminary analysis of a small number of in-depth interviews conducted with women who are at risk of breast and ovarian cancer. A common theme emerging from these interviews is the threat that healthy non-cancerous breasts pose to these women, and how and whether this threat should be medically managed.

Abstract Book prepared 18th July 2003

65

Saturday the 27 September 2003 at 16.00 - 17.00

Ruston, A.

University of Greenwich

BUREAUCRATIC CONTROL VERSUS PROFESSIONAL AUTONOMY: DECISION MAKING IN NHS DIRECT

NHS Direct is a 24hour telephone helpline with a remit to provide easier and faster health advice and information to the public. The NHS plan envisions that it will become the gatekeeper for all GP out of hours calls by 2004. If this policy is to be successfully implemented it is essential that the target of 90% of calls being completed within twenty minutes is met.

Lipsky (1980) argues that professionals exercise wide discretion in decisions about their clients and that when taken in concert, their individual actions become agency behaviour. Prottas (1979) suggests that they can thwart the attempts of their employers to define their responsibilities and observe their behaviours which would be pre-conditions for effective control.

Nurses working in NHS Direct are, however, subject to a considerable degree of control from the use of a computerised decision support system to calls being recorded, call times and deviations from recommended dispositions being monitored.

Nevertheless routinely collected data shows variation between nurses in lengths of calls and the extent to which they deviate from the recommended dispositions.

This paper reports on a qualitative study which used in depth interviews and observation to examine the behaviour of 30 nurses in one NHS Direct site. The data was analysed using ATLAS.

In spite of considerable bureaucratic control over their behaviour nurses still exercised discretion and developed patterns of practice which had the effect of limiting the number of calls taken. This has implications for the Government's plans for expanding the service.

Saturday the 27 September 2003 at 09.00 - 09.30

Sandall, J., Heyman, B., Hundt, G., Pitson, L., Spencer, K., Williams, C.

King's College

FEARING THE WORST? WHAT DO PREGNANT WOMEN FEEL AT RISK FROM?

Risk is a pervasive concept in the organisation of perinatal services, and women and their unborn babies are increasingly being reconfigured as objects of surveillance rather than recipients of care. One example is the introduction of a policy of universal prenatal screening for Downs Syndrome in the UK, of which the social and ethical implications remain to be explored. The majority of research on prenatal screening has focused on broader societal implications of routine screening for Downs Syndrome, or aspects of the testing process such as informed choice, and the psychological sequelae of screening and testing. Most of this latter work has measured levels of anxiety, but cannot tell us what women feel at risk from, or the relative importance of these concerns. While pregnancy and birth are routine life events, they can also be filled with uncertainty and a feeling of being 'at risk'. What do pregnant women fear in pregnancy, and what are the implications of this?

This paper explores women's beliefs and fears in pregnancy and birth and contextualises their perceptions of antenatal screening tests within this broader framework. We explore notions of risk as perceived by these women, whether it is associated with personal history and identity, and the implications for the reproductive choices that are made. Data is drawn from a cross-sectional survey of over 1,000 women in two sites in England which is part of a study investigating the implications of innovative methods of prenatal screening funded by the ESRC/MRC IHT programme.

Paper/Poster Abstracts - listed in alphabetical order of first author

Sunday the 28 September 2003 at 09.00 - 09.30

Sanders, T., Cobley, C., Coles, L., Kemp, A.

The University of Manchester

FACTORS AFFECTING CLINICAL REFERRAL OF YOUNG CHILDREN WITH SEVERE HEAD INJURY ('SHAKEN BABY' SYNDROME) TO CHILD PROTECTION AGENCIES

Aims

The research, on which this paper is based, aimed to identify the social and legal consequences when young children sustain a suspected non-accidental subdural haemorrhage; and to examine the clinical and social factors that impact on clinical referral decisions.

Methods

Data were collected from medical, social services, police and court files for information on the management of children with these injuries by various agencies in the South West of England and South Wales. Data were collected on the case management of young children from time of presentation to hospital, through to referral to police and social services.

Results

The paper shows that children who are most at risk of shaking injuries are likely to be very young babies between three and five months of age. They are most likely to come from deprived households where parental stability is weak and where social support for the carers is limited. Referral of children by paediatricians to child protection agencies is not always carried out, in cases where coexisting signs indicate a strong reason for referral.

Conclusion

It is recommended that paediatricians and other clinicians involved in the care of young children should embark on a multi-disciplinary process of assessment and training in the identification of non-accidental head injury in very young children and babies, to reduce their risk of future harm.

Friday the 26 September 2003 at 15.20 - 15.50

Scambler, G., Kelleher, D.

University College London

SOCIAL AND HEALTH MOVEMENTS: PROSPECTS FOR CHANGE

For many theorists the transition from organized to disorganized capitalism dating from the 1970s has witnessed a decline in old class-based movements focused on issues of material distribution and their displacement by new social movements focused on issues of lifestyle and identity. This paper reviews recent social movement literature and considers the repertoire of social and health movements extant in the UK. The source material ranges widely between transnational anti-capitalist and anti-corporate protests at one end of the spectrum to self-help groups in relation to particular conditions, like diabetes or epilepsy, at the other. A typology is developed of movements either directly or indirectly implicated in issues of health and health care. Each category of movement in the typology is anchored empirically. Finally, the paper reflects on the likely trajectory of movements pertinent to health and health care in the short- and medium-term and their potential to accomplish change.

Saturday the 27 September 2003 at 10.10 - 10.40

Scanlon, K.A., Harding, S., Hunt, K., Petticrew, M., Rosato, M., Williams, R.

Medical Research Council, University of Glasgow

INVESTIGATING CANCER RELATED KNOWLEDGE, BELIEFS AND ATTITUDES AND MEANS OF RAISING AWARENESS AMONG PEOPLE OF IRISH ANCESTRY LIVING IN BRITAIN

Aim

To gain an understanding of the knowledge base, beliefs and attitudes of Irish people to cancers and to adapt successful health promotion materials accordingly.

Background

First generation (Irish-born) and second generation (UK-born with Irish-born parents) Irish people living in Britain experience high incidence of and mortality rates from a range of cancers compared with the national average. Socio-economic position is an important predictor of these patterns but does not explain all of the excess.

Method

This is a qualitative study using focus groups and individual interviews with Irish people and with a comparison group of indigenous white British people in London, Manchester and Glasgow. Quota sampling is used to ensure representation across key variables including deprivation and migration status.

Findings

Fieldwork has been completed and formal analysis is ongoing. The main themes emerging so far appear to be an overall understanding of life style factors that influence susceptibility, experience of close relatives or friends who have had cancer, a possible lack of awareness of early signs and symptoms for cancers other than breast and lung cancer, and a general pessimism towards treatments. These factors are relevant to both the Irish and comparison groups but may disproportionately affect the Irish group.

Conclusion

Though preliminary, these findings suggest that factors amenable to modification may play an important role in explaining differences in cancer experiences between Irish people and the local population.

Saturday the 27 September 2003 at 16.20 - 16.50

Secker, J., Benson, A., Balfe, E., Lipsedge, M., Robinson, S., Walker, J.

Anglia Polytechnic University

PEELING THE ONION FROM THE INSIDE: UNDERSTANDING THE SOCIAL CONTEXT OF VIOLENCE & AGGRESSION IN A MENTAL HEALTH INPATIENT UNIT

The English National Service Framework for Mental Health stipulates that the highest quality of health care should be provided for mental health service users in the most efficient and effective manner. Incidents of aggression and violence militate against achieving that goal, yet such incidents are frequently reported in inpatient settings. For the most part previous research reflects a dualistic, perpetrator/victim conceptualisation of incidents. The study described in this presentation aimed to take a more systemic approach by treating violent and aggressive incidents as social interactions and by seeking to understand the social contexts in which they took place. Semi-structured interviews were carried out with 14 staff and two service users involved in a consecutive sample of 12 incidents. The results of two 'layers' of analysis will be presented and compared: a discourse analysis focusing on the function of the discursive devices used by two staff members and one service user in accounting for incidents in which they were involved; and a thematic analysis of 13 staff accounts focusing more broadly on the social context of the incidents they described.

Friday the 26 September 2003 at 16.40 - 17.10

Seymour, W., Lupton, D.

DISABILITY AND TECHNOLOGY: NEGOTIATING FREEDOM AND RISK

Technology offers the potential to free people with a disability from dependence on others by enabling them to participate more fully in society and to take an active and creative role in their own embodiment. However, both citizenship and social relationships involve reciprocal responsibilities, duties and obligations. While technology can enable participation and strengthen embodiment in significant ways, it may also increase susceptibility to a range of risks and dangers. On line relationships may fragment rather than consolidate and confirm the embodied self. Disconnected from the immediacy of corporeal participation, on line communication can intensify exclusion and deepen disadvantage.

Yet the promise of technology is more than a siren's song. By facilitating active participation, technology enables people to reposition themselves in relation to social structure. The expansion of spatial and personal boundaries can free people to reflect and question current attitudes and practices. In providing the opportunity to escape the narrow dimensions of disability identity, technologies may enable people to create innovative relationships and identities. Technical familiarity and competence engenders confidence in the ability to manipulate and control the environment and diminishes reliance on others. Released from the vagaries of bodily unreliability and dependence, people with disabilities may explore hitherto unimaginable opportunities.

Saturday the 27 September 2003 at 10.45 - 11.15

Shaw, S., Carter, Y.H.

Queen Mary, University of London

BUREAUCRACY GONE MAD? THE IMPACT OF GOVERNANCE ON RESEARCH IN PRIMARY CARE

Background:

Concern over pharmaceutical company sponsored research and the need to ensure high clinical standards in respect of the testing of medical products is one of the key drivers behind the development of research governance. This has led to the introduction of new procedures for all research undertaken within health and social care. In primary care, this is facilitated via a national network of Research Management and Governance (RM&G) Primary Care Trusts (PCTs). However, questions remain as to the effect that increasing management and administration will have on future capacity for research.

Methods:

Evaluation of a purposive sample of eight pilot PCT RM&G sites reflecting a range of geographical locations and organisational models. Semi-structured interviews with key informants (e.g. PCT R&D Lead, Board level representative) were audio-taped with consent, transcribed and analysed using Framework (Ritchie & Spencer, 1994).

Results:

Implementation of PCT RM&G systems was facilitated by the support of senior management in developing a research culture and linking this with commissioning / service development. By placing research governance within the context of the R&D facilitation, emphasis was also shifted away from any perceived administrative burden. However, there were persistent concerns about the potential effect of bureaucratic systems, such as issuing honorary contacts to non-NHS researchers, on research capacity.

Conclusions:

Bureaucracy surrounding the implementation of research governance in PCTs has led to anxiety that researchers may fail to address important questions. Administrative processes may overload a system that is still coming to grips with the effect of rapid organisational change.

Saturday the 27 September 2003 at 15.10 - 15.40

Shelton, P.

University of Central England, Birmingham

THE APPLICATION OF SOCIOLOGICAL KNOWLEDGE TO NURSING PRACTICE FOR PRE-REGISTRATION NURSES

Sociological and policy dimensions of health and health care are important and well established components of the education of healthcare professionals including nurses. Students often have difficulty with the forms of conceptualisation in sociological and policy discourse and often express doubts about the relevance of even highly applied knowledge to their experience (Cooke,1993, Porter1996 and Sharp, 1995). Changes to the structure of the curriculum on the pre-registration diploma mean that students will have the benefit of initial practice experience before they undertake the sociological/policy module in future. The research will take the opportunity to explore how such experience might be effectively utilised in enabling students to apprehend practice through relevant and accessible sociological reasoning.

In keeping with the exploratory nature of the study a qualitative methodology would be the most appropriate to encompass the multidimensionality of health care work, by revealing the ways student nurses make sense of applied sociological knowledge in the context of practice experience. A qualitative approach would also reveal how perception relates to practice, by enabling respondents to map out the territory under discussion in their own terms.

Saturday the 27 September 2003 at 16.55 - 17.25

Smith, S.R.

University of Nottingham

IS GENETIC INFORMATION EXCEPTIONAL? THE COMPEXITY OF THE GOVERNANCE OF DNA-BASED DIAGNOSTICS FOR COMMON DISEASES

Within the next decade it is predicted that an increasing number of DNA-based diagnostic tests for common conditions with a genetic component, such as cancers and heart disease, will enter clinical practice. However, there is debate about how these tests should be governed, with a number of commentators suggesting that regulation should be based on an assumption that the information produced by these technologies is 'exceptional', as it raises a number of important social, ethical and legal issues. Measures such as genetic counselling have been introduced to protect patients from the potential misuse of this data. In contrast, it has been argued that genetic information is not intrinsically 'different from other diagnostic data, and that new genetic tests should be handles in a similar fashion to established diagnostics. The manner in which genetic information is defined within a clinical setting therefore has major implications for related policy formation. Governance of current genetic technologies and medical diagnostics is based on a complex framework. combining levels of international, national, regional and local regulation and oversight. It is based on interactions between a variety of different institutions, including both governmental agencies, and clinical-professional oversight regimes. This paper argues that the way in which genetic information is constructed depends on the context of its production and use within specific clinical settings. Only by understanding the different forms of genetic knowledge will it be possible to develop suitable governance frameworks for these new clinical technologies.

Friday the 26 September 2003 at 14.00 - 14.30

Spilsbury, K.

St Bartholomew School of Nursing & Midwifery

WHO CARES? EXPLORING HEALTH CARE ASSISTANTS' WORK IN A UK NHS TRUST

The roles of registered nurses (RNs) are changing due to professional and policy imperatives. Existing research on the changing roles of RNs focuses on the roles and responsibilities they are acquiring, and in particular the progressive developments of specialist and advanced practice. However, research often fails to explore activities RNs are discarding as a result of these changes, the effect of these changes on patient care and nursing teamwork. In the modern health service, RNs cannot practice without the support of Health Care Assistants (HCAs). HCAs make up 2 0-40% of the nursing workforce (Thornley, 2000), their numbers are increasing (Buchan and Seccombe 2002), and a commensurate level of influence seems likely in the future.

This paper presents the findings of a three-year study exploring the boundaries of HCA practice in one NHS Trust. A case study approach with mixed methods of data collection (interviews and observation) provides the framework for describing HCAs' work and the role negotiations that surround this crucial component of NHS service delivery. An interactionist lens is used as a framework for analysis of HCAs' work, drawing particularly on Abbott's (1988) concept of occupational jurisdiction. Findings include the jurisdictional claims of HCAs, their social location in the workplace, HCA work content, and the competing tension between supervision of HCA practice and HCA claims on nursing's craft knowledge base.

This study is an exemplar of the methodological complexity of mixed method case approaches to complex social phenomena and their relationship to nursing practice and service delivery and organisation.

Friday the 26 September 2003 at 14.00 - 14.30

Staniland, K.

University of Salford

WILL THE RHETORIC OR REALITY OF CLINICAL GOVERNANCE HELP IN THE MEASUREMENT OF QUALITY NURSING CARE?

Medicine and nursing aspire to the highest standards of professionalism but it is evident that the new wave NHS management is bypassing traditional professional hierarchies. There is a strong current of opinion that the world of self-regulation is no longer tenable for health care professionals, as in the government White Paper 'A First Class Service' (1998), where it is stated that clinical governance would provide a framework to continuously improve the quality of the NHS. Ellis (2001) suggests that the modern health service by introducing the notion of clinical governance, is proposing that quality in this context can be identified, evaluated and managed and one way to measure it is through the process of clinical practice benchmarking.

In the consideration of the above, Mullally (2000) Chief Nursing Officer for England believes that the quality of the nursing care that our patients receive is fundamental to their health and well-being and to their experience of the health Service. A statement such as this raises questions as to what is meant by the nature of 'nursing care' the issue of 'quality' and best quality care and its measurement.

This paper will analyse and debate the proposal to measure the essence of care within a nursing context, presenting different viewpoints as to the possible success or failure of such a venture, against the rhetoric and reality of professionalism, clinical governance and current literature.

Friday the 26 September 2003 at 14.00 - 14.30

Stevenson, F.

University College London

PARTICIPATION: WHAT DOES IT MEAN FOR PATIENTS?

The issue of participation is very timely given the current political and research agenda. Although it is clear that participation is perceived as important in current policy, what is less clear is whether this issue is perceived as important by patients. This paper seeks to explore both the idea of what participation means to patients, as well as their perspectives about participating. It is based on a data set consisting of 53 interviews. The data draws specifically on responses to the questions: "thinking in general, what do you think make a good consultation with a doctor?" and "What about a bad one?" The questions came at the end of an interview focusing on a specific consultation about which the patient had also been interviewed before the consultation. In addition the consultation had been audio-taped. The responses received are explored in order to consider what people think about the issue of participation and their general preferences concerning participation in consultations. The findings are then considered in relation to the current research and policy focus on participation.

Saturday the 27 September 2003 at 14.35 - 15.05

Summerville, L.

University of Newcastle

GETTING ON: AN ETHNOGRAPHIC STUDY OF 'ORDINARY AGEING'

This paper presents data from work in progress. The research is an ethnographic study centred on a drama group of eight women aged between sixty-four and eighty years old, working in their local community in the field of health promotion orientated towards older people. The aim of the project is to explore older people's definitions of what is 'natural' and 'normal' in relation to ageing and later life and the impact these definitions and perceptions have on the establishment and maintenance of social relationships. The data highlights the importance of recognising the role of the body as both social construct and as agent of social generation and reproduction in the experience of ageing and later life. It draws our attention to the significance of the relationship between the physiological process of ageing and socio-cultural definitions of this period of the life course, illustrated by the symbolic use of the body in the creation of marginality, the use of the body as communicative currency during expressions of the experience of ageing, and the ritualistic and conscious positioning of the body in space as a means of communicating power and status. The project demonstrates the value of using participant observation as a means of exploring the experience of ageing and later life. The access to spontaneously generated data this approach offers allows the production of a comprehensive account of day-to-day experience that recognises the importance of non-vocal communication and context in the interpretation of inter-subjective relations.

Friday the 26 September 2003 at 14.40 - 15.10

Tanner, J., Timmons, S.

Derby City General Hospital,

OPERATING THEATRE NURSING; EMOTIONAL LABOUR AND THE HOSTESS ROLE

Emotional labour has been established as a significant factor in nursing work, though no studies have been done looking at emotional labour specifically in an operating theatre nursing context.

Design and Methods

20 theatre staff (16 nurses and 4 Operating Department Practitioners (technicians), from 5 UK NHS hospitals were observed in practice over a period of nine months by one of the authors. A second observer was also used on two occasions. Each of the staff were subsequently interviewed. The transcriptions of the observation fieldwork notes and the semi-structured interviews were analysed for themes and content using QSR NUD*IST.

Findings

The (predominantly female) nurses perceived that one of their responsibilities was 'looking after the surgeons'. We have described this as the 'hostess' role. This role consisted of two major areas of activity: 'keeping the surgeons happy' and ' not upsetting the surgeons'. Examples are given of how this was accomplished through talk and actions. The (predominantly male) Operating Department Practitioners did not see this as part of their work.

Conclusions

This 'hostess' role is a kind of emotional labour, though performed with co-workers rather than patients. Like other forms of emotional labour it is strongly gendered. The emotional labour performed by the theatre nurses was necessary to maintain what Glaser and Strauss (1968) call the sentimental order. The performance of the 'hostess' role and the emotional labour that it entails can take its toll on operating theatre nurses though the nurses observed and interviewed did not necessarily see it like that.

Saturday the 27 September 2003 at 11.20 - 11.50

Taylor, A.

University of Newcastle, New South Wales

CHALLENGING MEDICAL DOMINANCE? DIVERSE MIDWIFERY IDENTITIES IN AN AUSTRALIAN PUBLIC HOSPITAL

The management of childbirth in Australia has been under review since the challenges of the 'natural childbirth' movement in the 1970s and 80s. Various government reports have addressed the issue and there have been limited moves to promote a 'midwifery model' of care. This paper draws on an ethnographic study of a maternity unit which used case studies, interviews and observations in order to understand the impact of the changing professional and policy context on the routine care of childbearing women. In Australia, midwifery autonomy has been subject to competing discourses, firstly one of professionalisation, from Britain, where midwifery has limited autonomy in the public health system and secondly of radicalism from the USA where the previous exclusion of midwifery has created opportunities for lay midwives in private practice. This paper seeks to contextualise midwifery care and highlight its diversity, rather than seeing it a single 'midwifery model' in opposition to medical ddominance. In this Australian hospital midwives operated with different models of midwifery identity and practice, drawing on conventional, alternative and professionalising discourses. Midwives operate within the complex mixture of public and private funding and service provision which is a characteristic of the Australian health system. The paper looks at the diversity of ways in which midwives in this hospital moderated the public/private divide, their views on the possibilities for increasing their scope of practice and the extent to which they are able to provide individualised care to childbearing women in the Australian public health system.

Friday the 26 September 2003 at 14.40 - 15.10

Thoutenhoofd, E.

None

SITUATING OUTCOMES OF PAEDIATRIC COCHLEAR IMPLANTATION

This presentation considers the nature of benefit in paediatric cochlear implantation. Research in this area draws upon a wide range of possible outcomes, including personal and social development, communication and language development, educational placement and achievement, and quality of life and health economics assessments.

Although successes in cochlear implantation are publicly celebrated in their strongest formulations as victories of science over deficiency, the extent to which post-implantation outcomes are both demonstrable and persuasive critically depends on how deafness is to be defined, on theories of and approaches to natural language development, and on assumptions concerning the relationship between sensory experience and language modality.

In addition, any overall judgment concerning paediatric cochlear implantation needs to balance the implant professionals' practice-based resolution of deafness as hearing loss with (a) hearing parents' acutely felt responsibility to accurately identify potential life trajectories and future life-styles available to their deaf child, and with (b) deaf people's continuing experience of linguistic discrimination, educational underperformance, and social inequality.

In sum, research into outcomes of cochlear implantation reflects dichotomies that are profoundly social, centering on spoken/sign language status, social/medical projections of deafness, inclusion/exclusion in education, and social equality/inequality.

Saturday the 27 September 2003 at 10.10 - 10.40

Tiora, A.H.

Norwegian University of Science and Technology

LOCAL LUXURY OR DECENTRALISED DEMOCRACY? 3D TELERADIOLOGY AS ROUTINE

The development of telemedicine has until now been driven forward as a result of technology-developers' need for testing and evaluation. Telemedicine is an example of the quite typical case of "technology-seeking-solution" and the economic and medical potential is uncertain, at the best.

This paper presents a case in Mid-Norway where teleradiology is applied to 3D CT-scan images in routinised (yearly) check-ups of patients with aorta implant. A user (practitioner and patient) evaluation of the case is presented.

The paper questions the value of user evaluations of telemedical solutions as contrasted with medical and economic assessments. Can the fact that any patient will appreciate advanced medical services in the neighbourhood be used as an argument for telemedicine?

The paper concludes with a discussion of the factors behind a "technologisation" of health care services and how patient satisfaction is used as argument for relatively marginal changes, but with advanced technology and high cost.

Friday the 26 September 2003 at 16.00 - 16.30

Townsend, A., Hunt, K., Wyke, S.

University of Glasgow

MANAGING MULTIPLE MORBIDITY IN MID-LIFE: CONTRADICTIONS AND TENSIONS AROUND MEDICATION USE. A QUALITATIVE STUDY

Research suggests that 50% of patients with long term illness do not comply with prescribed medical regimens. The cost of this is potentially huge in financial, practical and emotional terms. This has led to a concern that the relationship between health professional and patients should be re-assessed and based more on shared decision-making, the illness experience of the individual taking 'centre-stage'. In order for this to be successfully accomplished, a more complete understanding of the chronic illness experience and medication use needs to be addressed.

This qualitative study explored the experiences of 23 people with chronic multiple morbidity and the place medication use plays in their overall management strategies. In the face of considerable illness people expressed ambivalence to taking medications in a range of ways.

Individuals used both drill-like routines to remind them to take medications, and self-regulated their use in an attempt to gain equilibrium, relief from distressing symptoms or some sense of a 'normal' life. They expressed both a reluctance to take medicines and an inability to be 'free' of them. Medications both enabled people to continue to function in social roles and acted as marker for their inability to perform such roles. They could validate and stigmatise.

These findings suggest that medication use carries meaning far beyond the simple management of physical experience and disease and can have an impact upon how people are viewed, and view themselves as morally competent in the face of illness.

Saturday the 27 September 2003 at 15.45 - 16.15

Traynor, M., Rafferty, A.M., Solano, D.

London School of Hygiene and Tropical medicine

CAN FEMINIST THEORIES OF KNOWING AND LITERARY THEORY EXPLAIN THE APPARENT RELUCTANCE OF NURSES TO IMPLEMENT RESEARCH FINDINGS?

This research aims to understand the problem of apparent reluctance to implement research among nurses through an empirical study based upon two related theoretical areas: feminist epistemology and feminist literary theory. The overall analytical orientation is discourse analysis, influenced by poststructuralism. These theoretical areas provide a context for understanding how nurses respond to the call to identify with scientific products. Feminist thought is turned to not with an assumption that it is applicable to nurses because the majority are women, but because such theories make it possible to investigate how different groups may have differing ways of knowing and reading.

The research is based on analysis of the transcripts of three focus groups carried out with qualified nurses from different practice specialities in which influences on practice were discussed. The analysis gave rise to a picture of nurses responding to an ideological dilemma between professionalising expectations that nursing practice should be based on sound science and an alternative discourse that emphasises nursing's orientation to the highly individualised context of the patient encounter. Through a number of discursive moves, nurses problematised the usefulness of research outputs in a way that supported their assertion of the use of experience and intuition as complementary to the use of research rather than in tension with it. The present research helps us to understand the complexity of the response of this group of clinicians to the drive for evidence based practice and moves us on from an understanding of nurses as poor implementers.

Sunday the 28 September 2003 at 10.50 - 11.20

Tritter, J., Sanidas, M., Daykin, N., Turton, P.

University of Warwick

TO BE INVOLVED OR NOT TO BE INVOLVED: THE QUESTION FOR USERS OF NHS CANCER SERVICES

A key cornerstone of the Labour government's model of the NHS is the extension of involvement by the public and patients across all aspects of healthcare from treatment decision making to evaluating and developing services. Despite the legal requirement to involve users there has been little consideration of the barriers facing this radical reorganisation of power and transformation of the professional cultures within healthcare. This paper presents findings from a three-year study of user involvement in cancer services funded by the Department of Health. We draw on a range of different data including case-studies of multidisciplinary cancer teams, interviews with users, surveys mapping user involvement experiences across all the Trusts and cancer voluntary sector organisations in Avon, Somerset and Wiltshire and a cancer patient population survey. Our findings suggest that while most NHS staff are committed to the idea of user involvement there are significant differences between categories of health professionals in their definition and willingness to actually engage with users. More importantly, our survey of a representative random sample of people diagnosed with cancer, indicated that 52% would be willing to be involved but that 29% of those that had been involved previously would not do so again. We go on to explore some of the factors that are linked to a willingness to be involved and discuss the larger implications of these for the pursuit of a model of empowered patient consumerism as a primary driver for health reform in England.

Saturday the 27 September 2003 at 14.00 - 14.30

Truman, J., Rankin, D., Backett-Milburn, K., Platt, S., Petticrew, M.

University of Edinburgh Medical School

'DROP-IN' SERVICES IN SCOTTISH HEALTHY LIVING CENTRES: WHAT DO THEY MEAN AND HOW DO THEY OPERATE?

The provision of New Opportunities Fund grants has led to the creation of 45 Health Living Centres (HLCs) in Scotland and a further 300+ in the rest of the UK. The HLC programme has been devised broadly to address the health needs of socially excluded people and populations. The programme advocates that HLCs establish a basis for partnership working whilst encouraging active user involvement in the design and delivery of services to tackle health inequalities amongst target populations.

This paper draws on the Scottish Executive funded process evaluation of HLCs, which involves the examination of six purposively selected sites on the Scottish mainland and islands. HLCs are employing a number of methods to attract their individual target audiences. One tool used in many HLCs, is the "drop-in" service, which is utilised to encourage user uptake of services and increase community consultation and involvement. Qualitative analysis of the development of "drop-in" services reveal that when bids are submitted in funding applications such services are poorly defined. Furthermore, it seems that HLCs may often not be aware of the operational characteristics prior to implementation. A further analysis of in-depth interviews and observations show that tensions exist between professionals' views of the utility and operation of such services and user-perceived utility. Secondly, changes in resources required for "drop-ins" can impact on the ability to deliver other elements of HLC services.

Abstract Book prepared 18th July 2003

Paper/Poster Abstracts - listed in alphabetical order of first author

Friday the 26 September 2003 at 15.20 - 15.50

Tutton, R., Kerr, A., Cunningham-Burley, S.

University of York

POSITIONING EXPERTS: BEYOND THE LAY-EXPERT DIVIDE?

Recent work in STS and sociology has investigated the changing dynamics of professional and lay knowledge and expertise about genetics, especially with respect to public consultation exercises and the role of patient support groups. A plurality of expertise can be found in a variety of new hybrid discussion fora where experts and publics engage with each others' views on the social implications of genetics. Yet other evidence suggests patients and publics are still in dependent positions in relation to experts, when they rely upon their guidance and advice both in the clinic and in wider policy making circles. This paper examines how groups with contrasting experiences of disability, disease, policy-making, genetic research and services, appeal to certain forms of knowledge and experience as they discuss the social aspects of genetics. We argue that expertise is a relational concept so that when people position themselves as particular kinds of experts, either implicitly or explicitly, they often position others as non-experts. However, people's multiple identities and the different contexts in which these discussions take place, means that expert positioning is both flexible and contingent. We examine expert positioning in different contexts where professionals and publics talk about the social aspects of genetics: in organised focus groups and in public debates and events in which professionals and publics participated. We conclude by considering the implications of our analysis for the lay-expert divide and the construction and use of expertise as developments in genetics and health are rolled out at population and individual levels.

Friday the 26 September 2003 at 14.40 - 15.10

van Teijlingen, E., Hundley, V., Rennie, A-M, Fitzmaurice, A., Graham, W.

Centre for Research on Women's Health. Aberdeen

MATERNITY SATISFACTION STUDIES AND THEIR LIMITATIONS: WHAT IS, MUST STILL BE BEST

Background

Health policy-makers world-wide are paying closer attention to factors in maternity care, which may influence women's satisfaction. This paper will examine some factors in the light of observations from previous studies of satisfaction with health services.

Design

National questionnaire survey.

Participants

All women in Scotland delivering during a 10-day period (n=1639). A total of 1,137 women completed and returned questionnaires, giving a response rate of 69%.

Data Collection

A self-complete questionnaire to assess whether recommendations for the maternity services in Scotland were being adopted in practice. Data were analyzed using SPSS.

Findings

Women were overwhelmingly satisfied with their prenatal, intrapartum and postnatal care. Reports of dissatisfaction were relatively low. However, there were differences in satisfaction levels between subgroups, e.g. the fewer the number of carers the woman had during childbirth, the more likely she was to be satisfied with the care received. Other factors appeared to influence reported satisfaction levels, such as characteristics of the care provided and the woman's psychosocial circumstances. The policy that a maternity unit operated had a significant effect on the value that women placed on some aspects of care.

Conclusions

Problems that may arise if satisfaction surveys are used uncritically to shape the future provision of maternity services. Service users tend to value the status quo, the implications are that innovations, of which users have no experience, may be rejected. Therefore, while satisfaction surveys have a role to play, we argue that they should only be used with caution, and preferably as part of an array of tools.

Saturday the 27 September 2003 at 15.10 - 15.40

Vassy, C.

University of Paris 13/University of Nottingham

FROM GENETICS TO PUBLIC HEALTH: DOWN'S SYNDROME SCREENING POLICY IN FRANCE

Down's Syndrome prenatal diagnostic and screening techniques have spread widely and rapidly in France over the last 30 years. This spread occurred in a context of scientific controversies about the effectiveness and the harmlessness of these various techniques and has triggered a debate about eugenicism among French philosophers, doctors and politicians. How did the knowledge about Down's Syndrome testing that was known only by a few geneticists at the end of the 1960's transfer from the laboratory into routine clinical practice? Why did the researchers invest in the development of these tests rather than others? Which political and administrative decision making processes have influenced the implementation of the tests? How has the access of a progressively widening public to prenatal testing been organized and funded? What has been the role of users in this diffusion?

This research study is based on the analysis of scientific papers, administrative reports, and legal texts analysis, and on semi-structured interviews with key players (geneticists, obstetricians, other healthcare professionals, decision makers in the Department of Health and the National Health Insurance System, users associations etc). The results highlight both the scientific and the political role of the researchers, the hesitations and the late involvement of the health authorities, the passive participation of the users and the social construction of the demand by healthcare professionals. This leads to questions about the contradictions and ambiguities of the various definitions of public health used during the whole process.

Saturday the 27 September 2003 at 14.35 - 15.05

Walker, L.

University of the Witwatersrand Johannesburg

CONFRONTING THE CRISIS OF MASCULINITY: NEW MASCULINITIES AND THEIR MEANING FOR MEN'S HEALTH IN SOUTH AFRICA

Recent sociological research argues that masculinity has become a 'problem': that men are seen to be in trouble collectively and by implication that men's health is in crisis. This is evidenced through increased eating disorders among men, men's falling fertility rates, higher rates of motor vehicle accidents, greater morbidity and mortality rates in relation to various diseases . . . a proclivity for domestic and sexual violence; overindulgence in drugs and alcohol; and increasing problems among young men in relation to alienation and suicide ideation (Dowsett 2002). In South Africa the transition to democracy has precipitated a 'crisis of masculinity'. Liberal versions of sexuality, which mark South Africa's new democracy, have had a number of highly contradictory consequences for women and men, as old notions of masculinity and male privilege have been destabilised. Orthodox notions of masculinity are being challenged and new versions of masculinity are emerging in their place. Some men are seeking to be part of a new social order while others are defensively clinging to more familiar routines. This paper explores how new masculinities are being constructed in contemporary South Africa and the effects of these on men's health. It does so through an analysis of in-depth interviews with men who have sought to create alternative versions of their own masculinity through participation in an organisation that brings together men who have been the perpetrators of sexual and domestic violence.

Saturday the 27 September 2003 at 10.45 - 11.15

Watson, N., Woods, B.

University of Edinburgh

"SITTING AT THE TABLE DOESN'T NECESSARILY MAKE YOU A DINER": A HISTORICAL ANALYSIS OF SPECIAL SEATING IN WHEELCHAIRS

The design and the use of wheelchairs changed throughout the last century. One such change has been the development of special or adaptive seating. These seats are individually formed, closely fitting, supportive seats designed as wheelchair inserts and aimed at people with severe postural impairments.

The seats aim to promote function and maximise comfort, thus improving the "quality of life" of the user. Special seating emerged in the last quarter of the 20th century from a multifaceted and multidirectional movement that transformed wheelchairs from simple tools of mobility into postural aids. The technological development of special seating afforded the possibility for people with learning disabilities and/or severe physical impairments to leave the confines of institutional life and access the wider community. On the surface, this would appear a classic case of technological impact: developments in special (or adaptive) seating resulting in social changes for disabled people. However, the social and technical processes involved in this movement and in the resulting technology were complex. Developments in special seating both arose from and influenced social change. In this paper, we examine the socio-economic and political processes that shaped the emergence and development of special seating along with an exploration of the impacts this technology had and the part it played in the shaping of disability politics.

Saturday the 27 September 2003 at 10.45 - 11.15

White, P.J., Latimer, J.E.

Cardiff University

BREACHING ORALITY: AN ETHNOGRAPHY OF VOICELESSNESS IN THE INTENSIVE CARE UNIT

Drawing on an ethnography of the intensive care unit, the paper explores the social significance of intubation (passing of a breathing tube). We show how intubation breeches orality, examining the effects of the infraction of the mouth for identity. The mouth is both the most sacred and yet the most profane bodily organ: we ingest, explete, suck, vomit, kiss, consume, collaborate, profane, theorise... Thus our humanness is partly accomplished through our mouthwork. Through analysis of bedside interaction we identify how an identity of the voiceless is accomplished. On the one hand medical and nursing management of the mouth effaces its civilising function and reconstructs the silent mouth as a life-sustaining passage and source of polluted risk. However, the patient as person rather than body is still ascribed an identity. Their current physical and physiological reaction is observed and interpreted by staff as an intrinsic aspect of who that person now 'is'. The family performs the patients identity by proxy, bringing into play past attributes to explain present reactions. Meanwhile the patients, whilst conscious, have ways of participating in interaction, but these are thwarted by the contingencies of their voicelessness. When other modes of communication are introduced, such as writing, there is a partial rescue of an untenable identity, but the 'real time' nature of communication is lost, recasting those at the bedside as interactional dopes. We end by breaching the notion that orality is essential to the performance of identity, but recognise how marginal the identity is of the voiceless.

Friday the 26 September 2003 at 14.00 - 14.30

Will, C.

University of Essex

RISK CALCULATORS AND THE PREVENTION OF CORONARY HEART DISEASE. LEARNING TO LOVE A MEDICAL TECHNOLOGY

In this paper I draw on the history of a technology, the risk calculator, to illuminate recent developments in the treatment of heart disease and to reclaim what we might call 'the social' embedded within an area of medical expertise. The risk calculator may be as simple as a table, but more sophisticated versions are now available to general practitioners as software. These calculators are increasingly used to determine who gets particular treatments (most obviously the expensive cholesterol lowering drugs, statins) and to define groups at 'high risk'. They were also fundamental to the recommendations of the recent National Service Framework on Coronary Heart Disease.

Drawing on the work of Bruno Latour and Marc Berg, I offer a critical account of the development of the risk calculator, to consider not only how risk calculators have come to be so important, but also the implications of the social factors embedded in their very forms. What is the significance of the different versions that exist? How useful is it to follow the controversies around their use or to address points of consensus? I argue that their (uneven) use has not only reflected the spread of evidence based medicine and treatment protocols, but has led, perhaps paradoxically, to a reaffirmation of the importance of the individual clinical encounter, lifestyle advice and personal behaviour change. Risk calculators are thus currently part of a wider negotiation about the form and content of general practice and the prevention of heart disease in Britain.

Sunday the 28 September 2003 at 10.50 - 11.20

Williams, C., Kitzinger, J., Henderson, L.

King's College London

ENVISAGING THE EMBRYO IN STEM CELL RESEARCH: MEDIA REPORTING OF THE ETHICAL DEBATES

How is the embryo defined, envisaged and imagined? Who speaks on its behalf, and how? Based on a systematic study of UK press and TV news reporting, this paper identifies the rhetorical strategies used to assert competing ethical positions and policy recommendations around embryonic stem cell research. I show how both sides use personification and appeals to identification to recruit support (for embryos on the one hand, for potential patients on the other). I also show how they promote very different ideas about the embryo's significance, size, and social embeddedness and present competing narratives about its origins, destiny and 'death'. The role of visual representation is key here. However, it does not follow the usual pattern whereby, in the anti-abortion debate, those 'on the side' of the foetus display its image while those who are 'pro-choice' shy away from this. In the stem cell debate the pattern is inverted, thus highlighting the role of technologies of visualisation and assessments of appearance in defining what counts as human.

The second half of the paper demonstrate how, in spite, or even because, of the apparently 'balanced' nature of reporting, the media coverage systematically marginalises women's perspectives, disregards more fundamental challenges to science, side-lines concerns about effectiveness or safety and curtails discussion of broader social and political issues. I will reflect on the media processes which help to restrict debate in this way and conclude by calling for a more inclusive and wide-ranging discussion of science ethics.

Funded by The Wellcome Trust Biomedical Ethics Programme

Saturday the 27 September 2003 at 16.00 - 17.00

Williamson, E., Goodenough, T., Kent, J., Ashcroft, R.

University of Bristol

PROXY CONSENT FOR CHILDREN: PARENT AND CHILD RESEARCH PARTICIPANTS' PERSPECTIVES ON THE USE OF GENETIC MATERIAL IN LONGITUDINAL, EPIDEMIOLOGICAL RESEARCH

This poster will address the issue of proxy consent in relation to the continued use of genetic material within longitudinal, epidemiological research. This poster is based on data derived from the Wellcome Trust funded EPEG project [Ethical Protection in Epidemiological Genetic Research: Participants' Perspectives]. The EPEG project consisted of focus groups and 1-1 interviews with both children [aged 9-11 years old] and adults, some of whom take part in a long-standing epidemiological study which includes the use of environmental, social and genetic information about children, mothers, and fathers.

The EPEG project explored how participants considered ethical protection (taken in its widest sense) in longitudinal, genetic epidemiology.

We found that: 1) Children currently underestimate the amount of control that they have with regard to their participation in research. 2) Children and parents' views of risk differed in such a way as to call into question the ability of adults to give genuinely informed proxy consent for their children. 3) Questions were raised about the 'right' of parents to consent to the long term use and re-use of data/biological material/genetic information in the future, when the person from whom such information had been collected could feasibly be of age to consent for themselves.

This poster will present data and findings from our research, and discuss their implications for the protection of children's interests in research. Our results have implications for both researchers and policy makers concerned with children's participation in biomedical research.

Saturday the 27 September 2003 at 14.00 - 14.30

Wilson, F., Walsh, C., Marshall, M., Gordon, F.

Combined Universities Learning Unit Medical School

THE EXPERIENCES OF LAY PEOPLE IN TEACHING HEALTH PROFESSIONALS

The involvement of patients/service users in interprofessional education is regarded as a logical step in developing a radical patient-centred partnership model of health and social care provision. The discourse around patient/service user involvement incorporates notions of empowerment, choice, and participation and suggests that interprofessional working requires a cultural shift in how professions learn both from each other, and from the 'expert' lay person. The Combined Universities Learning Unit is a two-year project funded by the Department of Health to facilitate and develop interprofessional learning. The exploratory stage of this project aims to capture the views of patient/service users and students involved in interprofessional education.

To explore the experience of 'expert patients' in interprofessional learning, a focus group is conducted with lay service users involved in an acute patients advisory group set up to inform an interprofessional initiative 'Professional Issues in Practice' (PIP), for undergraduate allied health professionals. Two focus groups are conducted with undergraduate students of allied health professions involved in the PIP programme. One-to-one semi-structured interviews with a small number of patients/service users will examine their experience of a joint learning exercise between medical and nursing students.

Data is explored within a phenomenological framework and key emergent themes provide insight into lay and student views of the 'expert patient' label, and the challenges or obstacles to patient/user involvement in interprofessional learning are discussed.

Abstract Book prepared 18th July 2003

Friday the 26 September 2003 at 16.00 - 16.30

Yuill, C.

The Robert Gordon University

<u>UNEQUAL BODIES, EMOTIONS AND HEALTH - THE CASE FOR CLASSICAL MARXISM?</u>

Throughout the eighties and nineties post-modernist, social constructionist and Focauldian perspectives held considerable sway in sociology generally and influenced much work within medical sociology. Recently such positions have been challenged, for example, by calls for a more critical realist perspective or a Habermasian approach. It may be timely to reconsider some of the traditions of the 'founding fathers', especially that of classical Marxism. For medical sociology in particular the classical Marxist tradition offers many useful contributions in theorising class and health inequalities. This paper will seek to outline how within classical Marxism ideas of emotion, the body, alienation and, of course, economics, could provide a powerful way of understanding the burgeoning literature on class and health inequalities, especially in reconciling the differences between the 'direct' and 'indirect' causes camps. Discussion will be made of the relationship between material factors such as poverty and the ongoing mindset of capitalism, alienation, and how they lead to an unequal distribution of health. Much of the theoretical perspectives for this paper will come from Marx but also strongly drawing from Ollman, Callinicos and Rees.

Saturday the 27 September 2003 at 10.10 - 10.40

Ziebland, S., Cheshire, J.

Institute of Health Sciences University of Oxford

<u>DIPEX PERSONAL EXPERIENCES OF HEALTH AND ILLNESS NARRATIVES: A</u> RESOURCE FOR COLLABORATIVE RESEARCH

The DIPEx (personal experiences of health and illness) charity runs a website based on collections of video and audio recorded narrative interviews. The research group is based in the University of Oxford's Department of Primary Health Care. www.dipex.org was launched in July 2001 and includes modules on several cancers (breast, prostate, bowel, cervix, and testis) and many more are in preparation for cancers of the ovary and lung, melanoma, epilepsy, chronic pain, RA, heart failure, palliative care, sexual health, people with Alzheimer's Disease and their carers and parents of children with congenital heart disease. We are collaborating with several UK research teams who are collecting interviews for future DIPEx modules. We are keen to encourage others to consider this route for disseminating their research to the public.

Interviews with a maximum variation sample of between 40 and 50 participants from all over the UK are collected and analysed for each of the modules. Each website module includes thematic analyses illustrated with around 200 short clips from the interviews. The DIPEx research team has consent from the participants to use the full interviews for broadcasting, teaching and research. We have begun to publish papers based on the interviews in peer reviewed medical and social science journals and believe that this is a rich resource for other researchers and for teaching.

We will present video extracts from the cancer interviews to illustrate:

- medical communication
- how participants use the interviews to address different audiences
- display of competence in illness narratives

Saturday the 27 September 2003 at 15.10 - 15.40

Zimmermann, C.

Princess Margaret Hospital, University of Toronto

UNCONSCIOUS COPING MECHANISM, CONSCIOUS CHOICE OR INTERPERSONAL RELATION? DISCOURSES ON DEATH DENIAL IN THE PALLIATIVE CARE LITERATURE

Terminally ill patients and their families are often referred to as being "in denial" of impending death. This study uses the qualitative method of discourse analysis to investigate the usage of the term "denial" in the contemporary hospice and palliative care literature. A Medline search (1970 to 2001) was performed combining the text words "deny" and "denial" with the subject headings "terminal care", "palliative care" and "hospice care" and restricted to English articles discussing death denial in adults. The 30 articles retrieved were analysed using a constant comparison technique and emerging themes regarding the meaning and usage of the words "deny" and "denial" identified. In all articles, denial was conceived as an individual psychological process. Three dominant subthemes were distinguished: denial as an unconscious "defence mechanism", denial as "healthy" and denial as temporary. The analysis focusses on the intertextuality of these themes with each other and with previous texts on the denial of death. Elements of the psychoanalytic definition of denial as an unconscious defence mechanism are retained in the literature but are interwoven with new themes on patient choice. The result is a discourse that is conflictual and at times self-contradictory but overall consistent with the biomedical model of illness. I propose an alternate clinical model where denial is a relation between two or more people in a social environment rather than a property of the individual and reflect on the implications of different conceptualizations of death denial for the care of the terminally ill.