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## Aims and scope

The objective of *Medical Sociology online* is to publish high quality articles in the broad area of medical sociology based on original research using qualitative and quantitative methods. As a publication of the BSA Medical Sociology Group, MSo has a special interest in promoting the work of all sections of the academic community, including postgraduates and first time authors as well as people who have achieved eminence in their field. MSo encourages and welcomes the submission of articles or commentary pieces on research methodology, ethical issues in research, and the teaching and learning of medical sociology.'

*Medical Sociology online* is supported by the British Sociological Association (BSA), and the BSA Medical Sociology Group (MSG),

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The BSA Medical Sociology Group exists to promote scholarship and communication in the field of the sociology of health and illness in the United Kingdom. The group is one of the largest and most active study groups of the British Sociological Association. Membership of the BSA brings benefits in terms of reduced conference fees and journal subscriptions, but most Medical Sociology group activities are open to non-members.

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For more information about BSA Medical Sociology Group, please visit [www.britsoc.co.uk/specialisms/52.htm](http://www.britsoc.co.uk/specialisms/52.htm)

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## Editorial Foreword

### University of Liverpool Editorial Team

We would like to welcome all readers to this first edition of *Medical Sociology online* (MSO). As many of you will be aware, MSO has grown out of *Medical Sociology News* (MSN), the previous publication of the British Sociological Association's Medical Sociology Group. While wishing to retain many of the newsletter functions of MSN, our team at the University of Liverpool has made two radical changes to the MSN format. Firstly, we have transformed MSN from a subscription based paper publication to this open access electronic format, and secondly, we have set up a peer-review system for longer articles. These changes have been made to make the journal more accessible to everyone interested in the sociology of medicine, and also in response to the desire of all authors, including those at a very early stage of their career, to publish in peer-reviewed publications. To reflect these changes, we have altered the title of *Medical Sociology News* to *Medical Sociology online* (MSO).

We will produce at least two editions a year, with the possibility of further issues depending on the material submitted to us. Details of how to submit can be found at <http://www.medicalsociologyonline.org/submissions.html>

The deadlines for submissions of articles intended for peer-review are here.

**Spring issue – 5<sup>th</sup> March 2007 (Published May 2007)**

**Autumn issue – 2<sup>nd</sup> July 2007 (Published October 2007)**

We see MSO as providing a place for publishing the work of both new and more established authors in the broad area of medical sociology. In this issue we have two articles offering insights into contemporary issues in very different settings, one from a service user perspective, the other from a practitioner perspective. Divya Rajaraman and Rebecca Surender examine attitudes surrounding HIV testing in Botswana, focusing upon patient perspectives of acceptability of HIV testing as an HIV prevention and care tool. Their paper contributes to debates surrounding ways to tackle the continuing HIV/AIDS epidemic in sub-Saharan Africa. In contrast, Helen Prosser and Tom Walley focus upon factors which influence GPs' prescribing of a new drug in the UK, adding to the growing body of work examining the marketing of drugs.

We want MSO to provide a platform for debate and critical review of important issues in the field of medical sociology, reflecting the interaction that goes on at conferences and meetings, both in academic and other settings, where issues of importance are discussed openly and frankly between colleagues. In the Opinion Piece, Gareth Williams reflects on the nature of 'real suffering' and how this has been represented (or under represented) in the works of sociologists. He also considers their contribution in making visible the connections between suffering, everyday life and wider social structures. Both Arthur Frank and Iain Wilkinson (winner of this year's Sociology of Health and Illness Book Prize) have responded to Gareth's paper, with Gareth providing his final thoughts in response to Iain and Arthur in *Shoulder to Shoulder*.

Robert Dingwall's plenary at this year's BSA Medical Sociology Group Conference, at Heriot-Watt University proved to be controversial. His impassioned talk challenged the imposition of what he describes as the '*illegitimate generalization of a model of research governance*' on research into health and illness. We have published his summary of the talk, and a response from Edwin Van Teijlingen, but hope that this is only the start of the discussion on the role of ethical review and research. Linda McKie's plenary critiques presumptions about gender and violence, and goes on to consider the complex issues surrounding the introduction of sociological insights around violence and everyday life into the planning and delivery of health care services. We are also publishing a response to this plenary from Dorte Gannik, which highlights a number of issues that the respondent feels should have been addressed in Linda McKie's paper, and we would like to invite others to engage with this important discussion.

One of the key roles of *Medical Sociology online*, alongside the JISC Mail *MedSocNews*, is to keep members of the medical sociology community in touch with one another. In Postgraduate Study and Awards and Congratulations we are celebrating the achievements of colleagues, and would also like to invite contributions to a new section, Research Abstracts, to publicise ongoing or future research in medical sociology.

In our conference section, we have included two complementary, and at times contrasting, views of the recent International Sociological Association (ISA) Conference in Durban, South Africa. Whereas Caragh Brosnan's informative review describes the conference and related visits in the area, Chris Scanlon takes a more critically reflective stance, and introduces the question that probably should be asked (and answered?) more often by people involved in the study of society: to what extent does our own academic praxis of attending conferences impact on the lived lives of others? To encourage responses to our published material, we have developed a response form to enable readers to email us directly with their views.

The Conferences section also includes a report by Susan Gregory and Linda McKie of the Second British and American Medical Sociology Conference which took place in Edinburgh in June 2006, and includes a summary of the plenary by Kath Melia, reflections by workshop leaders, a report of Mike Bury and Peter Conrad's discussion, as well as reports by postgraduates attending the conference. We also have Hayley Davies' review of a lecture by Marilyn Strathern and reviews of a visit by Hannah Bradby and others to the Old Operating Theatre at St Thomas's hospital in London. Rather than just providing summaries of what happened at various conferences, we want to develop this section to include reflective and informative pieces that give a real insight into particular conferences, meetings and other fora for discussion. If you feel you have something original and insightful to say about a particular event, we would very much like to hear from you.

Although Aunt Marge has taken a sabbatical, we have revived an old *Medical Sociology News* (MSN) feature: A Day in the Life of..., and Alex Scott-Samuel at the University of Liverpool has written our first contribution. Alex was a subscriber to the early editions of MSN, and this is the second time he has written such a piece. If anyone has a copy of his original Day in the Life we would be interested to see it, perhaps to reflect on any changes to the nature of academic life.

This first edition of *Medical Sociology online* is the product of many months' work by all of the editorial team. We are very grateful to the last editorial team from the University of Aberdeen for their support and advice when we first took on the editorial role, and to the continuing support of the BSA Medical Sociology Group and

Committee. We would also like to acknowledge the expressions of support that we have had from people in the wider community of medical sociology, who have encouraged us to continue with MSo, and promised to contribute to future editions. We are all looking forward to the production of our next issue in May 2007, which will include a new 'News, Views and Comments' section to incorporate your responses to the current edition. We welcome any feedback on the new format, and are looking forward to engaging with the vibrant medical sociology community over the next 2 years.



## **HIV testing in Botswana: Lessons for Policy and Practice**

**Divya Rajaraman**

*University of Oxford*

**Rebecca Surender**

*University of Oxford*

### **ABSTRACT**

Until the 1990s, public health responses to HIV/AIDS were closely associated with the protection of individual human rights. Consequently, measures such as routine screening were rejected on the grounds that they might violate individual rights, and increase discrimination. Recently however, the alarming spread of HIV/AIDS has precipitated renewed interest in voluntary testing as a key intervention, and the call for a scale up of testing services in countries with high HIV prevalence can be heard in both academic and policy forums. Nevertheless there remain concerns that routine HIV testing could be unacceptable to the public, thereby deterring health care seeking and harming population health. The current debate over policy direction calls for an examination of the acceptability of HIV testing interventions in high prevalence populations, and the various motivators for and barriers to testing. This information is crucial for gauging the likely impact of changes in HIV testing policies, and for informing future programme design and policy direction.

This qualitative study examines public attitudes towards and experiences of HIV testing in Botswana. It compares the views of those who have tested and those who have not in order to discover the key factors influencing decisions to test. Semi-structured interviews were conducted with forty adults attending outpatient clinics at the government hospital in Gaborone in 2004.

Findings suggest routine testing is acceptable and desirable amongst the sample. Although antiretroviral treatment and 'Prevention of Mother to Child Transmission' are strong incentives for testing, most respondents only test when advised by a health professional, often at a late stage of the illness. While knowledge of HIV and the benefits of testing appeared high, information alone is an insufficient catalyst for behavioural change. This observed gap between health information and health seeking behaviour is influenced by a complex interaction of social, environmental and structural factors.

### **KEY WORDS**

HIV/AIDS / Voluntary Counselling and Testing / Botswana / Public health interventions / behavioural change

## Introduction

During the 1980s and 1990s, global responses to HIV/AIDS were closely associated with the protection of individual human rights. Consequently some public health measures such as routine screening, partner notification and contact tracing were rejected on the grounds that they might violate individual rights, and increase stigma and discrimination (Danziger, 1996). An elaborate and arguably burdensome system of informed consent around HIV testing was instituted first in western countries and later in many developing countries, including in sub-Saharan Africa (Scheper-Hughes, 1993, Richards, 1999). In recent years however, the alarming spread of the epidemic in sub-Saharan Africa, together with the increased availability of treatment for opportunistic infections and viral suppression, has led to a reconsideration of past policies on testing. Some public health specialists and international organisations are now calling for a scale up of HIV testing services in high HIV prevalence countries, especially in conjunction with programmes for Prevention of Mother To Child Transmission (PMTCT) and other medical services (Piot, Feachem, Jong-Wook and Wolfensohn, 2004, De Cock, Marum and Mbori-Ngacha, 2003). Advocates of testing have drawn on evidence which demonstrates its role in reducing risky sexual behaviour (Marum, Campbell, Mswoya, Barnaba and Dillon, 2002), decreasing infectivity of persons living with HIV/AIDS (PLWHA) and improving access to treatment programmes (Salomon, Hogan, Stover, Stanekci, Walker, Ghys and Schwartlander, 2005). Nevertheless, there remain concerns that routine HIV testing at health services could be unacceptable to the public, thereby deterring health care seeking and harming population health (Heywood, 2005). Others have feared that the policy could result in discrimination and violence against those who are HIV positive (Abdool Karim, Abdool Karim, Coovadia and Susser, 1998, Rennie and Behets, 2006). The current debate over policy direction calls for an examination of the acceptability of HIV testing interventions in high prevalence populations, and the various motivators for and barriers to testing. This information is crucial for gauging the likely impact of changes in HIV testing policies, and for informing future programme design and policy direction.

Although previous research into attitudes towards testing in developing countries provided some important insights into barriers to testing, the existing data have limitations. Early studies gauged 'acceptability' through indirect measures such as uptake of testing in the context of clinical trials for PMTCT (Cartoux, Meda, Van de Perre, Newell, De Vincenzi and Dabis, 1998, Temmerman, Ndinya-Achola, Ambani and Piot, 1995). They also did not typically compare attitudes towards testing with actual take-up amongst study participants (Castle, 2003, Kalichman and Simbayi, 2003). This is an important area for investigation given that researchers have frequently observed a gap between intentions and actual behaviour in many health contexts (Fylkesnes, Haworth, Rosensvard and Kwapa, 1999, DeGraft-Johnson, Paz-Soldan, Kasote and Tsui, 2005, Glanz, Rimer and Lewis, 2002). Such studies also fail to shed light on any underlying differences in the attitudes and motivators between those who choose to test and those who do not. Finally, most published studies from developing countries have not been conducted in settings where antiretroviral treatment is available (Kalichman and Simbayi, 2003). Given that increased access to treatment has been used as a major justification for recommending routine HIV testing, it is necessary to consider attitudes towards testing where anti-retroviral

therapy is accessible and to determine the extent to which availability of treatment influences decisions to test.

This qualitative study seeks to address some of these issues by examining the attitudes towards and experiences of HIV testing amongst health-care seeking adults in Gaborone, the capital of Botswana. Significantly, the study compares attitudinal differences between those who have taken an HIV test and those who have not, in a developing country with access to antiretroviral treatment. This analysis sheds light on which factors appear to be most significant in influencing individuals' decisions to test and provides information about the process and dynamics of HIV testing. The analysis of the data and interpretation of the findings are informed by the Health Belief Model, a theoretical framework that has been widely used for understanding health behaviour and designing health education interventions (Janz, Champion and Strecher, 2002). Within this model, preventive health behaviour and/or behaviour change will be predicted by three sets of beliefs: perceived susceptibility (subjects perception of the risk of contracting the disease), perceived severity of leaving the disease untreated (both medical and social) and perceived benefits/barriers of taking the recommended health actions. The idea is that these beliefs work in concert to produce a decision to carry out the behaviour or not.

Botswana is a useful case study to explore some of these issues. It has drawn international attention in light of its high HIV prevalence - 37% of pregnant women testing HIV positive (UNAIDS, 2004) and its recent bold policy responses towards the HIV/AIDS epidemic (UNAIDS, 2003, Cameron, 2005, Nattrass, 2004). It was the first African country to institute free antiretroviral therapy for patients, and to introduce a policy of freely available HIV testing in government health services. Botswana thus provides a good case for the study of the main social and structural catalysts and barriers to the uptake of testing services. Moreover, given that Botswana is considered by many to have strong prospects for containing the epidemic (by virtue of political will and available resources and health care infrastructure), the success or failure of policy responses in Botswana may provide valuable lessons for other African countries aiming to control the epidemic.

## **Methods**

The study protocol and interview schedule received ethical approval from the Botswana Ministry of Health and the hospital's Institutional Review Board. The first author conducted semi-structured interviews with 40 adults attending outpatient clinics at the government hospital in Gaborone in late 2004. The study site is the only public hospital serving Gaborone and its outlying areas and thus receives all referrals in need of specialist attention. Interviewees were visiting the outpatient clinics for a variety of routine and specialised health services. They were aged between 18 and 49 and included health-care seekers from urban and rural areas (many had travelled a considerable distance from rural areas). Interviews were conducted in either Setswana or English. Adults who were healthy enough to sit comfortably through the interview were eligible to participate in the study. The last eligible person in the queue to see the healthcare provider was approached for interview, with the guarantee that they would not lose their place in the line. Although participants were initially selected randomly, the higher proportion of women than men attending the clinic resulted in a disproportionate number of women interviewees. In an attempt to balance the gender composition of the sample, more men were invited to participate in the latter phase of

recruitment. Forty of the 46 people approached agreed to participate in the study (87%). An informed consent statement was read out and explained to potential respondents.

While this is a small qualitative study which does not aim to make observations that are statistically representative, the sample is large enough to capture a range of adults who embody different socio-demographic characteristics and whose varied experiences can shed light on a wide range of motivations and barriers for HIV testing (Table 1). Respondents were asked if they had taken an HIV test; those who had were asked their HIV status. Twenty-three respondents (57.5%) reported having taken a test; of these, a quarter stated that they were HIV positive.

**Table 1. Socio-demographic characteristics of sample (n=40)**

	Not tested	HIV	HIV Tested	Total n (%)
<i>Gender</i>				
Male	9		7	16 (40)
Female	8		16	24 (60)
<i>Age (Years)</i>				
18-29	11		13	24 (60)
30-39	3		6	9 (22.5)
40-49	3		4	7 (17.5)
<i>Relationship Status</i>				
Married	3		2	5 (12.5)
Cohabiting	1		6	7 (17.5)
Steady partner	5		12	17 (42.5)
Single	7		1	8 (20)
Separated/Widowed	1		2	3 (7.5)
<i>Has Children</i>	9		16	35 (62.5)
<i>Recent Parent*</i> Child in past five years	6		8	14 (35)
<b>Total</b>	<b>17</b>		<b>23</b>	<b>40 (100)</b>

Interviews were tape recorded, translated and transcribed. A thematic framework identifying key issues and concepts was constructed, and the data were systematically coded, and synthesized by theme (Ritchie and Spencer, 1993). The processes for summarizing and coding the data, and arriving at reliable and verified conclusions, conformed to standard conventions of qualitative analysis (Becker and Bryman, 2004, Pope, Ziebland and Mays, 2000). Data collection was anonymous, and all names used in the results section are aliases that were assigned for an easier presentation of the data analysis.

## Results

### Knowledge about and attitudes towards HIV testing

All respondents had heard about the benefits of HIV testing and reported a high level of exposure to HIV education through a number of channels including the government's media-based campaigns (typically via radio, but newspaper and television also). Clinics and healthcare workers as well as friends, family and co-workers were also sources of information about the disease. The workplace was an important source of information for government workers (most of whom had attended HIV education workshops), though not for those working in the private sector. Despite generally high levels of awareness a few respondents felt that more HIV education was needed in rural areas and others noted that the word on the street about HIV did not always match the media information.

Opinions of HIV testing policies appeared to be significantly influenced by perceptions of government health services and health care workers. Most respondents expressed confidence that government health services had patients' best interests at heart, and said that they would agree to take an HIV test for diagnostic purposes if advised to do so by a health care worker. Significantly there was overwhelming support for a policy of routine diagnostic testing at health services amongst respondents (both those who had taken an HIV test as well as those who had not). Most thought that routine testing at health services would help to de-stigmatise HIV and make it a routine health concern. It was also generally felt that more routine HIV testing was important for early diagnosis of HIV infection and increased uptake of treatment programmes. One young man who had not himself taken a test said:

*"I think it would be better if patients are encouraged to take an HIV test when they come to the hospital...As I said, I have never had time to come to take the test, but even myself I should have been encouraged because I have been coming to the hospital for about a year now, but haven't yet been tested for the virus. But they could have found out a long time ago that I am infected and treated me accordingly."*

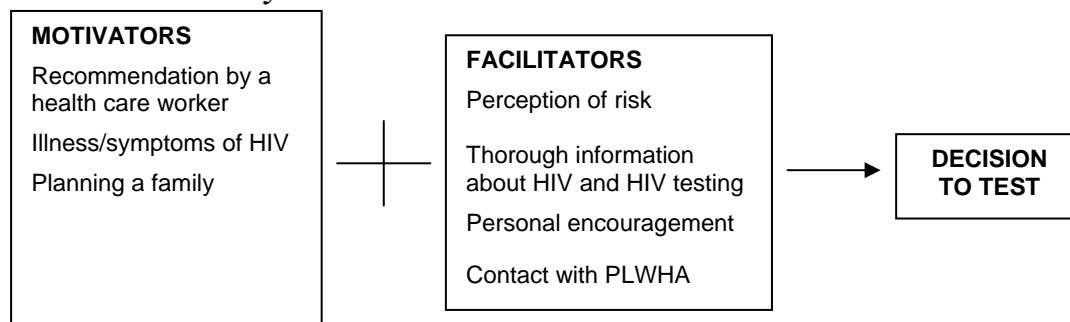
While many respondents preferred using anonymous testing centres because of the rapid same day results and the specialised counselling available, many expressed reservations about attending the 'anonymous' testing centres, because paradoxically they could immediately be identified as someone seeking an HIV test. Others talked about the advantage of testing at clinics because of access to follow up medical care if HIV positive, and the convenience of attending only one venue for all their health services. A very small minority of respondents described incidents that made them wary of the health system, for example, complaints about the lack of confidentiality when receiving an HIV positive test result, or concerns that records might be lost or misplaced at the clinics.

## Motivations for testing

Respondents who had taken an HIV test described the main factors that had motivated and facilitated their decision to test. Figure 1 summarises these.

Figure 1. Main factors influencing the decision to take an HIV test

### Recommendation by a health care worker



It was striking that the majority of people who tested for health reasons - even those who were seriously ill - only did so when prompted by a medical professional. Kabo (26, male, HIV negative) tested after consulting a neurologist at the government hospital:

*“I was encouraged to test by my doctor...He didn’t force me, he just encouraged me to go and do it. I did because I was concerned...and because the doctor was not sure if it was the virus that was causing my condition or something else.”*

Although Kabo appeared to have information and knowledge about HIV testing beforehand, it had not occurred to him to take a test before he was encouraged to do so by his doctor. Kabo, like many of the others in this study, was happy that he had tested and felt that the diagnosis helped to establish the best course of treatment for his condition. Even those who tested HIV positive expressed relief because their diagnosis informed treatment options. Connie, a 36-year-old unemployed mother of three, was fairly certain that she was HIV positive when she fell ill because her symptoms closely matched the HIV symptoms that she had heard about on the radio. However, it was not until her health deteriorated seriously that she consulted healthcare workers, who advised her to take a test. On testing HIV positive, Connie was glad for the immediate referral for further tests, and enrolment in the ARV programme:

*“I am glad because when I was sick I couldn’t eat and was always sad even if people tried to cheer me up. But after testing the sadness went away and my life went back to normal.”*

### Illness/Concern about possible symptoms of HIV

Only two respondents, both female, sought testing on their own initiative because they were concerned that they might be experiencing symptoms of HIV. Masego (22, HIV

negative) took an HIV test because she felt she was not receiving appropriate treatment for a skin condition and wanted to rule out HIV as a cause of her illness:

*“At the clinic they weren’t helping me so I had to do the test...I tested negative – that’s when I went back to the clinic and told them, ‘I’m HIV negative and I still have this rash so what can you do for me?’...The nurse said, now you have to go and see the skin specialist.”*

Margaret (46, female, HIV negative) a mother of three adult children decided to take an HIV test because she was constantly ill, and wanted to relieve her fears that she may have contracted HIV-related infections:

*“I felt that I was continuously sick and I didn’t know my status. I found it better that I go and take a test so that when doctors treat me I can talk to them knowing my status because sometimes an illness can make you prone to other illnesses. If you don’t know your status it’s difficult to know how to live.”*

### Planning a family

The possibility of protecting children from infection was also a strong and common motivator for taking an HIV test. Although all respondents expressed support for the principle of testing while pregnant, most who had actually tested during pregnancy or when planning children again only did so on the recommendation of a health care worker:

*“It was the doctors who encouraged me to test. The information they gave me that they were going to protect the kid is what made me do it...The only thing that made me take the test is that I was pregnant and I wanted to protect the kid.”* Mpho (25, female, HIV positive).

Most respondents with recent pregnancies had been counselled for testing at antenatal clinics. A minority had taken the initiative to take an HIV test when they wanted to plan a family, including two men. In most cases, respondents tested negative and decided to go ahead with their plans for pregnancy. In some cases, however, plans were radically changed by an unexpected HIV positive result. Leatile (36, male, HIV positive) had persuaded his partner to test with him in looking to plan for a family. On learning his HIV positive status, he resolved not to have children:

*“When you are in the state I’m in there is nowhere you can go, and you don’t have to dream and say, now we need to have a child. You don’t have to listen to people who say, ‘these people [health staff] are lying! I gave birth though I was HIV positive’. You don’t have to take those chances because if you do who is going to suffer?”*

While most respondents consciously made the choice to test once pregnant, one respondent described an experience of testing that suggested a lack of informed consent:

*“It was a must to know my status because I was pregnant. ‘The [clinic] staff wanted to know so that when I give birth I would know if I could breastfeed or not. It was a hospital test...I didn’t tell anyone. I tested because I had to.’”*  
Dineo (28, female, HIV negative)

Significantly, though Dineo did not seem to think she had a choice in the procedures, she did not object to them either:

*“For me it was just fine because I thought it was important for both the baby’s life and my own.”*

### **Additional factors facilitating testing**

#### **Perception of risk**

In addition to the above-mentioned motivators for testing, there was a range of ‘secondary’ factors that facilitated the decision to take an HIV test. Perception of risk was an important issue. Only four of the 23 respondents who had taken an HIV test had not considered themselves to be at risk for HIV infection when they tested (those people’s reasons included being a role model peer educator and pregnancy). Significantly, all the other respondents who had tested feared that they might be HIV infected, either because they were experiencing health problems which they believed might be HIV-related, or because they might have been exposed to HIV through sexual relationships or caring for PLWHA.

#### **Information about testing**

Having information about testing processes also appeared to help people make the decision to test. A 22-year-old female peer health educator spoke about the importance of having thorough information about the process and the implications of taking a test. Similarly, a 36 year old HIV positive man explained that he had little difficulty with testing because he was already familiar with where and how to get an HIV test as his aunt and mother were nurses who spoke openly about health issues including sexual health and HIV testing.

#### **Personal encouragement and contact with PLWHA**

Many who had taken a test mentioned the importance of personalised recommendations before and through the testing process. Dolly (43, female, HIV positive) decided to test after being advised to do so by nurses, but she explained how prior encouragement by a friend who had been very ill with AIDS facilitated her own decision:

*“One of my friends was very sick and she told me that if I am very sick and just give up on life then I will die. This advice from my friend motivated me and made it easier to go through the whole procedure...[My friend] is alive and she is now working. She is so fat and beautiful now.”*

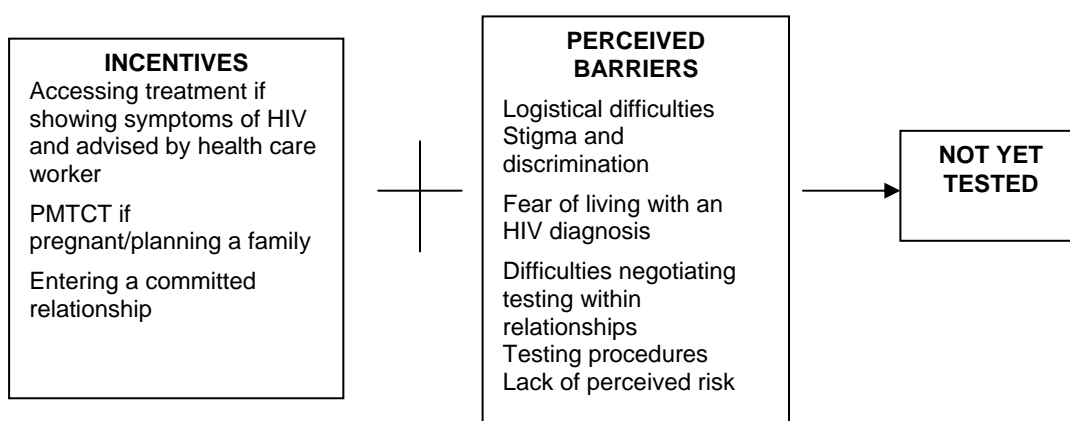


While contact with PLWHA who made dramatic recoveries after enrolling for treatment encouraged some to test, the opposite effect of witnessing the challenges they faced also motivated some respondents. Victor (36, male, HIV negative), a volunteer in a home-based care programme was so distressed by the experiences of the resident patients that he resolved to take an HIV test so that he could access treatment in a timely fashion if he were positive. Several other respondents noted that seeing their neighbours, friends and relatives be ill with and/or die from HIV/AIDS was a motivation to test, given the accessibility of treatment.

### Incentives and perceived barriers amongst those who have not tested

One of the key questions investigated was whether people who had taken an HIV test differed notably in attitudes or circumstances from people who had not tested. Figure 2 shows the stated incentives for and barriers to testing of people who have not yet tested.

**Figure 2. Incentives and barriers for testing**



### Incentives for testing

#### Accessing treatment

The possibility of accessing treatment if sick was the most commonly perceived benefit of testing amongst all non-testers. All respondents but one said that they would take an HIV test if advised to do so by a health care worker for diagnostic reasons, or if they started developing symptoms of HIV. Some respondents were interested in testing in the immediate future, but said that they lacked the courage or had not been presented with the right opportunity. They were nevertheless aware of the health benefits of knowing their status in order to access treatment if HIV positive:

*“I think about testing a lot. Even now I want to go for the test because I see that if it’s detected too late it becomes difficult for the pills to help you.” Janet (31, female, untested).*

Even respondents who were not interested in knowing their HIV status said that they would consider testing if they developed any symptoms of HIV. Oratile (32, female), said that she had no interest in knowing her HIV status as long as she was healthy because “*an HIV diagnosis was tantamount to a death sentence*”, but admitted that she would seek testing as a last resort in the case that she was very ill:

*“If, say, I’ve gone to many places and still don’t get any help then I would give in and take the test. It would happen if the other medications I’ve been taking don’t help me.”*

### Prevention of Mother to Child Transmission

Having a child was universally cited as a motivating factor for testing, given the possibilities of protecting a baby from HIV infection through the PMTCT programme. However, some respondents who supported the principle of PMTCT testing had not themselves tested, despite being recent parents. These respondents claimed that they had never been advised to take an HIV test by a health care worker, though this was impossible to verify.

### Entering a committed relationship

Interestingly, although relationships were not on the whole a strong motivating factor for those who had tested, those who were single and had not tested felt that it would be important to take an HIV test if they made a decision to engage in a committed relationship. Naledi (23, female) was typical in this respect:

*“...When a man comes into my life the first thing we’ll do is test for HIV...To some people it’s sensitive [to discuss HIV testing], but I think we should look at the fact that we live in a nation that is affected by HIV. To test for HIV doesn’t mean that you don’t trust your partner in any way.”*

### Perceived barriers to HIV testing

#### Logistical difficulties

Time was a clear obstacle in many instances, particularly if testing centres were some distance, testing was not guaranteed on the first visit, and the person seeking testing had to take unpaid leave from work. Philemon (28, male, not tested), a manual labourer, had been sickly for the past year and was advised by clinic staff to take an HIV test. Philemon visited a testing centre, but found it closed for administrative purposes and was told to return another day. At the time of the interview, he had not yet returned for a test, and did not consider it a priority. Several respondents mentioned not being successful the first time they visited a testing centre because of crowded facilities, administrative reasons, or equipment shortages. Lorato’s complaints (36, female, HIV negative) were typical:

*“More facilities should be built around, so that more people could go for a test without walking long distances...The place is always crowded. You have*

*to wait for long periods before you test or receive your results. Some people end up going back home without testing or taking the results.”*

Nevertheless, responses suggested that more important than the logistical barriers were the continuing social and psychological barriers to HIV testing in Botswana.

### Stigma and discrimination

Although there was some acknowledgment that attitudes towards HIV/AIDS were improving, most respondents felt that stigma and discrimination remain important deterrents to testing. Many argued that the stigma stems from the fact that HIV/AIDS is considered to be a Sexually Transmitted Infection. Naledi (23, female, not tested) talked about her concerns of being ostracised from her community if she were HIV positive:

*“I think nowadays everything is being done to stop discrimination against people living with HIV, but it is still there in society. They haven’t properly accepted people with HIV because those who have it say that that people are disgusted with them after they reveal that they are positive...I worry about losing friends and even relatives”*

The repercussion of an HIV diagnosis on the family of the infected person was also a consideration for some. John (36, male, HIV negative) talked about how he had avoided testing for many years because of the potential repercussions for his family:

*“If you are known to be positive, a lot of people start to say ‘Ah-ah, this person has AIDS’ and it ends up affecting the whole family because you have kids who are told every now and then about your status...Stigma like that, you wouldn’t like to pass that label onto your kids.”*

### Fear of living with an HIV diagnosis

A commonly cited barrier to testing was fear of not being able to live a ‘normal life’ if diagnosed as HIV positive. The reasons for this fear were complex. Respondents spoke of the psychological difficulties of dealing with an HIV positive diagnosis. Although Moses (24, male, not tested) had heard about the importance of taking an HIV test, he had never considered testing because of the psychological pressures:

*“If I have the virus, I’m going to be afraid because I would know that I’m nearing my death... You will live differently from the time when you think you didn’t have the virus...If you have the virus, even though there are pills available, you always think that this is it, I’m dying. I’m dying.”*

It seemed that the fear of living with HIV/AIDS was often influenced by the general ‘talk on the street’ about HIV/AIDS. Chawa (45, female, not tested) admitted that her worries about testing were linked to rumours that the anxiety of living with an HIV positive diagnosis is worse than the disease itself:

*“They say that a lot of people go insane after testing. They start talking by themselves and the disease kills them quickly but before they had tested they were just fine.”*

The perceived physical suffering associated with AIDS also frightened some out of taking a test. Kalo (26, male, HIV negative) took an HIV test after being advised by his doctor, but the perceived suffering of PLWHA initially made him reluctant to test:

*“Actually I’ve seen a lot of people suffering from the disease. I know some people are in great pain, so I was afraid that maybe I’ll suffer like them.”*

### Negotiating testing within marriage/relationship

Many respondents emphasised the difficulties of negotiating testing within a relationship. In some cases, respondents worried about issues of infidelity or blame, in other cases, the implications of sero-discordance (when one partner is HIV positive and the other HIV negative) for the future of the relationship was the biggest concern. Sethunya (23, female, not tested), the mother of a three year old, had never raised the subject of HIV testing with her partner because she thought that he would suspect her of being promiscuous and HIV-positive. She assumed that he would refuse to take a test and might even forbid her from testing. Another respondent, Kagiso (37, male, not tested), spoke about the issues of blame that had to be negotiated when thinking about testing in a marriage:

*“My wife went for a test...we had talked about it though it took her quite some time to make a decision to test. She said, supposing I go for a test and the records are positive that we have HIV/AIDS, how will we deal with it who has it and who has brought it into the family?”*

### Testing procedures

A few respondents criticised the testing procedures, especially poor counselling procedures. Leatile (36, male, tested) felt that only a fraction of those who visit the testing centres go ahead with testing due to the lack of adequate counselling and the videos showing the distress of PLWHA often played in the waiting room. Other respondents, however, felt that the counselling placed too much emphasis on clients’ option to withdraw from the process instead of giving them the confidence to go ahead with testing. Maureen (21, female, not tested) expressed her worries about the counselling procedures at the testing centres:

*“I prefer the clinics because if you go to the centres they ask you many times if you want to see your results. They keep on asking if you’re not scared and things like that...It’s scary because after you take the test they ask you a lot of times if you want to see your results. They tell you don’t be scared. I think that’s scary.”*

## Perception of low risk

Finally, as with the 'tested' group, perception of risk was an important issue among non-testers. Many respondents who had no interest in testing did not perceive themselves to be at risk for HIV infection. In a few cases, respondents were indeed low risk - that is, they had never been sexually active and had not been primary caregivers for PLWHA. Although perception of risk of HIV infection from caregiving appears to be higher than actual incidence in Botswana, there is evidence that there have been cases where caregivers appear to have contracted HIV infection from those whom they were nursing (Ndaba-Mbata and Seloilwe, 2000). This was largely a result of the high number of undiagnosed HIV/AIDS cases, poor information about how to protect oneself from HIV infection when providing care for PLWHA, and frequent lack of access to gloves and equipment amongst those who do wish to protect themselves (Jacques and Stegling, 2004, World Health Organization, 2000). However, other respondents appeared to have a misperception of their own risk, given their stated sexual history. While the majority of respondents who were not currently interested in testing said that they would consider doing so if they experienced symptoms of HIV, they did not give importance to testing for prevention. Some respondents paradoxically spoke of the growth of '*AIDS fatigue*' and a saturation effect from overexposure to HIV/AIDS information.

## Discussion

Despite the increased attention being given to the role of HIV testing as a component of prevention and care programmes, aggressive promotion of HIV testing continues to be contentious on the grounds that it may result in human rights violations, discrimination and a climate of fear and resistance. This study provides important information about attitudes towards and experiences of HIV testing in a developing country where antiretroviral treatment for HIV/AIDS is freely available through government health services. It examines the extent to which testing is acceptable and welcomed by the population, and considers which factors appear to be most important in influencing individuals' decisions to test or not.

Some caution must be exercised when assessing how generalisable the lessons from this study are for other areas facing serious HIV/AIDS epidemics. First, the majority of respondents lived in Gaborone or nearby towns and villages. As such, the findings may not reflect regional differences in knowledge about HIV/AIDS and attitudes towards health services and HIV testing. Secondly the qualitative study does not allow for an analysis of the influence of socio-demographic factors such as education, income and age on attitudes towards HIV testing.

Despite these limitations, the study provides some important findings and insights. Perhaps the most striking finding is that, contrary to some anxieties, HIV testing appeared to be fully acceptable to almost all study participants, and there was little fear or resistance to a policy of routine testing. Previous qualitative studies have revealed that, at the social level, stigma appears to have been an important deterrent to testing, and have recorded respondents' perceived stigma at being seen at test centres or fear of discrimination if known to be HIV positive (Lie and Biswalo, 1994, Wolff, Nyanzi, Katongole, Ssesanga, Ruberantwari and Whitworth, 2005, Castle, 2003, Sangiwa, van der Straten, Grinstead and VCT Study Group, 2000). Lack of confidence in health services or fears that health care workers would not keep test

results confidential also influenced attitudes towards HIV testing (De Paoli, Manongi and Klepp, 2004, Pool, Nyanzi and Whitworth, 2001, Fylkesnes et al., 1999, Castle, 2003, Wolff et al., 2005). In several countries, people have expressed reluctance to test because of anxiety about dealing with the impact of diagnosis on self, families and relationships (Castle, 2003, Meursing and Sibindi, 2000, Sangiwa et al., 2000, Wolff et al., 2005, Bakari, McKenna, Myrick, Mwinga, Bhat and Allen, 2000). In particular, the difficulty of negotiating partner testing or disclosing HIV status for women has been extensively documented. (Maman, Mbwanbo, Hogan, Kilonzo and Sweat, 2001, De Paoli et al., 2004, Sangiwa et al., 2000, Bakari et al., 2000, Wolff et al., 2005). In this study however, despite some ongoing concerns about stigma and the consequences of disclosure, no ethical objections to testing were raised. Rather, those who had tested were universally relieved that they had done so while those who had not tested hoped (and indeed wanted the assurance) that health care workers would advise diagnostic testing if they suspected HIV symptoms. Other studies in Africa have found that sick people often did not want to know their HIV status because of the absence of treatment (De Paoli et al., 2004, Campbell, Marum, Alwano-Edyegu, Dillon, Moore and Gumisiriza, 1997, Castle, 2003), and feeling that an HIV positive diagnosis effectively amounted to a death sentence (Bakari et al., 2000, Wolff et al., 2005). A notable difference in our study was that given the availability of treatment, all but one respondent said that they would like to take an HIV test if they developed symptoms of HIV/AIDS. This finding suggests that more aggressive promotion of HIV testing through health services, including a policy of routine testing, may be tolerated and even welcomed in other high prevalence contexts that can offer services and treatment. A corresponding and perhaps more controversial finding was that the study sample favoured clear direction from medical professionals over being offered choice. Respondents queried whether placing too much emphasis on the 'right not to know one's status' and counselling procedures which repeatedly gave clients 'opt-outs' had a deterring effect. This finding supports observations by other researchers that a strong emphasis on informed consent may create confusion and doubts about testing and be burdensome rather than reassuring patients about their rights (Richards, 1999, De Cock, Mbori-Ngacha and Marum, 2002).

In terms of understanding the complex motivators and barriers to testing, the strongest motivators were recommendation by a health professional, concern about one's health and PMTCT. It was particularly striking that the vast majority of respondents who had taken an HIV test, even those with obvious symptoms or those seeking to prevent transmission to their children, only did so after recommendation from a health care worker. In cases where respondents were not encouraged to test by a nurse or doctor, they often did not do so, even if they were ill or expecting a baby. Recommendation of a health worker thus appears to be the strongest influence in overcoming social and other barriers to HIV testing. These findings highlight the importance of placing healthcare workers at the frontline of any initiative to increase up-take of testing and also provide support for a policy of health personnel offering HIV testing routinely to patients. Equally, while the protection of (future or current) sexual partners was on the whole not a strong motivator for testing, the encouragement of friends and co-workers appeared to be an important influence. This finding is consistent with other results which have found that behaviour change is most highly associated with personal communication (Stoneburner and Low-Ber, 2004), and points to the importance of peer education campaigns and community mobilisation.

Most notably there was little to distinguish either the circumstances or the incentives of those who had tested and those who had not. While some had faced practical difficulties accessing testing services, logistical barriers were given relatively little emphasis. The primary difference between the groups appeared to be their respective perceptions of personal risk. Respondents who had not currently tested did not generally consider themselves to be at risk for HIV infection (sometimes incorrectly given their other information about sexual relationships or exposure). This finding is significant because it suggests that testing is still primarily treated as a diagnostic tool rather than a preventative health device, where people seek to find out their HIV status not only to access treatment if HIV positive, but also to protect themselves from future infection if HIV negative. While this may be encouraging to those who have expressed hope that the incentive of treatment will indirectly contribute to HIV prevention by increasing take up of testing (World Health Organization and UNAIDS, 2005, Hale, Makgoba, Merson, Quinn, Richman, Vella, Wabwire-Mangen, Wain-Hobson and Weiss, 2001) the findings from this study also entail some sobering information. The recent increased attention being paid to the role of HIV testing is typically based on a two-fold public health rationale. First, apart from the benefits of antiretroviral treatment, informing HIV positive people of their serostatus is crucial if they are to limit further transmission of the virus. Second, it is hoped that those who find out that they are HIV negative will take steps to protect themselves from infection in the future. However, as this study indicates, an emphasis on treatment on its own may further encourage primarily those who suspect that they have symptoms of HIV to take a test. As such, asymptomatic HIV positive people may continue to transmit the virus unknowingly while efforts at increasing knowledge of HIV status amongst those who are HIV negative may be less effective. The design and implementation of programmes to promote preventive testing amongst those equally likely to be HIV negative should therefore be a priority in efforts to control the spread of HIV/AIDS.

Finally, although knowledge and awareness of HIV appeared high in Botswana, it is clear from this study that information alone was not a sufficient catalyst for behavioural change. These results support other accounts of the limitations of conventional health education approaches which tend to rely on information giving alone as the basis of behaviour change (Imrie, Stephenson, Cowan, Wanigaratne, Billington, Copas, French, French and Johnson, 2001, Kelly, St Lawrence, Stevenson, Hauth, Kalichman and Murphy, 1992). To this extent, the results of this study suggest that to some degree beliefs do 'predict' behaviour; the relationship between both perceived susceptibility and perceived benefits/barriers and behaviour was evident. However, the findings also demonstrate that the relationship is neither simple nor clear-cut. It is apparent that the social and structural circumstances in which respondents lived also enabled or constrained their health related behaviour and thus health care seeking behaviour was influenced by a complex interaction of various social environmental and structural factors. Continued research on these issues is needed if future policy on testing is to be informed by a strong evidence base.

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## References

- Abdool Karim, Q., Abdool Karim, S. S., Coovadia, H. M. and Susser, M. (1998) Informed consent for HIV testing in a South African hospital: is it truly informed and truly voluntary?, *American Journal of Public Health*, **88**, 637-640.
- Bakari, J., McKenna, S., Myrick, A., et al. (2000) Rapid voluntary testing and counseling for HIV. Acceptability and feasibility in Zambian antenatal care clinics, *Annals of the New York Academy of Sciences*, **918**, 64-76.
- Becker, S. and Bryman, A. (Eds.) (2004) *Understanding research for social policy and practice: Themes, methods and approaches*, Policy Press, Bristol.
- Cameron, E. (2005) *Witness to AIDS*, Tafelberg, Cape Town.
- Campbell, C., Marum, E., Alwano-Edyegu, M., et al. (1997) The role of HIV counseling and testing in the developing world, *AIDS Education and Prevention*, **9**, 92-104.
- Cartoux, M., Meda, N., Van de Perre, P., et al. (1998) Acceptability of voluntary HIV testing by pregnant women in developing countries: an international survey. Ghent International Working Group on Mother-to-Child Transmission of HIV, *AIDS*, **12**, 2489-2493.
- Castle, S. (2003) Doubting the existence of AIDS: a barrier to voluntary HIV testing and counselling in urban Mali, *Health Policy and Planning*, **18**, 146-155.
- Danziger, R. (1996) An epidemic like any other? Rights and responsibilities in HIV prevention, *British Medical Journal*, **312**, 1083-1084.
- De Cock, K., Marum, E. and Mbori-Ngacha, D. (2003) A sero-status based approach to HIV/AIDS prevention and care in Africa, *Lancet*, **362**, 1847-1849.
- De Cock, K., Mbori-Ngacha, D. and Marum, E. (2002) Shadow on the continent: public health and HIV/AIDS in Africa in the 21st Century, *Lancet*, **360**, 67-72.
- De Paoli, M. M., Manongi, R. and Klepp, K. I. (2004) Factors influencing acceptability of voluntary counselling and HIV-testing among pregnant women in Northern Tanzania, *AIDS Care*, **16**, 411-425.
- DeGraft-Johnson, J., Paz-Soldan, V., Kasote, A. and Tsui, A. (2005) HIV voluntary counseling and testing service preferences in a rural Malawi population, *AIDS and Behavior*, **9**, 475-484.
- Fylkesnes, K., Haworth, A., Rosensvard, C. and Kwapa, P. M. (1999) HIV counselling and testing: overemphasising high acceptance rates a threat to confidentiality and the right not to know, *AIDS*, **13**, 2469-2474.
- Glanz, K., Rimer, B. K. and Lewis, F. (2002) 'The scope of health behavior and health education' In *Health behavior and health education. Third edition* (Eds, Glanz, K., Rimer, B. K. and Lewis, F.) Jossey-Bass, San Francisco, pp. 3-21.



- Hale, P., Makgoba, M. W., Merson, M., et al. (2001) Success hinges on support for treatment, *Nature*, **412**, 272.
- Heywood, M. (2005) The routine offer of HIV counseling and testing: A human right, *Health and Human Rights*, **8**, 13-19.
- Imrie, J., Stephenson, J., Cowan, F., et al. (2001) A cognitive behavioural intervention to reduce sexually transmitted infections among gay men: randomised trial, *British Medical Journal*, **322**, 1451-1456.
- Jacques, G. and Stegling, C. (2004) HIV/AIDS and home based care in Botswana: panacea or perfidy?, *Social Work in Mental Health*, **2**, 175-193.
- Janz, N. K., Champion, V. and Strecher, V. (2002) 'The health belief model' In *Health behavior and health education. Third edition*(Eds, Glanz, K., Rimer, B. K. and Lewis, F.) Jossey-Bass, San Francisco, pp. 45-66.
- Kalichman, S. and Simbayi, L. (2003) HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa, *Sexually Transmitted Infections*, **79**, 442-447.
- Kelly, J., St Lawrence, J., Stevenson, L., et al. (1992) Community AIDS/HIV risk reduction: The effects of endorsements by popular people in three cities, *American Journal of Public Health*, **82**, 1483-1489.
- Lie, G. and Biswalo, P. (1994) Perceptions of the appropriate HIV/AIDS counsellor in Arusha and Kilimanjaro regions of Tanzania: implications for hospital counselling, *AIDS Care*, **6**, 139-151.
- Maman, S., Mbwambo, J., Hogan, N., Kilonzo, G. and Sweat, M. (2001) Women's barriers to HIV-testing and disclosure: challenges for HIV-I voluntary testing and counseling, *AIDS Care*, **13**, 595-603.
- Marum, E., Campbell, C. H., Msowoya, K., Barnaba, A. and Dillon, B. (2002) 'Voluntary counseling and testing' In *AIDS in Africa. Second edition*(Eds, Essex, M., Mboup, S., Kanki, P., Marlink, R. and Tlou, S.) Kluwer Academic/Plenum Press, New York, pp. 527-538.
- Meursing, K. and Sibindi, F. (2000) HIV counselling - a luxury or necessity?, *Health Policy and Planning*, **15**, 17-23.
- Nattrass, N. (2004) *The moral economy of AIDS in South Africa*, Cambridge University Press, Cambridge.
- Ndaba-Mbata, R. D. and Seloilwe, E. S. (2000) Home-based care of the terminally ill in Botswana: knowledge and perceptions, *International Nursing Review*, **47**, 218-223.
- Piot, P., Feachem, R., Jong-Wook, L. and Wolfensohn, J. (2004) A global response to AIDS: lessons learned, next steps, *Science*, **304**, 1909-1910.
- Pool, R., Nyanzi, S. and Whitworth, J. (2001) Attitudes to voluntary counselling and testing for HIV among pregnant women in rural south-west Uganda, *AIDS Care*, **13**, 605-615.
- Pope, C., Ziebland, S. and Mays, N. (2000) Qualitative research in health care: Analysing qualitative data, *British Medical Journal*, **320**, 114-116.
- Rennie, S. and Behets, F. (2006) Desperately seeking targets: the ethics of routine HIV testing in low-income countries, *Bulletin of the World Health Organization*, **84**, 52-57.
- Richards, E. P. (1999) 'HIV Testing, Screening and Confidentiality: An American Perspective' In *HIV and AIDS. Testing, Screening and Confidentiality*(Eds, Bennett, R. and Erin, C.) OUP, Oxford.

- Ritchie, J. and Spencer, L. (1993) 'Qualitative data analysis for applied policy research' In *Analysing qualitative data*(Eds, Bryman, A. and Burgess, R.) Routledge, London, pp. 173-94.
- Salomon, J., Hogan, D., Stover, J., et al. (2005) Integrating HIV prevention and treatment: from slogans to impact, *PLoS Medicine*, **2**, 50-56.
- Sangiwa, M. G., van der Straten, A., Grinstead, O. and VCT Study Group (2000) Clients' perspective of the role of voluntary counseling and testing in HIV/AIDS prevention and care in Dar es Salaam, Tanzania: the voluntary counseling and testing efficacy study., *AIDS and Behavior*, **4**, 35-48.
- Scheper-Hughes, N. (1993) AIDS and the social body, *Social Science and Medicine*, **39**, 991-1003.
- Stoneburner, R. and Low-Beer, D. (2004) Population-Level HIV declines and behavioral risk avoidance in Uganda, *Science*, **304**, 714-717.
- Temmerman, M., Ndinya-Achola, J., Ambani, J. and Piot, P. (1995) The right not to know HIV-test results, *The Lancet*, **345**, 969-970.
- UNAIDS (2003), Vol. 2004 UNAIDS.
- UNAIDS (2004) *AIDS Epidemic Update. December 2004*, UNAIDS, Geneva.
- Wolff, B., Nyanzi, B., Katongole, G., et al. (2005) Evaluation of a home-based voluntary and counselling and testing intervention in rural Uganda, *Health Policy and Planning*, **20**, 109-116.
- World Health Organization (2000) *Caring for family members with HIV/AIDS and other chronic illnesses: the impact on older women and girls. A Botswana Case Study*, WHO, Geneva.
- World Health Organization and UNAIDS (2005) *Progress on global access to HIV antiretroviral therapy. An Update on '3 by 5'. June 2005*, World Health Organization, Geneva.

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## Why did GPs Prescribe Rofecoxib? A Qualitative Study of Risk Perception in the Uptake of a New Drug

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### ABSTRACT

The first Cox-2 selective non-steroidal anti-inflammatory drug (NSAID) in the UK, rofecoxib (Vioxx), was launched in August 1999. However, in September 2004 it was withdrawn from the international market because of concerns about its cardiovascular safety. The objectives of this study were to explore GPs' perceived risk of a new, innovatory drug (rofecoxib) and how this shaped decisions about prescribing and the processes of new drug adoption. Semi-structured interviews were undertaken with 107 GPs within 6 months of the launch of rofecoxib. Most GPs (63%) prescribed rofecoxib rapidly after its launch. Reasons for prescribing rofecoxib included: a perceived therapeutic advantage or gap in the market particularly in regard to safety, a high level of pre-launch awareness perhaps due to intense direct marketing, hospital prescribing and GPs' attitudes to risk. There was a general optimism about its value, derived largely from commercial information sources or colleagues. Some GPs were concerned about the long-term safety of rofecoxib but were reassured by their general familiarity with NSAIDs. Specifically, the findings highlight the role of social and contextual factors in GPs' perception and understanding of risk, and the various strategies they used to manage risk and uncertainty. Thus, the prescribing of rofecoxib can be situated and understood within a socio-cultural theoretical framework that reflects differing beliefs, values and experience in individuals' constructions of risk.

### KEY WORDS

new drug diffusion / rofecoxib/ prescribing / marketing / risk perception

### Introduction

Rofecoxib (Vioxx), was a new drug launched in the UK in August 1999. It belonged to a class of nonsteroidal anti-inflammatory medications (NSAIDs) called COX-2 inhibitors and was the first Cox-2 selective to be licensed. Conventional NSAIDs are associated with adverse effects such as an increase in the risk of gastrointestinal perforations, ulcers, and bleeds. The alleged advantages of COX-2 inhibitors, however, are that they provide the benefits of reducing inflammation but with a reduced risk of stomach ulceration and bleeding.

Like many other new drugs, there was a lack of good clinical data available at the launch of the product to support its effective and safe use in clinical practice. From a commercial perspective however, the manufacturer had to achieve rapid market penetration before a rival (celecoxib) was launched. There was, therefore, an intense marketing effort by the manufacturer: the advertising budget in the US alone for this drug was estimated to have exceeded the world wide advertising budget of Pepsi Cola and Budweiser beer (National Institute for Health Care Management Research and Educational Foundation, 2000). Marketing was also successful in raising awareness of rofecoxib: UK market research reported that 95% of GPs were aware of the drug and that 65% had prescribed it within 12 months of its launch, an extremely high rate (Pitt, 2002).

The first major clinical evidence of rofecoxib's superiority to existing NSAIDs in reducing the rate of serious gastrointestinal events did not come until November 2000 (Bombardier, et al., 2000), although early concerns were also raised about its cardiovascular risk profile. These concerns lingered, although the manufacturer vigorously defended the safety of its product (Gibson, 2004). But on September 30<sup>th</sup> 2004, rofecoxib was withdrawn from the international market because of concerns about its cardiovascular safety (Maxwell, & Webb, 2005). There has been much discussion about whether these concerns should have led to the drug's withdrawal at an earlier stage, and about how far they extend to other drugs of this class. General practitioners (GPs), as the main prescribers of NSAIDs, were the primary target of much of the promotion.

### **Risk Approaches and Implications for Medical Decision-Making**

The concept of risk has become integral to understandings of modern society (Beck, 1992; Giddens, 1991), and has had an increasing emphasis in explaining health behaviour and decision-making. Lupton (1999) identifies medical care and treatment, including drug therapy, as one of six major categories of risk that predominate the concerns of individuals and institutions in Western societies. There are various approaches to examining and analyzing notions of risk in the social sciences, the most dominant being the techno-scientific perspective, the cultural/symbolic perspective, and the social constructionist perspective (for a detailed discussion see Lupton, 1999). The techno-scientific perspective views risk assessment as a rational, technical approach as measured or estimated from empirical, scientific data (Adams, 1995). It has widespread appeal in industries assessing the risks of new technologies and within the health field (Gabe, 1995).

Indeed, it follows that the techno-scientific approach may appear logical within the paradigm of evidence-based medicine (EBM) through its implication that the benefits and harms of a treatment can be identified and quantified through appraisal of clinical research findings and scientific measurement and calculation. The EBM approach emphasizes the rational aspects of decision-making and assumes a logical linear progression of information acquisition and appraisal of all relevant drug attributes and possible courses of actions and outcomes. Risks, in keeping with this approach, would be managed according to this knowledge. However, new drug prescribing is an area of high uncertainty. When deciding to use a new drug, a doctor has to weigh up the balance between prescribing a possibly more effective treatment against the potential for unknown, possibly serious side effects. Comprehensive and precise data on the efficacy, safety and long-term effects of new drugs is difficult to

obtain, leading some commentators to argue that evidence may not be sufficient to support a new drug's effective and safe use in clinical practice (Dent & Hawke, 1997; Clarke, et al., 1998; Gale, 2001). For instance, randomized controlled trials (RCTs) of a new drug treatment exclude high risk patient groups, thus limiting the potential for discovering adverse drug reactions in a larger, more heterogeneous population (Ferner, 1996; Rawlins & Jeffries, 1991; Wu & Makuch, 2006). This raises interesting questions about how GPs interpret and manage risk when levels of knowledge may be indeterminate.

Despite these limitations in new drug data, it is not evident that even with accurate, comprehensive scientific information there would be agreement between doctors about the quantification and probabilities of risk. This can occur because of the varying ways in which doctors' perceive risk and respond to uncertainty (Bloor, 1976). Moreover, sociologists have repeatedly drawn attention to the way in which risk is not objective and measurable, but contingent, and better understood as a social construction (e.g. Adams, 1995; Douglas, 1986; Douglas & Wildavsky, 1982; Gabe, 1995; Lupton, 1999; Nelkin, 1989). This approach draws attention to the involvement of complex social and cultural processes in how individuals perceive and mediate risk. Central to this is the recognition of plural rationalities reflecting individual perceptions and meanings in understanding risk in the context of everyday lives.

Shortly after rofecoxib was launched, a qualitative study of factors influencing GPs' initial prescribing of a range of new drugs, including rofecoxib, was undertaken (Prosser, et al., 2003). Re-examining the interview data following rofecoxib's withdrawal from the market, the present investigation sought to gain a deeper understanding of how GPs assessed the risk of this new, innovatory drug, their approach to negotiating and managing risk, and how this shaped their decisions about prescribing. Mindful of Gabe's (1995) proposition of the need for a sociological approach to medicine and risk, this paper engages with an interpretive method, structured theoretically within an analytic socio-cultural framework of risk. The sociological implications of the study findings are considered in relation to examining the relationship between risk, knowledge and evidence.

## Methods

### Sampling

GPs in two health authorities were selected purposively by rates of prescribing of new 'black triangle' medicines (those designated by the licensing authority as requiring special reporting of all adverse events as their risk profile is as yet unclear) from Prescribing Analysis and Cost (PACT) data. Initial sampling was based on stratifying practices into tertiles according to their level of this prescribing. These tertiles were defined as high, medium and low prescribing practices. Purposive sampling was then employed to select a range of high, medium and low prescribing practices of the study drugs, the aim being to identify a comprehensive range of influential factors, and to capture a range of experiences and instances of prescribing amongst GPs. Purposive sampling also ensured that individuals and practices with a range of other characteristics were included, such as sex, number of practice partners and geographic location for example, urban and rural settings. The practices targeted for interview were selected by firstly dividing the frequency distributions of the total of indexed new drugs prescribed into tertiles. Sampling was then selected from the central

portion and tails of each distribution. Thus, both the average prescribing practices of new drugs as well as the outliers (ie. The high and low prescribing practices) were included.

### **The Critical Incident Technique**

GPs were shown a list of black triangle drugs including rofecoxib and asked which if any they had prescribed. This study is based on reported rofecoxib prescribing incidents. The critical incident technique (Flanagan, 1954) was then used to explore GPs' reasons for prescribing. This is an open-ended retrospective method that facilitates the investigation of significant occurrences, e.g. events, incidents, processes, issues. It is a way of using the individual experience to identify the factors that are recognised as important in defining what led to a particular occurrence. Thus, a critical incident is one that makes a significant contribution, either positively or negatively, to an activity or phenomenon. Generally, data are collected via a semi-structured interview, which is more flexible than a questionnaire or survey. Through allowing the interviewee flexibility to describe an event and talk about their experiences and views in their own words, the objective is to gain understanding of the incident from the perspective of the individual, taking into account cognitive, affective and behavioural elements (Chell, 1998). The critical incident technique therefore provides a rich and detailed set of data by allowing respondents to determine which factors are most relevant to them for the event being investigated. It was chosen for use in the present context because it provides an opportunity to obtain an in-depth account of actual prescribing events in everyday contexts from those in the best position to make the necessary observations and evaluations. At the same time, it reflects the natural way doctors think without imposing any a priori determination of what will be important. Thus, the researcher seeks to understand and construct decision-making from the viewpoint of the individual decision-maker.

### **Interviews**

Using a semi-structured interview, GPs were asked to recall the critical factors that had led to the initial prescribing of rofecoxib. The interviews were conducted by cueing and prompting the participant towards a detailed explanation of the events and the decision-making process, through first awareness of a new drug, information sources, factors influencing assessment, the critical and contextual factors leading to its initial prescription and the reasons for prescribing the new drug rather than an alternative. Respondents were encouraged to reflect in detail on their notions of the authority and legitimacy of new drug information and knowledge.

Interviews were conducted between August 1999 and February 2000, thus up to 7 months after the launch of rofecoxib. Interviews were tape-recorded and transcribed. The experiences and accounts of those studied served as the basis for data analysis, the aim being to work inductively from the data. As outlined above, data examination began tentatively during the fieldwork stage. However, a more detailed and systematic line-by-line analysis of the interview transcripts began once data collection was completed. This process meant that analysis remained grounded in the data and

challenged any a priori assumptions in relation to GPs' decision-making and what constituted knowledge, for example a rational, scientific process and 'evidence-based'. This was preceded with frequent readings of the transcripts to increase familiarity. Analysis proceeded with two stages: content analysis and thematic analysis. Content analysis produces a relatively systematic and comprehensive summary or overview of the data as a whole, whereas thematic analysis is more distinctive, typically addressing the issue of 'what is going on and why' in more analytic depth and detail. In this study, content analysis was used to address the question of what factors influence new drug uptake and how often these different factors were mentioned. Thematic analysis is used to explore how and even why new drug uptake occurs within particular situational prescribing contexts.

## Analysis

The initial process followed the methods of the critical incident technique (Flanagan, 1954). Thus, in order to manage the relatively large set of data, the process of content analysis identified the critical influential factors that emerged for each prescribing incident. These were listed and similar reasons coded into initial conceptual categories (e.g. pharmaceutical representative influence). The entire data set was categorized in relation to these concepts and grouped together by means of a coding system. In this way, content analysis provided a useful summary measure of the extent to which influential factors were distributed. At the same time, however, the technique of content analysis overlooks the importance of the process of negotiating meanings and makes little allowance for the contextual aspects of a situation and individual styles of interpretation. It is useful therefore, to integrate content analysis alongside other qualitative data analysis techniques that are able to uncover the dynamics of social processes and allow closer specification of the significance individuals attach to critical influences.

Secondly therefore, thematic analysis proceeded inductively following a grounded analytical approach (Strauss & Corbin, 1998) to further define the nature of influence and illuminate the underlying processes of decision-making. The data were repeatedly examined until all cited influences were coded in terms of these categories. Conceptual categories were further specified according to their characteristics (e.g. consultant influenced by observation; consultant influence by socialization, etc). The next step was to compare these categories and identify common analytical themes. Categories were then related according to context and interaction. This process effectively reduced the data into core categories specifying the nature of evidential sources and their relationships to various patient and treatment contexts. Three core sub-categories were developed from the interviews: readiness to prescribe; sources of information; managing uncertainty and risk.

Both the initial conceptual categories and core categories were constantly compared with each other and checked against the interpretation in order to revise and refine explanation. The eventual outcome was to provide a theoretical analysis based on the categories and themes arising in the data. Analytic notes and the initial creation of codes and categories were constituted from the interview data early on in the research when analysis and data collection were conducted simultaneously. The themes and questions that emerged in early interviews helped shape subsequent data collection. For instance, data were analysed for the way in which GPs referred to risk in individual prescribing incidents and recounted their understanding of risk in

relation to new drug prescribing. The data were organised and conceptually categorised with the aid of the computer software NVIVO (Richards, 1999).

## Results

107 GPs (76 male and 31 female) from 54 practices were interviewed, a participation rate of 73% of GPs and 77% of practices contacted. Of the 721 episodes of prescribing of black triangle drugs, rofecoxib was the second most commonly prescribed, after sildenafil (Viagra). Sixty-seven GPs (63% of total) had prescribed rofecoxib. Prescribing incidents based on others' decisions (i.e. continuation of a GP or hospital colleague initiated prescription) were cited by a further 13 GPs but are not further analysed here. Specific reasons for prescribing rofecoxib are listed in table 1. The findings can be categorised into three broad themes relating to factors influencing the uptake of rofecoxib: *Readiness to Prescribe; Sources of Information and Risk and Uncertainty.*

### Readiness to prescribe

The most common reason for GPs to prescribe rofecoxib was the perception that it was an advance over current NSAIDs, and filled a therapeutic gap:

*The thing that's swung it is it's got significant advantages over its competitors.. (GP4)*

*There's a very definite niche, it fills a definite hole. (GP7)*

This was largely based on the drug's alleged improved adverse effect profile over current alternatives. GPs saw its value in patients who were currently treated sub-optimally:

*There's a lot of problems with people who can't tolerate any NSAID because of gastric irritation problems and Vioxx has been launched on the premise that it doesn't cause these problems... it does actually seem to be a far better bet than its competitors.... it's a good choice. (GP98)*

Many GPs suggested that they or some of their patients had been expectantly waiting for rofecoxib or something similar:

*We've got a group of people for whom we'd love an anti-inflammatory that doesn't shred your stomach... It's a very limited group of people generally who have been waiting for it for a long time. (GP73)*

However, this may reflect good anticipatory marketing, creating a demand for the drug before its launch:

*A patient comes you think, ah, that's the drug I was thinking about, yes, this person might be appropriate to try it on. (GP27)*



*I initiated it because there's a lot of need...again we knew this was coming. I don't know where I heard about them. I read my magazines but you just see Vioxx on big pages, so I suppose it does come from the advert. (GP24)*

Nevertheless, according to the stated approaches of these GPs, prescribing is accepted in circumstances where clearly identifiable benefits and levels of expected utility are perceived to outweigh risks. However, as will become apparent in the following discussion, risk assessment was not readily expressed as an objective, measurable process within the techno-scientific approach that underpins evidence-based medicine.

## Sources of Information

GPs showed scant systematic or comprehensive search for scientific research evidence. Information was acquired opportunistically from commercial sources or the observation of consultant prescribing and judgement. In only 16 instances did GPs report having gained information from non-industry literature, with two claiming to have read about it in the Drugs and Therapeutics Bulletin and the rest in articles in non-peer reviewed journals (i.e. those free to GPs and financed by advertising, such as Pulse).

Many GPs spoke of an initial creeping or background awareness of rofecoxib, largely through advertising and the GP press.

*it may have been articles in things like GP or Pulse, those kind of ones. I couldn't say for definite, it may even be adverts in the journals as you're flicking through the pages. (GP90)*

*There was a lot of promotion on this one, it's everywhere in the magazines. (GP64)*

Four GPs acknowledged that they had prescribed rofecoxib solely on the basis of promotional literature:

*It was just the adverts in the rags that made me look at it. I haven't heard about it from anywhere else. (GP7)*

For 26 prescribers, the company representative was the sole information source:

*I've probably had about 4 or 5 patients that I have put on that. I met with the representative and I basically was quite impressed with the studies and the evidence that was put forward. (GP65)*

*I only actually saw the rep last week and I've used it twice since then (GP49)*

... and often seen as personally highly credible:

*The other reason for prescribing [rofecoxib] is the drug rep. He's probably one of the best that I know as a salesman. He's very persistent and very*

*sociable and so he can sell anybody anything, but I do take him with a pinch of salt, unless it's a good drug. (GP64)*

*Vioxx I've used that quite a bit. We've got a rep who I've known for fifteen years and I trust him. He's a proper pharmacist, he's not just any old rep and I value his judgement, so it means if he tells me it's a good drug I would go along with that. (GP82)*

The indirect influence of a hospital consultant was important in 30 incidents, in two ways: either by experiential knowledge, based on observation of the *effects* of rofecoxib prescribed at a consultant's request; or simply, observed consultant prescribing. GPs considered consultant use as validation of the drug's value and so provided an authoritative standard for GPs' own practice:

*One of the local rheumatologists has been using it quite a bit when I had barely heard of it, so that more or less tipped the balance in me deciding to give it a try. (GP26)*

*I didn't actually prescribe [rofecoxib] until some patients had come out from hospital on it. I was just a bit skeptical as to how good it was going to be, so seeing the effect of the drug in the patient, rather than just the fact that the hospital were prescribing it. (GP96)*

Furthermore, rofecoxib presented an alternative before referral, when GPs anticipated the action of specific hospital doctors:

*My influence really has been our local consultant rheumatologists who've gone potty on the stuff. I'm not a great one for trying things new, just because they're new, but now this has taken off it does seem to be quite useful... You've seen how well Vioxx suits the patient, the next patient who comes in with a similar sort of problem, you're thinking, 'I don't have to refer this patient to rheumatology, I'm going to try this one on Vioxx. (GP74)*

Patient requests for rofecoxib were influential in only a few incidents, in some cases inducing GPs' awareness of it:

*I actually first heard about this when a patient brought a newspaper cutting in. (GP47)*

### Risk and uncertainty

GPs' perception of risk plays a fundamental role in their decision-making. GPs were aware of the uncertainty around the early use of a new drug like rofecoxib, and many were ambivalent about its safety and outcomes due to a lack of long-term, scientific research evidence:

*I'm still a bit wary about giving something like Vioxx until it's got a bit more data behind it. (GP94)*

However, while gaps in GPs' knowledge can create uncertainty, the extent to which this is understood as 'risk' is not equal for all prescribing incidents and for all GPs, nor is risk perception restricted to the accumulation of scientific research information and an objective assessment of calculable probabilities:

This is quite a good idea in principle I think. I'm not sure that there are enough studies to make me happy with it. I'm happy to initiate it. The worry is that it hasn't been around that long yet, so again I don't know what it does to people in the long term. (GP77)

Indeed, the perception of risk, and the decision to prescribe rofecoxib, incorporates a high element of subjectivity and is open to individual interpretation. Risk and its negotiation are constructed around not only the nature and breadth of GPs' underpinning knowledge relating to rofecoxib, but also around individual risk preference and the perceived level of uncertainty and risk a GP is willing to accept in a given situation. As such, GPs arrive at their own notion of risk drawn from a set of influences that include personal beliefs, past clinical experience, social and cultural factors, social and professional relationships, concepts of trust and credibility and clinical contexts. What might be considered risky in one clinical situation or patient context may not be considered so in another. Furthermore, despite the indeterminate nature of new drug knowledge, risk and uncertainty are not a constant feature of prescribing. On the contrary, there were many prescribing incidents in which risk was not an issue, or in which risk was controlled and de-sensitised through various rationalities and practical reasoning that simplified decision-making. While there is considerable variation in GPs' understanding and response to risk, the data also point to certain patterns in the organization of how GPs conceive, negotiate and control risk.

Most obviously, most GPs felt that the benefits of rofecoxib outweighed the risks in particular patients:

*I'm a bit sceptical about new non-steroidals. I know there's a difference in the Cox 1, Cox 2 inhibitors but, you know, in terms of adverse effects... I had somebody with rheumatoid, who was really quite bad and in a lot of discomfort with it, despite being on methotrexate and opioids and everything, and couldn't tolerate Arthrotec, so I thought I'll give it a try. (GP68)*

... and, more importantly, that the risk of adverse effects was less than with other NSAIDs:

*I don't often prescribe new drugs but, I mean, really something like Vioxx, one has such problems with gastric problems that, you know, when somebody [the rep] says, 'this will not give gastric problems,' you really do have to listen. (GP21)*

For the most part, GPs considered an alternative treatment for individual patients based on their knowledge of the patient's previous medication history, or for those patients whom they considered at high risk of developing serious gastrointestinal (GI)

adverse events. Decision-making thus involved making complex evaluative judgements, weighing the potential risks and benefits of prescribing a new drug with alternative courses of action in individual patients. These instances emphasise the situated rationality of GPs' decision-making. Against this background, rofecoxib was seen as a rational alternative for many patients:

*There's a lot of problems with people who can't tolerate any NSAID because of gastric irritation problems and Vioxx has been launched on the premise that it doesn't cause these problems... it does actually seem to be a far better bet than its competitors.... it's a good choice. (GP98)*

*It's particularly very elderly patients who have previously had long-standing arthritis that has not been treated adequately...it's something to try and help them have a quality of life. (GP29)*

Thus, GPs tend to prescribe rofecoxib for those patients perceived to be at highest risk of not being managed effectively with other treatment. GPs' accounts conveyed the increase in risk acceptability of rofecoxib with an increase in their perception of its potential benefit. Here, risk-taking was viewed optimistically and rofecoxib distinguished as a means of challenging limited therapeutic options and providing opportunity for health benefit, or avoiding the risks associated with other medicines.

Furthermore, it seems that risk may be more tolerated when choice is constrained. In many prescribing incidents, judgements about risk therefore reflected not only characteristics of the risk itself, but also its contingency in relation to other potential risks if the drug was withheld. In a number of circumstances, the rationalisation of prescribing rested on the notion that doing something was better than doing nothing. While an orientation to matching the patient to a particular drug underpinned these decisions, a new drug was prescribed as a default action when preferred alternatives had been exhausted. In other words, GPs chose to take a chance rather than to accept certain losses. At this early stage in its market life, rofecoxib was restricted to particular cases, rather than used as a first choice NSAID:

*It's not quite the last resort but it's not a routine, there's got to be a good indication so you tend to have worked your way through the options already. (GP23)*

Other strategies to reduce risk were to limit duration of prescription, and paradoxically in the light of the main reason to use it to reduce risk, restrict use to relatively healthy patients:

*I wouldn't prescribe a four-month course, but I'd perhaps give it to them for a week to see how they got on. (GP71)*

*Vioxx, I didn't have much problem there because most of the patients were otherwise healthy. It's when you're dealing with a sick patient and it's a totally new class of drug, then I would tend to think, wait until I've seen it being used or recommended by hospital colleagues. (GP87)*

*I tend to be a little cautious, but I suppose it depends what it's for. If it's something like Vioxx where it's a relatively sort of benign condition OK, but*

*I'd be much more cautious with new blood pressure tablets, or diabetic tablets or something like that. (GP91)*

Previous experience of prescribing NSAIDs without serious adverse consequences...

*Another anti-inflammatory maybe it's a slightly better side effect profile, but it's just another anti-inflammatory, we're confident with using them, give it a go. (GP36)*

...and the observation of local hospital practice also helped to minimize uncertainty.

In contrast, however, in a very small number of incidents, there appeared to be a lack of congruence between the situational context, as described above, and GPs' reasons for prescribing. This might be explained by the notion that individual interest and attitudes towards rofecoxib affect risk perception, the interpretation of evidence and the timing of new drug initiation. It would appear that thresholds for the management of uncertainty differ between individual GPs. For instance, some GPs preferred to proceed cautiously, adopting a 'play safe, wait and see' policy, while others were more willing to apply risks and prescribe in the absence of solid or legitimate evidence, in order to offer innovation to patients. In short, risk-taking was essentially accepted and viewed as an indivisible part of driving medical progress and providing opportunity for improved therapeutic benefit:

*It's risky but you have to have risk built into the system to make progress, you can't stop every conceivable risk. (GP31)*

*Some of them you just think 'right well, I'll give them a go!' I'll initiate those in my practice to see how they get on. Vioxx because it's the only drug in it's class (GP4)*

Acknowledging uncertainty, GPs saw their initial prescribing of rofecoxib as experimental, a process in which the benefits and risks were tested through personal experience:

*The first time I used it was in the mother of a local GP who came to me and said my daughter said I should I try this. I said, oh great, I was looking for a guinea pig to try it on... (GP43)*

Crucially, it was the outcomes of interventions such as this that served to establish GPs' notions of efficacy and which encouraged or discouraged further use:

*I've not been terribly impressed with the results that I've had so far. Obviously if something is effective in one patient, I'm more likely to try it in another. If I have a lukewarm response or they have a reaction to it, then I'm reluctant to start somebody else on it. (GP41)*

## Discussion

This study illustrates the factors that affect the uptake of an innovative new drug: a perceived therapeutic advantage or gap in the market particularly in regard to safety, a high level of pre-launch awareness perhaps due to intense direct marketing, hospital prescribing and GPs' attitudes to risk. At the same time, GPs did not articulate risks in quantitative, measurable terms, and their accounts suggest that a techno-scientific approach does not satisfactorily account for the ways in which GPs conceptualize and manage prescribing risks. Rather, the prescribing of rofecoxib can be situated and understood within a socio-cultural theoretical framework that reflects differing beliefs, values and experience in individuals' constructions of risk. The findings highlight the role of specific social and clinical contexts in which risk is interpreted and characterized, and the various strategies GPs use to manage risk and uncertainty. This is contrary to the assumptions reflected within the evidence-based medicine paradigm, which purports that clinical practice should be based on rigorous scientific enquiry and evaluation. The key dimensions underlying GPs' risk perceptions and their relationship to knowledge are considered below.

Prescribing was invariably subject to the specific circumstances of individual patients and their experiences with previous treatment. Initial prescribing of rofecoxib was clearly not based on extensive published clinical evidence but on "a strategy of desire" (Scott & Ferner, 1994), and optimism about clinical benefits and lack of harm as yet unproven (Dowden, 2003). More importantly 'tacit' knowledge derived from socially mediated forms of evidence and personal experience reduced uncertainty and formed the conceptual and practical base for much prescribing. The GPs' accounts here, therefore, reaffirm the distinction between the formal rationality of science and what has been termed 'the art of medicine' based on clinical judgement and methods of practical reasoning. This is characteristic of much clinical practice (Armstrong, 2002; Gabbay & leMay, 2004; Greer, 1988).

GPs' perspectives represent the competing elements to risk-taking. In effect, approaches to risk are frequently contested, with many prescribing incidents illustrative of the tension between constraint and opportunity, with decision-making dependent upon interpretation of the risk within the context to which it is applied. To a large extent, the interpretation of risk is inseparable from, and framed around, the everyday reality of specific clinical and patient contexts. In this sense, orientations to risk can be understood as rational and contingent. Concern over a deteriorating clinical situation, the severity of illness symptoms and the lack of, or failure of, treatment alternatives were seen to expose patients to specific risks and to influence the ways in which GPs viewed prescribing rofecoxib as being a risk or not. Thus, while the prescribing of a drug may still be perceived to contain some element of risk, uncertainty could be de-sensitised when there was pressure to make people well or when specific circumstances restrained choice. GPs' accounts of weighing up options, and the rationalities and practical reasoning engaged with in decision-making, provide evidence of the clinical reflexivity shown in responses to risk.

What is more, the research data shows that risk is a contained feature of new drug prescribing in that there were many prescribing contexts in which risk was not a cause for doubt for GPs. This was observed in relation to GPs' own risk-taking preferences or because, to some extent at least, risk is regulated and assessed through accumulated clinical experience and professional knowledge sources. In relation to the latter, an important dimension of risk relates to subjectively based perceptions of trust and credibility embedded in social interaction and professional relationships. In

negotiating uncertainty and risk, GPs demonstrated their investment of trust in sources of information they felt were reliable and credible, and in whose judgement they felt was safe.

Likewise, information itself does not have a straightforward, rational impact on risk perception, but is evaluated through filters of trust. In this vein, the plausibility of others' prescribing was a specific target for trust, a common source being the hospital consultant. The essence of this is that evaluation of risk is a product of the interpretation of the information source and depends not simply on what is being communicated, but *who* communicates it. GPs frequently constructed risk perception on their knowledge and empirical observations of hospital prescribing and the clinical behaviour of others around them. These were frequently taken as expressions of assurance that GPs relied upon. This is reminiscent of Luhmann's (1979) description of trust as the "blending of knowledge and ignorance." In ascribing this perspective to clinical practice, trust is a way of negotiating uncertainty and complexity in the absence of scientific assurances. It is such findings that draw attention to the ambiguous nature of both knowledge and risk. This is also seen in the way that the relative benefits of rofecoxib were frequently interpreted on the basis of individual beliefs and attitudes and various implicit norms and systems of judgement, such as perceived information credibility; situated observation and clinical contexts; and embedded knowledge developed and internalized through prior prescribing of similar drugs and direct personal 'trailing'.

Evidence and risk are thus interpreted along a number of dimensions, which are predominantly informal and social, rather than scientific or technical, in character. This should perhaps not surprise us, and it may be argued that within the context of new drug prescribing, employing scientific rationality as a basis for certainty counteracts the possibility of improved therapeutic benefit. Since measurable objective risks and the safety of a new drug cannot be entirely specified and guaranteed at its launch, the need for reflective practice and clinical interpretation is inevitable if doctors are not to become paralysed by uncertainty. Equally of course, risk evaluations based on contextualised informal knowledge and reflective experience may not lead to "optimal" drug choice because of the tendency for selective interpretation of information.

In addition, these findings substantiate previous work on the diffusion of innovation in clinical practice in that they highlight the concept of a product's relative advantage, experiential testing and the role of social influence and local practice in decision-making (Coleman, et al., 1957; 1966; Greer, 1988; Fitzgerald, et al., 2002; Rogers, 1995). However, this study also reveals the importance of marketing, generally absent from diffusion models. Marketing not only raised awareness, but also influenced individual decision-making. Two recent North American studies have also shown this in relation to the coxibs: the first from Canada (Klein, et al., *in press*) showed in addition that availability of free samples to doctors was important to allow them to trial a drug in an individual patient, where patient co-payments were a disincentive. The second (Alexander, et al., *in press*) documents the peaks of intensive promotional activities initially to gain a place in the market, and later apparently intended to counter growing concerns about the risks of these drugs.

The reasons for GPs' application of information from representatives have been explored elsewhere (Prosser & Walley, 2003). Some GPs acknowledged their dependence on commercially driven information and gave what could only be a normative response, suggesting that the respected *Drugs and Therapeutics Bulletin* had been their source of information: in fact this journal published nothing on

rofecoxib until after our data collection, in November 2000 (Anon, 2000). That 75% of GPs in this sample had prescribed rofecoxib within six months of its launch illustrates the speed with which use of a drug can disseminate. However the use of rofecoxib stabilised over the next two years and it achieved 12% of the total market by volume (about 200,000 of the 1.7 million prescriptions in England for all NSAIDs dispensed in September 2004, and about half of all Cox 2 inhibitor prescriptions). Other countries reported more dramatic market penetration by Cox-2 inhibitors – over 50% of the market by number of NSAID prescriptions within one month of approval for reimbursement in Australia (Kerr, et al., 2003), and 40% at peak in the United States (Villaneuva , 2003). This relatively low use in England might be related to a number of factors including: confusion over how real the gastrointestinal benefits of Cox-2 inhibitors were; advice from the National Institute of Clinical Excellence (National Institute for Clinical Excellence, 2001), suggesting that these drugs should be restricted to high risk patients; uncertainty in cardiovascular disease; and the relative high cost of the drug and budgetary pressures on GPs.

A limitation of this study is that we relied on GPs' subjective recall of prescribing events. Their disclosure of contributory factors may perhaps be prejudiced by normative responses, as seen in some cases. Nevertheless, this is somewhat overcome by the validity of the critical incident technique which uses specific factual prescribing contexts, an interview structure that is probing and interactive, and because the interviews followed closely behind the actual prescribing events. This study is based on interviews conducted some years ago and it is not clear whether views about new drug uptake and its hazards have changed since, in particular since the high profile withdrawal of rofecoxib and new evidence undermining the perceived, but unproven, benefits of other established therapies (Minelli, et al., 2004). At the same time, there has been a growing awareness of, and unease about, the role of marketing with themed issues of the *British Medical Journal* and the development of organisations such as No Free Lunch (<http://www.nofreelunch-uk.org>) and Healthy Skepticism (<http://www.healthyskepticism.org/index.htm>), dedicated to promoting better understanding of marketing.

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**Table 1 – Reasons for prescribing rofecoxib in 67 GP initiated prescribing episodes** (more than one reason cited in many cases)

<b>Readiness to prescribe - Relative advantage</b>	
Better side-effect profile	35
Efficacy	8
Existing therapy sub-optimal	47
<b>Evidential sources</b>	
Pharmaceutical industry	35
Rep	30
Adverts/mailings	6
Hospital Doctor	30
Observation	11
Knowledge of consultant prescribing	10
Meeting or conference addressed by consultant speaker	9
BNF/MIMs	3
GP press	14
GP colleague	3
Journal	2
Pharmacist (local)	1
Pharmacist (hospital)	1
Patient request	11

## References

- Adams, J. (1995) *Risk*. London: UCL Press
- Alexander, G.C., Majumdar, S.R., & Stafford, R.S. Promotion and prescribing of coxibs during accumulating evidence of risk. *PLoS* (in press)
- Anon. (2000). Are rofecoxib and celecoxib safer NSAIDs? *Drugs and Therapeutics Bulletin*, 38, 81-86
- Armstrong, D. (2002) Clinical autonomy, individual and collective: The problem of changing doctors' behaviour. *Social Science and Medicine*, 55(10), 1771–1777.
- Beck, U. (1992) *Risk Society*, London: Sage
- Bloor, M. (1976) Bishop Berkeley and the adenotonsillectomy enigma: An exploration of variation in the social construction of medical disposals. *Sociology*, 10: 43-61.
- Bombardier, C., Laine, L., Reicin, A., Shapiro, D., Burgos-Vargas, P.H. R., Davis, B., Day, R., Bosi Ferraz, M., Hawkey, C.J., Hochberg, M.C., Kvien, T.K., & Schnitzer, T.J. (2000) Comparison of upper gastrointestinal toxicity of rofecoxib and naproxen in patients with rheumatoid arthritis. VIGOR Study Group. *New England Journal of Medicine*, 343, 1520-1528.
- Chell, E., (1998) The critical incident technique in *Qualitative Methods and Analysis in Organisational Research: A practical Guide*. G. Symon & C Cassells (Eds.) Thousand Oaks, CA; Sage.
- Clarke, W., Fisher, M., & Misson, J. (1998) Data available before products are launched are poor. *Letter to the British Medical Journal*, 316, 228.
- Coleman, J., Katz, E., & Menzel, H. (1966) Medical innovation: A diffusion study. Bobbs-Merrill.

- Coleman, J., Katz, E., & Menzel, H. (1957) The diffusion of an innovation among physicians. *Sociometry*, 20(4), 253-270.
- Dent, T.H., & Hawke, S. (1997) Too soon to market. *British Medical Journal*, 315:1248-9
- Douglas, M. (1986) *Risk Acceptability According to the Social Sciences*, London: Routledge
- Douglas, M., & Wildavsky, A. (1982) *Risk and Culture*, Berkeley: University of California Press.
- Dowden, J. (2003) Coax, COX and cola. *Medical Journal of Australia*, 179, 397-8.
- Ferner, R.E. (1996) Newly licensed drugs. *British Medical Journal*, 313, 1157-1158.
- Fitzgerald, L., Ferlie, E., Wood, M. & Hawkins, C. (2002) Interlocking interactions, the diffusion of innovations in health care. *Human Relations*, 55(12); 1429-1449.
- Flanagan JC. (1954) The critical incident technique. *Psychological Bulletin* , 51: 327-358.
- Gabbay, J., & le May, A. (2004) Evidence-based guidelines or collectively constructed “mindlines?” Ethnographic study of knowledge management in primary care. *British Medical Journal*, 329, 1013-1027.
- Gabe, J. (1995) Health, medicine and risk: the need for a sociological approach. In J. Gabe (Ed.) *Medicine, Health and Risk*, Blackwell Publishers Ltd: Oxford.
- Gale, E.A. (2001) Lessons from glitazones: a story of drug development. *Lancet*, 357, 1870-75.
- Gibson, L. (2004) Spanish drug editor wins case brought by Merck, Sharp & Dohme, *British Medical Journal*, 328, 307.
- Giddens, A. (1991) *The Consequences of Modernity*, Cambridge: Polity Press
- Greer AL. (1988) The state of the art versus the state of the science: the diffusion of new medical technologies into practice. *International Journal of Technology Assessment in Health Care*, 4: 5-26.
- Kerr, S., Mant, A., Horn, F., McGeechan, K. & Sayer, G. (2003) Lessons from early large-scale adoption of celecoxib and rofecoxib by Australian general practitioners, *Medical Journal of Australia*, 179, 403-407.
- Klein, D., McDonald, A., Drummond, N., & Cave, A. (In press) A qualitative approach to determine factors influencing coxib prescribing for musculoskeletal disorders in Alberta Canada. *Family Practice*
- Luhmann, N. (1979) *Trust*, Chichester: John Wiley.
- Lupton, D. (1999) *Risk*, London: Routledge.
- Maxwell, S.R.J., & Webb, D.J. (2005) COX-2 selective inhibitors—important lessons learned. *Lancet*, 365, 449-451.
- Minelli, C., Abrams, K.R., Sutton, A.J., & Cooper, N.J. (2004) Benefits and harms associated with hormone replacement therapy: clinical decision analysis. *British Medical Journal*, 328,371.
- National Institute for Clinical Excellence. (2001) *Guidance on the use of cyclooxygenase (COX) II selective inhibitors, celecoxib, rofecoxib, meloxicam and etodolac for osteoarthritis and rheumatoid arthritis*. London: NICE, 2001
- National Institute for Health Care Management Research and Educational Foundation. (2000) *Prescription drugs and mass media advertising*. Washington: NIHCM Foundation,
- Nelkin, D. (1989) Communicating technological risk: The social construction of risk perception. *Annual Review of Public Health*, 10, 95-113.
- Pitt, M. (January 2002) MSD: Vioxx/Rofecoxib - achieve a 95% level of awareness

- [http://www.allaboutmedicalsales.com/pharmareview/january\\_02.html](http://www.allaboutmedicalsales.com/pharmareview/january_02.html) Accessed 10th Feb 2006.
- Prosser, H., Almond, S., & Walley, T. (2003) Influences on GPs' decision to prescribe new drugs – The importance of 'who says what'. *Family Practice*, 20, (1) 61-68.
- Prosser, H., & Walley, T. (2003) Understanding why GPs see pharmaceutical representatives: a qualitative interview study. *British Journal of General Practice*, 53(4): 305-11.
- Rawlins, M.D., & Jeffreys, D.B. (1991) Study of United Kingdom product licence applications containing new active substances, 1987-9. *British Medical Journal*, 302, 223-5.
- Richards L. (1999) Using NVivo in qualitative research. Bundoora, Victoria, Australia: Qualitative Solutions and Research.
- Rogers, E.M. (1995) *Diffusion of Innovations*. New York: The Free Press.
- Scott, D.K., & Ferner, R.E. (1994) 'The strategy of desire' and rational prescribing. *British Journal of Clinical Pharmacology*, 37, 217-9.
- Strauss, A., & Corbin, J. (1998) Basics of qualitative research: Techniques and procedures for developing grounded theory. London: Sage Publications.
- Villaneuva, P., Peiro, S., Librero, J., & Pereiro, I. (2003) Accuracy of pharmaceutical advertisements in medical journals. *Lancet*, 361, 27-32.
- Wu, Y., & Makuch, R. (2006) Detecting rare adverse events in post-marketing studies: sample size considerations. *Drug Information Journal*, 40, 89-98.

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## Suffering Sociologists and the Sociology of Suffering

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*'He cried in a whisper at some image, at some vision – he cried out twice, a cry that was no more than a breath – "The horror! The horror!"'* (Conrad 1973: 100).

Suffering has been on my mind recently. It started with the spontaneous eruption of a very painful knee while travelling to attend the 38<sup>th</sup> Annual Conference of the BSA Medical Sociology Group at Heriot-Watt University. During the course of the next two days the pain and stiffness in my knee increased to a point where I was having difficulty walking, getting in and out of a chair, and putting on and taking off my trousers, shoes and socks. Hobbling to and from meetings and conference presentations, trying out all kinds of face-work techniques, but still feeling very sorry for myself, you can imagine how uplifted I felt by the news that the 2006 SHI Book Prize had been won by Iain Wilkinson for his book, *Suffering: a Sociological Introduction*.

Suffering has many meanings, or at least many usages. On the one hand, it may be employed lightly as part of everyday speech about what are called common complaints. For example, someone might say: 'I have been suffering from a bad cold'. Or in a consultation about a painful joint the doctor may ask: 'Have you ever suffered from gout?' In these instances the term is being used to refer to the experience of symptoms, unpleasant perhaps, but not something which stretches the limits of our imaginative grasp. On the other hand, there is something altogether heavier and darker, something to do with extreme pain or harsh and brutal conditions and experiences, something that we might think of as 'real suffering'. Some of these sufferings are of a catastrophic kind that it would be very difficult for us to imagine happening to us here and now, where we live. Others are more mundane, more everyday, but no less painful and distressing; things that just might happen to us at some time.

When we read or watch accounts of the experience of war and its consequences we are confronted by unbearable suffering. For those of us leading the comfortable life of the British middle class, television reports from Darfur and from Lebanon in recent months have been of this order. Similarly, two vivid historical accounts which I found almost too painful to read to their conclusions, in spite of the authors' storytelling skills, were an account of the Battle of Stalingrad (Beevor 1999) and a study of the Soviet Gulag (Applebaum 2003). One of the puffs on the back of Applebaum's book comes from a review in the *Spectator* magazine: 'This book is a monument to their [the Gulag inmates'] suffering, and to read it is to honour that suffering'. Suffering, in this sense, is something very big – in terms of both demographic scale and human intensity – and, as the review of Applebaum indicates, the readers are invited to feel that they too are participating in something important. Even more powerful, perhaps, are those studies, often autobiographical, which not only document examples of large-scale suffering but examine and reflect upon the meaning of suffering as such, as in the work of Primo Levi (1989). Other examples relate to things that are more personal, such as the experience of the loss of a loved one (see,

for example, Oz 2004 and McGahern, 2005, both of whose mothers died – the one from suicide, the other from cancer - when they, the boys and their mothers, were still young). These are not directly related to the clash of States and peoples in war (though Oz, in particular, makes the connections) but to the mundane events and petty cruelties of everyday life in particular times and places. If the writers had not told their stories we would not know anything about them.

The history of sociology, particularly medical sociology, is replete with studies of the sufferings of everyday life. There have been numerous explorations of pain, symptoms, chronic diseases and disabilities, loss, separation, disruption, upheaval, neglect and injustice ‘from the sufferer’s point of view’; and endless discussions about how to conceptualise, interpret and explain these things in ways that are properly sociological rather than clinical, psychological or journalistic. However, the confrontation with ‘suffering’ head-on has been a relatively specialised interest, even within medical sociology. The starting point for Iain Wilkinson’s prize winning book is that general sociology has steered clear of suffering altogether, and sub-disciplines like medical sociology have, for the most part, only addressed it incidentally. But does suffering need a sociological introduction? And does sociology need the concept of suffering?

Wilkinson, whose book has been ‘written as an invitation to dialogue and debate’ (ix), is not of course the first sociologist to enter this territory, as he himself acknowledges. Within medical sociology (which, for my purposes, includes medical anthropology), the field has been developed already by Arthur Kleinman (1988), Arthur Frank (1995) and others, over a number of years, moving from narratives of chronic illness to something that we might, or might not, want to call suffering. In Frank’s work suffering is not only difficult to imagine, it is difficult to speak about. It (whatever ‘it’ may be) appears to resist definition or representation, it is unspeakable or, to use an old religious word, ineffable. It is Joseph Conrad’s heart of darkness where Kurtz can only whisper: ‘The horror! The horror!’ or Edvard Munch’s iconic ‘Scream’. Wilkinson takes the work of Frank, Kleinman and many others from outside medical sociology, and uses it to explore the question of whether sociology is able to support the development of forms of thinking and imagination that enable us to understand the sufferings of others and to take action. The challenge for us as human beings and sociologists, is to confront the difficulties of ‘thinking with suffering’, using the experiences and accounts of people who have suffered to provide the material out of which more general sociological accounts can be developed. It is clearly not the case, as some have suggested, that suffering defies representation: think of hymns, psalms, blues, gospel, soul, poetry, living traditions of religious and artistic expression. What is clear, however, is that certain forms of representation characteristic of Enlightenment rationalism are not adequate vehicles for this task; and this clearly poses difficulties for a discipline that has emerged from the Enlightenment, and which depends on taking people’s talk about particular experiences and transforming them ‘scientifically’ into more general analytical categories.

And there’s the rub. None of the examples I have referred to from history or autobiography, except perhaps Primo Levi, could be said to be *about* suffering as such. They are all *informed* by suffering; they are not taking it as an object and developing general sociological accounts about it. The large-scale sufferings documented by Applebaum and Beevor, and the minute sufferings of the young Oz and McGahern are rigorous, scholarly and, in different ways, well ‘evidenced’ (as far as I am able to judge), but each account is also written with the kind of narrative drive

that is fuelled not only by evidence and theory, but also by deep moral sentiments and political commitments. One of the key arguments of Wilkinson's book is that sociology needs to reconnect with an intellectual tradition of moral sentimentality, from Adam Smith onwards, that permits compassion and sense of justice to be an integral part of sociological analysis. Perhaps the best modern example of an attempt to recapture this is Pierre Bourdieu's later work on 'social suffering', where he helps us to see that under conditions of globalisation the 'weight of the world' oppresses people and causes them to suffer in numerous ways, even where they are not starving to death or being brutalised by the State. If the concept of suffering helps us to make more visible the connections between social and economic change and the fabric of everyday life, experiences of poverty, homelessness and incapacity, and to write about them more powerfully than it seems to me that we should welcome it. If it deflects us into the vortex of subjectivity, then it seems to me that we are engaging with experiences that are better dealt with by poetry.

## References

- Applebaum, A. (2003) *Gulag: a History of the Soviet Camps*, Harmondsworth: Penguin
- Beevor, A. (1999) *Stalingrad*, Harmondsworth: Penguin
- Bourdieu, P. (et al) (1999) *The Weight of the World: Social Suffering in Contemporary Society*, Cambridge: Polity
- Frank, A. (1995) *The Wounded Storyteller: Body, Illness and Ethics*, Chicago: University of Chicago Press
- Kleinman, A. (1988) *The Illness Narratives: Suffering, Healing and the Human Condition*, New York: Basic Books
- Levi, P. (1989) *The Drowned and the Saved*, London: Abacus, Sphere Books Ltd
- McGahern, J. (2005) *Memoir*, London: Faber
- Oz, A. (2004) *A Tale of Love and Darkness*, London: Chatto & Windus
- Wilkinson, I. (2005) *Suffering: a Sociological Introduction*, Cambridge: Polity

## Suffering: The Elephant in Medical Sociology's Closet

### A complementary response to Gareth Williams.

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In Gareth Williams's observation that "the confrontation with suffering head-on has been a relatively specialised affair, even within medical sociology", I hear irony in the understatement of "relatively" and "even". As a philosophical thought experiment, I can entertain a possible utopia in which illness and injury still require medicine, but suffering has been effectively eliminated. Returning to *this* present world and most future-possible worlds, medicine is more than a response to illness; it's a response to suffering. Medical sociology takes its reason for being from the reality of suffering, and that renders ironic Williams's observation about lack of confrontation head-on. Suffering is medical sociology's elephant in the closet because it's there, it's big, it's what everybody is most worried about (would illness without suffering worry us half as much?), but it's what medical sociologists too often keep behind a closed door. Why hasn't the head-on confrontation with suffering been medical sociology's first order of priority?

As Williams notes, sociologists seek to generate "general analytical categories". This disciplinary telos arguably has a diminishing constituency, but dissenters are still a bit radical. General analytic categories have always been purchased at the price of sacrificing particularity, and to suffer is to feel isolated in one's particularity. To neglect particularity is to lose what makes the experience suffering. Particularities do have observable commonalities, and there's the tension: how to observe what is shared in common, and thus to compare sufferings, without dishonouring what is incomparable? The issue of what sociologists ever gain by generating any general analytic categories is especially difficult when studying suffering.

The complementary problem with analytic categories is that they wash out the emotional response in which humans recognize suffering. As I read about Williams's pain in his knees, I wince with the embodied memory of my own bad-joint weeks. Other stories elicit stronger responses. I write this commentary after what has been a bad healthcare week in Calgary. For the third time in several months, a woman has been forced to sit in the public waiting room of a hospital emergency department while she miscarried. Those who were also waiting for treatment sat in the crowded room and were forced to watch—some tried to help—as she hemorrhaged. Her husband pled for help and was told to return to his seat. As I read this story in my newspaper—actually several stories with common details—before I can name any feelings or identify thoughts, my body reacts; later I call that reaction a mix of anger, fear, pity and sadness. Later still, I begin to think about the network of actors—from triage nurse to Minister of Health—who routinised the possibility of that scene (Rankin and Campbell 2006).

Sociological thoughts morph into ethical ones: who is *responsible* for something like this happening, and now happening repeatedly? What kind of people are we who live in this city, that we tolerate one of our neighbors being treated this way? Sociology should be an important part of these thoughts, but the sociological part makes sense only among the other parts. By themselves, the sociological thoughts sound too much like the administrative apologies that reduce a person's suffering to

rationalisations of workloads, flow-through and *throughput*, one of the newest North American healthcare buzzwords, and not itself a bad idea, until its demands silence individual suffering.

A third reason why medical sociology has difficulty confronting suffering head-on is that any *study of* suffering is necessarily a *response to* that suffering. To confront head-on is more than to do research; it's an *encounter* in the existential sense. To encounter the suffering of the other is to experience a moral demand, a responsibility to what philosopher Emmanuel Levinas called the *face* of that other (Frank 2004). Sociology is uncomfortable with moral demands; these are at most objects of study. But to encounter suffering is to be called to take a stand on what are better or not as good ways to suffer *and* to respond to suffering (Kleinman 2006). Sociologists have good reason to avoid taking such stands, at least while acting as sociologists. Heretofore, little in the training of most sociologists makes them feel competent to engage moral positions as matters of morality. Sociology prefers technical accounts in which the data themselves are understood to indicate a direction of action—Durkheim's dream—thus finessing the need to take any moral stance. As a discipline, sociology might think about that, in terms of what training prepares our students to offer the kinds of responses that sociology's public expects in this new century.

My final reason for sociology's difficulty in confronting suffering is that such an encounter requires standing on the edge of what Williams calls "the vortex of 'unspeakable' subjectivity". Poised on that edge, it's easy to feel as Williams does, that such experiences are better dealt with by artistic forms of representation; or I'd add, better left to the voices of those who have suffered and survived long enough to speak of it. I believe those who would study suffering must approach that edge and stand there for long enough, because otherwise we betray what we should be honouring in our studies. But then the work of sociologists is to pull back, recognizing that sociology's task is what Williams aptly describes as making more visible the connections in which suffering is embedded. My own interest has been in connections between different stories of suffering, and connections between what happens to storytellers' bodies and what narrative resources they have available to create what they represent as *experience*. Other connections involve medicine and its technologies and economies; connections spread through the differential willingness of communities to recognize suffering and the ethics that shape those communities' responses.

I hope the award of the SHI Book Prize to Iain Wilkinson marks a new willingness of medical sociologists to bring the elephant out of the closet. That work is well underway; for a review of several recent sociological monographs that, in my judgment, confront suffering head-on, see Frank 2006. As more sociologists research suffering, I would offer one caution. The impulse of modernity is to seek to tame suffering; to conceal it in institutions and reduce it to its traces. Sociology, as a preeminently modernist undertaking, risks participating in that impulse to tame. Instead, we should be studying that impulse and resisting it.

I have sat through too many medical psychosocial PowerPoint shows in which suffering was reduced to so many stages, each with a slide's worth of bullets. Those presentations serve an administrative interest in creating an accountable to-do list. Whatever does not make the list—the true *mess* of suffering (Law 2004)—is rendered Other, unspeakable, and not that professional group's responsibility. Encountering suffering will be a mess, not least because it will precipitate slipping, and sometimes falling headlong, over the line that separates sociology from subjectivity, and poetry,



and ethics. But how long can you keep quiet about the elephant that is already in the room?

October 10, 2006

Note: In a recent issue of *The Hedgehog Review* (Geddes, Davis, and Frank 2006), social scientific responses to suffering are placed among artistic and poetic responses and representations. If we are successful, each part makes better sense within that whole.

## References

- Frank, A.W. (2004) *The Renewal of Generosity: Illness, Medicine, and How to Live*. Chicago IL, University of Chicago Press.
- Frank, A.W. (2006) At the margins of health: Qualitative methods and practice. *Qualitative Sociology*, 29(2): 241-251.
- Geddes, J.A., Davis, J.E. and Frank, A.W. (2006) Special issue on *Illness and Suffering*, *The Hedgehog Review*, 8(3), Fall. Institute for Advanced Studies in Culture, University of Virginia.
- Kleinman, A. (2006) *What Really Matters? Living a Moral Life Amidst Uncertainty and Danger*, New York, Oxford.
- Law, J. (2004) *After Method: Mess in Social Science Research*, London & New York, Routledge.
- Rankin J.M. and Campbell, M.L. (2006) *Managing to Nurse: Inside Canada's Health Care Reform*, Toronto and London, University of Toronto Press.

## The Problem of Suffering as a Problem for Sociology

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I am grateful to the editors for devoting some space to comments on my book *Suffering: A Sociological Introduction* and to Gareth Williams for his initial thoughts about this work. His opinion piece highlights two of the core problems that I present for further dialogue and debate. Firstly, there is the problem of how we might venture to conceptualise the brute facts of human suffering. Secondly, there is the matter of the forms of thinking and inquiry whereby these might be brought within the frameworks of sociological research and understanding.

Williams notes that, following writers such as Arthur Frank (2001), Arthur Kleinman (1991, 1995, 1999) and Pierre Bourdieu (1999), my work dwells in some detail on the ways in which symbolic forms of communication always appear to fall short of expressing what suffering actually 'is' in human experience. Quite rightly, he points out that, one would be quite wrong to understand such difficulties as a sign that suffering defies cultural representation. What is at stake here is the *adequacy* of words, music and visual imagery for conveying the existential character and moral meaning of human suffering. A great deal of our culture is devoted to the expression of suffering; but it seems that we are always left struggling to account for the existential and moral sufficiency of our attempts to make proper sense of this experience.

I do not believe that this is a peculiar problem for a post-Enlightenment culture; rather, it seems to me that the record of human history always speaks of humanity struggling to bring a sufficient meaning to the experience of suffering. Following Weber, I regard the problem of suffering as a constant spur within the dynamics of contrasting modes of rationalisation across and within cultures. However, I am inclined to understand some of the social and cultural processes implicated within the event of Enlightenment and subsequent conditions of modernity as giving rise to a heightened sensibility towards the conceptual and ethical failings of our shared attempts at communicating what suffering does to people. In this sense, the problem of suffering understood in terms of the difficulty of assigning a proper meaning to extreme forms of pain, appears to be more widespread and acute in our times. In my book I work to remind readers that this understanding is a component of Marx's thinking on the experience of alienation and immiseration, Weber's account of the social psychology of modern rationality and Durkheim's conception of the anomic division of labour in society. Accordingly, I present the social and cultural constitution of our sensitivity towards the problem of suffering as a neglected matter of analysis in classical sociology. It is this which leads me to suggest that a critical sociology of suffering would involve attempts at tracing out the ways in which our ongoing struggles to make suffering productive for thought and action contribute to broader dynamics of social and cultural change. I argue that the ways in which individuals and groups struggle to make sense of suffering should be *revisited* as a topic of sociological inquiry in its own right.

I hold back from suggesting that it might be possible for sociologists to piece together an adequate account of human suffering; rather, I seek to address the *difficulty* of realising this endeavour as a matter of sociological interest. In no way do

I intend to devalue the efforts made by writers such as Nancy Scheper-Hughes (1992; 1998) and Veena Das (2001) to highlight the (seemingly) more or less productive ways in which people “bear witness” to experiences of suffering so as to achieve a measure of cultural healing. Indeed, I am greatly concerned for social researchers to work at furthering our understanding of the potential for the bodily experience and psychic trauma of suffering to be moderated and modified through the lens of culture. However, it seems to me that the scope of research and writing on matters of ‘social suffering’ should not be limited to this interest. I would encourage a more elaborated analysis of the particular ways in which, it is not so much due to the cultural achievement of conveying the meaning of human suffering, but more as a consequence of making clear the crushing sense of *failing* to provide an adequate address for suffering that wider questions of humanity are brought to bear on the moral values enshrined within our individual actions, institutional behaviours and political decisions.

With this project in mind, I suggest that Hannah Arendt’s attempts to make sense of the “evil of totalitarianism” can be regarded as an example of the “critical praxis” of writing on suffering (Arendt 1951; 1994). I argue that her style of writing is designed to appeal to a shared sense of the difficulty of understanding what suffering does to people under the conviction that, this amounts to an opportunity to advance new terms of ethical and political debate. I note that Arendt displays a great sensitivity towards the ways in which our adopted styles of writing might be fashioned to either open up or deny space for a critical questioning of the moral meaning of harrowing events in human history. Moreover, I argue that it is with a particular interest in the practice of writing as a form of moral engagement with the existential meaning of human suffering that Pierre Bourdieu explains the wider purposes of his work in *The Weight of the World*.

I am prepared to stand alongside these writers in the hope that the practice of sociological writing about human suffering serves to render “visible” the dynamics of society, economy and culture in terms of their human consequences and costs to humanity. I believe that this should draw us to openly acknowledge the “unspeakable” subjectivity of those with experiences of extreme suffering. I argue that the value of such writing may well lie in the ways we are provoked by the failings of our endeavour to debate with the human/moral meaning of the “brute facts” of the harms we inflict on one another. I contend that the intellectual and ethical tensions borne under the failure to provide an adequate address for suffering have the potential to invigorate critical debate over the forms of society and culture in which we are made to live. I further believe that this incorporates a critical questioning of the social and moral value of academic sociology.

It seems to me that such practices are already well established within the cultural politics of modern humanitarianism. I understand these to have a long history that finds expression within the value placed by key figures of Enlightenment on *feeling for humanity* (a neglected theme within sociological accounts of this era). Where my thesis turns to raise questions about the enduring sociological value of intellectual traditions of debate on moral sentimentality, this is with a mind to establish grounds for re-invigorating methods of sociological and critical inquiry into the current force and manifestations of compassion within the public realm. There are many forms of

appeal to human suffering as a means to challenge modes of political decision, professional practice and policy formation. Indeed, in our times, it seems that some of the greatest expressions of political solidarity are mobilised with the aid of carefully crafted cultural representations of extreme violence and pain. It is under the conviction that a sociological voice should be heard within these arenas that my work is offered as an encouragement to further research, thinking and debate.

## References

- Arendt, H. (1951) *The Origins of Totalitarianism*, New York: Meridian Books
- Arendt, H. (1994) *Understanding and Politics (The Difficulties of Understanding)*, in *Essays in Understanding 1930-1954*, New York: Harcourt Brace & Co, pp.307-27
- Boudieu, P et al (1999) *The Weight of the World: Social Suffering in Contemporary Society*, Cambridge: Polity
- Das, V., Kleinman, A., Ramphela, M., Lock, M. and Reynolds, P. (eds) (2001) *Remaking a World: Violence, Social Suffering and Recovery*, Berkeley: University of California Press
- Kleinman, A. (1999) 'Experience and Its Moral Modes: Culture, Human Conditions and Disorder', in Peterson, G. B. (ed) *The Tanner Lectures on Human Values*, Salt Lake City, University of Utah Press
- Kleinman, A. and Kleinman, J. (1991) 'Suffering and its Professional Transformation: Toward an Ethnography of Interpersonal Experience', *Culture, Medicine and Psychiatry*, 15(3): 275-301
- Kleinman A. and Kleinman, J. (1997) 'The Appeal of Experience; The Dismay of Images: Cultural Appropriations of Suffering in Our Times', in Kleinman, A., Das, V. and Lock, M. (eds) (1997) *Social Suffering*, Berkeley: University of California Press
- Frank, A. W. (2001) 'Can we Research Suffering?', *Qualitative Health Research*, 11(3): 353-62
- Scheper-Hughes, N. (1992) *Death Without Weeping: The Violence of Everyday Life in Brazil*, Berkeley: University of California Press
- Scheper-Hughes, N. (1998) 'Undoing: Social Suffering and the Politics of Remorse in the New South Africa', *Social Justice*, 25(4):114-42
- Wilkinson, I (2005) *Suffering: A Sociological Introduction*, Cambridge: Polity

## Shoulder to Shoulder: a Rejoinder to Arthur Frank and Iain Wilkinson

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The serious tone of Arthur Frank's and Ian Wilkinson's responses to my 'opinion' is most welcome, as is this opportunity to write a rejoinder.

While a great deal of our culture embodies expressions of suffering, 'what is at stake', argues Wilkinson, 'is the *adequacy* of words, music and visual imagery for conveying the existential character and moral meaning of human suffering'. There is, in other words, an insufficiency in our attempts to make sense of experiences of suffering. Frank is quite blunt: although medicine is a response to suffering (whether or not the behaviour of doctors suggests this), and although medical sociology takes its reason for being from the reality of suffering, this reality remains 'the elephant in medical sociology's closet'. Both Frank and Wilkinson think that the acknowledgement of and confrontation with something called suffering is important in itself, and both seem to feel that something like a 're-moralisation' of sociology is important in order to be able to produce a critique of existing society that is informed by a 'feeling for humanity'.

It is not my intention here to track, attack or refute the arguments presented line by line, and there is much with which I agree, but a few comments seem to me to be in order. First, I am not convinced that it is actually the case that sociology in general and medical sociology in particular has failed to give adequate attention to suffering. As I indicated in my starting-point, the social sciences are full of empirical studies of things which give rise to suffering, or can be seen as forms of suffering in themselves. If the word 'suffering' itself is not common within sociological analysis, this may be because what Frank rightly refers to as the *very particularity* of sufferings makes any general concept of suffering inadequate. Secondly, it seems to me that what was important about the 'classical' concepts originating in the work of the 'founding fathers' of sociology – alienation, anomie, disenchantment or, indeed, stigma – was that they were, in their different ways, attempts to shift the focus from individuals and the cosmos to the dramatically changing social and economic structures, and forms of social interaction, by which those individual lives were being shaped. This is what made sociology something other than a big psychology or a secular theology. Although much of this work was a study of and a response to suffering, as Wilkinson notes in his book, it was recognised that interpreting and changing the world required disciplined philosophical or scientific analysis and political organization, alongside appeals to moral responsibility and the pursuit of what was thought to be good.

Nonetheless, I agree with both Frank and Wilkinson that academic sociology has in many ways exited the stage (left and right!) as far as the humanitarian response to sufferings in personal and public life are concerned. There are, no doubt, many reasons for this. At the institutional level, at least in the UK, social scientists are tied into processes of audit and assessment that make forms of engagement beyond those that bring money or professional reputation into their institutions difficult to sustain. At the intellectual level we seem to have entered a phase of hyper-rationalisation embodied by phrases like 'policy-relevant' and 'evidence-based'. While I am not

against the social sciences providing evidence for professional practice or policy development – indeed, I seem to spend a lot of my time doing this – the outcome can too often be technical accounts in which, as Frank puts it, ‘data themselves are understood to indicate a direction of action’; and sadly, *contra* Frank, I would say that those who think like this seem to be a growing rather than a ‘diminishing constituency’. The dominance of technical knowledge-constitutive interests, as Habermas (1972) referred to them, appears to release the social scientist from any requirement to consider the grounds of rationality, as did Weber, the interrelationship of morality and society, as did Durkheim, the engine of economic interests in society that Marx so powerfully critiqued or, indeed, any of the other manifestations of power and domination that have been explored by feminist, radical and critical sociologists over the last forty years.

So what is to be done? Frank argues that the impulse of modernity is not to alleviate sufferings but ‘to tame suffering; to conceal it in institutions and reduce its traces’, and that we should be studying that impulse and resisting it. I think this is similar to what Wilkinson means by emphasising the *difficulty* involved in piecing together accounts of human suffering, and the need for sociology to address this. Against this background, we clearly need something additional to powerful, emotionally-charged attempts to ‘bear witness’, of which there are now many examples, including the important work of Frank himself. Wilkinson argues that we need a ‘critical sociology of suffering’ involving us, as social scientists, in attempting ‘to make suffering productive for thought and action’.

How do we do this? It is clearly not simply a technical problem of method. It is a question of sociological imagination. Following Wilkinson, as he has followed Hannah Arendt and Pierre Bourdieu, we might say it requires the development of a ‘critical praxis’ of writing on suffering which opens up rather than closes down our engagement with the moral meaning of harrowing events in human life and history. Yes, but *how do we do this?* How do we do this unless we situate our critical praxis within some larger framework or narrative of ethics, politics and epistemology? And this is not easily done. If ‘God is dead and we have killed him’, as Nietzsche proclaimed: ‘Are we not perpetually falling? Backward, sideward, forward, in all directions? Is there any up or down left? Are we not straying as through an infinite nothing? Do we not feel the breath of empty space?’ (Nietzsche, 1974: 125). Bearing in mind the need to interpret this declaration very carefully, the intellectual and political drift prophesied by Nietzsche seems even more alarming now at a time – although not the first time – when the empty space seems to be filled not by constructive political engagement with human problems, globally and locally, but by various fundamentalist forms of the ‘will to power’ dressed up in secular or religious clothing as suits their particular purposes.

The solution for both Wilkinson and Frank, in different ways, is to encourage sociological work on the harsh realities of human experience to *stand alongside* others, shoulder to shoulder we might say. In Wilkinson’s theoretical frame of reference it means standing alongside those like Arendt and Bourdieu who want to confront the realities of totalitarianism or the impact of global capitalism. In Frank’s case it means engaging with the experience of the woman forced to sit in the public waiting room of a hospital emergency department while she miscarried. It may also mean standing alongside the doctor or the nurse working in the hospital emergency department. This form of ‘public sociology’, to use the concept promulgated in recent years by Michael Burawoy (2004), should involve standing alongside others not only to share the suffering, as fellow human beings, but in order to situate the sociological

analysis within a context of politics and civil society, and to enable us as sociologists to engage with forms of lay knowledge and community-based action which can infuse and sharpen our own thinking. Developing critical or public sociology in this way might just protect us from falling into the sweet and sour soup of sentimentality and evidence-based unreason.

For those of you who might have been concerned about my painful knee, on returning from Heriot-Watt my general practitioner was very helpful and referred me for an immediate appointment in A&E. The orthopaedic registrar on duty resisted the temptation to aspirate (ouch!) with my full support, sent me home, and very kindly called me on my mobile later in the day to say that he hoped my knee would be better soon – which it is!

## References

- Burawoy, M. (2004) 'Public sociologies: contradictions, dilemmas, and possibilities', *Social Forces*, 82, 1603-1618
- Habermas, J (1972) *Knowledge and Human Interests*, London: Heinemann
- Nietzsche, F. (1974) *A Nietzsche Reader*, Harmondsworth: Penguin, p 202 (quotation originally in *The Gay Science*, published in 1882)

## **Confronting the Anti-Democrats: The Unethical Nature of Ethical Regulation in Social Science**

Summary of Plenary Address to Annual BSA Medical Sociology Group Conference, Heriot-Watt University, Edinburgh, September 2006

### **ABSTRACT**

The system of ethical regulation erected in the biomedical sciences, for good historical reasons, has become a major threat to the social sciences and their proper role in a democratic society. This paper is not an argument against ethical conduct in research with human subjects but a challenge to the illegitimate generalization of a model of research governance based on the particular risks and challenges confronting biomedical researchers.

### **The Rise of Research Governance in Biomedicine**

Conventional histories of the rise of research governance in biomedicine pivot on the Nuremberg Medical Trials and the code of 'permissible medical experiments' set out in their final judgement (Annas and Grodin 1992; Schmitt 2004; Weindling 2004). Later scholarship has questioned the integrity of some of the prosecution evidence (Hazelgrove 2002) and the application of the Code's principles in the victors' biomedical communities (Beecher 1959; 1966, Papworth 1967, Jones 1981, Rothman 1993). More recently, it has also become clear that the extent to which moral principles governed research prior to World War II has been understated (Halpern 2004), although there were already campaigns for greater regulatory intervention (Lederer 1995).

The years since World War II have seen an increasing elaboration of research governance. In the UK, human subjects review has mainly developed since 1991 within the specific field of health care, through the National Health Service (NHS) controlling access to staff and patients rather than research institutions controlling their employees' projects. It is only comparatively recently, since the publication of the Economic and Social Research Council's (ESRC) Research Ethics Framework (REF) in 2005, that British institutions have been required to have internal processes equivalent to those of Institutional Review Boards (IRB) in the US.

There is, though, no case for regulation in the social sciences comparable to that historically established in biomedical research. The risks to human subjects are not comparable and the power relationship between researcher and researched is so different as to render prior scrutiny irrelevant and inappropriate. The rise of ethical regulation in social science is driven by a demand for ceremonial conformity, which, in turn, is a vehicle for professional dominance and, increasingly, for the interests of the office-holders and bureaucracies generated to service this demand. This 'regulatory creep' is colonizing new groups, practices and institutions and intensifying the regulation of practices that already come under its jurisdiction (Haggerty 2004).



## The Potential for Abuse

The Nuremberg Medical Trial is central to the official history of ethical regulation. But official histories are designed to supply legitimacy to contemporary actors rather than a disinterested analysis of the past (Dingwall and Strong 1985). Critics of ethical regulation are always told that it is essential to prevent similar abuses. Two points should be made. First, the relatively developed regulatory environment of 1930s Germany did not hinder the abuses chronicled at Nuremberg (Morin 1998). Second, this cheapens the historical uniqueness of the Nazi medical experiments in the same way as the constant invocation of the Holocaust in relation to every contemporary act of genocide.

A few minutes with Google gives much detail on the Nazi medical experiments. They underline the capacity of the biomedical sciences to harm those who take part. Death or serious disability is always in the background, as at Northwick Park<sup>1</sup> this summer. They also exemplify the potential power of biomedical scientists in clinical or experimental situations through defining and controlling the situation in ways that constrain the possibilities of exit.

Social scientists cannot, however, harm human subjects in any comparable way. We have no research technique that carries an inherent risk of immediate death or serious physical damage. We have no power to impose ourselves on people. Social scientists are guests in other people's lives – if anything, the power lies with our informants who oblige us to behave with circumspection in exchange for the privilege of accessing information that they control (Murphy and Dingwall in press). Given the risks of biomedical investigations, and the relationships of power and dependence in which they are embedded, it is entirely reasonable that investigators should not be judge and jury in their own cause, that someone should look over their shoulder and check that participants are not being exposed to dangerous substances or techniques and that they are not being oppressed. In the social sciences, only some psychological experimentation may require the same review. We may also identify some groups whose status to withhold co-operation from researchers is compromised and who might qualify for protection, although it is hard to see who they might be. Children, people with learning disabilities, elderly people and people with mental health problems rarely have such limited capacity as not to be able to decide for themselves whether or not to co-operate with research. Ethical review may even compromise their autonomy (Edwards et al. 2004).

At no point are we going to forcibly inject dependent patients with irreversibly toxic green stuff. Why are we treated as if we were going to?

## Why Governance?

Halpern (2004) describes the way in which the growth of governance is associated with wider cultural shifts within the US since the early 1960s, which led to a declining sense of community obligation and an assertion of autonomous individual rights. Traditional systems of social control in medical research lost their legitimacy in this environment (Freidson 1970). However, the development of codes and enforcement processes reflects the outcome of political struggles for advantage (Heimer et al. 2005). These contests are not yet well-documented but include the desire of hospital

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<sup>1</sup> Six healthy individuals who were part of a drug trial run by Paraxel to test an anti-inflammatory drug, called TGN1412, manufactured by TeGenero, fell ill with multiple organ failure after being administered the drug.

managements to lay off litigation risks, of physicians to sustain their professional dominance, and of lawyers to develop new markets.

In identifying the issue of legitimacy, Halpern signals a way of understanding the rise of ethical governance in terms other than the simplistic enlightenment narrative of bioethics. Her work is part of a tradition of institutional analysis that examines how organizations are structured by interests rather than values, as they compete for resources in a changing environment. Organizational legitimacy refers to the degree of cultural support that can be derived from the organization's environment. However, that environment is neither static nor homogenous, with other organizations both competing for the symbolic and material resources associated with legitimacy and competing to supply those resources in return for the alliance of others to their particular projects (Scott 1991). Bioethics, for example, may both supply legitimacy to an organization and derive resources – jobs, grants, influence on policy, etc. – from that association.

In determining their strategy for acquiring legitimacy, organizations converge on the forms of the most successful entities in their market. Three processes drive this movement towards isomorphism: coercive; mimetic; and normative. Isomorphism is unrelated to efficiency or effectiveness, but is critical to the perceptions of the organization as reasonable, rational, competent, ethical, etc. However, those perceptions may be more important than the organization's actual economic performance in securing the necessary flow of material and symbolic resources, especially in the public sector where performance is hard to define and measure (DiMaggio and Powell 1991).

The remorseless spread of ethical governance is essentially isomorphic as organizations copy fashions set by market leaders, who, in turn, cement their advantages by circumscribing others. Consider the ESRC's Research Ethics Framework (2005) ([www.esrc.ac.uk](http://www.esrc.ac.uk)). It has no justification from a change in the risks of social science research. We have not suddenly developed new techniques that can kill people. The ESRC's case can be found at 4.1.2.1 and 4.1.2.3.1. Their argument is essentially that everyone else is doing this sort of thing, so ESRC needs to do it as well or it will not be treated as legitimate. The first item, the spread of interdisciplinary and transdisciplinary research, is normative isomorphism, claiming professional dominance in shared projects; the second, third and fourth are mainly mimetic and the last two are coercive. In the process of mimicking other organizations, of course, ESRC is also supplying legitimacy to them, as much as deriving it. If ESRC copies the Department of Health, the Department's Research Governance Framework becomes more acceptable and the opportunities to resist it become more constrained. The need for regulation goes unquestioned. There is no suggestion that ESRC might open a debate about the relevance of this approach in the social sciences.

ESRC are, of course, doubly unlucky in this respect because, as so often happens, they have come late to the bandwagon. Ethical governance has run into serious opposition elsewhere. Even in the UK, the Central Office for Research Ethics Committees (COREC) (2006) has been seeking to roll back NHS oversight of health services research so that its committees can concentrate on their international legal obligations in relation to clinical trials. Some of the strongest opposition to this is coming from governance committees and their officers, who are simultaneously complaining of overload and reluctant to cede any jurisdiction. In a way, we should not be surprised by such expressions of self-interest in the guise of high principle, but

it adds weight to Haggerty's (2004) comment that once a structure has been created, it will inevitably seek to expand its jurisdiction and to increase its access to resources.

To see the sources of resistance, however, we need to look across the Atlantic. The US, the home of ethical governance, is also the centre of the emerging challenge to its overreach.

### The Worms Turn

In his essay on the relationship between the social sciences and their rivals in the field of commentary on contemporary social life, Phil Strong (1983) explores the tensions that arise where both parties use similar methods of inquiry in different institutional contexts. Is sociology 'slow journalism' or journalism, 'instant sociology'? What are the costs of sociology's concern for rigour, system, cumulation and precision in the marketplace for ideas? In this case, what are the costs of regulating the same enterprise in different ways, particularly when the result is to handicap those elements that would generally be thought of as most disinterested, reflexive, unconstrained by partisan passions, etc.? Take covert research. Journalists like Barbara Ehrenreich (2001; 2005) and Polly Toynbee (2003) engage in it, write books that sell in large numbers, and generate great public excitement about the findings. Ehrenreich's recent books, *Nickel and Dimed* and *Bait and Switch*, both made the New York Times Bestsellers list. However, Ehrenreich faked CVs and references in both cases, to conceal her identity as a journalist and social investigator. The books are widely assigned to US sociology undergraduates and held up as examples of the sort of thing that sociologists *ought* to do – but neither would pass an IRB or an ESRC-compliant REF committee because of the lack of consent among the parties documented in them, although most names and identifying details have been changed.

As Haggerty (2004) points out, deception has become a staple not only of journalism but also of entertainment. It is also increasingly important in law enforcement, where the line between surveillance and entrapment is ever more finely drawn. It is unsurprising that we increasingly question the fairness of restricting serious academic inquiry, while tolerating reality TV, hoax shows and ever-more intrusive security work.

### Governance as Censorship

The parallel with journalism is important because of the place of the First Amendment in US political culture. This is the entrenched provision that bars Congress from making laws that would abridge either the freedom of speech or the freedom of the press. Both are seen as such fundamental values that no transient politician should be allowed to compromise them. In a recent paper, Philip Hamburger (2005), a law professor at Columbia University, has argued that the US IRB system breaches this Amendment. Research is, in a legal sense, a form of speech and research publication is covered by the definition of 'the press'. IRB review represents a form of licensing of speech or of the press. It is, in effect, a censorship of ideas, so that only those approved by the prior scrutiny of government agents may enter the public domain. If censorship of the press is unlawful in the US, then so is censorship of researchers.

The UK does not have such a robust approach to freedom of speech and the press. The European Convention on Human Rights has a much more qualified approach, and it would be more difficult to argue against government censorship on constitutional grounds. However, it is worth considering why the authors of the US constitution felt

that this was such an important principle. The First Amendment formed part of the Bill of Rights sponsored by Jefferson and the Anti-Federalists, who were seeking to prevent the creation of a dominant central state power in the new nation. Free inquiry and free dissemination of the results through a public realm accessible to all citizens were fundamental checks on authoritarian government and its abuses. Of course, there were, and still are, many issues about whose voices are heard in the public realm and about whose interests and inquiries are supported. Nevertheless, the underlying principle is of the greatest importance: the abridgement of free speech, free commentary and free inquiry is a step on the road to tyranny.

### **Fetishizing Consent**

Where does this leave research participants? If the censorship being erected in the UK is antithetical to the basic principles of liberal democracies, are informants to go unprotected? Do they not have rights to consent? The European Convention on Human Rights (ECHR) seems to endorse this constraint, particularly in stating that free speech may be constrained *for the protection of the reputation or the rights of others*. But this, of course, begs the questions of whose reputation and whose rights? Democracy is also about the mutual accountability of citizens to each other, which requires openness to proper inquiries about the justification of the reputation or the entitlement to rights. Medical sociologists should be among the first to recognize this because of its centrality to Talcott Parsons's (1952) account of the sick role. Parsons's great insight was that illness and medicine had to be understood within the sociology of deviance. Parsons saw that illness was the term that we happened to use to describe unmotivated deviance. The distinction between motivated and unmotivated deviance was a critical solution to the maintenance of order in modern societies. Motivated deviance – crime – elicited a coercive response, which isolated offenders and provided for correctional treatment. Unmotivated deviance – sickness - elicited a supportive response, where the resources of the community might be deployed for the temporary sustenance of the deviant. Medicine was the control agency charged with adjudicating on the validity of the claims for support and guiding the sick person back to a productive role within society. The sick role revolves around an inherent conflict between the well and the sick: how can the well be sure that their support will not be abused? How can the well avoid being asked to write blank cheques for the care of the sick?

This links to another ethical debate: what makes taxation legitimate? This rests on democratic assent. If this assent is to be adequately informed, however, there must be evidence that tax revenues are being spent efficiently and effectively, and probably equitably and humanely. If tax is raised simply to support the pet projects of legislators without regard to those questions, it is intrinsically unethical, extortion rather than taxation (von Mises 1996). Both the administrators and the recipients of benefits from taxation have an obligation to participate in properly conducted inquiries to demonstrate to taxpayers that their funds are being disbursed in ways that achieve the intended goals. Patients may be properly required to participate in research to establish that they are appropriate tenants of the sick role, that support to them is proportionate to their need and that they are complying with the prescriptions for limiting that claim for support, whether by seeking recovery or maximizing their fitness to contribute productively. Similarly, physicians, and other health system personnel, may be required to co-operate with properly conducted research to determine whether their claims on the taxpayer are proportionate to their conduct of

their adjudication on claims to the sick role and their therapeutic efforts to discharge claimants from that role. The same principles apply to insurance-funded health care, where the balance is between those who are paying into the pool and those who are drawing from it, whether as administrators or physicians, or as patients. With very few exceptions in the modern world, the sick depend on other people's money and goodwill and are a particularly condign case of the mutual accountability of citizens.

Two further comments need to be made here. One is to clarify the concept of 'properly conducted research'. By this, I am thinking of research that is done in a technically competent fashion. I do not, however, want to replace the REF by a mandated process of technical peer review for every project that every social scientist might want to do, whether or not it requires external funding. This simply substitutes one illiberal process for another. If we believe a free society requires free researchers as much as free journalists, then all prior licensing regimes are barriers to innovation and free communication of ideas.

The second is to address the issue of consent. John Harris (2005) has argued that there may be a positive moral duty for us all to participate in biomedical research, since we all benefit from it. This should not be subcontracted to the poor and economically vulnerable who respond to the financial incentives used to recruit most biomedical research subjects. There are many circumstances in which communities may compel people to contribute to public goods: this may be one of them. My argument is similar, in the sense that the obligation to participate in social science research may be one of mutuality, of allowing one's behaviour to be audited in the interests of other community members who are funding it or need information to determine whether to trust the claims that one is making. This applies to everyone, because we all derive benefits from our participation in that moral community. However, I place less weight than Harris on the issue of compulsion. We must not fetishize informed consent – but we can approach this as a pragmatic rather than as a principled matter. As a question of good research practice, and the self-interest of the professional researcher, we should seek to obtain consent wherever this is reasonably possible. This is, however, a dynamic process, not a form designed solely to manage litigation risk. It involves the construction of a customized relationship between researcher and researched, where the researched are offered explanations tailored to their level of understanding and concerns, not presented with legalistic formulae that require an advanced education to be intelligible. Social scientists are not homeland security personnel. We cannot force our informants to provide information. We depend on their co-operation and goodwill – but these ends are not served by the ESRC's demand for written evidence of a contract of consent. Contracts are designed to manage adversarial relationships. We cannot function in conflict with our informants.

### **What is to be done?**

It is easier to point to the flaws in the present systems of ethical governance than to lever their destruction. Clearly some of the enthusiasm with which COREC has addressed the task of reforming the NHS system comes from the frustration of NHS planners, managers and policymakers with finding access to crucial information being obstructed by a system of their own making. However, that is not, in itself, enough to topple an edifice that depends on its own weasel vocabulary of motherhood and apple pie. Surely only the corrupt among us have anything to fear from a review? There is, however, now abundant evidence that the corrupt have little to fear, while honest and

conscientious scholars, seeking to engage in research intended to enrich the public realm, are subject to pettifogging obstacles, designed to bolster the power of the organizations charged with governance. The more processes can be extended and elaborated, the more resources these organizations can command and the more power accrues to their personnel to determine what scholars are, and are not, allowed to think and say – and to determine what passes into the public fora of debate and democratic deliberation. Only a saint would resist the corruptions that flow from this power – and we do not live in a world of saints.

*If we apply neo-institutionalist thought, however, we can see points of vulnerability. We need to deprive these bodies of the oxygen of legitimacy. This creeping tyranny feeds on our reasonableness. We must stop colluding and call it by its proper name, a process of censorship that is disabling to the democratic values by which we seek to live. Ethical governance and professional ethics should not be confused. Ethical governance is about censorship and the exercise of power. Whatever the motives for which it is advanced, it is profoundly anti-democratic. Professional ethics is about respect for our common humanity and the mutual obligations that this creates. It is about integrity and virtue in our scholarship. Those are real values, values of liberty that always challenge those who dislike democracy and prefer to sustain a world where their views and assumptions will go unexamined and unquestioned.*

## References

- Annas, G.J., & Grodin, M.A. (1992) *Nazi Doctors and the Nuremberg Code: Human Rights in Human Experiments*. Oxford: Oxford University Press.
- Beecher, H. (1959) Experimentation in man. *Journal of the American Medical Association*, 169: 461-78.
- Beecher, H. (1966) Ethics and clinical research. *New England Journal of Medicine*, 24: 1345-60.
- COREC (2006) Central Office for Research Ethics Committees, *Building on Improvement*, National Patient Safety Agency, London.
- DiMaggio, P.J. and Powell, W.W. (1991) 'The iron cage revisited: institutional isomorphism and collective rationality in organizational fields'. Pp. 63-82 in Powell, W.W. and DiMaggio, P.J., eds. *The New Institutionalism in Organizational Analysis*, University of Chicago Press, Chicago.
- Dingwall, R. and Strong, P.M. (1985) The interactional study of organizations: a critique and reformulation. *Urban Life* 14: 205-31.
- Edelman, L.B. and Suchman, M.C. (1999) "When the haves hold court: speculations on the organizational internalization of law". *Law and Society Review*, 33: 941-991.
- Edwards, S.J.L., Kirchin, S., Huxtable, R. (2004) Research ethics committees and paternalism. *Journal of Medical Ethics* 30: 88-91.
- Ehrenreich, B. (2001) *Nickel and Dimed: On (Not) Getting By in America*, Henry Holt, New York.
- Ehrenreich, B. (2005) *Bait and Switch: The (Futile) Pursuit of the American Dream*, Henry Holt, New York.
- Freidson, E. (1970) *Profession of Medicine* Dodd, Mead: New York.
- Haggerty, K. (2004) Ethics creep: governing social science research in the name of ethics. *Qualitative Sociology* 27: 391-414.

- Halpern, S.A. (2004) *Lesser Harms: The Morality of Risk in Medical Research*, University of Chicago Press: Chicago.
- Hamburger, P. (2005) The New Censorship: Institutional Review Boards. *The Supreme Court Review*, 2004 :271-354.
- Harkness, J., Lederer, S.E. and Wikler, D. Laying ethical foundations for clinical research. *Bulletin of the World Health Organization* 79: 365-6.
- Harris, J. (2005) Scientific research is a moral duty. *Journal of Medical Ethics* 31: 242-8.
- Hazelgrove, J. (2002). The old faith and the new science: The Nuremberg Code and human experimentation ethics in Britain 1946-73. *Social History of Medicine*, 15, 109-35.
- Heimer, C.A., Petty, J.C., and Culyba, R.J. (2005) 'Risks and rules: the "legalisation" of medicine'. Pp. 92-131 in Hutter, B. and Power, M., eds., *Organizational Encounters with Risk*, Cambridge University Press, Cambridge.
- Jones, J.H. (1981) *Bad Blood: The Tuskegee Syphilis Experiment*, Free Press, New York.
- Katz, J. (in press) Ethical escape routes for underground ethnographers. *American Ethnologist*
- Lederer, S.E. (1995) *Subjected to Science: Human Experimentation in America before the Second World War*, Johns Hopkins Press, Baltimore.
- Morin, K. (1998) The standard of disclosure in human subject experimentation. *Journal of Legal Medicine* 19: 157-221.
- Murphy, E. and Dingwall, R (in press) Informed consent and ethnographic practice. *Social Science and Medicine*
- Papworth, M.H. (1967). *Human Guinea Pigs*. London: Routledge and Kegan Paul.
- Parsons, T. (1952) *The Social System*, London: Routledge and Kegan Paul.
- Rothman, D.J. (1993). *Strangers at the Bedside: A History of how Law and Bioethics Transformed Medical Decision Making*. New York: Basic Books.
- Scott, W.R. (1991) 'Unpacking institutional arguments'. Pp. 164-82 in Powell, W.W. and DiMaggio, P.J., eds. *The New Institutionalism in Organizational Analysis*, University of Chicago Press, Chicago.
- Strong, P.M. (1983) 'The rivals: an essay on the sociological trades'. Pp. 59-83 in Dingwall, R and Lewis, P., eds. *The Sociology of the Professions: Lawyers, Doctors and Others*, Macmillan, London.
- Schmitt, U. (2004). *Justice at Nuremberg: Leo Alexander and the Nazi Doctors' Trial*, London: Palgrave.
- Toynbee, P. (2003) *Hard Work: Life in Low-Pay Britain*, Bloomsbury, London.
- Von Mises, L. (1996) *Human Action* (Fourth Edition), Irvington: Foundation for Economic Education.
- Weindling, P. (2004) *Nazi Medicine and the Nuremberg Trials: From Medical War Crimes to Informed Consent*. London: Palgrave.

## Reply to Robert Dingwall's Plenary 'Confronting the Anti-Democrats: The Unethical Nature of Ethical Regulation in Social Science'

Annual BSA Medical Sociology Group Conference, Heriot-Watt University, Edinburgh, September 2006

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Dingwall's paper, challenging the mushrooming of ethics committees and their power over social research, hit a sore nerve in many researchers in the audience. The NHS research ethics application process has become bureaucratic, time consuming and generally restrictive. Whilst the scope of NHS Local Research Ethics Committees has expanded over the past decade include not only research conducted on NHS patients, but also on NHS staff and research conducted on NHS premises. There is mounting pressure on researchers from the UK funding councils, (e.g. ESRC, MRC) the larger non-governmental funding bodies (e.g. the Wellcome Trust) and to a lesser extent academic journals to acquire some kind of ethical permission.

Many UK universities have had "in place some limited ethical review, usually in the form of one or two 'psychosocial' or 'behavioural' research ethics committees to oversee non-clinical human subject research" (Williams-Jones & Holm 2005: 400). Several institutions have moved to a university-wide ethics committee (or committees) for human subject research, such as for example Cardiff University (Williams-Jones & Holm 2005: 39), or the University of Dundee.

The increased emphasis on research ethics by funders and universities alike is far less driven by ethical considerations of research subjects and more by the perceived risk to organisations, such as the funding bodies and universities. In our risk-averse culture such organisations obviously perceive the 'need' for more control over social researchers. Consider for example, the opening sentence under the heading 'What are the main principles governing good research?' in the University of Dundee's *Code of Practice for Research Ethics on Human Participants*. This sentence is not related to potential harm to research participants, but to the potential harm to the organisation: "We expect that all staff and students of the university conduct themselves at all times in a way that does not bring the university into disrepute."

One point I would like to challenge is Dingwall's comments that sociologists do not do harm in their research. Of course, most of the time we do not harm, because as sociologist we are very sensitive to the needs of our research participants, we are more open-minded and reflective, etc. More likely we do no harm because those in power largely ignore our research findings. But occasionally we do harm our participants, not just in the conducting of 'unethical' in the infamous Humphrey tearoom trade study. I put 'unethical' as some have argued that Humphrey study made significant positive contributions to his study population (Lenza 2004). On a much smaller scale I have upset people in my interviews. If I had not been raking up old issues they unlikely have been thinking about it at the time. We need to consider this psychological harm (or at least emotional) we put research participants under. We often prepare small handouts to give to interviewees stating that if talking to us



about XXX has upset you or raised particular issues, you can always contact your GP (for health care studies), a genetic counsellor (for genetics studies), your teacher (for school-based studies) and/or organisations such as ChildLine (for studies with young people). Where possible we try to give precise details, such as names and telephone numbers of genetic counsellors who have agreed to speak to participants at short notice or the telephone number for ChildLine.

However, the fact that we might put psychological stress on participants is something social scientists need to be aware of, it does not mean we need more ethics committee to vet the proposed research in more and more detail. What we do need is a realisation that doing ethical sociological research is the responsibility of each and every one of us! And that making research ethics (or at least the process of applying for it) a bureaucratic tick-box process can be counterproductive!

Finally, there a positive side to the process of applying for research ethics permission, whilst there “is considerable work in preparing an ethics committee application and this can at times seem onerous, however, it should be remembered that quality of the research proposal will be improved by early consideration of these details” (Van Teijlingen & Cheyne 2004: 210).

## References

- Lenza, M. (2004) Controversies surrounding Laud Humphreys’ tearoom trade: an unsettling example of politics and power in methodological critiques *International Journal of Sociology and Social Policy* **24**: 20-31.
- University of Dundee (2006) *Code of Practice for Research Ethics on Human Participants*,  
[http://www.somis.dundee.ac.uk/court/policy/research\\_human\\_participants.pdf#search=%22dundee%20university%20ethics%20committee%22](http://www.somis.dundee.ac.uk/court/policy/research_human_participants.pdf#search=%22dundee%20university%20ethics%20committee%22) (accessed 6<sup>th</sup> October 2006).
- Teijlingen van, E.R. & Cheyne, H.L. (2004) Ethics in midwifery research, *RCM Midwives Journal* **7**: 208-10.
- Williams-Jones, B. & Holm, S. (2005) A university wide model for the ethical review of human subjects research, *Research Ethics Review* **1**: 39-44.

## The Hidden Injuries of Everyday Life: Violations, Care and Health

Plenary Presentation, Annual British Sociological Association Medical Sociology Conference, Heriot-Watt University, Edinburgh, September 2006

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### ABSTRACT

This paper has two main, interrelated aims: first, to identify and critique presumptions about gender, violations and everyday life that continue to frame and inform the processes of health policy and service development; and, secondly, to reflect on translating sociological work into formats that can inform debates and raise the capacity for social change.

Drawing upon illustrative material the paper considers how discourses, policies and services continue to emphasise physical forms of violence, place the onus upon the agency of those experiencing violence (more often than not women, by encouraging them to leave home and relationship), and so promotes a narrow conceptualisation of violence in relationships. The social and gendered hierarchies evident in policies and services reinforce inequities and suffering. How we define and work with concepts and policies originates from, and is connected to, the broader workings of society. It seems as if the complex inter-weaving of masculinities, violence and cultures while recognised in many debates, continues to be marginalized from dominant discourses, policy and health care processes.

Recent debates on public sociologies provide the context for the second part of the paper. Sociological work on the politics of everyday life offers sociologists an informed position from which to engage with the development of policy and practice work. If one of our goals is to document and analyse social structures and processes, the sociology of health and illness can render visible the dimensions of the hidden injuries of everyday life. For many of us, however, this is uneasy terrain. It creates permeable boundaries between the academy, users, and those involved in service development and delivery. Not least are concerns about the dilution of 'the sociological' in any translation of research findings into arenas of policy, politics and practice.

### Introduction

In this plenary I have chosen to discuss health policy and domestic violence; to focus upon violences in everyday lives and the impact of these on, and implications for, policies, services and practice. In the closing section I reflect on constructing bridges across sociological work, policy and practice.

In addressing these issues I draw upon a decade of empirical and theoretical work on gender, violence and care. Central to this work are collaborations with academic and professional partners and I would like to acknowledge intellectual and practical

debts to many, some of whom are here today. Of course, while this paper synthesises a range of work it reflects personal interpretations and views - any errors are my own.

I am going to start with a resume of an interview with a nurse that was conducted during research that informed the development of resources for doctors and nurses on domestic violence. Susan Davidson (not her real name) is a nurse working in an accident and emergency department that serves the population of a large city with a diverse suburban and semi rural hinterland. She works evening shifts to maximise her income. Like many health care staff she dreads Friday and Saturday nights when an increased number of drunk and abusive patients arrive for treatment. The noise of people shouting and arguing adds tensions to the already pressured workload; 'sometimes your head is thumping with the noise and then you think, oh no, you might be slapped or punched', Susan commented. In the *mêlée* of noise and suffering many patients are seeking reassurance and a sense of security, along with treatment. Susan works hard to provide support and comfort but the drunks seem irritating and time wasting when set alongside the consequences of a traffic accident or the person who has been attacked for no apparent reason. She knows she should not express these views but this is how she feels.

And then there are the patients who are on the receiving end of longer-term physical and psychological abuses. She recognises the stunned and startled state of these patients, overwhelming women. She speculates about the circumstances in which violence was inflicted. There are explanations of how injuries were sustained that don't quite hang together, and partners or relatives that hover, never leaving her alone with the patient. These patients seem so vulnerable. Others reappear week after week and seem to back up the dubious tales of how injuries were sustained, generally by remaining silent or nodding meekly. All too often silence is followed by apologies for time wasting, delivered during treatment. This can be frustrating but she knows that challenging these stories can add to the tensions and risks the woman is already trying to traverse. These encounters are made all the more poignant given Susan's own experiences of domestic violence in a former relationship. She makes sure there is relevant information left lying around hoping this could be a trigger to women leaving a violent relationship. Susan comments that you have to wait until a woman is ready to manage the consequences of disclosure otherwise you could make matters worse. Recognising violence, remaining silent, trading off care for the patient and care for the woman while treating the injuries: - webs that inter-weave and draw attention to the dilemmas of the being at one and the same time professional, woman, human being.

This interview with Susan was undertaken as part of a study funded by the Queen's Institute for Nursing Scotland. Over a two year period consultation was undertaken with health care professionals, women and relevant organisations on how best to support the process of disclosing abuse. These data informed the development of resources, and along with training and guidance for health care professionals and policy makers, a government led strategic and partnership approach to domestic violence has evolved across Scotland. Those of us on the group that developed these resources, including myself as chair, became acutely aware of the double jeopardy many health care workers face as both professionals addressing the impact of violent acts and as people with everyday experiences of violence in family, friendships, relationships and neighbourhoods.

Nadine Gordimer (2003) comments that the suffering caused by violence is senseless, persistent and demoralizing and for perpetrators there is a hollowness in holding power over others (Card, 2002; Mason, 2002). A cursory look around the week's news

illustrates how violence impacts on lives. There are on-going international conflicts with deadly consequences for the people involved. At home the news offers evidence of the daily toll of violence; murder, assault, rape, intimidation, bullying, harassment, fear. Acts of violence have painful and challenging outcomes.

Our silences, however, can be deafening to those caught in webs of abuse. Sociology has addressed violence and domestic violence, but largely within gender and women's studies and in the arena of work on risk, professions and organisations. Despite the obvious relevance to sociology of health and illness, violence in everyday and intimate practices has not been a key concern (Hearn, 1998; Ray, 2002). Studies have considered, for example, perceptions and experiences of violence among health care professionals but limited attention has been paid to how practices of violence and abuse frame policies, services and experiences of health and well-being in myriad ways.

The title of this presentation was inspired by the book *The Hidden Injuries of Class* by Richard Sennett and Jonathan Cobb. Published over 30 years ago the book presented an analysis of observation and interview data on the 'cultural valuation placed on the traditional work of men' (Sennett and Cobb, 1972: 42). It explored how men experienced and perceived their lives. During interviews issues about powerlessness and adequacy emerged. Feelings cloaked by the everyday routines of maintaining a job and engaging in home life but illuminating frustrations and indignities felt by so many but rarely spoken about. I have adopted and adapted the ideas of Sennett and Cobb on notions of hidden and everyday to explore the cultural valuation placed on gender, violence and everyday experiences.

We know that violence against women is characteristically under-reported for a number of reasons including shame, fear of scepticism, disbelief or the threat of further violence and this is the case in many countries. As Amnesty International (<http://web.amnesty.org/actforwomen/index-eng>) comment 'the failure to investigate the true extent of violence allows governments, families and communities to ignore their responsibilities'.

What else do we know about violence against women? Available data reports: -

- ⌘ USA: 85% recorded cases of domestic violence are reported by women
- ⌘ Russia: no legislation on domestic violence
- ⌘ WHO: 70% female murder victims killed by partners

In the UK:

- ⌘ a call is placed every minute of the day to police seeking assistance
- ⌘ only 35% of calls lead to formal reports
- ⌘ 1 in 4 women across adult life course experience domestic violence
- ⌘ 25% of those who experience domestic violence do so for the first time during pregnancy
- ⌘ there is a higher rate of repeat victimisation than any other crime

⌘ In 2004 the cost to public services was at least £5.7 billion

Having noted that domestic violence is predominately violence perpetrated by men on women known to them I would now draw attention to the comment of Bob Connell (2000: 215): 'though most killers are men, most men never kill or even commit assault' and this is the case both within and outside the context of the family. So although not all men are violent, violence appears to be an accepted part of the male repertoire. On occasions, such as war, violence is sanctioned and even promoted by the state. At any time an emphasis on 'stranger danger' ignores evidence of the everyday experiences of violence in intimate relationships. This furthers ideas that men who perpetrate acts of violence are somehow obviously different from the 'ordinary family' man (Collier, 1995).

Evidence bears out gender asymmetry. Men perpetrate 90% of all violence, in public spaces and in and round the home and intimate relationships (Archer, 2000). Naming men's violence is becoming more common, but this has sometimes been accompanied by the misleading, view that women's violence is as common as men's. These claims of gender symmetry in domestic violence largely draw upon the quantification of acts of physical assault and self-defence (Fiebert, 1997). Michael Kimmel (2002) asserts these claims are based upon misinterpretations of data. Women can be violent, but much of this is in defence of their children or themselves. As James Nazroo (1995) has concluded men's physical strength means that women are more likely to experience physical harm and sustained psychological fear. Men's violence to known women can be found everywhere - in the refugee camp in Darfur, the townships of Durban, the middle class households of Durham - in times of conflict and times of peace. The term 'men's violence to known women' more accurately identifies and describes men's violence in relationships and families.

Underpinning service organisation, delivery and development on violence is health policy. Policy can appear one of the most gender-neutral of concepts. Yet not only is much policy and policy development constructed by and through assumptions about gender, but also much policy and policy development can be understood as policy on gender and gender relations. Gender constructs policy, as policy constructs gender. Much of what I argue here is applicable to policies on a range of issues but the topic of 'domestic violence', offers vivid illumination of key concepts and themes.

### *Definitions*

Let me start with the word 'violence'. As Jeff Hearn (1998) comments violence is not one simple act but is shorthand for a range of acts and experiences in people's lives. It is most readily associated with physical acts which marginalises psychological, economic and even sexual violations. Achieving a sense of menace is a common goal of perpetrators. Psychological distress is a powerful way of exerting control, and one that can be hard to document and challenge. The word violence can diminish interpretations of the multi-layered relationships between the interpersonal and structural. Power and gender relations can also be obscured by the use of the word violence. Violent acts and behaviours cannot, however, be divorced from social agency or social structures.

Connotations of violence shift in time as well as space. Historical ideas about domestic violence have changed and a prime example is the evolution of policies and services to support women to leave violent relationships, but the stigma and reduced

economic circumstances remain for women and children who leave the family home. So not surprisingly women, as a category, and regardless of any direct experience of physical or psychological violence, learn from childhood social nuances and practices to avoid potentially violent situations.

Violence is evident in numerous aspects of our culture; through newspapers, on the TV, the internet, in sport, in relationships, and between strangers. Violent activities may also be a separate and regular activity for some; for example, those who utilise the football culture for violent behaviour. The state and other organisations and institutions also determine meanings of violence. Definitions are structured through the inclusion and exclusion of actual or possible actions or experiences; for example documenting physical injuries rather than psychological abuses.

The term 'domestic violence' is associated with the home and privacy. Together with the apparently ungendered nature of the term, domestic violence, inadequately reflects, even diminishes the extent and nature of the problem. At the supranational level, the World Health Organization's (2002) use of the term interpersonal violence captures the context of intimate relationships but does nothing to highlight the gendered nature of violence.

The Scottish government has adopted a written definition which states that domestic violence is overwhelmingly violence perpetrated by men on women known to them. The term adopted in Scotland is domestic abuse rather than domestic violence. The word 'abuse', many argue, better represents the psychological dimensions of violence and helps to shift the emphasis from physical manifestations to the ongoing manipulation of power in intimate relationships (Scottish Executive, 2000: 5). A compromise was reached, however, with the retention of the word domestic. To talk of men's violence to known women was considered too distant from the language of professional practice and everyday discourses. While a number of positive consequences have resulted from the term domestic abuse, and the strategic partnership approach, work in Scotland, as elsewhere, has emphasised women's experiences and agency and less so everyday violence, masculinities, and gender (Skinner et al., 2005).

### **What's the Problem? Locating Violences in Policy and Practice**

The assumed location and nature of domestic violence illuminates an apparent demarcation of the private and the public. I note here the breadth of debate in sociology, social policy and public policy on the concepts of, and interplay between public and private. Time precludes an in-depth consideration of these concepts, and their relevance to the development and implementation of policies. I would, however, draw attention to Bourdieu's (1996: 25) comment, '[T]he public vision ... is deeply involved in our vision of domestic things, and our most private behaviours themselves depend on public actions, such as housing policy or, more directly, family policy.' The public and the private are both material social arenas and heavily gendered ideological constructions. As concepts they can have quite different forms, meanings and significances for different social categories, specifically, in this context, for women and men (Bose, 1987; Hearn, 1992).

Health care settings seek to make available private spaces that patients may have an opportunity to discuss personal circumstances, injuries and illness. The hidden nature of domestic violence makes privacy imperative in the context of health care : -

so violence that takes place in the private arena of relationships has potential to be addressed in the quasi private context of the NHS. However, uneasy tensions between professionals and patients with regards personal relationships, family life and gender roles render privacy a complicated business in health care settings and practices.

Mainstreaming is an approach that had been adopted by governments and public sector bodies across the globe. At the United Nations 4th World Conference on Women in Beijing in 1995 one of the most important and innovative outcomes was a provision calling on the UN and its signatory states to 'mainstream' gender issues across the policy process, 'so that, before decisions are taken, an analysis is made on the effects on women and men, respectively.' Although the notion of integrating or mainstreaming gender issues across the policy process had antecedents in the previous two decades, the official recognition and endorsement of mainstreaming as a formal goal of all the states in the UN system has provided a global mandate for change, and a template against which to judge both national and international policies. Mainstreaming offers a framework and methodology that draws heavily upon gender audit and has come to dominate many debates and activities around gender and equality. So far, however, it has had relatively little impact on policies and services that address gender and violence. Views on the effectiveness of the approach vary. For some, mainstreaming offers the potential to 'transform organizations and create a culture of diversity' (Rees, 1998: 27). Others contend that there are many versions of mainstreaming and these are merely 'crafted to fit neoliberal administrative models' (Bacchi and Eveline, 2003: 113). As a result this can silence women because it removes gender as a process and practice from organisational and political agendas by shifting the focus to target setting and attainment.

Even with such developments, across the diffuse range of policies and agencies gender analysis continues to be focused mainly upon policy users and outcomes, rather than policy creators or policy-makers. The ways in which social relations and structures shape the representation of 'what's the problem?' has been considered in some arenas and projects but these remain limited and with varied outcomes (Bacchi and Eveline, 2003). A major drawback is that fundamental values and practices are rarely addressed. To do so would necessitate challenging long-established ways of working in policy and organisational arenas. Furthermore, it would take time (the excuse used, to fend off many critiques). It would require the reconfiguration of power and resources, including gendered power and resources, in both policy process and supporting social and political structures. Much political – and policy - effort goes into sustaining the legitimacy and interests of heteronormativity in post-industrial society, and, as a result, offers an assumed naturalness to resultant gendered inequities. One obvious example is the presumption that underpins many health and education policies that unpaid work of relatives, generally mothers and women, will provide essential informal care and support (McKie et al, 2002).

The WHO World Report on Violence and Health (World Health Organization, 2002: 1) has the stated aim of challenging the 'secrecy, taboos and feelings of inevitability that surround violent behaviour.' The report provides information and ideas for those responsible for public health decisions and policies at the national level, as well as for those working in related services or projects. Noting the crucial role of health services as often the first point of contact with statutory services for those who have experienced violence, the report calls for partnership working across criminal justice and other departments or agencies concerned with human rights and familial relations. Nevertheless, recommendations in this WHO report are again gender-neutral through words such as 'people', 'parents' and 'partners'. In proposing

treatment programmes the need to discuss gender issues is noted, as is the potential for counselling services for men who abuse partners. Regardless, the overall approach is highly individualised and one in which 'people' are encouraged to 'take responsibility for their actions'. Noting that 'violence is often predictable and preventable', that 'complacency is a barrier to tackling violence' and self-interest may reinforce violence (World Health Organization, 2002: 35), there is no engagement with critical studies on men, gender and violence (Connell, 1995, 2002; Hearn, 1998, 2002; Hearn and Parkin, 2001).

### *Masculinities, Violences and Culture*

Although the study of men is not new and men have studied men for centuries but often as an 'absent presence' (Hearn, 1998). This 'absent presence' is indicative of the manner in which 'men' as individuals, groups or as categories have generally not been problematised. Academic work has frequently failed to interrogate and gender the genealogy of ideas and empirical work. Studying gender is gaining ground, as is critical studies on men.<sup>2</sup> In many arenas it is now clear that gender is about both men and women and, not solely women. This gendering of men is evident in contemporary analyses of men in society and reflects the changing experiences of men in their contemporary lives; experiences that often run counter to those anticipated.

Nevertheless, there remains resistance to considering men's practices as gendered, to 'naming men as men' (Hanmer, 1990; Collinson and Hearn, 1994; also see Cockburn, 1991). Men's practices are so heavily embedded in existing social, economic and cultural relations that their dominant practices are equated with what is considered to be the normal, the usual, or even the official way of doing things. Patricia Yancey Martin (2001) in her studies of decision-making suggests men's practices are constructed as ordinary, mundane, usual; women's are noteworthy, quirky, or worse. All too often the notion of gender neutrality is premised upon a masculinist, ablist approach to policy and practice. [Here I would also draw attention to debates in disability studies where not unrelated concerns have been voiced about the formation of policies and services. See Hughes et al., 2005.]

Even with evolving studies on men and masculinities, the gendered nature of violence, generally continues to be 'underanalysed and underproblematized' in most policy processes and debates (Bacchi, 1999: 168). So while legislation and service provision has achieved an increased prominence, especially in support of women who are experiencing violence, critical studies of men have not had the impact on policy work that might be anticipated. For example, the Council of Europe (2004) document Responses to Violence in Everyday Life in a Democratic Society differentiates between a victim-orientated approach and offender-orientated prevention. Employing a gender neutral approach the gendered nature of violence is largely ignored. Focusing narrowly upon the offender has implications for policies and activities. This leads to a focus on perpetrators within the criminal justice system, rather than a critical engagement with violences in the everyday more generally.

<sup>2</sup> For example the EU FP5 Research Network 'The Social Problem of Men' (2000-3). See [www.cromenet.org](http://www.cromenet.org) and Kimmel et al. (2005).



## A Duty to Care? Connecting Research and Policy

Sociology enables us to chart and better understand where and how we live, to identify trends in social change and to explore the implications of these. Sociological analysis offers explanation and ideas that can infuse debates and decisions on the content and implementation of programmes that aim to address social problems. In the case of domestic violence sociological work was evident in various dimensions of the government led strategy in Scotland. This ranged from the naming of men's violence to known women as domestic abuse rather than domestic violence, to documenting trends in violence that are utilised in resources and training, to informing initiatives that support women and children to leave violent relationships, and to an evaluation of work with men who perpetrate violence.

Sociological work is not based upon the experience of any one individual – or any one study - but is accumulated through critical engagement within the discipline and through dialogue with other groups and subjects. C. Wright Mills (1959) in *The Sociological Imagination* called for a sociology that relates 'personal troubles' of the individual to 'public issues' and social structures. The continued popularity of his ideas indicates that many of us are working towards a sociology that weaves across structure and agency.

Research in the sociology of health and illness has had a notable impact on wider policy and practice developments. In many ways this is not surprising given the relevance, the topics we consider have to contemporary political and public agendas. There remains, however, a hierarchy in sociology that positions theoretical work at the pinnacle. Ironically many of us in the sociology of health and illness have been criticised for not being theoretical enough and undertaking research that is too orientated to health services research which is said to lack theoretical engagement. So are we, our funders, and users, deriving full benefit from the array of research? Ensuring research is evident in addressing questions such as 'what's the problem?' and 'what action might follow?' requires pathways for dialogue. Producing a succinct set of recommendations, drawn from peer reviewed research, is a critical stage in the construction of pathways across the arenas of research and policy. The terrain over which we construct pathways, however, is vast and peppered with peaks and troughs.

The location we find ourselves working in, the availability of funding, and our political predilections all have a bearing on the choices we make about what to research, the methods we choose, and what happens to findings. Still there are some for whom the idea that sociology might play a role in defining social problems and policy content seems irrelevant or even dangerous. Oft cited reasons include the loss of a sociological dimension to explanations in the process of translating findings into action, as well as the potential dilution of the intellectual basis to academic work. The uniqueness of a sociological perspective can get 'lost in translation' as theory and findings meet the worlds of policy and practice. To divorce ourselves from dialogue and engagement, however, is naïve. The richness of theoretical and policy work on inequalities, chronic illness and longevity, to cite but three topics, reflects how theory is buffeted, challenged and even enriched through documenting and analysing social change .... and vice versa.

Let me draw this section to a close with posters from an Amnesty International Campaign. This made a virtue of the notion of the 'cover-up' – hidden - through drawing upon spoof adverts for make-up to confront people's reticence about violence against women. The campaign drew on survey data which found that 30% of

respondents felt hitting a woman in certain circumstances was OK, although 70% recognised that domestic violence continues to be associated with stigma and shame. Why is violence against women tolerated, justified, ignored, hidden? And why, despite the broader evidence base, does it continue to be framed as a problem for women, managed by women in health and social care services? Having worked with the task group funded by the Queen's Nursing Institute for Scotland to research domestic violence and offer evidence and ideas for action I have to conclude that even with the construction of pathways between research, policy and practice, action on violence against women remains partial and feminised.

## Concluding Comments

Despite the work of supranational and non-governmental organisations and numerous critiques from feminist and profeminist researchers, policies emerge and evolve from discourses that remain relatively ungendered (Hearn, 2002, Weldon, 2002, McKie 2006). Market economies and governmental systems marginalize the experiences of women as well as other groups and people. Legal and economic systems promote a neo-liberal notion of equality of opportunity as a basis to public and health policies but this is based upon unspoken, unacknowledged gendered underpinnings that render equality of outcomes virtually impossible. Engaging in theoretical pluralism and empirical work can assist revealing the gender in policy work. Part of that requires we engage more critically with notions of the public and the private through the interrogation of concepts of the social, ... and rework boundaries between services / structures, public / private. This could offer potential to develop social theory and research, policies and services to form the basis to tackling the gendered nature of much violence. As Bacchi (2004: 183) asserts:

*... gender cannot be bracketed off; rather, its implications need to be confronted.... we need policy analyses which bring together the study of concepts and their uses. ... (Bacchi, 2004: 183)*

Critical studies of men's practices exist (Hearn, 2004), as does evidence on the gendered workings and impact of social problems such as, violence by men towards women and children known to them (Stanko et al., 2002). It is time to reshape the use of the evidence base, and processes of gender analysis, to start with men, and men's practices, and moves towards policies and practices that engages with these in their myriad manifestations (Bacchi and Eveline, 2003). Translating this body of work into definitions, policies and practices is proving complex and challenging. The practice of sociology is not easy; nor should it be.

With regards research findings we might offer options that consider:

- ☞ the parameters and constraints of the government or funding body
- ☞ the applicability of suggested ideas and actions
- ☞ supporting evidence behind ideas and actions
- ☞ advantages and disadvantages of selecting one option over another

We can provide evidence, reasons and argument that is drawn from, and retains, the sociological. In undertaking that work we need to challenge presumptions about gender, violence and the everyday. Susan Davidson, the

nurse quoted in the introduction, commented 'we do like to think we live in a peaceful and civilised society but just look around!'

A relevant initiative I would draw attention to, and encourage comments upon, is the network Global Research on Violations, Organisations and Everyday Life ([www.grovenetwork.org](http://www.grovenetwork.org)). Jeff Hearn and I co-ordinate this virtual network that has the aim of exploring and supporting trans disciplinary and trans sector work on violence, gender and organisations. In conclusion, our research, and our voices, can work to shatter the silences that surround some of the hidden violations of everyday life.

## Acknowledgements

I would like to thank the organisers of the 2006 British Sociological Association Medical Sociology Conference for the invitation to present this plenary address, and Gillian Bendelow for chairing the session. Special thanks to Sue Gregory for comments on an earlier version of this presentation and to Jeff Hearn for insights, ideas and intellectual challenges.

## References

- Amnesty International (2006) Stop Violence Against Women, <http://web.amnesty.org/actforwomen/index-eng>
- Archer, J. (2000) Sex differences in aggression between heterosexual partners: A meta-analytic review', *Psychological Bulletin*, vol 126: 651-80
- Bacchi, C. (1999) *Women, policy and politics: The construction of policy problems*. London: Sage
- Bacchi, C. (2004) 'Policy', in P. Essed, D. T. Goldberg and A. Kobayahi (eds) *A companion to gender studies*. Oxford: Blackwell
- Bacchi, C., and Eveline, J. (2003) 'Mainstreaming and neoliberalism: A contested relationship', *Policy and Society*, vol 22, no 2: 98-118
- Bose, C.E. (1987) 'Dual spheres', in B.B. Hess and M.M. Ferree (eds.) *Analyzing gender. A handbook of social science research*. Newbury Park, Ca.: Sage, 267-85
- Bourdieu, P. (1996) 'On the family as a realised category', *Theory, Culture and Society*, vol 13, no 3: 19-26
- Card, C. (2002) *The Atrocity Paradigm. A Theory of Evi.*, Oxford University Press, Oxford
- Cockburn, C. (1991) *In the way of women: Men's resistance to sex equality in organizations*. Basingstoke: Macmillan
- Collier, R. (1995) *Masculinity, Law and the Family*. London: Routledge.
- Collinson, D. and Hearn, J. (1994) 'Naming men as men: Implications for work, organization and management', *Gender, Work and Organization*, vol 1, no 1: 2-22
- Connell, R. W. (1995) *Masculinities*. Cambridge: Polity
- Connell, R. W. (2002) *Gender*. Cambridge: Polity
- Council of Europe (2004) *Final Report of the integrated project: Responses to violence in everyday life in a democratic society*. Strasbourg: Council of Europe

- Fiebert, M. 1997. 'Annotated bibliography: References examining assaults by women on their spouses/partners,' in Dank, B. and Refinette, R. (eds.) *Sexual harassment and sexual consent*. New Brunswick, NJ: Transaction
- Gordimer, N. (2003) Testament of the Word, *The Guardian*, 15<sup>th</sup> June
- Hanmer, J. (1990) 'Men, power and the exploitation of women', in J. Hearn and D. Morgan (eds.) *Men, masculinities and social theory*. London/New York: Unwin Hyman/Routledge
- Hearn, J. (1992) *Men in the public eye: The construction and deconstruction of public men and public patriarchies*. London: Routledge
- Hearn, J. (1998) 'Theorizing men and men's theorizing: Men's discursive practices in theorizing men', *Theory and Society*, vol 27, no 6: 781-816
- Hearn, J. (2002) 'Nation, state and welfare: The cases of Finland and the UK', in B. Pease and K. Pringle (eds.) *A man's world? Changing men's practices in a globalized world*. London: Zed Books
- Hearn, J. and Parkin, W. (2001) *Gender, sexuality and violence in organizations*. London: Sage.
- Hughes, B., McKie, L., Watson, N. and Hopkins, D. (2005) Loves Labour's Lost? Feminism, the Disabled People's Movement and an Ethic of Care. *Sociology*, 39, (2), 252-275
- Kimmel, M. S., Hearn, J. and Connell, R. W. (eds) (2005) *Handbook of studies on men and masculinities*. London: Sage Publications
- Martin, P.Y. (2001) 'Mobilizing masculinities': women's experiences of men at work', *Organization*, 8(4): 587-618
- Mason, G. (2002) *The spectacle of violence: Homophobia, gender and knowledge*. London: Routledge
- McKie, L., Gregory, S. and Bowlby, S. (2002) 'Shadow times: The temporal and spatial frameworks and experiences of caring and working', *Sociology*, vol 36, no 4: 897-924
- McKie, L. (2006) Sociological Work on Violence: Gender, Theory and Research. *Sociological Research On-line*, 11, 2; <http://www.socresonline.org.uk/11/2/mckie.html>
- Mills, C. W. (1959) *The Sociological Imagination*. New York: Oxford University Press
- Nazroo, J. (1995) 'Uncovering gender differences in the use of marital violence: The effect of methodology', *Sociology*, vol 29, no 3: 475-95
- Ray, L. (2000) *Memory, Violence and Identity in J. Eldridge, J. MacInnes, S. Scott, C. Warhurst, and A. Witz (eds) For Sociology. Legacies and Prospects*. York: Sociologypress. Pages 145 – 159
- Rees, T. (1998) *Mainstreaming equality in the European Union*. London: Routledge
- Scottish Executive (2000) *National strategy to address domestic abuse in Scotland*. Edinburgh: Stationery Office
- Sennett, R. and Cobb, J. (1972) *The Hidden Injuries of Class*. New York: W. W. Norton & Company
- Skinner, T., Hester, M. And Malos, E. (eds.) (2005) *Researching gender violence: Feminist methodology in action*. Cullompton: Willan Publishing
- Stanko, E., O'Beirne, M. and Zaffuto, G. (eds) (2002) *Taking Stock. What do we Know About Interpersonal Violence?* Swindon: ESRC
- Weldon, L. (2002) *Protest, policy and the problem of violence against women. A cross-national comparison*. Pittsburgh: University of Pittsburgh Press

World Health Organization (2002) *World report on violence and health*. Geneva: World Health Organization

### **Biographical Notes**

#### **Professor Linda McKie**

([www.lindamckie.org](http://www.lindamckie.org)) is Research Professor in Sociology at Glasgow Caledonian University ([www.gcal.ac.uk](http://www.gcal.ac.uk)), Associate Director Centre for Research on Families and Relationships ([www.cfr.ac.uk](http://www.cfr.ac.uk)), and Visiting Professor at the Swedish School for Economics and Business Administration, Helsinki ([www.hanken.fi](http://www.hanken.fi)). After completing her Ph.D. research at the University of Durham in 1989 she undertook research on gender, health and health promotion. Prior to moving to Glasgow Caledonian in 1999, Linda was a senior lecturer in the Department of General Practice and Primary Care at the University of Aberdeen. Her research included the dietary beliefs and practices of older people, smoker's beliefs about the benefits of smoking, smoking cessation services in primary health care, and the process of disclosing domestic violence in the context of primary healthcare. Current research interests include gender, violence and social change, and organisations, work and care. In 2004 she was elected to the Academy of Social Sciences. Linda is also a trustee of the British Sociological Association, Evaluation Support Scotland, and the Institute for Rural Health.

## Response to Linda McKie's plenary address

**Dorte Gannik**

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I was disturbed by the fact, that what was supposed to be a sociological analysis of the subject - or at least a suggestion of the pressing need for a sociological analysis - turned out more to be a one-sided feministic attack on the other sex.

For instance, I missed the lecturer's acknowledgement of the emotional/social/societal framework surrounding intimate and family violence. In no way do I find domestic violence acceptable, but the context in which it takes place is an inseparable part of the issue. Strangely enough McKie herself pleaded that violence cannot be divorced from social structure, yet she pursues exactly that line in her argument.

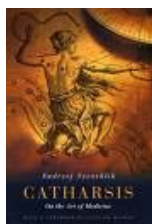
I also missed her recognition that injuries may take other forms than physical/bodily violence, that women inflict injuries upon others as well, for example by way of insults or humiliations, and that indeed such injuries may be part of the broader picture.

I further find it dangerously narrow-sighted to idealise feminine characteristics while condemning masculine aggression. Aggression in general, including masculine aggression, has different sides to it, but it is not necessarily desirable to do without it. Beware of a society pervaded by measures of safety, regulation, control and care, like the one we now seem to be heading towards!

In this connection I must say that I wonder why the lecturer did not at all touch upon the increasing dominance of women/feminist values in society, especially among the younger generations, and the possible adverse consequences of this. Indeed, these questions might become the subject of interesting sociological work.

Some of McKie's general remarks seem to suggest that her goal, or ideal, is a world without violence. This strikes me as naïve at best. Anyway it calls for a far more stringent analysis and definition of the concept and context of violence. This was what one could fairly have expected from a plenary address in a sociological conference.

## Book Reviews



Andrzej Szczeklik

***Catharsis: On the Art of Medicine.* Chicago**

University of Chicago Press. 2005 £13-00 (pbk) (ISBN 0-226-78869-5) 161pp.

**Reviewed by K. Neil Jenkins, Newcastle University**

The foreword by the Polish author Czeslaw Milosz, a friend of Szczeklik, lauds the author as a great doctor and great friend of the arts. The choice of a Nobel Prize winner for literature is an apt choice. So being because the book has very little to say about medicine or science as such, it is more of a display of the authors erudition in Greek mythology and the arts. This in itself would not be wholly problematic except for three things (and I am excluding its underlying apologia for medicine as well as the author's curious multiple references to the sagacity of Pope John Paul II).

Firstly, the book sets itself up as focusing on the doctor-patient relationship, "answering the patient's call for help is the doctor's calling. And that's where myth enters into that encounter between two people. The doctor and the patient begin to share the same, primeval dream, and together they set out in search of the elixir of life." (Szczeklik 2005:32) Yet there is nothing on the doctor-patient relationship throughout the book, indeed there is little said about the practice of medicine except in vague allusion.

Secondly, what the author too frequently does is take key words and describes their Greek origins or sources, their use in literature, and then spuriously connects them with other equally spurious ideas and fails to say anything meaningful about medicine. Some examples will give a flavour of the book: "Outside the hospital on Skawinska Street Cracow, which for the final years of his life was a second home to the popular cabaret star Piotr Skrzynecki (he [Skrzynecki] christened it the "hotel of dreams"), stands a sculpture dedicated to his memory. It features two acrobats, a man and a woman, balancing in defiance of the force of gravity. It reminds us of the wizardry of the Great Magus from the Piwnica pod Baranami cabaret, as well as the art of medicine, which borders between life and death. Both have a common origin in magic. This particular origin of medicine is worth remembering nowadays, as it transforms itself into a science." (Ibid. 53) One might expect to find out why it is worth remembering this 'origin of medicine' but we are not told, and it is left as apparently self-explanatory. Instead we move directly onto what can be our second example: "When we measure the gaps between consecutive heartbeats over a period of several minutes, we notice that in many of us there are tiny differences between them, and that they deviate from the average by hundredths of a second. This reminds us of the musical tempo rubato, which is a typical feature of Chopin's work. There are lots of familiar definitions of Chopin's work..." (Ibid. 60).

In my reading the text does not do anything or go anywhere, it is just a litany of name/knowledge dropping with spurious connections to medicine and/or science which is very exasperating. Take this final example: "Comparing the orbit of the planets around the sun and the circulation of blood within the human body makes us



think of music.” (Ibid. 66) I am not against discussing myths and the arts and their relationship to medicine *per se*, but here, in my opinion there is no critical examination of them so nothing is really said or learnt, they are just related/retold with very little reason or import.

Thirdly, is the irony when the author deals with the issue of *catharsis*, the book’s title you may recall, and states: “However, Aristotle was the first to make *catharsis* the mysterious enigma that it remains to this day. In his *Politics* he brings up the word *catharsis* and promises to discuss it in detail later on, in view of its key significance. However, he returns to it only once more in his *Poetics*, where he addresses the issue tersely and ambiguously.” (Ibid. 70) The irony being that the author here does exactly what he criticises Aristotle for, as one learns nothing substantial about *Catharsis* from this book.

However, the book is well translated in that the sentences flow and it is grammatically an easy read. Although for a book which so heavily references mythology and literature, an index might have been appropriate.

Finally, this mix of random scientific fact and art based upon myth and lore, rather than strengthening medicines non-scientific elements, seems to weaken the non-scientific medical values and, incredibly, also the role of science in medicine too. After reading the book and writing the above I sourced another review of this book in the *BMJ*. This reviewer was much more poetical in his appraisal, but I agreed wholeheartedly with the comment: “I don’t really know who would read this book, because it is overtly pointless,” (Barraclough, 2006:1458). Consequently, in light of the above I cannot recommend it.

## References

Barraclough, K. (2006) *Catharsis: On the Art of Medicine* [Review]. *British Medical Journal*; 332:1458



Ross Coomber and Nigel South (Editors)  
***Drug use and Cultural Contexts 'Beyond the West'***  
 London: Free Association Books. 2004 £18.95 (pbk)  
 (ISBN 1-8534-3743-3). 219pp.

**Reviewed by Clare Thetford, University of Liverpool**

The aim of this book is to stimulate debate about how to achieve ‘appropriate accommodation of difference and diversity within the context of international drug controls’ (p 17). Certainly, it provides food for thought and challenges western conceptualisations of drug use and associated problems. The editors seek to challenge the socially constructed meanings we attribute to drug use in the west by presenting examples of both problematic and non-problematic drug use in other cultural contexts. In particular, they raise considerable doubts about the appropriateness of the ‘war on drugs’ supported by countries such as the USA and the UK, indicating that these



policies can create and compound the health and social problems surrounding drug use.

The book begins with an introductory chapter written by the editors in which they make some thought-provoking statements. For example, they suggest that in some cultural contexts the use of drugs such as cocaine or heroin need not be problematic and can indeed play an important role in society. They draw special attention to informal social constraints surrounding drug use in other cultures, comparing them in both nature and effectiveness to the formal legal controls imposed in western cultures. They suggest that informal restrictions often prove to be far more effective at preventing drug-related problems than any of the criminalising formal approaches of western countries.

Coomber and South have brought together a collection of papers written by people from different cultural backgrounds. These are used to present examples of the many diverse ways in which different drugs are used for different purposes, and within different contexts to those in the west. Each paper is quite distinct from the others, not only in what drug is being discussed, but also in the approach to describing and representing a picture of drug use in these different cultural contexts. These include the use of psychoactive drugs in Brazil and Mexico; coca in Bolivia and Argentina; opium use in India; qat use in Yemeni culture; alcohol consumption in Bolivia and among Native North Americans; ganja in Jamaica and heroin in Kenya. While by no means a comprehensive representation of the numerous forms of drug use in different cultural contexts around the world, these examples more than adequately support the points made by Coomber and South.

What this book does particularly well is to show that use of drugs, often perceived as problematic in the west, is not necessarily so in either health or social terms (see for example, chapter 5 on opium use in Rajasthan, India where addiction is not considered to be problematic), and that problems can be introduced with the imposition of restrictions and criminalisation of drug use, as well as the imposition of western norms surrounding drug use.

The book suggests that it is western conceptualisations of drug use, alongside social and economic inequalities, that mean drug use is problematic, rather than the availability of and use of the drugs themselves. It shows that western countries are yet again guilty of interference in the politics and practices of other countries and cultures in which they impose their own set of problems upon others, based upon western notions of deviance. Indeed, the evidence provided in this book shows that in many societies, and in other contexts, drug users are not considered deviant as they often are in the west. In fact, drug use can be seen to strengthen social systems, rather than pose threats to stability as in the west. The book implies that drug use is socially and culturally defined, as are the problems surrounding the use of drugs, both licit and illicit. It is particularly interesting in some of the examples provided, that health problems associated with drug use, commonly explained as 'biological' in the west, are absent in users of the same and similar drugs in other cultures.

All chapters make the distinction between both public and private use of drugs and discuss many other social and cultural norms and regulations. They each discuss the effects of legislation regarding the use of particular drugs and provide examples of resistance to the imposition of legal restrictions. Each chapter also acknowledges differences in drug use among different sections of each society, and demonstrates the effects of social and cultural restrictions on the use of drugs by detailing differences in the way groups governed by one set of rules use drugs differently to groups governed by other rules.

A concluding chapter to bring all these ideas together, drawing upon the rich contextual examples provided throughout the book would have been useful but was lacking. The introductory chapter highlights some of these issues but the book does not develop these ideas further by examining them together and in relation to each other, as well as in comparison to the west. The aim of the book was to stimulate debate, with a focus on the appropriateness of international drugs policies. It certainly causes the reader to think about how drug use is often perceived but some of the issues highlighted in the different chapters could have been examined more closely to arrive at some more specific arguments. The book hints at areas worthy of further investigation, including international policies and how western nations conceptualise and approach drug use but leaves the job of exploring these issues further for someone else to take up.

This book would make a welcome addition to reading lists for students of drug use, public health and social sciences. It also makes for a really fascinating and enjoyable read for other researchers within many disciplines, extending beyond those working in the drug use field.



Michael Pryke, Gillian Rose, and Sarah Whatmore  
(Editors)

**Using Social Theory: Thinking through Research.**

London: Sage Publications/The Open University Press.  
2003 £19.99 (pbk). (ISBN 0-7619-4377-3) 196 pp.

**Reviewed by Yves Laberge, Université Laval, Canada.**

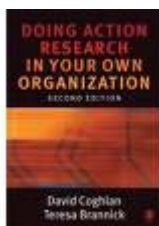
In *Using Social Theory: Thinking through research*, Michael Pryke, Gillian Rose, Sarah Whatmore, all academics at the Open University, have gathered nine texts about the research process, referring extensively to methodological and epistemological issues. All nine contributors teach geography in various universities in United Kingdom. This is not a book designed for selecting a specific research method, but rather a group of essays about the many questions that arise when research is conducted. In that sense, the book might be helpful for graduate students who would need to refer to social theory in the first year of a master's degree, and could possibly serve as an addendum for academics who are teaching advanced courses in methodology. In the short preface, the three co-editors explain that this book was designed as the basis for their own course on "Human Geography, Philosophy and Social Theory" (p. ix).

This concise book is an inspiring and often insightful read. In the first chapter, John Allen reminds us that in all research, "questions are produced, not found" (p. 17). The second chapter by Nigel Clark refers to French social theory, using the concepts of Gilles Deleuze and Jacques Derrida like "deconstruction" and "event" (p. 30). In chapter 4, Doreen Massey questions the hidden thoughts and ideologies behind discourses and disciplines, highlighting the "power relations" that exist (p. 87). The only chapter that mentions issues directly related to medical sociology is Nigel Thrift's, entitled "Practising Ethics (Ch 6), which refers to ethics committees and

doubtful research practices, for instance those in nazi Germany, and scandals in biomedical research that occurred in the 1970's (p. 116).

As a whole, *Using Social Theory: Thinking through research* has some very good points. But I see here a well written book about social theory as seen within the cultural studies perspective, which is not bad *per se*. However, I doubt that all sociologists and economists would recognize themselves in a book that could rather be ranked into the humanities sector. *Using Social Theory* is far from boring, and the most interesting chapter in my eyes would be Nick Bingham's essay on "Writing reflexively". Here Bingham draws on the work of sociologist Howard Becker to understand the impacts of narrating an experiment without any distance (p. 146). In other words, how does one make sense of results in research?

I was surprised to see how much most contributors quoted noted francophone academics who wrote about the everyday life in a laboratory, like Bruno Latour, Isabelle Stengers, Michel de Certeau. My only quibble would be about dates; when authors mention and quote historians and social theorists like John Dewey, Williams James, Michel Foucault (p. 17), It would be useful to know exactly when these people lived and died, just to help students put these different thinkers into a historical perspective. In summation, this is a timely book about relevant issues and it should invite young scholars to think more about the unquestioned elements that are taken for granted in every piece of research.



David Coghlan and Teresa Brannick  
***Doing Action Research in Your Own Organization***  
**(2nd edition).**  
 London: Sage. 2005.£19.99 (pbk). (ISBN:1-41290247- 9)  
 168pp

**Reviewed by Anne-Marie Martindale, University of Liverpool**

The boldness of the front cover accurately reflects the approach taken by its authors. Coghlan & Brannick set out their aims and objectives in a clear, confident style, which is matched by their concise and focused use of language. The liberal use of diagrams, case studies and end of chapter exercises all help to rapidly immerse the reader into the key debates and practical issues concerned with action research.

The book is divided into three parts, which is explained in the preface. Part one, *Foundations*, sets the scene, providing just the right amount of theory and praxis to place the reader firmly within the action research dynamic. Part two, *Issues and challenges in researching your own organization* explores the different forms an action researcher can take, within an organization. The final part, *Implementation*, examines the issues involved with designing and conducting your own research. The contents are drawn together in a short conclusion and the reader is left with a helpful list of insider action research considerations.

In this second edition, the authors hope to draw on their experience and the considerable array of new writing to provide the potential practitioner with a more current and informed action research account. The book is designed for those with an

additional role as a short-term researcher within their organisation, and for those in academia who may supervise such projects. Refreshingly the authors urge the reader to engage with other named texts early on in the preface. This has three key benefits: practitioners can fill in any remaining knowledge gaps; the authors' claims can be critically assessed and the researcher can save time, through conducting focused literature searches.

The initial chapter, *Understanding Action Research* sets the scene for the first part of the book. The authors do not waste time on unnecessary historical material; instead they focus immediately on key definitions of action research. Two are provided, Reason and Bradbury's (2001), and Shani and Passmore's (1985). They opt for the latter "Action research may be defined as an emergent inquiry process in which applied behavioural science is integrated with existing organizational knowledge and applied to solve real organizational problems..." (Shani and Passmore, 1985, in Coghlan & Brannick: 2005:3), though it is not absolutely clear why this definition was favoured. A little more critical discussion about the reasons why might have provided the reader with some additional, experiential, insight.

Having defined action research (AR) the authors swiftly move on, grounding the approach concisely within a historical and theoretical framework. Although a substantial amount of relevant information is contained within the next few pages (4-9), those without a background knowledge of social theory might struggle to make positivism, hermeneutics and critical realism relevant to their own project. However, as stated earlier, the reader is encouraged to use the book in conjunction with other sources of information. A brief history of AR is provided, which takes into account its various disciplinary influences, including management science. More detailed definitions are given by key authors and presented in an easy to read, list-like, style. The chapter concludes with a concise overview of the influences of the last two decades, including action learning, participatory enquiry and reflective practice.

The final two chapters in Part one *Enacting the Action Research Cycle* and *Learning in Action* continue in the same practical vein. Key practical and theoretical debates examining the stages of research and the skills required are summarised in an easy to read and digest format. The exercises at the end of the chapter are particularly useful in enabling future practitioners to envisage what they are hoping to achieve from the research and assessing their existing knowledge.

Part two examines *Issues and Challenges in Researching your own Organization*. This section places the researcher firmly within their organisational setting, examines the duality of their role and tries to tease out some of the ethical and political dilemmas located within the AR framework. Again, the subject matter is set out clearly and concisely in user-friendly language. Chapter 5, *Preunderstanding Role Duality and Access* is particularly useful. The authors set out the key tensions and the potential repercussions associated with AR. However, having recently experienced the frustrating actions of gate-keepers, I would have liked a little more practical advice on what to do in such cases. Chapter 6 *Managing Organizational Politics and Ethics* does not suffer in this way. Building on the work of Greiner and Schein (1988) Coghlan & Brannick explain 10 key power relationships which need to be considered and managed. Authoritatively written, these few pages are some of the most important in the book. Examining relationships between the researcher, their managers, subordinates and the clients funding the research, it is possible to apply the information beyond AR, to research in general.

After a highly practical and dynamic second section I looked forward to reading the final one (*Implementation*) and gaining advice on research analysis and report

writing. However, I felt slightly let down. The subject matter becomes more abstract and to some extent removed from the immediate business of research. Part three starts with a chapter entitled *Implementing your action research project* and contains information on the need for change, data generation and the role of technology. The next two chapters examine inter-level dynamics in AR and the use of frameworks to study organizations in action. It is not until the final chapter that we receive information on how to write an AR dissertation. Though all the salient issues are covered, for example methodology and dissemination, this highly significant chapter would benefit from additional length and depth. There is little space dedicated to examining the ramifications of the research report, or their potential impact on the insider-researcher's career, either positively or negatively. The conclusion does to some extent make up for this absence with a rule of thumb guide to AR, reproduced courtesy of Shepard (1997).

The experience of the authors is obvious from the start. Key history, theory, practical issues and current developments are set out clearly, using concise and user-friendly language. The use of short paragraphs, bullet points and diagrams enables the reader to identify separate, but related concepts and issues. The end of chapter exercises also helps to consolidate learning and give the first-timer a valuable opportunity to think through important research considerations. In places, particularly the final section, the book would benefit from a more practical and less abstract account, for example, a guide to what to do when things go wrong, rather than a summary of current findings. However, this does not detract from the utility of *Doing action research in your own organization* by Coghlan & Brannick and I would have no difficulty in recommending this book to researchers from a wide range of backgrounds.

## References

- Greiner, L. E. and Schein, V. E. (1988) *Power and Organization Development: Mobilizing Power to Implement Change*. New Jersey: Prentice Hall.
- Reason, P. and Bradbury, H. (2001) *Handbook of Action Research: Participative Inquiry and Practice*. London: Sage Publications.
- Shani, R. and Passmore, B. (1985) Organization inquiry: Towards a new model of the action research process, in Warrick, D. D. (ed.), (1985) *Contemporary Organizational Development: Current Thinking and Applications*. New York: Scott, Foresman and Co.
- Shepard, (1997) Rules of thumb for change agents, in Hoy, J. C., Van Eynde, D. F. and Van Eynde, D. C. (1997) *Organization Development Classics: The Practice and Theory of Change--The Best of the OD Practitioner*. San Francisco: Jossey-Bass.



Stefan Timmermans and Jonathan Gabe  
***Partners in Health, Partners in Crime: Exploring the Boundaries of Criminology and Sociology of Health and Illness***

Oxford: Blackwell Publishing. 2003.£21.99 (pbk). (ISBN: 1-4051-0539-9) 200pp

**Reviewed by Susie Page, University of Greenwich.**

Timmermans and Gabe, in an excellent introduction discuss how ‘*Contemporary jurisprudence and health care intersect at a densely populated borderland and it is this overlooked borderland that forms the [focus of the book]*’ (p: 6).

The introduction is followed by a rather oddly placed chapter reporting findings from a study concerning the different approaches to substance-abuse treatment in a French ‘drug clinic’. The book is then organised around two distinct areas; ‘Care Providers as Experts and Victims of Crime’ and ‘Invoking and Controlling Madness’. The first area contains two chapters. One, authored by Timmermans, concerns the interplay at the point of a death, between the worlds of the criminal investigator (forensic experts) and the organ-procurement agencies. The insights offered around the professional power struggles associated with the changing dynamics of this relationship, in addition to those around the medico-legal interface, would also sit well in a text on the sociology of the professions.

The other chapter in this section by Elston *et al* explores the nature of violence against doctors (in this case, General Practitioners) which, as Timmermans and Gabe suggest (p:11), provides a particularly interesting context for exploring the relationship between medicalisation and criminalisation. The pertinence of the analysis offered here is interesting since at the time of writing (Autumn 2005) the media reports figures of 40,000 attacks on mental health nurses by psychiatric inmates in England in 2004 (*O’Hara M. The Guardian, Wednesday October 19<sup>th</sup> p: 3*) whilst at the same time zero tolerance policies towards violence are widespread in many social and workplace environments.

The themes of freedom, coercion, treatment and imprisonment that are apparent within the early chapters of the book recur in the four chapters that form the second section where ‘... *the explicit links made between mental health and criminal behaviour in policy and legal circles*’ (p: 1), are explored. A key concept here that is sometimes explicit, and sometimes less so, is that of risk assessment; a concept that seems increasingly to permeate all walks of contemporary life, not least the criminal justice system and the health care arena.

The work reported here addresses; the emergence of a mental health ethos in juvenile justice systems and the implications of this (Armstrong), Canadian media depictions of the conflation of mental illness and criminality (Olstead), Actor Networks, policy networks and personality disorder (Manning) and finally, the pathologising of cultural difference in American criminal courts (Reddy).

This is a very interesting book and, I suspect, heralds a fruitful academic partnership between the worlds of sociology, medical sociology in particular, and criminology. The role of power in its various guises is, in many ways, a connecting thread throughout the work presented. With both law and medicine historically depicted as institutions of social control it is perhaps surprising that an examination of

the interplay between 'mad' and 'bad' and how these are constructed and managed, has not emerged before now. Most students and teachers of sociology, medical sociology, and criminology as well as mental health practitioners will find something of interest here. Yet, as fascinating as much of the book is, a notable omission concerns health professionals who become 'mad or bad' and turn against those for whom they are supposed to be caring. Shipman is an obvious, but not sole, example and of course there are a number of cases in which nurses have killed babies for whom they were caring as well as cases of elder abuse and sexual abuse of clients and so forth. Assuming studies related to this area (i.e. gross professional misconduct or 'Caring and Criminality') are in progress, the 2<sup>nd</sup> edition should prove even more stimulating.



Joanne Lynn

**Sick to Death and Not Going to Take It Anymore!  
Reforming Health Care for the Last Years of Life.**

*Berkeley: University of California Press/ New York: Millbank Memorial Fund. 2004. £15.95 (hbk) ISBN: 0-5202-4300-5) 217pp.*

**Reviewed by Maggie Hammond, University of Liverpool**

I came to this book having worked for three years as a researcher on the European CareKeys project (Vaarama et al, in press). The purpose of CareKeys has been to address the contribution of care services to the well-being of frail older people and to produce tools to enable the managers of services not only to provide resource-efficient care, but care with the priority of maximising the quality of life of the recipients. I was therefore well-primed to embrace this book with enthusiasm, and I was not disappointed.

What I particularly appreciated was the absolute passion of Joanne Lynn. She is a clinician specialising in chronic illness and end-of-life care, and a senior scientist with the RAND Corporation, a non profit institution, 'that helps improve policy and decision making through research and analysis', and that tackles everything from energy and the environment, to health care. Although the book is soundly aimed at the health care policies and systems in the USA, there is much succinct and extremely thought provoking material relating to the wider issues of institutionalised attitudes towards the last phase of life.

Our current approach to ageing seems to have two main foci: healthy ageing and care of the dying (e.g. hospice care). However, because of medical and social advancements that have increased life expectancy, many more people are now living the final tenth of their lives with disabilities after surviving a stroke, with progressive dementia, and / or with frailty (a syndrome defined as at least three of the following five symptoms: weight loss, muscle weakness, slow walking speed, exhaustion, and low physical activity). This can mean years of increasing dependency, complex management and adaptation, requiring occasional acute medical intervention, and yet



having every potential to maintain meaningful relationships, activity, and quality of life.

This group of the population requires services that meet their needs for medical management and personal and social care in a flexible and responsive way that supports them in achieving their personal goals. In addition, these services should be organised according to need, rather than by disease or place of care. The author makes the brilliant point that the cause of death in a person with multiple illness and frailty is like the fall from the high wire: the fall only kills because the person was on the high wire in the first place. With suitable support in place, the individual can be kept off the high wire.

We have, of course, the National Service Framework for Older People (DoH, 2001), which sets out 8 standards, including the promotion of person-centred care; and the single assessment process, which aims to integrate health and social care services. Recently, *A New Ambition in Old Age* (DoH, 2006) has added to this the framework the theme of 'joined up care', emphasising that although progress is certainly being made, there is still not enough attention paid to meeting assessed needs with appropriate services. We have every possibility of enabling the provision of such care in the future. We have acknowledged the shift in demographics, the voluntary sector and 'service user' organisations give voice to the needs of informal care givers, and we increasingly enable multidisciplinary team care. Projects like CareKeys may also contribute by providing methods of measuring meaningful service outcomes and monitoring the quality and reliability of care.

Joanne Lynn is a woman with a mission. Her book provides an 'agenda for action', including priorities for individual and corporate care providers, policy makers, voluntary groups, philanthropic groups, and even television, film and newspapers. With enough will, this book suggests, good care for all can be a reality.

## Notes

<sup>1</sup> RAND Corporation website: <http://www.rand.org> accessed 24 October 2006

## References

- DoH (2001) National Service Framework for Older People [http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPAmpGBrowsableDocument/fs/en?CONTENT\\_ID=4096710&chk=yLadyI](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPAmpGBrowsableDocument/fs/en?CONTENT_ID=4096710&chk=yLadyI) accessed 24 October 2006
- DoH, Philp I (2006) A new ambition for old age: Next steps in implementing the National Service Framework for Older People: A resource document [http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\\_ID=4133990&chk=b2B13z](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4133990&chk=b2B13z) accessed 24 October 2006
- Vaarama M, Pieper R, Sixsmith A. (eds). (In press) *Care-related Quality of Life in Old Age*. New York, Springer.





Dennis Raphael, Toba Bryant and Marcia Rioux (Editors)  
**Staying Alive: Critical Perspectives on Health, Illness,  
 and Health Care.** Toronto: Canadian Scholars' Press.  
 2006. £26.99 (pbk) (ISBN 1551302969) 408pp

**Reviewed by Fernando De Maio, Simon Fraser University, CA.**

This useful text examines a broad range of issues related to medical sociology using an overarching perspective based on political economy. It is a welcome addition to a growing body of literature on the social determinants of health. The book's Canadian focus should be of interest to medical sociologists in the UK; the book develops a useful comparison of the origins and development of the Canadian and US health care systems, along with important comparisons with Sweden and the UK based on regimes of welfare capitalism.

The book begins with four strong chapters which contrast epidemiological, sociological, political economy, and human rights approaches to health, illness and health care. These chapters are written in a way that makes the perspectives accessible to undergraduate students; the authors clearly present the traditional foci of these perspectives and draw attention to their respective limitations. The chapter on sociological perspectives includes discussion of the role of theory in health research, including thoughtful sections on structural functionalism, symbolic interactionism, conflict theory, feminism, and postmodernism. Overall, these chapters provide a good foundational understanding of the differences between approaching health issues at the cellular, organ, individual, or population levels of analysis.

However, although the book presents a useful comparison of epidemiology, sociology, political economy, and human rights, it would have benefited from a stronger discussion that acknowledges the common methodologies employed by researchers working from these perspectives. In particular, the book would be strengthened by a more nuanced discussion of the role of quantitative methods. For example, the book includes a critique of contemporary epidemiology for focusing too much on individuals and suggests that this focus is due to the development of computers which "keep many researchers stuck in the individual risk factory". Yet, it is this same capability which enables the study of income distribution through measures such as the Gini coefficient – measures that are central to more critical research by sociologists or political economists, or indeed, social epidemiologists.

The book continues with a strong set of chapters on the social determinants of health. The roots of this field of research are correctly traced back to the writings of Virchow and Engels, and important questions about the effect of medical care on improvements in mortality rates since the 1900s are raised. The book's Canadian focus strengthens these chapters, which include discussion on the health status of Canada's Aboriginal peoples as well as Canada's 'healthy immigrant effect', wherein the health of immigrants (which is on average *better* than that of Canadian-born people at the time of immigration) *deteriorates* after settling in Canada.

Three chapters examine Canada's health care system – described by the editors as the 'crown jewel' in Canada's welfare state – in more detail. In particular, this section of the book examines the political and social factors that led to the development of Canada's health care system, which unlike the US system, is based on

the principles of universality, comprehensiveness, accessibility, and public administration. These chapters also examine some of the controversies apparent in current discussions on health care reform in Canada, including issues of public versus private financing, and the role of profit. Readers from the UK will find these chapters useful in understanding similarities and differences with the NHS. The book concludes with critical discussions of the social construction of disability and illness, the pharmaceutical industry, public health concerns in Canada, the US, the UK and Sweden, and the future of health research in Canada.

I have used this text in my undergraduate course on medical sociology. The book has been well-received by students, and if used alongside additional sources, I believe it can serve as a valuable introduction to medical sociology.



Kate Gerrish and Anne Lacey (Editors)  
**The Research Process in Nursing (5<sup>th</sup> Edition)**  
 Oxford: Blackwell Publishing. 2006. £19.99 (pbk) (ISBN 1-4051-3013-X) 576pp.

**Reviewed by Julie Anne Woods, University of Liverpool**

This 5<sup>th</sup> edition of 'The Research Process in Nursing' edited by Kate Gerrish and Anne Lacey has been extensively revised and re-written. The new editors have re-structured this new edition of a well-established book to reflect current practice and developments in nursing research. The book is designed to be relevant to nurses undertaking educational courses in research from pre-registration to masters' level and will also be helpful to nurses in clinical practice who are either involved in research, or who need to understand and implement research findings in their clinical practice.

The content of this book provides a thorough, accessible and systematic journey through the research process. The book is clearly presented, chapters are well written and referenced, and practical examples are cited throughout. This latest edition adds chapters on validity and reliability, case study and longitudinal research.

A great deal of valuable information is presented in a logical and easily readable way and the stated aim to 'enable reading and understanding of research' is largely met within the acknowledged restraints of the enormity of the subject. Each chapter of the book is intended to be complete in itself, and this means it is useful in making sense of particular issues that the novice researcher may have difficulty understanding, as topics are clearly indexed and therefore easy to find. The glossary is comprehensive and explains most research terms in an understandable way.

As a nurse needing to design a research proposal for my MSc, I was a complete novice. I needed a research textbook that contained all of the relevant information, but was easy to understand and interpret. I found the book invaluable as it clarified research terms and concepts in a way that was easily understandable and relevant to my needs at the time. It is a large textbook and would take a long time to read through and understand completely, and I would have found it difficult to use the book this

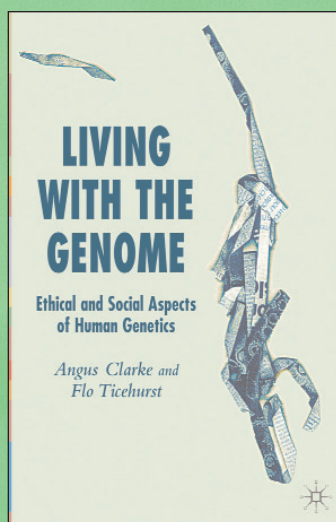
way. The editors have designed the book in such a way that particular relevant research topics can be easily identified and individual chapters can be selected in order to clarify the researchers knowledge and add to their understanding. I personally found the book easier to use in this way, and when I had completed my project was interested to find that I had looked at most sections and chapters in the book at some time during the course of my research.

If I was asked to undertake any further research I would use this book again as I believe it would be useful for both novice and experienced nurse researchers. I have also found it very useful and helpful as an aid to interpreting existing research findings in order to develop my 'evidence based' clinical practice.

This book is directly relevant for hospital and community nurses of all specialities and because the research process is the same irrespective of the discipline studied, allied health professionals, such as physiotherapists, will also find this book relevant and useful.

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## Submitting a book review

MSo welcomes the submission of book reviews within the discipline of medical sociology. A list of books available for review will be published in each edition (see below), and books may be obtained from the editorial team. However, the editorial team will also be happy to consider reviews of books not listed, provided they are of relevance to the medical sociology community. There is no prescribed format for reviews, although reviewers should provide the full reference of the book, including the price, number of pages and the ISBN. Book reviews should be no longer than 1000 words. Completed reviews should be submitted as a Microsoft Word document via email to [MSO@liverpool.ac.uk](mailto:MSO@liverpool.ac.uk). Book reviews will not be subject to peer review, and the decision to publish will be made by the editorial team. The editorial team also reserve the right to edit articles prior to publication.

The editorial team would also strongly encourage readers of MSo to specify particular areas of medical sociology that they would like to see book reviews in, or key medical sociology texts they would be interested to read a review on.

## Books available for review

Martine Rothblatt (2004) *Your Life or Mine: How Geoethics Can Resolve The Conflict Between Public and Private Interests In Xenotransplantation*. Aldershot: Ashgate.

Colin Francombe (2004) *Abortion in the USA and the UK* Aldershot: Ashgate.

David M. Oshinsky (2005) *Polio: An American Story. The Crusade That Mobilized the Nation Against the 20<sup>th</sup> Century's Most Feared Disease*. New York: Oxford University Press.

Tudor Hart, J. (2006) *The Political Economy of Health Care Health and Society Series*. Bristol: The Policy Press.

Allen, D. and Pilnick, A. (2006) *The Social Organisation of Healthcare Work*. Oxford: Blackwell Publishing.

Shakespeare, T. (2006). *Disability Rights and Wrongs*. London: Routledge

Kuhlman, E. (2006). *Modernising Health Care: Reinventing professions, the State and the Public*. Bristol: Policy Press.

**If you wish to review one of books listed above please contact the editorial team, [mso@liverpool.ac.uk](mailto:mso@liverpool.ac.uk).**

## **The Sociology of Health and Illness (SHI) Book Prize**

The Sociology of Health and Illness (SHI) Book Prize is awarded annually each September to the author(s) or editor(s) of the book making the most significant contribution to the sub-discipline of medical sociology / sociology of health and illness. All nominations for the prize should be published during the three years preceding the award, and the winning author(s) / editor(s) receive a prize of £1000.

### **2006 Book Prize**

This year's panel, convened to judge the nominated books, consisted of Mildred Blaxter, Oonagh Corrigan and David Rankin.

The following books were short listed for the 2006 award.

Rob Baggott, Judith Allsop & Kathryn Jones  
**Speaking for Patients and Carers**  
*Palgrave Macmillan*

Lisa Smyth  
**Abortion and Nation: The Politics of Reproduction in Contemporary Ireland**  
*Ashgate Publishing*

Iain Wilkinson  
**\*Suffering: A Sociological Introduction**  
*Polity Press*

Alan Petersen  
**\*Engendering Emotions**  
*Palgrave Macmillan*

Simon Dyson  
**Ethnicity & Screening for Sickle Cell/Thalassaemia**  
*Churchill Livingstone*

Andrew Lakoff  
**Pharmaceutical Reason: Knowledge and Value in global psychiatry**  
*Cambridge University Press*

Monica Konrad  
**Narrating the New Predictive Genetics: ethics, Ethnography and Science**  
*Cambridge University Press*

The award was announced by chair of the committee, Mildred Blaxter at the Annual General Meeting of the BSA Medical Sociology group at Heriot-Watt, University, Edinburgh, September 2006.



The 2006 winner as judged by the committee was **Suffering: A Sociological Introduction**, by **Iain Wilkinson, Senior Lecturer in Sociology in The School of Social Policy, Sociology and Social Research, University of Kent.**

\* Look out for reviews of these books in forthcoming editions of MSo.

## **2007 Book Prize**

Nominations are now being sought for the 2007 SHI Book Prize.

The BSA Medical Sociology Group will award this prize to the author(s) or editor(s) of the book judged to have made the most original and significant contribution to the sub-discipline, published within the last 3 years.

Nominations can be made by an individual or a publishing company who have not been involved in editorship or authorship of the book that has been nominated.

A full copy of the rules and a nomination form can be found at the website:

<http://www.britsoc.co.uk/specialisms/103>

Nominations must be received by **28<sup>th</sup> February 2007.**

A list of short listed books will be included in the Spring 2007 Edition of MSo.

## Postgraduate abstracts 1<sup>st</sup> edition November 2006

This section of Medical Sociology Online provides the opportunity for postgraduate researchers (at any stage of their research) to publicise their research and to create networking opportunities with other researchers in the field. Work in progress or recently completed work can be included.

PhD students, post-doctoral researchers, other researchers new in post and students completing a Master's degree by research are encouraged to submit details of their research project.

To submit for the next edition of MSo please go to  
<http://www.medicalsociologyonline.org/submissions.html>

### Sara Louise Elliott Edwards



Sara Edwards, began her PhD in March 2006 on a full-time basis and expects to complete in 2009. She is based within the department of primary care at the University of Liverpool.

Funded by the Medical Research Council (MRC), the thesis is currently titled, 'The impact of doctors' perceptions and emotional responses during consultations with patients who present medically unexplained symptoms in primary care.'

### Supervisors

Professor Peter Salmon (University of Liverpool)  
Professor Chris Dowrick (University of Liverpool)

### Aim

An investigation into how GPs' management of medically unexplained symptoms can be improved.

### Objectives

1. Gain an insight into why GPs propose somatic and other responses for patients with medically unexplained symptoms.
2. Test the hypotheses that somatic responses are related to (i) perceptions of patients' intentions, (ii) GPs' negative emotional reactions to the consultation.
3. Identify influences on, and effect of, GPs' own goals to disengage from, or to please the patient.

4. Explore which kinds of GP responses patients experience as meeting or negating their needs for legitimating explanation and support, and why patients moderate or escalate their presentation following these responses.
5. Establish how these findings can best be used educationally with GPs.

## Methods

The research is being conducted using a transdisciplinary approach.

1. Triangulation of consultations with GP and patient interviews.

GPs will be asked to record consultations with consecutive patients and to fill in a checklist to identify patients who they feel demonstrate medically unexplained symptoms. The consultation will be analysed using the Liverpool Clinical Interaction Analysis Scheme, a coding scheme developed from previous research conducted by Salmon & Dowrick (supervisors).

Semi-structured interviews will also be conducted with both the patient and the GP individually within seven days of the consultation. The tape-assisted recall method will be used during the interview to help participants reflect on the interaction which took place during the consultation. Thematic analysis of patients' and GPs' interviews will be conducted in parallel.

The research will include 30-40 recorded consultations involving patients with medically unexplained symptoms. Interviews will be conducted with both the patient and the doctor from each of the consultations and thus 60-80 participants will be included in the study.

2. Focus groups with participating general practitioners.

On completion of the study, focus groups will be conducted with participating GPs (approximately 30) to enable respondent validation of the findings, and to identify opportunities and barriers concerning their implementation in educational interventions.

## Stage of research process

Having successfully obtained ethical approval and conducted my pilot study, I am currently liaising with practice managers and meeting with GPs to organise the fieldwork, which will begin in the New Year.

## Contact details

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## Dr Kate Weiner

Kate Weiner, based at the University of Nottingham took up a full time ESRC/MRS post-doctoral fellowship in April 2006, to be completed in March 2008.

### Title

'Lipids, genetics and coronary heart disease: the construction of a field.'

### Aims and objectives

The aim of my doctoral research was to explore the empirical basis of the geneticisation thesis, by looking at the place of genetic discourses and practices in one specific area. The thesis focuses on familial hypercholesterolaemia (FH), a treatable hereditary cholesterol condition associated with high rates of coronary heart disease (CHD). It asks how much and in what ways patients with FH and professionals involved with the condition construct FH and CHD as genetic conditions.

The aims of the fellowship are (1) to disseminate the findings of my doctoral research to social science and medical audiences through publication and conference presentation and (2) to develop and extend this work by undertaking limited further research and developing research proposals concerned with the emergence of a genomic model of CHD in biomedical discourses and with patients' constructions of FH and raised cholesterol.

### Methods/approach

The doctoral work employed a number of qualitative methods drawing upon several different types of data sources. The main methods were:

1. **Analysis of biomedical literature**, including a small number of recent commentary papers providing general accounts of CHD and selected publications of professional members of HEART UK, the main UK health charity involved with inherited lipid disorders and cholesterol.
2. **Ethnographic work** with HEART UK, involving observation of the organisation's public activities and analysis of the documents it produces.
3. **Interviews** with 10 staff and senior members of HEART UK, and with 31 people with FH recruited through a large lipid clinic in the north of England. Lipid clinics are specialist outpatient clinics concerned with the care of people with a range of lipid disorders, including, but not limited to FH.

### Arguments/results to date

My doctoral research establishes that there are a number of models of CHD and suggests that biomedical professionals involved with HEART UK largely do not focus on genetic models of CHD in their own research. Furthermore, HEART UK's activities do not focus on genetics in relation to CHD risks generally or in relation to FH. The organisation was characterised by a CHD culture rather than genetic disease culture.

When people with FH explained their condition, they always included some talk of heredity. However, the condition was framed in a number of, sometimes, contradictory ways. Their accounts of CHD in general did not draw heavily on

genetics. Even their explanations of cases of CHD in people with FH were not fixed on the hereditary aspect, but drew on a range of factors. In short, lay models of CHD, embodied by the idea of the 'coronary candidate', appear to be very tenacious, even where specifically hereditary explanations are available.

These people with FH situate the condition as part of normal, acceptable, unavoidable, treatable and manageable illness and drew a firm boundary between it and 'serious' genetic diseases. Reproductive decision-making was not seen as a relevant theme in relation to FH. Their talk revealed a strong sense of responsibility for their offsprings' welfare, but a looser sense of obligation to wider kin. This again suggests that these interviewees did not construct FH through a strongly genetic frame.

In sum, the analysis suggests that FH is not understood or managed within a strong genetic frame, and that neither professionals involved in HEART UK, nor people with FH, provided or contributed to radically new or geneticised accounts of CHD.

### **Conclusions/recommendations**

The research suggests that geneticisation overstates the transformatory potential of genetics, and that factors such as the availability of effective therapeutics, the sites where care takes place, the disciplines involved, and existing lay and professional models of disease are important for the construction of a particular field. Furthermore, in arguing that FH is not associated with a strong specific disease identity or community, the analysis questions the notion of biosociality, suggesting that it may be less relevant to some biological states or conditions than to others.

Please see the Congratulations! section for details of Kate's publications and conference presentations.

### **Contact details**

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Telephone: 0115 846 7173

## **Congratulations**

**Dr Carol Eastwood**

[Carolmoi@hotmail.com](mailto:Carolmoi@hotmail.com)

Congratulations to Carol Eastwood who was awarded her PhD from the University of Teeside in July 2006. Her thesis is titled: 'Endometriosis: medical delegitimation and the reconstruction of narrative identity.' This thesis was self-funded.

### **Planned written work**

'The Social Construction of Endometriosis: Discourses of Gender, Race and Class' (working title). To be submitted to *Medical Sociology*. This paper will focus on how biomedical texts have constructed this disease in ways which reveal longstanding cultural assumptions and prejudices about women and their bodies, gender, class and race. It therefore offers an epistemological challenge to biomedical understandings of endometriosis.

Carol also hopes to write pieces on how the narrative method used in the thesis has helped to reveal aspects of sufferers' sense of self and identity.

A further piece is planned to show how selves are threatened by contested or delayed diagnosis. Carol intends to write about the use of her own personal experience of endometriosis and the construction of her own narrative as a way of arriving at key themes in the thesis.

### **Conference presentations**

Paper presented, 'Endometriosis and the problem of delayed diagnoses', BSA Medical Sociology Conference, University of York, Sept, 2000.

Paper presented, 'Endometriosis and medical delegitimation' Title of Conference: 'Gender and Biomedicine', University of Teeside, March, 2001.

Paper presented, 'Endometriosis and the medical encounter', Title of Conference: 'The Gendered Medical Encounter', University of Teeside, October: 2001.

Paper presented, 'Endometriosis and Threats to Femininity'. Title of Conference: 'Gender and the Illness Experience', University of the West of England, July: 2002.

### **Future directions**

Currently applying for an ESRC small grant with Prof. Jill Radford and Dr Anna Van Werch. The theme is the problem of delayed diagnosis of endometriosis amongst adolescent girls.

## Dr Jane Richardson

[j.c.richardson@keele.ac.uk](mailto:j.c.richardson@keele.ac.uk)



Congratulations to Jane Richardson who was awarded a PhD from Keele University for her thesis titled, 'Living a life with chronic widespread pain.' Her PhD, funded by the NHS(E) Capacity Building Programme was awarded in November 2005. Jane is now in post as a Lecturer in Health Services Research, Centre for Primary Care Musculoskeletal Research, Keele University.

### Associated written work

Richardson JC, Ong BN & Sim J. (2006) Is chronic widespread pain biographically disruptive? *Social Science and Medicine*. 63 (6); 1573-1585.

Richardson JC, Ong BN & Sim J. (2006) Remaking the future: contemplating a life with chronic widespread pain. *Chronic Illness*, 2(3); 209-218.

Richardson JC, Ong BN & Sim J. (In press) Experiencing chronic widespread pain in a family context: giving and receiving practical and emotional support. *Sociology of Health and Illness*.

Richardson, J.C., Ong, B.N. & Sim, J. (2004) 'Idle Devils' and 'Household Engineers': Identity in chronic widespread pain. In D. Robinson, C. Horrocks, N. Kelly and B. Roberts (Eds.) *Narrative, memory and identity: theoretical and methodological issues*. Huddersfield; University of Huddersfield Press; pp.183-191.

### Associated conference presentations

Using a life grid for qualitative interviewing in health. Social Science & Medicine Annual Conference, Leeds, 2006.

Remaking the future: contemplating a life with chronic widespread pain. Society for Academic Primary Care Annual Conference, Keele, 2006.

"It's always the little things, isn't it?": living everyday life with chronic widespread pain. BSA Medical Sociology Conference, University of York, 2005.

Making the invisible visible: communicating chronic widespread pain. UK Federation of Primary Care Research Organisations Conference, Bristol, 2005.

Experiencing chronic widespread pain in a family context: complexities in caring. BSA Medical Sociology Conference, University of York, 2004.

### **Dr Kate Weiner**

[kate.weiner@nottingham.ac.uk](mailto:kate.weiner@nottingham.ac.uk)

Telephone: 0115 846 7173

Congratulations to Kate Weiner who was awarded a PhD for her thesis titled, 'Patient and professional constructions of familial hypercholesterolaemia and heart disease: Testing the limits of the geneticisation thesis.' The PhD was awarded by Nottingham University in May 2006. The full thesis can be viewed at <http://etheses.nottingham.ac.uk/archive/00000190/>

Kate began an ESRC/MRC postdoctoral fellowship at the University of Nottingham in April 2006. Please see postgraduate research abstracts for further details.

### **Written work in progress**

Weiner, K., A genetic future for CHD? Submitted to Sociology of Health & Illness.

Weiner, K., and Durrington, P.N., Patients' understandings and experiences of FH, Submitted to British Medical Journal.

Weiner, K., "Government and industry are impressed that we've actually got patients on the committees": the construction of expertise and participation within H.E.A.R.T. UK. Submitted to Social Science and Medicine.

### **Conference presentations**

"Government and industry are impressed that we've actually got patients on the committees": constructing expertise and identity within H.E.A.R.T. UK, BSA Medical Sociology Group Annual Conference, Heriot-Watt University, Edinburgh, 14-16 September 2006.

Patients' understandings of familial hypercholesterolaemia, HEART UK 20<sup>th</sup> Annual Medical & Scientific Meeting, University of Kent, Canterbury, 28-30 June 2006.

Are we giving up on geneticisation? CSG and CESAGen 3<sup>rd</sup> International Conference on Genomics & Society, Renaissance Hotel, Amsterdam, 20-21 April 2006.

Are we giving up on geneticisation? PFGS Ninth Colloquium, Cardiff University, 31 August – 2 September, 2005.

What happens when a genetic condition leads to a common and treatable disease? Patient constructions of FH, CESAGen 2<sup>nd</sup> International Conference on Genomics and Society, The Royal Society, London, 12-14 April 2005.

What happens when a genetic condition leads to a common and treatable disease? Patient constructions of FH, BSA Medical Sociology Group Annual Conference, University of York, 16-18 September 2004.

A genomic future for coronary heart disease? 4S & EASST Meeting, Ecole des Mines, Paris, 25-28 August, 2004.

A genomic future for coronary heart disease? CESAGen 1<sup>st</sup> International Conference on Genomics and Society, The Royal Society, London, 2-3 March 2004.

## Report on the ISA XVI World Congress of Sociology

**Caragh Brosnan**

*University of Cambridge*

I recently attended the International Sociological Association's XVI World Congress of Sociology, held in Durban, South Africa, from 23-29 July, thanks to a postgraduate bursary from the Foundation for the Sociology of Health and Illness. Being in the final year of my PhD, the Congress provided an excellent opportunity to present my research in an international forum, and to gain a global perspective on the current trends and potential future directions of the profession. The week involved a packed schedule, from the opening ceremony on Sunday night to the final Presidential Session the following Saturday. With more than fifty research committee sessions on at any given time, the choice of what to go to each day was overwhelming. I had papers in two of the Sociology of Health research committee (RC15) sessions, and mainly attended this stream, which in itself had a very varied programme, ranging from sessions on men's health and women's health, to bioethics, to the regulation of professional groups. However, I also attended many other streams, and, having lately been confined to concentrating on my own specific thesis topic, it was refreshing to have a whole week in which to explore different areas of sociology!

I was particularly pleased to be able to attend the first World Congress held in Africa. The theme was 'The Quality of Social Existence in a Globalising World', and the relevance of this topic was reinforced throughout the week, both during the paper sessions and each time we ventured outside of Durban's heavily policed International Convention Centre and engaged with the society around us - one clearly in transition. On Wednesday morning I joined a small group of delegates from RC15 on a visit to St Mary's Hospital, which serves an impoverished community on the outskirts of Durban. We met the staff and were given a tour of the hospital, whose main challenge is tackling HIV/AIDS, with approximately one third of the local population infected. Although St Mary's has instigated a successful anti-retroviral treatment programme, we were told that due to lack of resources, many people remain on the waiting list. Meanwhile, the infection rate is compounded by poor living conditions, malnutrition, lack of education, patriarchal family structure, sexual violence and stigma. Back at the Congress that afternoon, I attended a session on the Sociology of HIV and AIDS and enjoyed a lively debate between South African sociologists over exactly how these various factors interact. This inspired me to explore the issues further by attending related sessions in the Family Research, Women in Society, Sociology of Population and African Thematic Foci streams. That the same problem can be studied from so many perspectives within one discipline, reminded me of the richness and diversity of sociology. So, as well as meeting lots of people and coming away with some ideas for my current work, I discovered fresh areas of interest and was left with a renewed appreciation of the purpose and usefulness of sociology itself. Overall, attending the Congress was a rewarding experience and I am very grateful to the SHI Foundation for its assistance.

## A personal reflection on the ISA Durban Conference

2006

**Christopher Scanlon**

*RMIT University, Australia*

In Stanislaw Lem's satirical novel *The Futurological Congress*, the accident-prone Ijon Tichy attends the Eighth World Futurological Congress at the Costa Rica Hilton. A sense of unreality dominates proceedings. After the US consul and his staff are taken hostage by a guerilla outfit, the US ambassador delivers a speech on the need for international co-operation surrounded by six burly bodyguards with their guns on the assembled scholars. An Indian delegate is shot while reaching for his handkerchief. Responding to the hostage takers, the authorities contaminate the water supply with a drug with effects similar to those of Ecstasy.

Even without the mass outbreak of love, the Futurological Congress was always bound to be an odd affair. The large number of delegates meant that speakers were allotted 4 minutes in which to deliver and defend their papers. To deal with such severe time restrictions, each paper, distributed and read beforehand, was composed of numbered paragraphs. Discussion and debate was conducted solely by reference to the numbers. '3, 7, 2, 11, from which it followed that 22 and only 22!!', the head of US delegation triumphantly exclaims while defending his paper. 22, it turns out, means the end of the world.

While the 2006 ISA World Congress of Sociology held in Durban in August never reached the heights of unreality as Lem's imagined Congress, it nevertheless had an unreality all its own. To be fair, this unreality is not exclusive to the ISA, but is a feature of most such gatherings. There is, after all, something preposterous about travelling half way around the globe to spend a week or so with a couple of thousand of one's colleagues, most of whom you'll never see again, delivering and hearing papers that have to be fit into neat half-hour blocks on subjects that, it must be said, in many cases, struggle to rise beyond the parochial conditions within which they first arose.

It's particularly ironic when the speakers make reference to the plight of the world's poor or the environmental crisis taking over the globe, given that the lives of many of the delegates (myself included) depend on the continuation of such structural inequalities, or that just days or hours earlier, we stepped off long haul flights that directly contribute to said environmental crisis.

As with Lem's imagined Congress, the security situation in Durban compounded these absurdities. These were real enough. Checking into the hotel, I was advised not to leave the premises. If I should want anything from the shops – a two minute walk away – a hotel employee would fetch it for me. Not being very good at following rules where curbs on freedom of movement are concerned, I ignored such advice and spent days wandering around downtown Durban, slowing only slightly when a number of delegates were assaulted during the first days of the conference.

The response of Durban's authorities was a massive and visible security presence. The daily ten minute walk from the hotel to the conference venue was accompanied by 2–3 police on every second corner and regular passes from numerous flat-tray utility vehicles with yet more police riding in the back.



This had an immediate effect on the security and wellbeing of the delegates. Local businesses and taxi drivers told of how much they liked such large conferences, since for those few days, at least, the crime rate dropped noticeably. While I was thankful for their presence, every time I saw a utility vehicle with cops standing in the back, I had to wonder whether they had been re-deployed from somewhere else and what was happening in those communities while the conference was on.

Most delegates seemed to take such absurdities in their stride, if they noticed them at all. Their approach to dealing with the unreality of the situation was to confine themselves to the hotel–conference venue–restaurant triangle, ferrying between each via taxi, while bitching about the whole situation. This was not a wholly unreasonable response given that threats to personal wellbeing and security were very real. It does call attention, though, to the ethics and sustainability of this mode of life; a mode of life that is structured around reconstituting places such as Durban to attend to the needs of globally mobile workers who plonk down for a moment and then up and on to the next mega-event.

The economists will no doubt tell us that places like Durban are better off for such events in the longer term, and that without them they would slip even further behind in the global economy. That may be true, but, as John Maynard Keynes once noted ‘Economists set themselves too easy, too useless a task if in tempestuous seasons they can only tell us that when the storm is past the ocean is flat again’.

Lem’s satire ends with Ijon Tichy discovering that the preceding events and the world that he had taken to be real is nothing more than a pharmaceutically induced simulation. In reality, the world is on the brink of environmental collapse and the solution, such as it is, is to put whole populations in to drug-induced hallucinations. Walking around central Durban, away from the rarefied atmosphere of the convention centre and beach front hotels, along street after street of the bored and unemployed, the benefits of such events — intellectual or economic — seemed a world away and the thought that there has to be a better alternative than global talk-fests grew more insistent.



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## Picture Credits

- 1 Chris Scanlon dining in Durban (Photo: Clare Thetford)
- 2 Township on the outskirts of Durban (Photo: Clare Thetford)
- 3 Police in Durban. Source : [www.voiceoftheturtle.org/raj/blog](http://www.voiceoftheturtle.org/raj/blog). Accessed 15.11.06
- 4 ICC Convention Centre, Durban. Source : [www.ICC.co.za](http://www.ICC.co.za) Accessed 15.11.06
- 5 Street Scene in downtown Durban (Photo: Chris Scanlon)

## References

Lem, Stanislaw, *The Futurological Congress (From the Memoirs of Ijon Tichy)*, trans. Michael Kandel, Continuum Books, New York, 1974

Maynard Keynes, John, *A Tract on Monetary Reform*, MacMillan, 1923.

## Christopher Scanlon

is a research associate of RMIT University's Globalism Institute and a co-editor of Arena Magazine ([www.arena.org.au](http://www.arena.org.au)). His recent research was concerned the wellbeing of communities, specifically the links between social participation in the arts and health.

## **Review of Marilyn Strathern's lecture in British Museum 2nd February 2006: Anthropology and Medical Research.**

**Hayley Davies**

*University of Warwick*

The over-subscribed attendance at this evening lecture held in the grand architectural structure that is London's British Museum was affirmation of Dame Marilyn Strathern's prominence in the field of anthropology, sociology and medicine. Strathern is renowned for her international research and for her work on gender relations and feminist scholarship; legal anthropology; knowledge and intellectual property; English kinship and the new reproductive technologies; and biotechnology and bioethics, to name just some areas of her expertise.

Strathern opened the lecture by discussing the role of anthropology in medical research. The discipline's contribution to medical research in the developing world, and its way of 'making things better', she claimed, was its recognition of the importance of context. By studying and becoming familiar with local knowledge, beliefs and practices, anthropologists attempt to make sense of, and understand, social actions or behaviours characteristic of that context or setting. In doing so, she suggested it was possible to take a different perspective on matters and most importantly, she indicated that this was useful in medical research where cultural beliefs concerning the origins of, or treatment of, illness differed from Western perceptions. Her lecture highlighted the tension between the approach of medical research and social science research.

Much of her discussion was informed by her position as a committee member for the Nuffield Council of Bioethics, in particular, her attendance at a workshop, co-hosted by the South African Medical Research Council, entitled 'The ethics of research related to healthcare in developing countries' in February 2004. Reporting on medical research discussed at this workshop, she relayed to the audience that researchers involved in this study had commented that the Kenyan participants recruited to provide blood samples for pharmaceutical research seemed to have little real knowledge of why blood was being taken. Among the locals, there were many speculative theories as to why blood was being taken. While she acknowledged that this type of research was potentially exploitative, she suggested that one way of overcoming this was through gaining informed consent; the imparting of knowledge to the potential research participants in order for them to make an educated decision as to whether or not to participate. This, it seems, was where anthropology fitted in – imparting knowledge and attempting to understand how locals produced their own knowledge.

The relatively powerless and vulnerable position of research participants was identified and attributed to the 'gap in knowledge' between them and the researcher, (and to individual and family needs for improved health care). Furthermore, the difficulty of encouraging individuals to participate in research was magnified where health needs were considerable and would not be addressed by any other agency. Absent from Strathern's account was an explanation of the drawn out process of developing successful drugs, and that the drugs, especially when new to the market, with no available alternative, would be financially unviable for most ordinary Kenyan

individuals to purchase. The unaffordability of the drugs that they are helping to develop further would only serve to exacerbate the often unequal relationship between the researcher and the researched that she reported upon.

While knowledge was a central theme throughout the lecture, and was seen as a prerequisite for informed consent, Strathern highlighted that in the Western world we assume that our knowledge is paramount and superior while often overlooking its limitations. Strathern was a member of the working group set up to follow the Select Committee of the Department of Culture, Media and Sport's recommendations on repatriation of Aborigine bones. Her understanding of the issue was that for the Aborigines, the human remains belonged to their ancestors and were significant to the Aborigines in a way that no knowledge gained by scientists in the United Kingdom from such remains could possibly compare. Here, she highlighted that it was not knowledge that was important but being 'party to a certain type of relationship' which defined their entitlement.

Strathern concluded the lecture by taking questions, any enjoyment of which was somewhat hampered by the lack of audio-technology and by her immodest and unresponsive approach. The combination of technical problems and her apparent disinterest in the questions received was by far the most disappointing aspect of the lecture. However, the lecture did draw attention to one significant dilemma: Strathern highlighted the altruistic contribution of anthropology to medical research in serving to reduce the power inequality between researcher and research participants. But taking a different perspective, does the involvement of anthropologists and sociologists in this type of medical research represent them collaborating in the exploitation of these people?

## References

Culture Media and Sport Committee, Seventh Report. Cultural Property: Return and Illicit Trade (18 July 2000).

'The ethics of research related to healthcare in developing countries: a follow up discussion paper'. 2005. Nuffield Council on Bioethics. London. Online. Available: [http://www.nuffieldbioethics.org/fileLibrary/pdf/HRRDC\\_Follow-up\\_Discussion\\_Paper.pdf](http://www.nuffieldbioethics.org/fileLibrary/pdf/HRRDC_Follow-up_Discussion_Paper.pdf) [accessed 6th February 2006].

## Visits To The Old Operating Theatre Museum

**Hannah Bradby**

University of Warwick

[H.Bradby@warwick.ac.uk](mailto:H.Bradby@warwick.ac.uk)

### *The Old Operating Theatre Museum*

Address: 9a St Thomas Street, London, SE1 9RY

Telephone: 020 7188 2679

Web: <http://www.thegarret.org.uk/>

Opening hours: 10:30-5:00pm

Admissions: Full price £3:25, Child (under 16) £2:75, Family (up to 2 adults and 4 children) £10:00

On a cold, sunny February day a dozen students from the University of Warwick, Department of Sociology, converge on an unprepossessing London address just south of the river Thames. Inside the welcome is friendly and a cup of coffee is available, alongside a bowl of blood-letting leeches.

The main event of our visit is a lecture given by the museum curator, which involves describing St Thomas's hospital in its heyday. The lecturer tells engrossing and detailed stories from the point of view of various characters: the dashing fearless surgeon, the injured impoverished Londoner, the rowdy medical student. So compelling is the re-enactment of an amputation (using a brave student volunteer), that I worry that the paler students might faint before we arrive at the final unsterilised cat-gut suture. The curator tells me she developed the characters that populate her lecture in a creative writing evening class. This, perhaps, explains the sense I have of her being a witness from the past. This is appropriate for our party, since it is mainly made up of students of the sociology of story who are writing their own fictionalised accounts of death and disease.

Three students give their own interpretations of the visit below. We hope that these persuade you to visit for yourself. The leeches, by the way, are fed on the Museum staff's own blood and the only donations required by visitors are pecuniary.

## First Impressions of the Old Operating Theatre

**Natasha Shpakovata**

*University of Warwick*

The first impression of the Old Operating Theatre of St. Thomas's is slight disappointment, for one expects a rather grand Victorian church building containing a large museum and an impressive theatre (somebody must have thought it worth displaying to public). What one finds is a two-room museum in the basement of a church hidden behind the scaffolding and no viewing of the theatre.

However, having overcome the disappointment of choosing the wrong time to visit, one is more than impressed. The collection contained in the tiny museum (try to ignore the fact that this is the basement where they used to keep the coffins) is fascinating, ranging from a multitude of herbs and spices used in medicine of the time, to absolutely horrifying obstetric tools, and the lecture is informative and well... atmospheric.

The thing that strikes one throughout is that women had it tough in Victorian times. From the above mentioned tools of torture to the fact that an average nurse earned 20 GBP per year compared to 1000 GBP per operation earned by famous surgeons (all men, of course), from the fact that for quite some time men had a theatre to have operations in, while women were operated on in the wards, to the bad reputation of women working as nurses. The drawings and models in the museum depict important-looking men and caring-looking women over children's beds, in the good old gender role assignment – the men are the clever ones pronouncing the reasonable, studied diagnosis and the women are there to soothe, care and, let's face it, clean up.

How must it have felt for women to have horrible operations without anaesthesia in front of dozens, perhaps hundreds of upper class men, in a theatre smelling of smoke, food and blood, by a surgeon whose main purpose is probably to display his skills rather than save your life? It is definitely worth visiting the Old Operating Theatre just to be able to imagine a tiny bit better what it must have been like to be poor, and to be a woman, in Victorian England.

## Evelina Children's Hospital – Now and Then

**Gemma Pargeter**

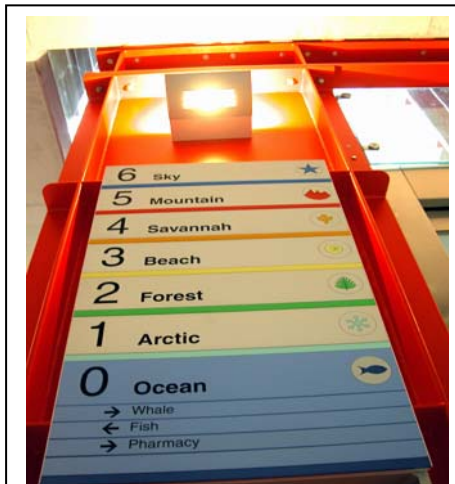
*University of Warwick*

An easy stroll from London Bridge station and down St Thomas Street brought me to the Old Operating Theatre situated within the old St Thomas Church. Arriving at the church was somewhat of an anti-climax as I gazed up expectantly to see the old building suffocated (or perhaps supported?) by masses of scaffolding. Needless to say I had doubts as to what I would find inside. However, upon entering the church crypt, where the old operating theatre museum is currently being housed, I was greeted with the authenticity of a musky smell that only old buildings can muster, which immediately had the effect of transporting me back in time.

It felt quite exciting gazing around, and being surrounded by, so many artefacts from the history of St Thomas's. The piece that caught my eye was a life-size model of a wrought iron cot with a child's figure inside and two life-like adults looming over



The model at St Thomas Church is a lifelike reconstruction of this photograph, of Rothschild standing at the foot of a child's cot in the Evelina Hospital



This photograph was taken at the new Evelina Children's hospital, reflecting the child-friendly signposts marking each floor of the hospital with the use of colour and pictures.

the cot to see to the child. This was to represent the Evelina Children's Hospital which was built in 1869, funded by Rothschild in memory of his late wife Evelina, who had died in childbirth.

A small plaque above the cot illustrates the history of the Evelina hospital and the changes it has undergone throughout its lifetime, such as joining Guy's hospital with the introduction of the NHS and moving its location to Guy tower in the seventies. This piece is particularly interesting as it marks the re-opening of the hospital in 2005, which was built on the grounds of St Thomas's, and is in keeping with Rothschild's expectations of a special place for children of all different backgrounds.

The new hospital is an exciting one that has been built with the help of its patients, the children, to create a child friendly hospital that

is as welcoming as Rothschild had hoped.

Walking back into the bright daylight I stepped back into the 21<sup>st</sup> Century with the clear intention of visiting the Evelina Children's Hospital to see it for myself.



## A Review of a Visit to the Old Operating Theatre

**Anna Robottom**

*University of Warwick*

Visitors to the Old Operating Theatre may be met with an initial feeling of disappointment; the original roof space is currently undergoing renovation work, and so the museum has been temporarily relocated into the crypt of the building, thus lacking some of the history one may otherwise experience. However, once inside, the museum has the feel of entering an old curiosity shop, with shelves stacked full of different herbs, potions and even leeches. The museum is not for the faint hearted, with one cabinet holding instruments used in nineteenth century childbirth; the cervical dilator being enough to make any women glad they live in a century of anaesthetics. For those of a more technical nature the museum offers computer programmes which perform virtual operations, although our investigations of this led only to the repeated lobotomy of the unfortunate man on screen. A word of warning to anyone scared of needles; this procedure involves an image of the same man being injected into his eyeball. The museum is by no means based solely on off-putting imagery; displays are accompanied by written information, and there is a small selection of activities for the younger visitor. A large proportion of our time was spent listening to a talk by one of the museum's curators, and this proved very interesting. The speaker has an obvious wealth of knowledge; any questions put to her were dealt with in depth, and were sure to lead on to other related areas. The Old Operating Theatre is a useful source of information to anyone holding an interest in the history of medicine, in particular the development of amputations in the nineteenth century.



# Recipe for Amputation

**Hannah-Marie Davis**

*University of Warwick*

## **INSTRUMENTS REQUIRED:**

Tourniquets – 2 for amputation  
Compress for artery  
Large amputating knife  
Smaller amputating knife  
Large Straight edged scalpel  
Small scalpel  
Small hook  
Amputation saw  
Small light saw  
Bone nippers  
Lint  
Dressings  
Compresses for stump  
Blood box filled with wood shavings

## **Time:**

Dependent upon skill of surgeon

## **Audience:**

Middle class medical students who wish to observe the amputation of some vagrant's leg without anaesthetic.

*N.B. should be armed with a strong stomach and obligatory glass of wine.*

## **Step 1**

Don the surgeon's coat which is slightly stiff with old bodily fluids. If in doubt about which is the correct garment, sniff. The surgeon's coat should have the pungent aroma of rotting flesh, aged pus and putrefying blood.

## **Step 2**

Address the audience of eagerly awaiting, if not slightly merry medical students whilst offering the patient a blindfold (to prevent patient from having to suffer the audience's glare). Instruct assistant to firmly hold the patient down and to keep the patient as motionless and quiet as is humanely possible whilst the said patient is having a limb amputated (no anaesthetic or pain relief).

## **Step 3**

Take the amputation knife (long thin blade and straight handle) and in one swift circular move sweep round the circumference of the limb which is to be amputated. Repeat this circular cutting motion, cutting deeper each time. Once, you have successfully divided the muscle tissue exposing the bone, return the knife to the velvet lined box (no need to worry about sterilization, the patient is probably infected with something anyway).

*N.B. It may be useful to strategically place the blood box (filled with wood shavings) under the operating table to minimise mess.*

**Step 4**

Retract the tissue back from the bone. This may require some firm tugging. It is essential to preserve some tissue to create the stump later so do not cut away and discard all tissue at this stage.

**Step 5**

Take the amputation saw and quickly saw through the bone in a backwards and forwards motion. If the bone is proving to be particularly hardy, utilise the bone splinter and chip away! To finish off this stage, use the bone knippers to trim the end of the bone into a relatively neat semi circular shape.

*N.B. If the patient is still unlucky enough to be conscious, this stage may be difficult due to the patient squirming. It may be necessary to use another assistant to keep the patient still.*

**Step 6**

Dispose of limb into bucket.

**Step 7**

Using the small hook, wheedle out the blood vessels and pull on them firmly in a downward direction. Then tie with silk knots. Work as fast as possible as the patient will be bleeding heavily now.

**Step 8**

To create a neat stump fold tissue over the bone in a delicate manner and arrange in the neatest way possible. In order to hold everything together and encourage a neat heal bandage quickly and heavily, using several compresses to stem the free flowing blood.

**Step 9**

Address audience with a brief comment on the amputation and take a limited amount of questions.

**Step 10**

Finally, administer the patient with aspirin to help with pain relief.

## **British and American Medical Sociology Conference**

### **Medical Sociology in the 21st Century: Themes and Trends, Dilemmas and Debates.**

University of Edinburgh, June 2006

**Susan Gregory,**

*University of Edinburgh*

**Linda McKie**

*Glasgow Caledonian University*

#### **Background and Role of the Conference**

The first British and American Medical Sociology conference was the brain child of Mike Bury (Royal Holloway University of London) and Peter Conrad (Brandeis University), who wanted to bring together medical sociologists from Britain and America, with the potential to develop future projects and careers. They also wanted to create an environment that would allow a real opportunity for discussion and debate – something that also does not happen very much in modern academic conferences driven by the numbers of conference papers to be presented. The conference was designed around working groups with topic areas (reflecting key issues in research, policy and practice) with a final discussion plenary. The groups were interspersed by plenary presentations from international scholars. That conference took place at Royal Holloway in 1999 and, by all accounts, was a great success, leading to a range of new, renewed and deeper collaborations.

The second International Medical Sociology conference was organised by another British and American collaboration: Susan Gregory (University of Edinburgh) Linda McKie (Glasgow Caledonian University) Jonathan Tritter, (University of Warwick) Karen Lutfey (New England Research Institutes) and William Cockerham (University of Alabama at Birmingham). The conference was held in Edinburgh in June 2006, and has been equally as successful attracting delegates from across the world. As well as Britain and America, people came from: Australia, Canada, China, France, Greece, Ireland, Italy, Israel, Norway, and The Netherlands. They came from across the academic career spectrum, and varied settings, from traditional university departments to dedicated independent research centres.

Professor Kath Melia, (Head of the newly formed School of Health in Social Science, University of Edinburgh), opened the event with a welcome plenary from the University of Edinburgh and a talk entitled 'All Roads lead to Medical Sociology'. Three further plenary sessions included: Professor Joan Busfield (University of Essex) who spoke on 'Consuming Pills: Needs, Wants and Desires'; Professor Ken Judge, (University of Glasgow but on his way to the University of Bath in September 2006) who spoke on 'Tackling Health Inequalities: a tide turned but mountains yet to come' and Professor Bernice Pescosolido (Indiana University) who spoke on 'Dismantling the Many 'Us vs Then' Walls: Pathways for the future of Medical Sociology'.

Conference participants took part in one of 5 working groups: Chronic Illness; Changing Structures of Health; Gender and Health; Health Inequalities; and Medical Knowledge. Each group met on 3 occasions during the course of the conference and were invited to identify issues of particular relevance to the topic in the 21<sup>st</sup> century and ideas of ways forward for theory and research. The groups were aided by two facilitators who had been pre-recruited from the conference delegates. Each group developed different ways of undertaking the exercise which is reflected in the way in which this has been recorded, but it is also interesting to note the overlap in ideas and thoughts that came out of these different topic areas. The following linked documents contain a précis of the feedback from each of the 5 working groups and of the discussion that followed.

- Group A - Chronic Illness
- Group B - Changing Structures of Health
- Group C - Gender and Health
- Group D - Health Inequalities
- Group E - Medical Knowledge.

Utilising the structure of the original conference, the conference organisers added a number of innovations: Mike Bury and Peter Conrad, the organisers of the original conference, were invited to act as discussants in the feedback plenary. They had a roving brief to look in on all of the groups, to liaise with the facilitators, and to bring their own 'take' on what was discussed. After the facilitators provided an outline of the areas of interest discussed in the 5 groups, Mike and Peter, who had had a roving brief to attend and contribute to the group discussions, took turns in providing their own personal take on the issues that had arisen, summarised in Report from Discussants and Comments from the Floor.

Virginia Olesen (University of California, San Francisco) was invited to chair this session, to manage time and inputs to ensure every one had an opportunity to speak. This was followed by a final plenary 'Futures, Networking, Funding and Publications', introduced to provide space to take ideas further and the potential for developments directly or indirectly following on from the conference to be explored. A funding opportunities document (produced by the University of Edinburgh Research and Innovation Department for the conference) had been circulated in advance of the conference to aid thinking for future collaborative work and delegates were encouraged to share information about a range of future opportunities, including publications. The final, 'futures', plenary invited sharing experiences and information about the potential for future work in medical sociology, both collaboratively and individually. A number of publishing opportunities were suggested, Potential for Funding and Publications. Participants were encouraged to consider planning for a third such conference, in America this time if possible, and preferably earlier than in another seven years time. To that end, suggestions from delegates have been recorded and appear in Feedback from Workshop Facilitators.

In addition, and in the spirit of promoting the careers of future medical sociologists, five PhD students were invited to attend the conference, supported by 5 bursaries funded by the Sociology of Health and Illness Foundation. A brief report on his or her experiences is provided from each bursary holder in Reports from PhD Students.

## A Day in the Life...

**Alex Scott-Samuel**

*University of Liverpool*

[alexss@liv.ac.uk](mailto:alexss@liv.ac.uk)

September 7 2006: following a few e-mails and my first pint of filter coffee, the day starts with a meeting with research colleague Helen West. We are piloting a mental wellbeing impact assessment (MWIA) tool on selected aspects of the Liverpool Capital of Culture 2008 programme. The tool was developed by a consortium of statutory and voluntary public health and mental health agencies in London and the North West: as well as the Liverpool piloting exercise, health / social care partnerships within the region and in London are also testing it out on local policies and projects. Helen and I draft the scope (or study design) for the tool's first outing in Liverpool.



Next comes a telephone conference, with my academic colleagues Debbi Stanistreet, Dan Pope, Viren Swami and yours truly sat around my speakerphone - at the other end of which is Clare Bamba, our research collaborator at Durham University. We are engaged in several studies following up our publication last year identifying patriarchy as a possible cause of men's universally shorter life expectancy. In the current academic climate, which is overshadowed (as all researchers will know only too well) by the virtual obsession of higher education institutions with the forthcoming Research Assessment Exercise, there is inevitably a trade-off between the need to develop sound theory and test it out adequately, and the pressure to publish. In addition, men, gender and health is a subdiscipline barely out of its infancy, with its 'paradigm wars', ideological disputes and other developmental growing pains by no means resolved. Our team - containing as it does qualitative and quantitative researchers encompassing political science, social policy, evolutionary psychology and social epidemiology - is not immune to the uncertainties which these dynamics cause. As always, we have an interesting meeting.

For the café society enthusiast which I count myself, Liverpool is blest with an *embarras de choix*: we lunch at one of the university's quality venues (characteristics of a good café for me relate not only to the food and the coffee but also to the presence of natural light, the décor, the view, the clientele, and hopefully, the music. There are no less than 4 'acceptable' cafes within five minutes walk of my workplace - and 10 minutes away is my 'favourite café in the world', the Green Fish in Upper Newington. My favourite restaurant on the other hand is Soul Mama in St Kilda, Melbourne).

Lunch is followed by a catch-up meeting with Debbie Abrahams, just back from leave. Debbie is deputy director of IMPACT, the International Health Impact Assessment Consortium, which I co-founded in 2000. Current work includes health impact assessments (HIAs) of antisocial behaviour policies; HIA capacity building with Liverpool PCT and City Council; the MWIA project; and various HIA consultancy commissions. There are also requests to run a training course in Mississippi and to undertake capacity building work with the government in Chile (and also, with the primary care trust (PCT) in St Helens). We peruse a draft produced

by the university's Business Services, of a licence to enable a new HIA consultancy in Florida to use our training materials. Finally, we discuss with some trepidation the imminent decision by the European Commission on our 13-partner bid for an HIA development project.

More e-mailing and coffee is followed by a meeting with the R&D director and an analyst from the Cardiothoracic Centre Liverpool, which is applying for foundation trust status. They want to carry out an HIA in support of the application. Also at this meeting is Nigel Fleeman, a researcher with Liverpool Public Health Observatory (LPHO). After helping launch HIA in the UK in the 1990s LPHO resumed its role of undertaking R&D projects commissioned by the Merseyside PCTs. Recently however, these commissions have included HIAs of the Government's 'Choice agenda', and also of a series of NHS capital developments in Liverpool – the latter undertaken by Nigel.

Finally, I listen to the university's irritating voicemail prompt message, and pick up a call from the HQ of the Keep Our NHS Public (KONP) campaign (I'm on its steering group in my capacity as co-chair of the Politics of Health Group). I will be speaking at KONP's fringe meeting at the forthcoming Labour Party conference, together with Frank Dobson, Neal Lawson and others. I'm looking forward to this opportunity to spell out what a progressive, publicly-provided health service might look like – as opposed to the 'modern', increasingly privately-provided NHS of Blair's neoliberal vision.

#### Websites

IMPACT – [www.ihia.org.uk](http://www.ihia.org.uk)

Liverpool Public Health Observatory – <http://www.liv.ac.uk/PublicHealth/obs>

Keep Our NHS Public – [www.KeepOurNHSPublic.com](http://www.KeepOurNHSPublic.com)

Politics of Health Group – [www.pohg.org.uk](http://www.pohg.org.uk)

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# MSo



## Medical Sociology Online

**Formerly Medical Sociology News (MSN)**

*Medical Sociology online (MSo)* will publish high quality articles in the broad area of medical sociology based on original research using qualitative and quantitative methods. As a publication of the BSA MedSoc Group, *MSo* has a special interest in promoting the work of all sections of the academic community, including postgraduates and first time authors as well as people established in their field. *MSo* encourages and welcomes the submission of articles or commentary pieces on research methodology, ethical issues in research, and the teaching and learning of medical sociology.

Medical Sociology online is now seeking articles

Deadline for Spring issue – 5<sup>th</sup> March 2007

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for full submission details, or email the editors on [MSo@liv.ac.uk](mailto:MSo@liv.ac.uk).

## **British and American Medical Sociology Conference: Medical Sociology in the 21st Century: Themes and Trends, Dilemmas and Debates.**

University of Edinburgh, June 2006

### **Feedback from Working Group A: Chronic Illness.**

This group identified the following areas of interest.

Firstly, changing practices of medicine (professional/patients interface) in which there was noted a growth in both monitoring/surveillance by medicine and individual responsibilities in and assessing of risks. It was felt that as a result there has been an increase in symptomatology coupled with the emergence of subcultures of illness (exacerbated by genetic material).

Second, there was a discussion of definitions of chronic illness and how these had changed. A notion of 'chronicity' was suggested as the consequence of medical monitoring with use of the term 'condition' as an indicator of change in focus. Multiple pathways into and out of chronic illness 'conditions' led on to the idea of monitored selves made responsible for avoiding either acute onset or relapse that might lead to 'biographical diffraction' compared to the 'biographical disruption' that Bury originally described concerning the impact of chronic disease.

Finally the group identified the area of experience in context. It was noted that the idea of surveillance medicine should be tempered with the realisation that not all sections of society enjoy the same level of medical care or attention. Those out of reach of medicine might (paradoxically) consider themselves as 'healthy' and among the poorest, financial benefits and employment opportunities would influence decisions on how 'healthy' they need to appear, with family, race and gender issues still impacting on diagnosis and treatment of different chronic diseases. Nevertheless a culture of consumerism, with a requirement to appear attractive, youthful and 'healthy', results in an expanding designation of people who are symptomatically ill that contrasts with a need to appear healthy and be morally responsible. The formation of activist groups and changing professional response in the light of this (e.g. Arthur Frank's 'remission society') means that experience then arises not just in the context of illness but with the making of context by patients who share what they have undergone. This raises issues about the status of patient's stories (the patient's view) as valid and truthful records of the experience of chronic illness.

### **Feedback from Working Group B: Changing Structures of Health**

The group identified an overview, that interaction of 'systems' suggests the consideration of spectrums that range from: macro (secondary care / policies) to micro (local level and familial interactions), or from the biomedical to the complementary. Within this overview the following areas of interest were identified:

Firstly, culture and organisational arrangements, including social networks and political debates (e.g. cancer drugs; expectations versus finance).

Second, choices and tensions. A series of bifurcations including: decentralisation / integration (cross national and cross UK differences in approaches); public / private;



professionals (expanding team) / public; citizenship / consumer pressures and tensions and resolutions.

### **Feedback from Working Group C: Gender and Health.**

The group identified the following three areas of interest:

Firstly the politics/policy/political economy spectrum, in which they discussed the women's health movement and whether this was a success. It was noted that there was differential successes in various arenas, the implications of cultural/national differences, and the criteria for success was important

Second, whether Sociological forces silence or amplify gender? (for example a source of silence might be seen in ethics committees).

Thirdly the blind spots of medical sociologists, their omissions and sticking points, which might be: personal; disciplinary; cultural; falling into the cracks/between two stools; International migration and health / health of families.

### **Feedback from Working Group D: Health Inequalities**

The group identified three areas of interest:

Firstly, the intersection of politics/policy/research, within which the following observations were made: national service provision structure (at macro level) shapes practical engagement strategies; striking cross-national differences; social service systems structure (at meso level) influences intervention opportunities and therefore research agenda; points of entry for intervention vary dramatically (e.g., how much attention do social scientists expect to get from their politicians? How useful is that attention?).

Second, different philosophical frameworks implicit in varying social contexts imply different theoretical/practical research agendas and interventions, within which the following observations were made: a "social justice" framework in UK offers more opportunities for broad interventions compared to the US; Theoretical framework may not be necessary for interventions, but these do shape opportunities

Third, the groups discussed the case study in terms of how health inequalities in working poor families might be approached. Within this context, the following recommendations were made: the need for as wide a diversity of approaches as possible; intervention vs. general research; the examination of a multiplicity of sociological pieces: geography, family structure, caregivers' health status, and the incorporation of intellectual neighbours would be helpful, such as sociology of work, sociology of family, bioethics, biogenetics, historical sociology.

### **Feedback from Working Group E: Medical Knowledge**

This working group began by noting that it was difficult to proceed with this topic in the absence of any shared reading or set of questions to address, and even the impossibility of identifying a single "knowledge" to discuss. Thus, it was decided to focus attention to sociological knowledges of medical knowledges, and the following three areas were identified:

Firstly, mapping medical knowledges, within which the following comments were made: The lack of a key text on sociological perspectives on medical knowledges, so an outcome of the group could be a text (not textbook) to map transformations of medical knowledges over time, and corresponding sociological knowledge(s). This could incorporate historical, cross-national and interactional mapping. Key would be the local and global contexts for knowledge production, and taking account of science studies and other related fields of knowledge. Concepts such as "bricolage" and "hybrid" were seen as more useful than those of "boundary" and "border" in guiding such a project.

Second, the group imagined a specific empirical project asking what people do \*as\* medical knowledge, beginning from differing locations, suggesting sites such as: a hospital, tracing pathways through the hospital system ethnographically and comparatively, possibly continuing through pharmaceutical industries and technology firms. The usefulness of detailed cross-national comparisons was abundantly clear. Another location might be: the pharmaceutical industry, tracing through medical education, clinics, and hospitals to explore the forms, formats, and uses of medical knowledge produced at various sites, and to reflection sociological constructions about medical knowledges in these sites.

Finally the group had ideas for future conferences: to provide more structure to the working groups (such as pre-reading one or two (short) key texts in advance) and less structure to the plenary sessions was proposed, (with seminars, led by plenary speakers). This, it was suggested, might have been more productive than lectures followed by questions and answers.