What's in this issue
Editorial

‘Ethics’ is a key theme of this issue. The report from the Scottish medical sociology group’s one day conference on research ethics has abstracts of presentations on philosophical and sociological aspects (Mairi Levitt), legal dimensions (Sarah Elliston), a person centred approach to consent (Jan Dewing) and ethical issues in research with people with learning difficulties (Kirsten Stalker) and young people (Janet Shucksmith). We also have an article which will be of great interest to many readers on how to maintain confidentiality when archiving data from Gill Backhouse at Qualidata. The Scottish group also advertise a forthcoming discussion on data archiving, where Gill Backhouse will be speaking.

We remind readers that the deadline for registering for this year’s BSA Medical Sociology Conference is approaching, with 31st July as the last date when bookings can be guaranteed - do contact the BSA, not us, for further details. At this year’s conference we will find out the winner of the first Sociology of Health and Illness Book of the Year prize. For those looking for some summer reading, there is a very strong shortlist, and we publish brief comments on the shortlisted books from those who nominated them. This issue also has a short report on the feedback from delegates of last year’s conference, and one item for discussion at this year’s AGM: a change in the constitution.

Congratulations to Stuart Nairn, who was recently awarded a PhD - his abstract is in this issue. We also have interesting reports from three previous recipients of Phil Strong Prizes - Simon Lewin, Chis Ntau and Elizabeth Stopp, and we have details of this year’s prize.

We also have the usual notices, conference reports, reports from regional and national groups and book reviews, including one of the long awaited text by Parmesan and Brie on discursive estimation, which Prof Savourie-Custard has kindly reviewed for us.

Finally, we bring the call for new editors of Medical Sociology News to your attention - do contact any of the current editorial team informally if you would like to find out more about what it entails.

The Editors
Call for new editors for Medical Sociology News

To produce three issues a year of Medical Sociology News, on behalf of the BSA Medical Sociology Group, from January 2003 (volume 29).

Medical Sociology News has around 350 subscribers around the world, and is a major channel of communication for medical sociologists to share conference reports, news and views. Articles are not peer reviewed, but reach a wide readership and are often requested as reprints. Subscription also entitles readers to access to the medsocnews jisc email list, which advertises job vacancies, conferences and other events of interest to readers.

The Editorial Team is responsible for maintaining the subscription list, commissioning copy, organising book reviews likely to be of interest to readers, producing and distributing the newsletter. The BSA funds administrative costs and up to three free places at the BSA Medical Sociology Conference for the editorial team.

The job would suit a group of medical sociologists based at the same or nearby institutions who would like to:

become more involved in the work of the BSA Medical Sociology Committee
extend their network of colleagues or
gain some experience of editing
raise the profile of medical sociology within their institution

The current team have divided up the main responsibilities as follows:

Co-ordinating copy, chairing editorial board, main contact (Judith Green)
Book reviews (Geraldine Barrett)
Design, layout, liason with printers and Web pages (Michael Traynor)
Liason with the BSA Medical Sociology Committee (Geraldine Leydon)
Jiscmail list (Simon Carter)

Our administrator, Kelly Lawless, maintains the subs list, accounts and deals with enquiries.

Do contact any of us (see Medical Sociology News back pages for contact details) for further information about the job.
The British Sociological Association

MEDICAL SOCIOLOGY GROUP

Annual Conference 2002

September 27th - 29th
University of York

Plenary Speakers will be

Dr Marina Barnard
Centre for Drug Misuse Research
University of Glasgow
who will speak on:

Breaking into silence: the rude incursions of the sociologist

John McKinlay

Senior Vice president and Chief Scientist, (New England Research Institutes) and Consultant, Division of Medicine, Massachusetts General Hospital (Harvard Medical School)
who will speak on:

Medical Sociology: Where have we been and where are we going?

Further details available from: bsamedsoc@britsoc.org.uk
and the BSA Medical Sociology Group web site:
http://www.britsoc.org.uk/about/msconf.htm
Proposed amendment to the BSA Medical Sociology Group constitution

The following amendments are needed to the Medical Sociology Group’s constitution to take into account the fact that the Foundation for the Sociology of Health and Illness now exists (see Med Soc News 27 (3) p3). This will be raised at the AGM (held at the conference on 28th September).

Clause 6 to read:

In pursuance of its objectives, the Group will strive to maintain its collegial relationship with the independent charitable company, the Foundation for the Sociology of Health and Illness, owners of the journal Sociology of Health and Illness (SHI).

a) Two members of the Editorial Board for SHI shall be elected by those attending the Group’s AGM, whether BSA members or not.

b) When matters of mutual interest are being discussed, the Trustees of the Foundation and the Editors of SHI shall be invited to nominate one representative each to attend and speak at meetings of the Group Committee.

Amend Clause 11 (v):

(v) to receive a report from the editorial team of SHI and elect two members to its Editorial Board (as per 6b above).

Hannah Bradby
for BSA Medical Sociology Committee
Phil Strong Memorial Prizes 2002/3

The BSA Medical Sociology Group Committee welcomes applications for the Phil Strong Memorial Prizes to be awarded at the Group’s AGM at the annual conference on September 28th 2002. The conditions for the award have been revised and should be consulted prior to application (http://www.britsoc.org.uk/about/philstr02.htm).

The deadline for submission of applications is 30th August 2002 and they should be sent to:

Phil Strong Prizes
British Sociological Association
Unit 3F/G
Mountjoy Research Centre
Stockton Road
Durham
DH1 3UR.
The Commonwealth Fund
Harkness Fellowships in Health Care Policy

The Commonwealth Fund of New York is pleased to announce the Harkness Fellowships in Health Care Policy, and to invite applicants for the 2003-2004 fellowship cycle.

The Harkness Fellowships in Health Care Policy provides a unique opportunity for promising health policy researchers and practitioners (e.g., physicians, health services managers, government officials, and journalists) who are early in their career to spend six to 12 months in the United States conducting a policy-oriented research project and working with leading U.S. health policy experts.

Fellows must demonstrate a strong interest in health policy issues and propose a research study that falls within the scope of the Fund’s national program areas. Among the issues the Fund addresses are improving health insurance coverage and access and improving the quality of health care services. Its quality programs focus not only on general issues but also on the needs of specific groups, including underserved populations, young children, and frail elders. Studies that include comparisons between the United States and the applicant’s home country are encouraged.

The Fund will provide extensive support to successful fellows to help them develop and shape their research proposals to fit the U.S. context. Through its extensive network of contacts, the Fund will help identify and place fellows with a mentor who is an expert in the policy area to be studied. In collaboration with the U.K. Selection Committee, a home country mentor, who will act as a liaison with the U.S. mentor and supervise any cross-national comparisons that are to be conducted as part of the study, will also be identified after selection.

The deadline for receipt of applications is October 1, 2002. In order to apply, applicants must be a citizen of the United Kingdom, Australia, or New Zealand and submit a formal application. Up to nine Harkness Fellows in Health Care Policy will be selected annually.

Each fellowship will provide up to $75,000 (U.S.) in support, which includes round trip airfare to the United States, a monthly stipend, support toward any portion of the study conducted in the home country, project-related travel and other research expenses, tuition for related academic courses, and health insurance. In addition, a family supplement is available to fellows accompanied by a spouse and/or children.

To obtain a brochure and application materials, please contact Robin Osborn, Director, International Program in Health Policy, The Commonwealth Fund, One East 75th Street, New York, NY 10021, United States (Telephone 001 212 606 3809, Fax 001 212 606 3875, Email ro@cmwf.org), or see The Commonwealth Fund’s World Wide Web home page (http://www.cmwf.org).
PhD Abstract

Stuart Nairn (University of Essex)

Culture, Health and the Emergency

Abstract

This thesis is a cultural analysis of the emergency. It an area that only a few sociologists have addressed, although there has been attention paid to the 'non-emergency', or the 'inappropriate'. In this research, I intend to examine this gap in the literature by asking three questions:

1) What is an emergency?
2) Why has the emergency such a high profile?
3) What is the cultural context?

It is my argument that the emergency is a socio-historical construct and has emerged in a context that is conducive to an emergency aesthetic. Therefore, the emergency is not some easily defined and discrete category. It is a product of a professional desire to delineate a new speciality that is consistent with, and a reinforcement of, a biomedical approach to health and illness. But there are also many factors external to medicine that has contributed to what I will call the moment of the emergency.

Throughout the thesis, I explore this tension between the internal dynamics of the practice of emergency care with its semiotic presence. I will do this using a variety of data. These will include professional journals, narratives, cinema, television and newspapers. For example, I will examine the uses of cardiopulmonary resuscitation and air ambulances both from the perspective of efficacy and their cultural aesthetic, which, I will argue, influence day-to-day practice.

I emphasise the cultural more strongly in the latter part of the thesis where I examine cinematic representations of extreme events in such films as Godard’s Weekend and Cronenberg’s Crash. I then analyse how these extremes are tamed in television soaps and the way recent train accidents have provoked a socio-political crisis and the way that the emergency operates in these contexts.

It is my contention that the emergency is primarily associated with an aesthetic of progress. However, there is also an underlying anxiety about the emergencies focus on the disturbing and its dehumanising consequences.

s.nairn@ntlworld.com
Medical Careers of Batswana Doctors

Chris Ntau

Introduction

At a joint conference of the British Sociological Association Medical Sociology Group and European Society of Health and Medical Sociology held at the University of York on the 14th - 17th September 2000, the BSA Medical Sociology Group awarded me, and two others, the Phil Strong Memorial Prize for 2000-01. The award was for £650.00, to defray costs incurred during my fieldwork in Botswana. It is in this regard that I gratefully report that the prize money was fully utilised as intended. This short paper briefly discusses the subject matter of my research, where the study was conducted and lastly my personal experiences and reflections on interviewing doctors in Botswana.

Context of the study

This study was carried out in Botswana, prompted by the mass exodus of health care providers from the Botswana government service to join the private sector, international agencies or to work overseas. In recent years, nurses have left the Botswana health care system in droves, at a time when their services were most needed, given the HIV/AIDS scourge afflicting the country, to join the British National Health Service and other health care systems. The departure of skilled manpower from the public service is particularly worrisome since such movement frustrates the Botswana government’s localisation process and capacity building efforts. The government of Botswana designed the localisation programme so as to enable qualified citizens to assume positions of responsibilities when expatriates leave at the end of their contracts. While it is normal for any organisation to lose some staff to other organisations, the loss of citizen doctors from the public service in Botswana is a serious setback, considering the resources expended by the government and the time it took to train them. Almost all Botswana’s citizen doctors were, and continue to be trained at medical institutions abroad at a considerable cost to the government and the duration of medical studies is long. Over the years, the government has trained a number of medical doctors, nurses, physiotherapists and other related health specialists. However, the government has not been successful in retaining these trained personnel. In 1999, there were 488 medical doctors practising in Botswana. Out of these 488 medical doctors, 435 or 89% of them were expatriates mainly from east Africa, India and Cuba and only 11% were Batswana citizen doctors. Moreover, 50% of citizen doctors in the country were employed by non-governmental health facilities.

This study is therefore being undertaken in Botswana to investigate how the conditions within the Botswana health care system contribute to medical migration, albeit inadvertently, and to understand the factors that influence citizen doctors to leave Botswana’s public service and “seek greener pastures” elsewhere, both within and outside the country. It is hoped that the study, will assist in policy formulation of better ways of dealing with migration of doctors so enable the government retain its trained personnel.
Research sites

In Botswana, citizen medical doctors working within the public sector are normally placed when first qualified at the two-referral centres, in Botswana’s capital city, Gaborone and in the northern city of Francistown. This is done to expose young doctors to various kinds of conditions in the country before proceeding to further specialist training, and to allow them to work under the guidance and supervision of specialists. In pursuance of citizen doctors, it was logical therefore to carry out this study at the two mentioned areas. Additionally, private citizen medical practitioners in the two cities were also interviewed.

Another research site included in the study was the hospital owned by a mining company, where a few citizen doctors are employed, located in a small diamond-mining town, located about 200 kilometres from Gaborone.

Research design

This study was designed to be qualitative in nature, so as to allow the emergence of rich data and a meaningful depiction of the situation by the doctors themselves. To facilitate this process, semi-structured interviews were conducted with citizen medical doctors in Botswana, both in the public service and the private health sector and other purposively selected key informants. Almost all citizen medical doctors, as mentioned earlier, were trained at government expense at institutions abroad and therefore it was important to understand their views as to what could be the ‘push’ factors in the Botswana public health sector. In other words, an opportunity was afforded citizen medical doctors to ‘tell their stories’ as to what could be frustrating them in the Botswana’s public health service, and as such lead them to decide to quit the public service.

Also, it was considered important to understand from citizen medical doctors, what could be the ‘pull’ factors either abroad or within the Botswana private health sector. At the time of the interviews, some of the doctors were still working within the public sector, although a significant number of them intimated that they were contemplating quitting. Some had already left the public service and have established private medical clinics.

Despite problems encountered during the data collection period, (described below), 18 interviews were conducted with doctors in the public sector and eleven citizen doctors in the private health sector were interviewed.

Personal reflections and Experiences

Interviewing doctors was a multistage process, involving a number of players before the interview could actually take place. The first stage started with the Office of the President, seeking a research permit. A quick response from the Office of the President gave me a false belief that things ahead would be smooth. Although obtaining the research permit was quick, more hurdles lay ahead. More permissions were required to actually start interviewing the respondents. The second stage involved requesting permission from the participating hospitals. Delays were experienced at this stage as officials took their time to respond. In one particular case, a response came after three months, following a
series of phone calls.

Once permission was granted by participating institutions, the next stage was to speak to doctors, and agree on the appointment date. A phone call to the hospital led to the hospital receptionist, who then put the researcher through to the doctor. On a bad day, it was normal to wait a long period, before getting through to the doctors. On getting hold of the doctor, I quickly introduced myself, emphasising that I was studying at a foreign university. Naming the university was helpful, in terms of getting some doctors’ cooperation, as all of them had studied outside the country. The research purpose was explained and then, an invitation extended to a doctor to participate. Guided by the doctor’s schedule, an appointment date would then be agreed, which was by no means, a guarantee that an interview would actually take place.

On the agreed day, if an interview was scheduled in the afternoon, a morning reminding call was important. If the interview was in the morning, one-day advance reminder was sufficient. Cancellations and postponements were the norm, especially with doctors employed in government institutions and government officials. Reasons ranged from “I was ‘on call’ last night, so, I wouldn’t make it today,” or “he/she is in theatre”, to “still seeing patients”. Undoubtedly, interviewing doctors especially in conditions where they are too few, or facilities are seriously understaffed, requires a lot of patience. However, once interviews were underway, doctors readily opened up, and “told their stories” of the “joys” and “hurts” of the medical profession.

The process of data analysis has started and it is already clear that all was not too well within the Botswana public health service. Citizen doctors had a lot to say about working in Botswana’s health facilities and generally about the unsatisfactory working conditions, which ultimately led many to leave or consider leaving government service. Topping the list of push factors from the public service, was the long and arduous working hours, giving them little time to attend to their social life and studying. This was mainly due to the shortage of doctors and other health care workers within the hospitals. Further, the HIV/AIDS scourge afflicting the country exacerbated the situation. Many patients were referred to the referral centres, and all hospital beds were occupied during the time when the interviews were conducted. The majority of patients were said to be suffering from opportunistic infections closely related to HIV.

Poor remuneration by the government was also frequently mentioned. The meagre wages earned was considered not commensurate with the long hours that were put in. Most frustrating was the system of differential pay between citizen doctors and their foreign counterparts. Expatriate doctors, in addition to the basic salaries, were given ‘contract additions’, so as to “entice” them to come and to continue working in Botswana. Citizen doctors considered this practice unfair, since, as doctors, they had the same qualifications and were doing the same job.

Further, perceived lack of recognition of doctors by the government was stressed, especially their input with regard to matters pertaining to directing health policy issues within the Ministry of Health in Botswana. They felt unappreciated, unwanted and excluded, and having no role to play, hence decided to leave.

Although data analysis is still at a preliminary stage, however, the density of information and the wealth of ideas coming from the transcripts makes one to read them carefully,
deeply, thoughtfully and comprehensively, for the results of this study could have far reaching policy implications. The recommendations from this study could contribute in some way to policy formulation in better ways of dealing with migration of medical doctors. And as a result, the Botswana government will be able to retain her skilled personnel and consequently meet her obligations of providing good quality care services to the nation, as envisaged in the nation’s vision document, “Vision 2016: Towards Prosperity for All”.

**Acknowledgement**

This study was partially supported by a grant made available by the BSA Medical Sociology Group through the Phil Strong Memorial Fund, for which I am deeply grateful. Through such assistance I was able to traverse the interiors of Botswana pursuing citizen medical doctors to interview them.

**Footnote**

1 Botswana is the country  
Batswana are citizens of Botswana  
Motswana is a citizen of Botswana  
Setswana is the national language in Botswana

**C. G. Ntau**

Postgraduate student at the Royal Holloway University of London, Department of Social and Political Science
Reports from the Phil Strong Postgraduate Memorial Prize - II

Simon Lewin

My doctoral thesis aims to explore how workplace organisation and professional roles in tuberculosis (TB) clinics in Cape Town, South Africa impact on the response of health professionals to a training programme designed to change their attitudes and practices. Tuberculosis is an important public health problem in South Africa and cure rates for the disease have consistently remained well below the national target. Previous studies examining ‘adherence’ to treatment have shown that the care of TB patients is divided into a series of tasks, each performed by a different health worker (Dick and Pekeur 1995; van der Walt and Swartz 2002). It has been suggested that this ‘task orientation’ prevents continuity of care and undermines patient-provider relations by allowing clinic staff, who are mainly nurses, to distance themselves from the psycho-social needs of patients. Few studies, however, have examined how other dimensions of the organisation of nursing work shape the relations among providers and between providers and users. Indeed, there has been little sociological research on nursing work in South Africa or other developing country settings. This is surprising, given that nurses constitute the largest group of health providers in these settings and often act as ‘gatekeepers’ within the health care system.

The implementation of a training programme for the staff of TB clinics in Cape Town provided me with an opportunity to explore clinic culture and how this impacts on provider-patient relations and on efforts to change professional practice. My study, conducted over two years, used mainly ethnographic methods such as participant observation and interview.

The Phil Strong Memorial Prize provided the resources for a field visit to Cape Town to complete data collection in the study clinics. Earlier data collection had suggested that many aspects of nursing work were ritualised and that these rituals served to construct and maintain power relations between providers and users in the clinics. The field visit sponsored by the Memorial Prize allowed me to both collect further data to explore this idea and to discuss my findings with colleagues working in South Africa. These discussions were very valuable in shaping my ideas regarding the role of ritual in TB care and the implications of ritualised activities for efforts to change professional practice.

This analysis of ritual in TB clinics has now developed into a PhD chapter and I plan to develop it into an academic paper later this year. I hope that this study will contribute to the body of work on the sociology of healthcare in less developed countries. It would have been difficult to take these ideas further without the funding provided by the Memorial Prize, and I am therefore most grateful for the opportunities that the Prize presented.

Simon Lewin
Department of Public Health and Policy
London School of Hygiene and Tropical Medicine
References:


The Phil Strong Memorial Prize money has enabled me to complete important fieldwork in respect of my PhD Research. This has included one trip to Belgium where I spent two days working at a centre where conventionally trained GPs practice mostly homoeopathy. Additionally, the prize money has enabled me to travel to Suffolk to interview other Complementary Therapy Practitioners and conduct a survey on four groups of Complementary Practitioners.

I have attended a specialist training course run by Southampton Health Authority and not offered by my University. This was to learn how to use NUDIST a qualitative data analysis software package.

Finally, through the prize money I have been able to attend a specialist conference that has been very important to my research in terms of networking and linking my own research with other developing areas. I have detailed below a more precise breakdown of how the prize money has been spent.

Conferences/specialist workshops:

Nudist Training Course @ £15.00 per day £ 30.00

Oxford Health Policy conference £ 27.50

Exeter 8th Annual Symposium on Complementary Health Care £327.55 (including accommodation, travel and attendance).

Fieldwork:

Surveys : Complementary therapists
65.55 (GPs, Acupuncturists and Homoeopaths)

134.96

Interview costs : Travel to Suffolk 44.00
Travel to Belgium £134.95
British Sociological Association

London Medical Sociology Group

Venue
King’s College London, Room 1.16, Franklin Wilkins Building, Stamford Street, London SE1 8WA.

Nearest tube and rail: Waterloo

MEETINGS 6PM - 7PM

Everyone is welcome to attend LMSG meetings - the group has no formal membership. At each meeting there is a presentation by a speaker, followed by discussion that continues over drinks and supper in the local pub.

10 July Genetic susceptibility and identity - a case study of haemochromatosis Paul Atkinson
Cardiff University

11 September The social construction of health behaviour David Armstrong
King’s College, University of London

9 October Moral issues in GP consultations
Kathryn Ehrich King’s College, University of London

13 November Risk thinking in psychiatric wards Jaqueline Davies, Paul Godin & Bob Heyman
City University

11 December Christmas social (all welcome)

For further copies of this programme please contact Paul Godin 020 7040 5933. To receive details of all LMSG meetings by e-mail contact Mark Newman, m.newman@mdx.ac.uk or visit the BSA website: britsoc.org.uk/about/medsoc.htm Joint LMSG Organisers: Richard Compton, Paul Godin (Convenor), Rachel Grellier, Bairbre Kelly, Chris McCourt, Mark Newman, Susan Robinson & Margaret Rogers.
Scottish Medical Sociology Group Present

A roundtable discussion on:
DATA ARCHIVING: What do historians and sociologists think?

Discussants:
* Odette Parry and Natasha Mauthner, authors of ‘Whose data are they anyway? Practical, legal and ethical issues in archiving qualitative research data’. Sociology (in press).
* Rob Perks, British Library, curator of national sound archive
* Gill Backhouse ESRC Qualidata, advice and acquisitions office

Venue
Glasgow Caledonian University
The afternoon of Friday 11th October 2002

Numbers are limited for this event so to express an interest please contact:
Linda McKie by email: L.Mckie@gcal.ac.uk
Putting the Sociology of Cancer on the agenda

In recent years the Sociology of Health and Illness has tended to have a relatively low profile at the annual BSA meeting, in part due to the annual Medical Sociology Conference. The Sociology of Cancer Study Group sought to reverse this trend and organised a Conference Stream on the Sociology of Cancer at this year’s BSA conference in Leicester.

The annual sociology jamboree was attended by some 600 people and successfully showcased the diversity of our discipline. Amongst the offerings on areas as diverse as globalisation, consumption and childhood were four 90-minute sessions focused on the Sociology of Cancer. The eight papers that were presented drew on research across the UK and Finland and highlighted sociology’s growing interest in cancer.

The first session dealt with ‘emotion’, specifically with how it is studied and how it relates to our sociological understanding of cancer. Anne Lanceley, “Emotions in cancer care: Patients’ emotions revealed through personal metaphor forging”, spoke about how cancer nurses and people with cancer manage their own emotion. She illustrated examples of the way metaphor provides a way of understanding some of the inner experience of emotion. Listening for metaphors within conversation with and between cancer patients and health professionals revealed much about the different strategies that are used to convey the experience of cancer and its management.

Some of these issues were echoed in Clare Moynihan’s paper, “Men communicating: An exploration into male communicating patterns in the context of genetic prostate and testicular Cancer”. Moynihan argued for gender to be considered as a relational concept. She provided examples of how masculinity shapes the management of cancer and is illustrated through communication within families. Stereotypes about men are pervasive and limit opportunities for men to tell their stories, just as the dominance of a model of cancer based on studies of breast cancer limits alternative ways of understanding people’s experience.

The second session in the Stream was started by Jonathan Tritter and his paper “Is there a place for a ‘sociology of cancer’?”. Tritter argued that sociology has had little impact on policy and practice but has much to offer. He suggested that sociology could help to conceptualize and model the experience of cancer, the role of the social, as well as the public perception of cancer. He further suggested that these sociological approaches have implications for all those touched by cancer, those who plan and provide their care, as well as those who seek to understand and document their experience of illness.

Applying a key sociological concept Taina Taskila-Åbrandt in her paper, “Cancer patient and work - Experienced stigmatization at the workplace”, explored the ways in which people with cancer who return to work often felt stigmatized or were discriminated against. Taskila-Åbrandt noted that we choose our occupation, but not those we work with and that stigmatization is not automatic, but dependent on a range of different factors.

The third session in the stream examined media accounts of cancer. Mary Dixon-Woods in her paper “Parenting a child with cancer: accounts from newspapers and parents”,
explored how the media adopts and recycles dominant idealized notions of cancer. Parents’ actual experience of subordinating their own needs and the stress of emotional labour was rarely apparent in newspaper accounts. Rather, media accounts tended to concentrate on the ways parents championed their children’s rights and entitlements.

Exploring the impact of the presentation of cancer in the media Rachel Hardyman and Geraldine Leydon’s paper, “Popular media as a means of increasing public awareness of health issues: The case of cancer”, examined the relationship between a Coronation Street storyline on cancer and calls to a national telephone helpline (CancerBACUP). There was a dramatic increase in calls to the helpline during and following the broadcasting of the cancer story line. This increase was also associated with stories in the print media. Predominantly contacts were not from people diagnosed with cancer, but rather from people who were concerned that they might have cancer. Hardyman and Leydon concluded that the media might serve as a useful mechanism for promoting cancer awareness, but that caution is required because it can engender alarmist portrayals and responses.

The final session of the Sociology of Cancer Stream looked at the way cancer service providers work. Ziv Amir and Judy Scully, “Support mechanisms, multi-disciplinary team working and mental health”, explored how teams developed and worked in providing care for people with breast cancer. Using extensive qualitative data they explored how team working promoted the development of support networks that helped individual health care providers manage their stress and emotional responses to cancer.

The last paper in the Stream also explored how health professionals provide care. In their paper, ”Involving cancer service users in health care decisions: The role of communication and information”, Simon Evans, Michail Sanidas and Jonathan Tritter explored how the likelihood to become involved was related to the nature of the doctor - patient relationship. Those patients who felt there was good communication with their doctor were more willing to be involved in the evaluation and development of services. The need to understand how and why people choose to be involved is essential if such policies are going to be successful for the continued development of patient centred health services.

The response to the call for papers, as well as the attendance at the conference, was a clear indication of the scope for a Sociology of Cancer. Interestingly many of those who came to hear the papers had experienced cancer. Perhaps this is a case of Sociologist study yourself. The BSA conference provided an excellent opportunity for sociologists of health and illness to explore connections with the wider discipline of sociology.

Jonathan Tritter, Geraldine Leydon and Clare Moynihan
Scottish Medical Sociology Group One Day Conference on Research Ethics

Introduction

At the beginning of this year the Scottish Medical Sociology Group held a one-day Conference on Research Ethics. This ‘hot’ topic has a number of implications for health and social care researchers that were discussed and debated at the Conference and which are briefly introduced below.

Mairi Levitt presented philosophical and ethical principles that underpin social research. Mairi contends that explicit recognition and debate about these principles such as, justice, benefice, non-maleficence and autonomy, could benefit research teams and guide practice.

Sarah Elliston provided an overview of the legal dimensions of research ethics. Sarah acknowledges that there are no legal cases in the UK about research and this means that it is not possible to give definitive legal guidance for researchers. However, Sarah suggests that researchers need to abide by legislation and use it as an ethical framework to guide practice.

Jan Dewing called for a re-think about the ways in which people with dementia are included in research. She advocates an approach whereby the person with dementia is continuously included in the consent process and calls for researchers to develop innovative ways of communicating with this group of the population.

Kirsten Stalker described a participatory approach to including people with learning difficulties in research. She proposes that this involves developing processes that redress the power imbalance between the researcher and the researched. For example, as a means of giving research participants a degree of control over the ways in research findings are articulated and reported, participants could co-present at conferences.

Janet Shucksmith situates the ethical issues for researching children within their socio-political positioning. Children’s lack of power generally has implications for research. Janet suggests that an important way of improving research practice with children is by focusing on the ‘virtues’ of the researcher.

Joan Orme introduced the new Codes of Ethics for Social Work Research. Joan believes that whilst ethical codes are an important, it is only through openness and accountability to the social research community that researchers will genuinely develop ethical practice.

BETTER TOGETHER? PHILOSOPHICAL AND SOCIOLOGICAL PERSPECTIVES ON ETHICS IN RESEARCH

Mairi Levitt, Centre for Professional Ethics, University of Central Lancashire, Preston

Ethical issues arise at every stage of research from the initial choice of topic to the use to
which the knowledge is put – sociologists do not claim that the choice of topic is ethically/value neutral nor decline any responsibility for the application of knowledge generated by their research. Sociologists are especially well equipped to consider the broader social, cultural and political context in which research takes place and is disseminated but can be reluctant to look more closely at the values inherent in ethical guidelines, such as those of the BSA. It is here that philosophers, in particular ethicists, may have something to tell us.

Initial ethical questions about research include, why is this research being funded now? What is the history of this research topic? Will the research legitimate a particular approach and cut off alternative approaches? What issues may arise from a relationship with these sponsors/funders? C. Wright Mills' warning is perhaps even more pertinent today with the increasing pressures to win research funding from sources other than the traditional social research councils: ‘Do not allow public issues as they are officially formulated, or troubles as they are privately felt, to determine the problems that you take up for study’ (Mills, 1959, p226). In multidisciplinary teams ‘the issues officially formulated’ may not include, for example, an examination of how medical criteria are constructed and applied.

The commitment of sociologists to question received wisdom and be critical may lead to a certain embarrassment about ethics and morality. Ethicists criticise sociologists for moral relativism and a lack of openness about their own values and perspectives on morality despite their willingness to offer practical and prescriptive conclusions for policy changes. The BSA statement of ethical practice does claim a cross-cultural moral authority and acknowledges its use of the ethical codes of the American Sociological Association and the Association of Social Anthropologists of the Commonwealth. The basis for its moral authority appears to be principlism rather than, for example, deontology or utilitarianism. There is evidence for the ubiquitous four principles (justice, beneficence, non-maleficence and autonomy) as well as other values like openness and integrity. The statement is introduced as ‘a set of obligations to which members should normally adhere as principles guiding their conduct’. Principles can only be action guiding in conjunction with other information but provide a common starting point especially in multidisciplinary teams where different imperatives are operating. The specific content has to be thrashed out in the group. Moral philosophy can help us think about the content of our shared values (not necessarily adopting the four principles with their stress on autonomy). A commitment to question received wisdom and be critical should not prevent us from discussion, debate and formulation of the shared values which underlie ethical research.

LEGAL DIMENSIONS OF RESEARCH ETHICS

Sarah Elliston, Lecturer in Medical Law, University of Glasgow

No legal cases in the UK have specifically dealt with gaining consent to take part in research of any kind so any guidance on this issue must come from general legal principles. It is fair to say that the basis of most research in the UK rests far more upon
what is regarded as being ethical than what is known as being legal.

People over sixteen are presumed to be able to decide for themselves whether or not to take part in research. However, it has been suggested that since research may not have direct benefits for the people involved, “particular care” should be taken to ensure that potential research subjects have the fullest possible information about the proposed research. (See the Department of Health, Reference Guide to Consent for Examination or Treatment, Chapter 1, para 15). In order for consent to be legally valid the person must be given sufficient information to evaluate whether she wishes to be involved and must freely give agreement. There are two possible legal actions for failing to give adequate information – assault and negligence. However, since assault relies upon there being unwanted physical contact and negligence relies upon there being harm suffered as a result of failure to disclose information, neither legal action may be particularly helpful to an aggrieved participant in the situation of sociological research. Potentially more relevant may be the rights established under the Human Rights Act 1998, particularly the right to respect for private and family life, which encompasses the right to make decisions about one’s own life as well as the concept of respect for privacy. The HRA 1998 places responsibility on all public authorities to ensure that the Convention Rights are respected and, although this has not been definitively ruled on, it is likely to apply to all public authority employees in the course of their work and possibly to all publicly funded work.

Where the person is over sixteen and there are doubts about her ability to give a legally valid consent to treatment, the provisions of the Adults with Incapacity (Scotland) Act 2000 may be applicable. This Act applies where the adult is incapable of acting; making, communicating or understanding decisions or retaining the memory of decisions. In all cases incapacity must be by reason of mental disorder, or of inability to communicate because of physical disability. Section 51 concerns research and states that “No surgical, medical, nursing, dental or psychological research shall be carried out on any adult who is incapable in relation to a decision about participation in the research unless [a number of conditions specified in the Act are satisfied]”. Sociological research may or may not come under this provision. If it does not, then it is likely that regard must be had to the general provisions of the AWI(S)A 2000 to establish whether research may proceed. If it does, research under s51 requires a certificate of incapacity to be made out by a medical practitioner and the specified conditions to be met, including review of the research by a properly constituted ethics committee. The research provision is expected to come into force in summer 2002, along with codes of practice on its implementation. Information concerning the Act and Codes of Practice are available at the Scottish Executive Web Site: http://www.scotland.gov.uk/justice/incapacity/

Where the person is under sixteen, the Age of Legal Capacity (Scotland) Act 1991 provides that “[A] person under the age of sixteen years shall have legal capacity to consent on his own behalf to any surgical, medical or dental procedure or treatment where, in the opinion of a qualified medical practitioner attending him, he is capable of understanding the nature and possible consequences of the procedure or treatment” (s2(4)). It is believed that this provision is broad enough to cover consent to medical research but again, there may be doubts whether this includes sociological research.

If the research is not covered by s2(4) it may be that a young person can give consent on her own behalf under s1, which allows a child to give a valid consent to a transaction of a kind commonly entered into by children of that age, provided that the terms of the
transaction are not unreasonable. It will be a question of fact whether the transaction meets this criterion.

If the child is unable to consent to take part in research herself, it is likely that the child’s parents can give consent. However, under the Children (Scotland) Act 1995, parental rights are only available to enable parental responsibilities of safeguarding and promoting the health, welfare and development of the child to be carried out. Research by its nature may not benefit the child. Nevertheless, it is widely recognised that inability to lawfully carry out research with children would prevent advances in knowledge that might help children in the future. By analogy with court cases, where parents have been permitted to agree to interventions which, although not in the best interests of that child, are not against the interests of such a child (e.g. blood tests for non-therapeutic reasons) it seems to be accepted that research may be carried out on the basis of parental consent. Professional guidance by many bodies, such as the Medical Research Council and in the Department of Health Guidance on Consent (above) include a number of recommendations including that the research must involve no more than minimal burden; have no or minimal risk to the child; must be impossible to carry out using people who can consent; must benefit children and must not proceed where child is unwilling. These provisions are similar to the approach required under the Adults with Incapacity (Scotland) Act 2000 for research with adults who cannot give a legally valid consent. If parents can consent to research on incompetent children, it would seem entirely appropriate that competent children should be able to give a legally valid consent to take part in research. Nevertheless, the lawfulness of research upon young people is so far untested by the courts.

Unfortunately it is not possible to give definitive legal guidance on the basis of consent to research in the absence of court rulings on the matter. Clarification of doubts in this area, preferably through legislation, would be welcome.

FROM RITUAL TO RELATIONSHIP: A PERSON CENTRED APPROACH TO CONSENT IN QUALITATIVE RESEARCH WITH OLDER PEOPLE WHO HAVE A DEMENTIA.

Jan Dewing Consultant Nurse Milton Keynes & Associate Fellow RCN

As part of the move towards including persons with dementia in research processes the issue of consent needs to be revisited. The traditional competency based approach to informed consent in research with older people who have dementia is unhelpful and sets an inbalanced moral space for the researcher-participant relationship. The person with dementia is often excluded as proxy consent is sought through others and doubly excluded as informed consent draws on the very abilities that are diminishing. This presentation called for a person centred inclusionary approach to consent, that values the interests of all parties involved, including the person with dementia as a way forward in person centred research.

The presentation described work in progress on a theoretical foundation and an evolving
method for including persons with dementia in consent processes. Examples were used to demonstrate the way that people with dementia indicate their willingness to explore initial and on going consent. The method and methodology presented is underpinned by two beliefs. First, that people with a dementia are often more capable at participating in consent than is assumed. Participatory consent is an on going process that is relationship based and dementia sensitive. Second that consent is given or indicated not only by words or sometimes without words through behaviours and body language.

A paper will shortly be published in Dementia: The International Journal of Social Research and Practice. 1 (2) in June 2002

ETHICAL ISSUES IN RESEARCH WITH PEOPLE WITH LEARNING DIFFICULTIES

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The changing role of people with learning difficulties in research raises challenging ethical questions. The most important of these is probably the issue of unequal power between researcher and ‘researched’. Thus, ethical considerations, or a value base, should guide our decisions about what we do and how we do it from the beginning. Have people with learning difficulties been involved in choosing the research topic? If not, is it a subject which is important to them? Will the outcome of the study make a positive change or contribution to people’s lives? Will the research have a participatory element and if so, how is that best achieved?

In recent years, increasing attention has been paid to the issue of informed consent and how to seek it from people who may lack understanding of the concept. In research with people with learning difficulties, and with disabled children, colleagues and I have produced ‘Agreement Forms’. These are small leaflets with a photograph of the researcher and colourful illustrations showing positive images of disabled people: they set out in straightforward language what the study is about and what participation will involve. The individual is asked to sign the form, or someone else can witness their verbal agreement. Initial consent is always sought by someone well known to the individual, but we also treat consent as an on-going process.

Difficulties can arise if a respondent reveals that he or she is at harm, or risk of harm. For this reason, it may be best to offer people qualified confidentiality: that is, to say that if they tell us someone is hurting them, then we will need to pass on this information to someone who can help. In practice, we would encourage the person to do so themselves. Arguably, failure to ensure such information is reported could be tantamount to colluding in abuse.

Our respondents give us data but what do we give them in return? We need to be wary of claims that research empowers those involved. Participatory research may have this effect, if for example people learn new skills and gain in confidence, but it is more likely to be the researcher’s career which benefits. In ethnographic research, there is a risk of intruding in people’s lives and/or raising expectations of continuing friendship which may
not be realised. As other researchers have argued, we could encourage a more shared process of negotiation regarding people’s terms of engagement, and withdraw from research relationships at the pace set by individual respondents.

People with learning difficulties have little redress in terms of what published research says about them. Therefore accountability is an important aspect of analysis. This can be promoted through giving maximum ‘voice’ to respondents when reporting findings, recording and reporting non-verbal communication and through respondent validation exercises. Dissemination should be in accessible formats, sent or delivered directly to participants. More could be done to involve people with learning difficulties in the process, eg: through co-presenting findings at conferences.

There is a growing literature on ethics and participatory research with people with learning difficulties but much of it is about general principles. We need to document issues that have arisen in particular studies, open up the discussion to hear the views of people with learning difficulties and thus learn from each other’s experiences.

GETTING BLOOD OUT OF A STONE? THE ETHICS OF RESEARCH WITH YOUNG PEOPLE

Janet Shucksmith, Department of Sociology and Anthropology, University of Aberdeen

The argument in this paper is that the ability to draw rich and valid accounts from young people is intricately bound up with ethical issues. Such a shift takes the researcher away from the role of plunderer of information to one of facilitator and enabler for allowing children’s and young people’s voices to be heard.

It is important to establish the case at the start for children’s competence. The Code of Conduct, Ethical Principles and Guidelines of the British Psychological Society in 2000 still bracketed children with ‘participants who have impairments that limit understanding and/or communication such that they are unable to give their real consent.’ But children are not cognitively incompetent. Too often developmental models give the impression that they are, but examination of lived childhoods shows us that this is a gross oversimplification. Even leaving aside the justice of pursuing an approach which gives more credence to young people’s accounts – there are innate gains in terms of improved validity from revising this viewpoint.

The lack of acceptance of children’s competence has consequences for a whole range of issues over which adults feel that they must offer protection. It is almost impossible for researchers to approach children directly. Their socio-political positioning means that adults must give permission for access. This takes precedence over the young person’s right to participate in the decision and to talk with researchers. It is one of the many settings therefore in which children’s rights are exercised by adults on their behalf. Sometime gatekeeper permission becomes a substitute for the true permission of the child to take part, or becomes a secondary concern. Much work that is carried out in the school context is inscribed by differential power relations, making it very difficult for children and young people to opt out of participating. The additional consent of the parent may also be required by some authorities, though there is little consistency over this. Activities undertaken by the whole class (e.g. group discussion) may be seen as sufficiently like the pattern of activity usually followed by the children that teachers will assume their right to give permission on children’s and parents’ behalf. Since children
have little or no effective choice about which bits of the curriculum or the school day they participate in, they – by extension – have little or no right to opt out of these sorts of sessions.

Sometimes research with young people in school settings bears no relation to young people’s own concerns but is used as a way of accessing data about family issues. Do researchers fail in a moral duty if they don’t respect the privacy of the child and home and their role in supporting the child in safeguarding it?

A little discussed aspect of this is what happens even when researchers are assiduously pursuing permission in terms of the order in which permission is sought. The denial of access by a parent may constitute a denial of the right of the child to participate, where he/she is keen to take part.

In relation to the issue of informed consent, it is clearly important that a climate is created in which young people can gain understanding of the aims, methods and likely use of any research to which they are asked to contribute. The activities of ethics committees at the initial planning stage of research may obscure the need for continuing reassurance and renegotiation with participants throughout the course of the contact as new issues arise and different demand are made on participants.

Making information packs or sheets attractive and readable for young people in language that is clearly understood is greatly to be desired in this respect, but can only be a poor substitute for really telling young people before allowing them to give their consent.

There may also be a tension between a desire to ensure proper informed consent and a need not to feed vocabulary and concepts to young people. In a study of mentoring with three groups of vulnerable young people currently being undertaken within our research group, the borrowing of vocabularies and frameworks by young people to explain their situation was marked.

Some have suggested that a different suite of methods is required in order to work with rather than on vulnerable young people to avoid reinforcing the powerlessness of, for example, very vulnerable groups, who feel they are frequently the subjects of interrogation by professionals about areas of their lives that are often regarded as private by other groups.

One way in which the imbalance of power between researcher and researched has been addressed is by allowing young people the right to be interviewed in pairs. Others argue for a form of research that gives children and young people control over the research process and methods. What may be lost in terms of standardisation is gained in terms of engaging children and promoting fluency.

How do we manage the situation when, having involved young people in a more participatory way, we get to the stage of dissemination? Young people may be misled into a belief that a single piece of research is likely to have a profound impact on policies, the provision of services and so on.

Given the variety of errors into which we can all plunge regarding research with young people, what measures should we think of taking to improve the ethical nature of research with this group? Revision of the language of ethics codes to encompass some better understanding of children’s cognitive competence might be very welcome, but we are more likely to improve practice by concentrating on the virtues of the researcher than by the refining of codes of conduct.
At all stages of the research process, from inception, resourcing, design, investigation and dissemination, social work and social care researchers have a duty to maintain an active, personal and disciplinary ethical awareness and to take practical and moral responsibility for their work.

Both the process of social work/care research, including choice of methodology, and the use to which any findings might be put, should be congruent with the aims and values of social work practice and, where possible, seek to empower service users, promote their welfare and improve their access to economic and social capital on equal terms with other citizens.

In the case of all those who are the subjects of research, but particularly those made vulnerable by age, health, disability or social disadvantage, social work and social care researchers must retain a primary concern for subjects’ welfare and should actively protect participants from physical and mental harm, discomfort, danger and unreasonable disruption in their daily lives or avoidable intrusions into their privacy.

Social work and social care researchers must not tolerate any form of discrimination based on age, gender, race, ethnicity, national origin, religion, sexual orientation, disability, health, marital, domestic or parental status and must seek to ensure that their work excludes any unacknowledged bias.

In establishing the aims and objectives of their research, social work and social care researchers are to consider the ascertainable consequences of their actions for the users of social work/care services, both in particular and in general, in order to ensure that the legitimate interests of service users are not unwarrantably compromised or prejudiced by the proposed investigation.

In their chosen methodology and in every other aspect of their research design, social work researchers are to ensure that they are technically competent to carry out the particular investigation to the highest standards of social science as currently understood, recognising the limitations of their own expertise. In relation to research carried out primarily for educational or instructional purposes, this responsibility is shared by the student’s supervisor.

In relation to every participant to the research process, including service users, colleagues, funders and employers, social work and social care researchers have a duty to deal openly and fairly. In particular, there is a duty to inform every participant of all features of the research that might be expected to influence willingness to participate, especially but not exclusively when access to services may be, or may be perceived to be, dependent on participation.

Only in cases where no alternative strategy is feasible, where no harm to the research subject will arise and where the greater good is self-evidently served, are procedures involving deception or concealment permissible for social work and social care researchers.

The social work and social care researcher will at all times respect the individual participant’s absolute right to decline to participate in or to withdraw from the research programme, especially when the researcher, is by any means, in a position of authority over the participant.

Participation in any social work/care research activity is to be predicated on the freely given, informed and acknowledged consent of the research subject. Particular care must be taken in obtaining the consent of those who have impairments that might limit understanding and/or communication. Third party consent in the case of those who are
incapable of giving consent directly may only be obtained from a legally authorized person.
Consent must be secured through the use of language that is readily comprehensible to the research subject and which accurately explains the purpose of the research and the procedures to be followed.
Any data or other information produced in the course of social work/ care research is confidential except as agreed in advance with the research participants (including research subjects) and proscribed by law.
Social work/ care research findings must be reported accurately, completely and without distortion and note any significant variables and conditions that may have affected the outcomes or the interpretation of the data. This includes a duty to report results which reflect unfavourably on agencies of the central or local state, vested interests (including the researchers’ own and those of sponsors) as well as prevailing wisdom and orthodox opinion. In addition, social work and social care researchers, have a responsibility to make every reasonable effort to ensure that public communications of their work reported through the mass media, do not contain unfavourable stereotypes or other derogatory or damaging representations of service users or are otherwise misused.
The publication of social work research findings should properly and in proportion to their contribution, acknowledge the part played by all participants to the research process.
Symposium of Social Aspects of Death, Dying and Bereavement

The eleventh one-day symposium on social aspects of death, dying and bereavement was again held at the University of Leicester on Thursday 8th November 2001. The symposium continues to function as a useful forum for both new and established academics to present and discuss their research in a friendly and supportive environment.

Following a few words of welcome by Dr Cath Exley, a member of the organising committee, the morning’s programme began with two contrasting, yet equally fascinating accounts concerning end-of-life decisions. In her paper ‘Death, Symbolism and Mythology in Western Medicine and their Significance to the End-of-Life Medical Treatment Decision’ Judith Wester discussed the various ways in which Western medicine might benefit if it adopted a non-empirical, less physician-centred dimension to the dying. Utilising the twin concepts of spirituality and Greek mythology, Wester noted how the “medicalisation” of death and dying has led to a “strategic” omission of the soul or any non-empirical dimension to being. To remedy this situation Wester believes both professionals and individuals should embrace aspects of transcendence and sacredness when faced with end-of life decisions and their own mortality. In the next paper, ‘Euthanasia and the media’ Elke Hausman highlighted the ways in which the media represents euthanasia, both as a positive and negative “event”. Hausman’s analysis centred on the way press representations of euthanasia are structured around either a ‘major’ discourse which she calls ‘terminal illness discourse’, in which euthanasia is constructed more as a tragedy than criminality and can, therefore, be seen as morally justifiable or a ‘minor’ discourse, ‘the voluntary euthanasia discourse’, in which the ‘taker of life’ is portrayed as somehow playing ‘God’. Susie Page, in her paper ‘Preparing for and performing sudden death - the contribution of the Resuscitation Training Officer (RTO)’, explored the ‘strategic’ ways in which Resuscitation Training Officers construct and contribute to the way emergency deathbed scenes are ‘performed’. She argues that these ‘sites of death’, in which the ‘body’ takes centre stage as defibrillators and other paraphernalia are assembled, exposes the way emotions are unthinkingly and often unselfishly put on hold while individuals ‘perform their given roles’.

The afternoon’s programme began with Anne Eyre discussing how those bereaved by disaster - as opposed to those deaths which might be considered more ‘normal’ or ‘natural’- are treated in the wake of their loss. In a paper entitled ‘Person, property or public interest? Understanding post-disaster relationships’, Eyre used such tragedies as the Marchioness disaster to focus on the complexities and sensitivities of dealing with the survivors of this unique form of mass death. For Eyre, the ‘professional agents of death’ are often insensitive to or often overlook the feelings of the bereaved and their loved ones in the hours, days and weeks following disaster; a situation which may well impact upon aspects of their grief and mourning. In a contrasting, yet, equally fascinating paper, Jan Draper & Jenny Hockey raised the possibility - in line with much post-modern thinking on the subject - that identity is currently in a state of flux? In a paper entitled ‘Constructing Pre and Post-Life Identities’; the pair highlighted the parallels between transitions into and out of life by suggesting that, as social agents, our identities are neither ‘securely’ embedded nor enshrined in physical affirmations or in social membership. On the contrary, modern technology is now capable of transcending the
events of birth and death; thereby ‘extending’ identity beyond the ‘normal’ limits of the life course, primarily through the use of ultrasonography and memorialisation. Draper and Hockey suggest, therefore, that such practices generate a greater proximity between the unborn and the deceased is being secured.

The latter part of the afternoon session focused on the field of palliative care and began with a paper by Sarah Li entitled ‘Symbiotic Niceness’; a theoretical concept which claims to understand the range of special skills and strategies which are mutually adopted by professionals and patients to help facilitate the management of dying in a palliative care setting. Drawing inspiration from Goffman’s notion of ‘presentation rituals’, Li suggested that displaying ‘niceness’ through talk helps to form a contractual relationship between professional and patient in which individuals are morally obliged to perform in a right and proper manner. For Li, then, the performance of ‘niceness’ - the paying of compliments or displaying consideration - is seen as a two-way emotional process in which the enthusiasm and warmth of the professional relies on and feeds off the ‘niceness’ of the patient. The day’s final paper ‘The Complexities and Uncertainties of Getting Started: Negotiating the new dilemmas facing researchers in palliative care’ by Anita Sargeant, focused on the topical issue of undertaking research in a health care setting and the problems of consent and negotiating access. According to Sargeant an absolute barrage of political reforms - of which The Human Rights Act 1998 and the Data Protection Act 1998 are but two - have simply created yet more hoops for erstwhile researchers to jump through before they are allowed access to their respective spheres of study. For Sargeant, this has far-reaching implications for the research process in general and more particularly on research in a palliative care setting. For instance, will the process of gaining access to the participants be made more complex because of the rules governing personal formation? Are palliative care practitioners given many of these restrictive guidelines still prepared to allow imminently dying patients to voice their views?

Questions from the floor merely consolidated the view that good quality research is subject to increasing layers of bureaucracy and legislation and is, therefore, in no way simply an automatic gateway into the intimate sphere of death, dying and bereavement. This rounded off what was a very successful conference, which continues to generate many interesting questions and discussions; some of which will no doubt be addressed at next year’s gathering.

Next year’s symposium will take place on 7 November 2002 in the Dept. of Epidemiology and Health at the University of Leicester. The organising committee are: Catherine Exley, Stephen Handsley and Carol Komaromy. Further details will be available shortly.

**Stephen Handsley**

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The one-day conference in Old Aberdeen on Thursday 28th March brought together a range of academics researching and teaching in the field of medical sociology in Aberdeen and beyond. The morning sessions highlighted some of the work conducted in at the University of Aberdeen and The Robert Gordon University. Janet Shucksmith gave an overview of medical sociology in Old Aberdeen, Jenny Greener did the same for Foresterhill. John Love presented a range of medical sociology projects he has been involved in at The Robert Gordon University. It was recognised that there are more people involved in medical sociology in Aberdeen as many had put in apologies for the day.

In the afternoon sessions the following papers were presented:
Kate Philip Healthy Respect: A Scottish Health Demonstration Project
Lydia Lewis Gender and treatment decision making in mental health
Maureen Porter Reproductive Health after Caesarean Section
Karen Forrest To tell or not to tell / young people & genetics
Caroline King Every Child Matters? Inter-agency working in relation to children with chronic medical conditions in mainstream schools
Edwin van Teijlingen SAFE and International Maternity Care

The conference was organised jointly by sociologists from Foresterhill (Edwin van Teijlingen and Jenny Greener) and from Old Aberdeen (Janet Shucksmith and Kate Philip). Approximately 25 people attended the day, representing the University of Aberdeen and The Robert Gordon University as well as two colleagues who travelled up from the two universities in Dundee. The day was supported by the British Sociological Association’s Scottish Medical Sociology Group. The lunch and refreshments were kindly provided by the Institute of Applied Health Sciences at the Medical School.

It seems that Medical Sociology, which has a long and distinguished history in Aberdeen dating back to the early 1950s and the work of Raymond Illsley (who later became professor of Medical Sociology at the University of Aberdeen) and colleagues, is still very vibrant today. The general feeling at the conference was that there is a lot of medical sociology research going on in Aberdeen, but that some of it was ‘hidden’. In terms of networking, the day gave many the opportunity to find out more about colleagues doing similar kinds of work, and to exchange ideas and email addresses. We hope that it will be possible to mount further events and to keep those with an interest in medical sociology in touch with one another.
How preserving confidentiality in qualitative health research can be compatible with preserving data for future use.

Gill Backhouse

In recent years Qualidata has become increasingly aware of a dilemma faced by researchers when preparing data for archiving, particularly those working in the socio-medical field. The Economic and Social Research Council (ESRC), the UK’s leading funding agency for economic and social research requires all award holders to offer their data, both quantitative and qualitative, for archiving. This policy clearly optimises the resources expended on data collection by making them available for future use by other researchers and avoids duplication where relevant research data already exist and are accessible.

However, a dilemma arises when an ESRC funded researcher in the health field must comply with conflicting recommendations of the Research Ethics Committee. For example, they may stipulate that data be destroyed at the end of the project to ensure complete confidentiality. In view of this, Qualidata made contact with the newly established Central Office for Research Ethics Committees (COREC) to discuss these issues. COREC’s view was not opposed to archiving health data but that ethical issues of consent and confidentiality are of paramount importance. By bringing these concerns regarding archiving to the attention of members of Research Ethics Committees and qualitative researchers, Qualidata hopes to make progress with the debate. In the meantime there are a number of options to preserve confidentiality both for the duration of the research project, and, to preserve data for future use.

Researchers need to be fully aware of the legal situation regarding the confidentiality of the interview material. The ESRC recognised this some years ago and commissioned a legal firm Allen and Overy, in consultation with the social science research community, to provide legal advice on the issue of confidentiality. Based on their report, the ESRC have produced their “Guidelines on Copyright and Confidentiality: Legal issues for social science researchers” which is available on the ESRC website at: http://www.esrc.ac.uk/esrccontent/DownloadDocs/wwwcopyrightandconfidentiality.doc

In the Guidelines, the ESRC refer to a legal obligation to maintain confidentiality. This is a ‘duty of confidentiality’ which is not contained in Parliamentary statute, but is incorporated in case law, and implies that confidential information given to a researcher may not be passed to a third party without the explicit permission of the informant. What constitutes ‘confidential’ is not clearly defined and can be whatever the informant considers is confidential or would expect to be treated as such. A ‘duty of confidentiality’ also arises when the researcher has volunteered to keep the information confidential. Exceptions to this are when the police request data which is relevant to a case under investigation and when a court subpoenas the data, and informants should be made aware of this.

Recent legislative developments in the Data Protection Act 1998, which came into force
on 1 March 2002, contain the principle that data collected for one purpose cannot be used for another, which at first sight presents further potential problems regarding archiving and the re-use of data. How can the principle of confidentiality of data be compatible with preservation in an archive open for access to future unspecified usage?

In fact an exemption for research data is provided for in the Data Protection Act, which allows anonymised data collected for research purposes to be stored and used for secondary analysis by future researchers. The answer in all cases to the dilemma faced by researchers, who are required to offer their data for archiving, is to ensure confidentiality by thorough and appropriate anonymisation. Written consent from participants to archive the data further avoids potential future misunderstanding.

This requires the allocation of project time and resources to prepare for archiving from the beginning. For example, it is recommended that the removal of names from the data, and their replacement with pseudonyms, is undertaken as they are collected. This is, after all, good research practice. Careful scrutiny for other identifying information in the data is also required. For example, the identity of a research informant with a rare medical condition, or who holds a senior position in an organisation, could be recognised even when names are removed. In these special circumstances, further steps are needed to prepare the data for archiving, including obtaining consent to use the information where confidentiality cannot be guaranteed. This has been particular successful when transcripts are seen and approved by the informants, who are then fully aware of the information they are consenting to archive. In fact, we are seeing more instances of informants being more than willing for their data to be archived even without preservation of confidentiality, contrary to the expectations of many researchers, if given the opportunity to approve transcripts.

Safeguards are also in place at the archives themselves, when the data are accessed. Unless a depositor of data researcher stipulates otherwise, the data are accessible only to bona fide researchers and their credentials are verified by each archive. For example, the UK Data Archive which holds the largest collection of digital data in the social sciences and humanities in the UK, requires all users to undergo a registration process to enable them to access data, including on-line data. A further safeguard is an undertaking signed by all users of archived data, that, despite thorough checks by the researchers and the Archive, should any identifiable information inadvertently remain in the data, the user will not reveal this information. This forms a legally binding contract.

The impact of the Data Protection Act has been to encourage a greater openness to informants about the purpose of the data collection, its storage and usage and this is to be welcomed. Therefore researchers need to be fully aware of this and implement it in their own research practice. This openness leads to a greater onus on the researcher to obtain consent from respondents; to this end, appropriate information must be provided and if archiving data is anticipated, consent for this, must be obtained.

Much has been written on consent in relation to medical treatment and research practice. There is on-going debate amongst the research community and developments in the legal arena on the subject of consent; many websites proving very useful in disseminating this information, in particular those addressing health research such as Dept of Health, Medical Research Council, and the Central Office for Research Ethics Committees which also has a comprehensive list of link to other relevant websites.
Consent is too complex an issue to explore here in any depth but I would like to make the following points.

There has been a growing tendency, and legal requirement in some cases, to involve users of services in providing feedback and evaluation of publicly funded services. There has been a simultaneous move to seek information for research from those who previously may have been excluded for reasons of mentally incapacity, disability, or age. With consequently greater emphasis on the rights of individuals, it is no longer acceptable for authority figures or carers to speak on behalf of people with a disability or children. This inclusion in research of people not previously consulted presents an additional challenge to researchers in obtaining fully informed consent. Ethical and legal problems in these respects are being addressed and the consequent developments in the skills of interviewers. Qualidata is also assisting in addressing these issues by providing information on our website on interviewing children and people with learning disabilities, in addition to providing general guidelines on confidentiality and consent. We would welcome feedback on researchers’ experiences in obtaining consent in these circumstances and we will shortly be providing various examples of consent forms on our website.

Understandably, researchers due to their unfamiliarity with archives do experience difficulty in explaining to research participants how their data will be preserved and made available when archived. The surest way to provide accurate information to research informants about the procedures for storage, access and use of data in archives, is to visit them yourselves. If you have already searched on-line catalogue records or visited in person, you cannot fail to be engaged by the wealth of resources available to researchers, not only in the socio-medical field but across the whole range of social science disciplines. Qualidata’s searchable on-line catalogue of archived qualitative research data provides details of qualitative datasets stored at the UK Data Archive and in archives across the UK. This can be accessed freely from our website. We have a user support team who can be contacted if you have a specific request or are interested in a particular subject area.

**Relevant websites**

Qualidata http://qualidata.essex.ac.uk
Qualidata’s information on Confidentiality and Informed Consent

http://www.qualidata.essex.ac.uk/creatingData/confidentiality.asp
Further links
http://www.qualidata.essex.ac.uk/creatingData/furtherreading.asp

UK Data Archive http://www.data-archive.ac.uk/

ESRC http://www.esrc.ac.uk
ESRC Guidelines on Copyright and Confidentiality: Legal issues for social science researchers
http://www.esrc.ac.uk/esrccontent/DownloadDocs/wwwcopyrightandconfidentiality.doc
Gill Backhouse is the Advice and Acquisitions Officer for Qualidata and the UK Data Archive
Delegates’ comments on the 2001 BSA Medical Sociology conference

Many thanks to all 62 delegates ((18% of the 354 registrations) who responded to the e-mailed request for feedback on the 2001 conference. We were relieved and delighted that almost all of you had something positive to say about the conference and your comments were overwhelmingly friendly endorsements of the organisation and content of the event. Numbers of positive and negative comments were balanced on, for instance, the York campus, vegetarian and vegan food on offer, coffee and tea service and the time slots available for papers. Criticism of specific aspects of the conference was usually balanced by a positive comment from another delegate. For instance the standard of papers was described as ‘truly appalling’ by one delegate and as ‘going up markedly’ with ‘virtually no boring ones’ by another (long-serving) delegate. Similarly, the service of coffee in parallel with the papers was seen as admirably ‘flexible’ by one person and as preventing easy conversation between delegates by another.

We will be making some changes to the conference organisation over the next few of years to try to accommodate your suggestions. In 2002 we plan to open registration earlier, to provide data projectors, a laptop/jc in every room (to permit powerpoint presentations without delegates needing to bring their own computer) and we hope to make a draft conference programme available on the website a couple of weeks before the conference. In 2003 we plan to have plenary sessions to open and to close the conference, giving another opportunity for the whole conference to gather together. By 2004 we plan to run the conference from Thursday afternoon to Saturday lunch time (instead of Friday afternoon to Sunday), but will keep to the second fortnight of September since delegates declaring in favour of holding it earlier in the month numbered only 26. New buildings planned at York University should mean that by 2004 it would be possible to hold a conference dinner and the accommodation should offer more flexibility for entertainment programmes.

All delegate comments on food and accommodation will be passed (in anonymised form) to the York Conference office, which is keen to try to respond to them constructively. The conference is likely to remain at York University for the foreseeable future since it offers a number of features that are not available elsewhere for a similarly reasonable price, namely an adequate number of big enough rooms for presentations, together with delegate accommodation and catering facilities all in close walking distance.

We hope that you continue to support the Medical Sociology Group conference with such warmth and affection and we welcome any further comments that you have on its content and organisation.

Hannah Bradby for the Medical Sociology committee
The sociology of health and illness book of the year, 2002, prize

The sociology of health and illness book prize which will be awarded for the first time this year at the Medical Sociology Group Annual General Meeting (5:30pm, University of York), during the 2002 annual conference. Four books have been short-listed. The particular contribution to the sociology of health and illness that the book makes is described below by the sociologist who made the nomination.

Nominated by Carol Emslie.
Writing about ‘the body’ has become highly fashionable. However, few social scientists have attempted to engage with biological science. I nominated Lynda Birke’s book for this prize because her biological training prompted her feminist analysis of the social and cultural construction of the body. Rather than the more common analysis of the body’s surface, she engages with the way that the inner body is represented in biomedicine. She examines the abstract diagrams which represent bodies in medical texts and traces scientific ideas about the insides of bodies from dissection to reading displays on machines. I came across this book when I was writing about heart disease and I still find her case study on the heart, as a focus of metaphoric association and as a site of increased medical surveillance, particularly illuminating. The book is also extremely accessible with great pictures!

Nominated by Ronnie Frankenberg.
“The composition of vast books is a laborious and impoverishing extravagance. To go on for five hundred pages developing an idea whose perfect oral exposition is possible in a few minutes! A better course of procedure is to pretend that these books already exist, and then to offer a resumé, a commentary”.* I suppose many if not most people in MedSoc feel some sympathy with this ironic view of Borges’s, so the first question about any book by a colleague might be was it really necessary and if so why. We can, and usually do, say what we need to in a paper or two. This book, unlike many, seems to me to be necessary for many telling reasons; Ethicists tend to prefer philosophers, theologians or even psychologists to us as advisers. This will show them what they are missing. First, Lock provides, and makes strange in the technical sense, vivid and readable, even moving analytic descriptions of both operations involved, donor and recipient. Second she situates these procedures in the biographies of the participants before and after the event. Third she situates them in the history and tradition of Western and Oriental views of bodily death (not orientalist or in other ways patronising, she has studied Japanese practice and thinking at first hand, at length and in Japanese) and she is as aware of both Japan and of Canada as modern as well as traditional societies and explains why. She uses a comparative method as it should be used to point not only to similarity and difference but also to the non-inevitability of particular views and practices. It is not a matter of exoticism but of science and rational thinking applied in different ways. She demonstrates in detail the rational impossibility of absolute and uniform certainty within
and between particular social and historical traditions.

Lock is, of course, alongside Scheper Hughes, Virginia Olesen, Bryan Turner and others, well known as a pioneer of the recognition of the significance of embodiment in sociological study. This book brings these particular dry bones (so to speak) to life. One of the major reasons for its importance is that its clarity makes it an ideal exemplar for both would-be medical sociologists and prospective clinicians (nursing, medical or other) to read at the beginning (and perhaps again at the formal conclusion) of their course of studies in order to see the relationship between theory and practice; humanism and science, personal and political. Finally, she accomplishes what we all aspire to, but usually fail to achieve, she makes clear and demonstrates in a way even sociological purists will find hard to refute the relevance for the general understanding of society at large, of sociology in, of and for, medicine. Medical sociology is still often despised and even its practitioners discriminated against as merely one of several narrow “applied” subdisciplines. Finally she reminds us as medical sociologists of what we can learn from writers as far apart in outlook, space and/or time as Bronfen, Bauman and Borges, Hacking and Heidegger and Hertz; Leach, Latour and Law, or Titmus, Tolstoy and Toynbee and, of course, alas only by virtue of her reporting, countless Japanese Scholars and Practitioners.

*The Borges quotation is from the Foreword to ‘The Garden of Forking Paths’ (1941) reprinted in ‘Fictions’ (1944) which is reprinted in turn in ‘Jorge Luis Borges’ (1999) newly translated by Andrew Hurley Collected Fictions Allen Lane: The Penguin Press at p67. The quotation continues “That was Carlyle’s procedure in Sartor Resartus, Butler’s in The Fair Haven—though these works suffer under the imperfection that they themselves are books, and not a whit less tautological than the others. A more reasonable, more inept, and more lazy man, I have chosen to write notes on imaginary books. Those notes are ‘Tlon, Uqbar, Orbis Tertius’ and ‘A Survey of the Works of Herbert Quain’.”

Nominated by Robert Dingwall.
Timmermans’ book is a classic ethnographic exposé of ‘conventional wisdom’. The idea that CPR should be attempted universally has become increasingly prevalent, in the UK as much as in the US. Timmermans shows how few ‘great saves’ really occur. Doctors, patients and relatives are locked into a myth that wastes health care resources in the undignified treatment of dead or dying people. This is a shocking book, in the best sense of that word - it made me think in a very different way about something that I had never previously questioned. That’s what great sociology is about.

Nominated by David Field.
I nominated this book because it presents the first sustained attempt to provide a sociological conceptualisation of grief. The understanding of grief in Western societies has been shaped by psychological frameworks, especially psycho-dynamic ones, that focus upon the phases or stages that the grieving person passes through. Apart from Lyn Lofland’s essay on loss, sociologists have not attempted to analyse the social dimensions of grief and how the experience of this emotion depends upon and is shaped by the social contexts and relationships of the bereaved. Walter’s very readable tour de force utilises Durkheim’s concepts of integration and regulation to discuss ‘the integration of the
dead and the living, and the regulation or policing of grief’, drawing upon a range of anthropological and contemporary material to support his analysis. His book demonstrates the central significance of social factors in shaping the experience of grief and the variety of ways that bereaved people reshape their relationships with those who have died. In doing so it challenges some basic assumptions of current psychological stage/phase conceptualisations of grief, especially the assumption that the grief is ‘resolved’ by ‘moving on’ from and ‘letting go off’ one’s connection with the person who has died. The book demonstrates the contributions that a sociological perspective can make to the support and care offered by those working with the bereaved and has been well received by those working in the area of bereavement research.

Further details of the book prize can be found on the Medical Sociology Group website. http://www.britsoc.org.uk/about/medsocindex.htm
This remarkable book is unlike any other I have reviewed, for a variety of reasons. Firstly, at 700 pages and with 34 chapters, the sheer scale of the collection is vast. The editors state that the book is not definitive, but represents a creative work in progress. However, the collection certainly provides a unique insight into the current debates and issues which frame disability studies. The three editors all have a longstanding interest in disability studies, combining a variety of different backgrounds and a diverse range of experiences, and this manifests in the way that the chapters range across academic disciplines. Consequently, the book is aimed at a wide audience including disabled people, practitioners, academics and those involved in forming social welfare policies.

The collection is divided and organized into three major sections: The Shaping of Disability Studies as a Field (Part 1); Experiencing Disability (Part 2); and Disability in Context (Part 3). Individual chapters are well organised, with most containing a chapter overview and conclusions, plus directions for future work in the field. This helps guide the reader around what might initially seem to be an almost overwhelming abundance of choice. Each chapter aims to provide a review of a specific area and in the majority of cases, this remit appears to have been comprehensively achieved with little obvious overlap. I say, ‘appears to’, because I have to state that as yet, I haven’t read every chapter in detail. Those that I have read reflect my particular interests at the moment, which perhaps makes it a bit unfair to single them out. However, so far I have particularly enjoyed chapters by Gareth Williams on ‘Theorizing disability’; Adrienne Asch, ‘Disability, bioethics and human rights’; Tom Shakespeare and Nick Watson, ‘Making the difference: disability, politics, and recognition’; Ian Basnett, ‘Health care professionals and their attitudes toward, and decisions affecting disabled people’; and Philip Ferguson, ‘Mapping the family: disability studies and the exploration of parental response to disability’. Hopefully the chapter titles give some indication of the scope of this collection.

In the Introduction, the editors note that, ‘In a world population of 6 billion people, 80% of all disabled people reside in developing countries’, leading them to pose the question: How can the disability studies field understand and contribute to our knowledge of this world and offer perspectives on how to ameliorate the lives of disabled people worldwide? With that in mind, authors were asked to make their chapters as international as possible, and to select international examples of their arguments where possible. The editors also state that they confronted these issues by inviting contributors from different national origins. For me, the lack of authors contributing perspectives from developing countries is one notable omission in this collection. Possibly this reflects difficulties in identifying suitable contributors – certainly it reflects how wide the gap still is between so called ‘developed’ and ‘developing’ countries, and how little we know about the majority of disabled people. Hopefully, if there is a 2nd edition of the collection this can be remedied.

Having said that, I think that this impressive collection offers a significant contribution to
the field of disability studies. Anyone with even the slightest interest in this area will find much to interest and stimulate them. The editors hope that this handbook will encourage others to take on the challenge of advancing the field in understanding and practice, and I’m sure that their hopes will be fulfilled. At £60, this is an expensive book for individuals to buy, but if you borrow it from the library I can guarantee (well, almost) that you just won’t want to return it!

Clare Williams, King’s College London


The book gives an excellent insight into the process of regulation and control of medicines in the European Union (EU) as well as the politics surrounding it. Abraham and Lewis give a very detailed account of the process of medicine regulation, which is more complex in the EU than in any national regulatory system (p.113). The book covers a wide-range of sociological topics such as, for example, pressure group politics, the working of regulatory bodies, the role of the pharmaceutical industry as transnational corporations, consumer groups, the role of the state, including competition and co-operation between European nation states, the working of the elite network of scientists in the pharmaceutical industry, government and industry-funded academic experts (the so-called technocracy).

The book explains why transnational pharmaceutical corporations want European, and indeed, global harmonisation of medicine regulation. The authors paraphrase C. Wright Mills in saying that “citizens may feel they are living in a time of big decisions, but they know they are not making any.” Without coming across as conspiracy theorists, the authors provide some worrying examples of the ‘games’ played by the pharmaceutical industry. Abraham and Lewis (p. 81) remind us that:

“Industry interest in developing a global strategy stems from political pressure to reduce health costs combined with continuing regulatory demands, both of which contribute to longer development times and shorter product lifecycles. A shorter ‘time to approval’ translates into a quicker return on investment. European and global harmonisation helps to achieve this goal because more markets can be accessed more or less simultaneously, in theory at least.”

The very same reasons why most “very British” companies are see keen on the introduction of the Euro in this country!

Regulating Medicines in Europe has two-and-a-half pages of Abbreviations and acronyms, indicating that this is a highly specialised technical field of research. The methods chapter lists the response rate from industry representatives and regulatory bodies the three main countries highlighted in Regulating Medicines in Europe, namely
Sweden, the UK and Germany. Some how unsurprisingly, the response rate is lower in
the UK than in the other two countries. “... the British regulatory authorities were less
interested in helping and participating in the research than their Swedish counterparts,
whose enthusiasm facilitated a greater number of regulatory contacts and respondents.”
Perhaps reflecting the more secretive approach of UK industry to everything, from dealing
with staff (e.g. labour relations), the public (e.g. environmental issues or food labelling) to
the state (e.g. influencing politicians and civil servants).

This book will appeal to a wide-range of scholars. For example, students of transnational
companies, social policy (especially European integration and pressure groups), public
health and medical sociology.

I have two criticisms of this, otherwise excellent, book. There are a few too many very
long sentences with quite technical detailed information. The worst one is perhaps (p.
84):

“While Directive 75/318/EEC extended the framework provided in 65/65/EEC by
setting out the particular requirements relating to applications, including the
qualifications and roles of experts and the assessment of the product dossier,
Directive 75/75/319/EEC also … (+ 47 more words!!!)"

Although the Index looks pretty comprehensive at first glance, it often lets the reader
down. This is the case for both terms specific to this field of study as well as more
general terms. For example, the Netherlands according to the Index appears only once,
whilst I came across it on a least three pages. More importantly, according to the Index
one of the key terms in this book ‘Committee on Safety of Medicines (CSM)’ appears on
only three pages. Without conducting a detailed search I found it on at least 14 pages. It
is likely that Routledge has subcontracted the indexing. My own experience is that
authors get the best possible index by suggesting terms of inclusion to the indexer
working for the publishers, and checking what the indexer has produced.

Edwin van Teijlingen, University of Aberdeen

Dickenson DL. (Ed) 2002 Ethical Issues in maternal-fetal medicine Cambridge:
Cambridge University Press (ISBN 0 521 66474 8 Pbk £24.95)

Although this book identifies as its target audience clinicians, philosophers and lawyers,
any sociologist looking for an accessible introduction to some of the major ethical issues
in maternal-fetal medicine will find this book useful. In contrast to some of the ethics
literature, this book aims to focus on ‘everyday ethics’, rather than hypothetical situations.
The contributors of the 21 chapters include clinicians, ethicists, lawyers, philosophers,
political scientists and sociologists who generally write from a feminist perspective. The
contents are divided into five sections by stages of pregnancy, within which the authors
cover four main areas:

The balance of power in the doctor-patient relationship and the justifiable limits of
paternalism and autonomy;
The impact of new technologies and new diseases;
Disability and enhancement;
Difference - focusing here on the extent to which the clinician should respect the tenets of other faiths in a multicultural society, even when s/he believes requested interventions or non-interventions to be morally wrong.

In the first area there are thoughtful chapters from practising clinicians including obstetrician Wendy Savage, on a woman’s right to refuse, and conversely, to choose a caesarian section; and obstetrician Susan Bewley, on the moral arguments used to justify society acting against pregnant women, on behalf of their unborn children. With so much emphasis placed on the role of women in terms of fetal harm, the chapter by Cynthia Daniels, an American political scientist, entitled ‘Between fathers and fetuses: the social construction of male reproduction and the politics of fetal harm’, is a very welcome attempt to redress the balance.

Many of the chapters in the second area explore the benefits and dilemmas of the ‘choices’ which are resulting from the impact of new technologies. The ethicists and philosophers who have contributed to this book tend to focus on the individual woman or couple involved. In contrast, Elina Hemminki takes an epidemiological approach, exploring the ethical questions raised by population based antenatal screening programmes, whilst Donna Dickenson moves into wider issues of justice in her chapter on the ownership of embryonic and fetal tissue. In terms of ‘new diseases’, general practitioner Paquita de Zulueta considers the ethical dilemmas inherent in the care of HIV positive pregnant women.

As might be expected, the section on disability and enhancement contains diverse perspectives. Paediatrician Neil McIntosh writes from a clinician’s perspective of the ethical issues involved in withdrawing life-sustaining treatment, whilst sociologist Priscilla Alderson’s chapter reviews contrasting positions on the advantages and disadvantages of prenatal counselling, tying this in with prevailing images of disability. Drawing on her research, she then compares medical and counselling images of disability with the views of adults who have a condition which is screened or tested for prenatally. In this way, she poses thought provoking reflections on the nature of disability, and the possible impact of prenatal screening on maternal-fetal relationships.

The final area, on difference, includes a comprehensive chapter by the Finnish political scientist Sirkku Hellsten, who addresses the question of where legitimate cultural difference in obstetric and gynaecological practice ends and discrimination against women begins. Writing from a public policy perspective, she offers practical solutions to some of the difficulties of multicultural working, drawing on her experiences of working in Tanzania.

Some of the statements found within this book may surprise sociologists, but will also alert them to the differing perspectives of other disciplines. For example, a chapter on ‘non-compliance’ is recommended by the editor (a Professor of Ethics) for ‘drawing our attention to the way in which this apparently value-free term is used to reinforce the physician’s power and to label the patient as an object of concern rather than a partner in the clinical relationship’. The editor herself does point out that the power of the doctor is still too widely ignored in conventional bioethics, which, she states, tends to perceive the
patient as autonomous and independent. However, this example serves to further reinforce the importance of multidisciplinary debate and collaboration in these complex and critical areas.

Clare Williams, King’s College London


This is a lively and well-written attack on the extension of medicine into ‘inappropriate’ areas. The book covers health scares and moral panics, the regulation of lifestyle, debates about the merits of screening, the politics of health promotion, and the ‘crisis’ of modern medicine. For social scientists there are references to many familiar names (Dubos, Friedson, Giddens, Fukuyama,) and many of the general arguments are not controversial for a sociological audience. For example, it would be difficult for a sociologist to dispute the following. ‘The pre-eminent role of health in Western society since the early 1990’s is linked to a significant shift in the boundaries between the spheres of public and personal life, and to changes in the relationship between the state and the medical profession.’ (p163). Although Fitzpatrick is familiar with a broad range of material from a wealth of sources, this book is not, in any narrow sense, an academic treatise. It is a rare example of a polemic that champions, among other things, medical autonomy, the need for greater respect for more scientific research and for a firm line to be drawn between medicine and politics.

The book is unusual in calling for a radical separation of medical from social concerns. As a left wing activist GP he wants politics kept out of the consulting room and scientific ‘advances’ given free reign. The book is iconoclastic and wide-ranging. His targets are many and varied and he often gets in the killer punch. He has little sympathy with social constructionist critiques of scientific knowledge. For him, scientific endeavour ought not to be curtailed by environmental or any other concerns. Interest in the body is symptomatic of narcissism; scientific and environmental concerns about GM food are misplaced and moves to restrain scientific advances are simply the product of the ‘fatalistic outlook of contemporary society’ (156). Other fashionable sociological causes get short shrift. A greater role for lay people in the regulation of medicine is condemned. This is because lay members of the GMC are agents of state control rather than providing a mechanism for public accountability.

Fitzpatrick’s style is provocative, but it rarely failed to raise a smile. I particularly liked his arguments about screening. His argument will not surprise many readers of Medical Sociology News in its questioning value of mass screening programmes. In an ironic twist he points out that the men’s health movement start to demand screening tests at a time when there is increasing scepticism (and resistance to) routine medical screening of women. ‘Whereas the early women’s movement rejected medical inspection of the cervix as an act of symbolic domination, the modern men’s health movement invited rectal penetration as a symbol of its subordination to medical authority’ (p56). His other target is health promotion. As a committed couch potato I smiled contentedly when I found some (slim) justification for my physical laziness, ‘..health promoters firmly believe that
exercise is conducive to a healthier lifestyle. It would appear to be faith rather than science that justifies medical calls to the public to take up exercise’ (p53). Hooray. He objects to health promotion not just because of the limited evidence for their claims (apart from tobacco), but because intervention in people’s lives is of dubious value and morally objectionable.

This is not a dispassionate academic study - more a diatribe against trends in health policy – particularly those policies associated with New Labour. The central complaint, from this full-time inner city GP, is that New Labour reforms are compelling medics to ration scarce resources whilst simultaneously regulating the behaviour of their patients. This is not a detached or balanced review of the evidence on either of these points but it certainly raises a few key questions.

For a self avowed political doctor, rather unexpectedly, he wants the line between politics and medicine to be much more firmly drawn, His conclusion is that the task of doctors should be ‘treating the sick and leaving the well alone’ (p173). Defending the autonomy of the medical profession is the only way rank and file doctors can escape the charge of being part of the intrusive and politically suspect New Labour health policy. For Fitzpatrick, the abject state of the medical profession is exemplified by the imposition on GPs of, ‘continuous formal instruction and regulation, mentoring and monitoring, support and counselling…what will patients think of doctors who have so little faith in themselves that they put their trust in formal procedures of assessment and regulation?’ (p167). His manifesto includes a call for a renewal of trust in medics with a reminder that the basis for this trust was, supposedly, its grounding in scientific research. He calls, therefore, for a ‘renewed commitment to medical science’ (p168). The book is thought provoking, great fun and extremely useful for stimulating debate among students, particularly those who preach the virtues of physical exercise.

Rob Mears, Bath Spa University College


This fascinating and wide ranging book, blending social history, cultural analysis and medical sociology, emerged out of a Conference held in Barcelona in 1998. It offers a wide range of case studies of public health campaigns by European governments, and the forms of representation they used to get their message across, in the immediate post-1945 era and beyond, when the relationship between the state and the medical profession had changed dramatically. The strength of this volume however is that it does not just project this new relationship as simply a general and vague sociological trend, but pursues it through detailed case studies taken from the authoritarian south, the more democratic north and (former) state socialist east of Europe. These show in concrete historical terms how public health practices have been socially and politically constructed and projected into the popular domain.
The central focus of the book, as outlined in Ilana Löwy's introduction, is to show the complex ways in which cultural ‘images’ or representations of health problems and issues, were processed through scientific discourses, clinical practices, public health endeavours and political action in different European countries after World War II. Certain key themes emerge as issues of the moment, which are approached in rather different ways according the national context, such as the campaign to eradicate tuberculosis, and the need to increase the supply of healthy babies. The growing prominence of cancer as a public health issue is also a strong theme that grows ever more insistent. Distinct differences between Western and Eastern Europe emerge with the political aspects of public health ‘under’ stated in capitalist democracies and transmitted in professionalized ‘technicist’ ways, while in state socialist societies they are ‘over’ stated as health professionals were unambiguously defined as servants of the people, i.e., the state. The opening up of archives in respect to the latter, enables a much clearer picture to emerge including, as Gurjeva's chapter on Russia shows, the existence of political debates and conflicts around health issues. The focus on Franco's Spain and after in three fascinating chapters enables us to see how within an authoritarian but market-capitalist society, the politics of public health were resolved in statist rather than liberal directions. There are also two interesting chapters on government policies towards, alcohol use and cigarette smoking in the British context.

Although the central focus of the book is on the immediate postwar era, many chapters take the story up to the present day. All things considered, this is an essential book for anyone interested in the sociology of comparative European health policy, which has seriously neglected the politics of public health in general, and the cultural dimensions of health policies and practices in particular. The book is also richly illustrated in ways that would make it excellent also for teaching purposes, for example, around the cultural and historical deconstruction of health promotion messages. You should certainly order it for your library, and think of buying it yourself.

Mick Carpenter, University of Warwick


This book examines the intersection between disability and various stages of the life course (including childhood, youth, transitional periods, adulthood, parenting and old age) in 13 different countries (including South Africa, Japan, Iceland, Australia, Russia and the former USSR, Jordan, India, the USA and the UK). Such an global perspective is rare - as Mark Priestley notes in the Introduction, most disability research ignores the majority world.

The first section of the book is quite theoretical. “Repositioning Disability and the Life Course: A Social Claiming Perspective” by Sarah Irwin suggests that the growth of the disability rights movement in recent decades is due to changes in the “claiming position” of disabled people and that “social claiming” is a useful theoretical approach to disability
and the life course.

Many of the chapters involve disabled people explaining the barriers they experienced in specific cultural contexts. In “A Journey of Discovery”, Swampa McNeil provides a personal story of growing up in the North East of India. Likewise, Kaido Kikkas tells of his life in Estonia before and after the fall of the Soviet Union in “Revisiting the Iron Curtain”. In “The Hidden Injuries of ‘A Slight Limp’”, Devorah Kalekin-Fishman describes her experiences growing up in the USA as a disabled child of Polish immigrants. These personal stories remind us that experiences of disability change with time, place and culture.

The need to acknowledge the ways in which development, poverty and disability interact, particularly in the majority world, is a consistent theme. “Marginalisation and Disability: Experiences from the Third World” by Anita Ghai, “Work and Adulthood: Economic Survival in the Majority World” by Majid Turmusani and “A Complicated Struggle: Disability, Survival and Social Change in the Majority World” by Emma Stone make this connection explicit. All stress the interconnection of poverty, development, impairment and disability. The argument that disability is a life and death issue in many countries is also the focus of a chapter by Gregor Wolbring entitled “Where Do We Draw The Line? Surviving Eugenics In A Technological World”. The need for social justice policies addressing poverty is also a theme of “Disabled Children: An Emergency Submerged” by Sue Philpott and Washeila Sait. They argue that disabled children are one of the most vulnerable groups in South Africa, bearing the brunt of poverty and inadequate service provision. Disabled children are often excluded from services designed for disabled adults as well as from mainstream children’s services.

Both social change and self-empowerment are important in the lives of disabled people. Elana Iarskia-Smirnova’s Chapter on “Social Change and Self-Empowerment: Stories of Disabled People in Russia” examines the ways in which the lives of two disabled people have been structured by disability, time and space, gender, class, and the availability of services. “Life event histories and the US Independent Living Movement” by Deva Kasnitz explores the impact on disabled people of contact with other disabled people. Kasnitz suggests that in terms of positive outcomes for disabled people, been part of a critical mass of disabled people is as important as being fully integrated in society.

Marian Corker’s chapter “Revisiting Deaf Transitions” emphasises that deaf people epitomise the problems associated with the social model of disability, in particular separating discussions of impairment and disability. She also highlights the importance of researcher reflexivity and theoretical innovation in discussing disability and the life course, warning that researchers must recognise the richness of lived experience rather than being stilted by epistemic orthodoxy.

Many of the “case studies” of various aspects of the life course are very important, theoretically and politically. “The Possibility of Choice: Women with Intellectual Disabilities Talk about Having Children” by Kelly Johnson, Rannveig Traustadottir, Lyn Harrison, Lynne Hillier and Hanna Bjorg Siguronsdottir is an excellent contribution. It examines the ways women with intellectual disabilities are often positioned as “unfit” to be a mother and highlights the ways in which the legitimate desires of these women to have children are often denied because of family and social pressure.
“Failing To Make The Transition? Theorising The ‘Transition To Adulthood’ For Young Disabled People” by Kay Tisdall is another important Chapter. It examines the usefulness of a cross-fertilisation of ideas from the literature on childhood, youth transitions and disability studies. Tisdall suggests that literature on youth has tended to ignore disability issues, while the transitional literature on young disabled people has failed to effectively incorporate gender, class and ethnicity. Each of these bodies of literature, however, has an important contribution to make. Transitional literature emphasises the importance of focussing on both agency and structure in its treatment of biographies, youth literature moves beyond a simple focus on “school to work” (although it is often underpinned by problematic assumptions about the virtues of independence) and childhood literature emphasises the need to examine adult surveillance of young people’s lives. The link between social structures and the lives of individual disabled people is also a theme of “Using Life Story Narratives to Understand Disability and Identity in South Africa” by Ruth Morgan.

“Breaking My Head in the Prime of My Life: Acquired Disability in Young Adulthood” by Allison Rowlands emphasises that traumatic brain injury is the most common cause of impairments for people under 40 in Australia. Rowlands suggests that the loss of friendships is one of the most emotionally significant elements of this experience for young people with a brain injury. In “Ageing with Disability in Japan”, Miho Iwakuma points out that two-thirds of people with physical impairments in Japan are over 60. Disability and ageing are therefore inextricably linked. The parallel myths of old age and disability are also explored in an excellent chapter by Nancy Breitenbach called “Ageing with Intellectual Disabilities: Discovering Disability With Old Age: Same or Different?”.

My main reservations about this book revolve around two issues. First, some of the authors seem to imply that the use of life narratives means they are “giving voice” to disabled people in an uncomplicated and unmediated way. The problems with such a standpoint are most obvious in Ruth Morgan’s interviews with a person who has aphasia. One quote in particular demonstrates the importance of the researcher in both the process of story telling and interpretation. The individual comments “Shuttle all over the world, but long time ago, shuttle all over the world, and now nobody”. The researcher interprets this quote as meaning “She has become disillusioned with her comrades in the struggle who now occupy positions of power in the current government and who seem to have forgotten her”.

My second concern with this book is the epistemological status given to the impairment/disability divide and the social model of disability. Given that global experiences of disability are an emerging and under-explored area of academic investigation, it seems premature to claim that the social model must be central to all research and action in the majority world. Yet this is precisely what some of the authors, especially Emma Stone and Mark Priestley, seem to be suggesting. Indeed, Priestley dismisses extensive criticism of the impairment/disability divide as a “false debate” (p.245). I think this conclusion is inconsistent with some of the chapters in the book, particularly the chapter by Mairian Corker who attests to the significant political and theoretical problems this distinction causes for deaf people.

Mark Sherry, Oregon Health and Sciences University
In this important new work, Margaret Vickers argues that most organisations assume that if you look well, you are well, so people with a chronic, invisible illness are relegated to the margins of working life. They are “organisational fringe dwellers” who experience a “passage of trauma” from diagnosis to disclosure and beyond. Managers often use euphemisms like “rationality”, “objectivity” or “efficiency” when they refuse to employ a person with such an illness, or when they restructure a company so that such people no longer have positions. “Organisational based inhumanity”, Vickers warns, is often coated in economic rationalist rhetoric.

People with invisible illnesses are often so marginalized in the workplace that they prefer the pain of silence to the stigma of disclosure. The invisible nature of their illnesses means that when they do disclose, their illnesses are often trivialized or ignored by colleagues and employers. Some of the stories of organisational responses to personal illness in this book are quite harrowing - such as a woman who was made redundant four days after returning to work from a mastectomy.

Margaret Vickers seems to have a unique ability to draw personal details from research participants. In this book, they openly and honestly discuss intimate physical, social, financial and sexual experiences associated with their chronic, unseen illnesses. The reason for this level of disclosure, I suspect, is because Vickers is an “insider”. She has Multiple Sclerosis and throughout the book, she reflects on the ways in which these issues have affected her own life. She has shared her story with the participants, as well as the story of her husband, who experienced a brain hemorrhage while she was conducting the research. These personal experiences are not just integrated as interesting anecdotal data, but are thoroughly integrated into Vickers’ theoretical and methodological framework. Her approach is to be honest, reflexive and self-critical.

I recommend this book not just to students of medical sociology, but also to students who are struggling to find an appropriate methodology or theoretical framework for their research projects. Vickers openly discusses the problems that she experienced trying to recruit participants from a hidden population, the challenge of finding an appropriate theoretical framework (she finally settled on Heideggerian, hermeneutical phenomenology) and the difficulties of drawing appropriate boundaries when you are positioned as an “insider”. All of these are common problems for students conducting research, and Vickers’ honesty will undoubtedly make the journey easier for others who are facing similar problems.

While this book is an important addition to the literature on chronic illness, it is also a beautifully written piece of work. “Work and Unseen Chronic Illness” is one of those rare treasures which leaps from the page and grabs you on both an intellectual and emotional level. I found myself so enthralled; I was desperate to finish it, desperate to know what happened to the participants, to the author, and to her husband. The intimacy of the writing style greatly enhanced my pleasure in reading this book.

Mark Sherry, Oregon Health and Sciences University
There are now a great many texts intended to deliver basic knowledge in qualitative techniques to undergraduate students in the health and social sciences. The problem for students, as for more experienced researchers, is that qualitative techniques are highly labour intensive and time consuming in practice. They are also difficult to learn to use effectively, and because of the technical demands that they place on researchers – as well as the epistemological underpinnings on which they are founded – restricted to small study groups. Thus it is not uncommon to find study groups of less than 30 subjects generating hundreds of pages of text for analysis. Such analysis is always ungeneralisable to larger populations. It is against this background that Parmesan and Brie have sought to develop an entirely new approach to qualitative technique that will take us beyond the interpretive paradigm.

This monumental book is devoted to two key ideas. The first is that the detailed, systematic and empirically oriented approach to qualitative data analysis that has been given priority over the past century needs to be rethought and reshaped in the face of the increasing demands on students, teachers and researchers to deliver results quickly, at minimal cost, and vitally, to provide the answer known to be required by the research sponsor. There is no doubt that small scale qualitative studies are expensive, and that the indeterminacy of their results (filtered through varieties of theoretical positions and epistemological forms) often runs counter to the expectation of research sponsors that spending on research will deliver a useable answer to the questions that they ask, and that this answer will be the one that they require. The second idea that Parmesan and Brie develop is that much is already known about the ways in which subjective accounts are constructed and discursively delivered on almost any topic that is likely to be the focus of a research question. Moreover, they argue that this technical knowledge about the formation of accounts has its corollary in the existence of a large body of empirical knowledge about what many social groups believe and perceive about the circumstances in which they find themselves. Once again, there is a considerable degree of truth to this. Most researchers, and indeed many students, now conduct extensive literature searches and reviews that reveal more or less the precise dimensions of a given social phenomenon before any field research is conducted and data collected. In addition, a reading of existing studies normally suggests that nothing new or different is likely to be encountered prospectively.

Against the background to these two problems in qualitative research, Parmesan and Brie develop a pair of key methodological innovations. The first of these is discursive estimation. Put simply, this relates to the body of knowledge that already exists about the ways that qualitative data is constructed. Given the existence of this knowledge, they argue, it is possible to almost exactly predict what the respondent in any given interview will say. This means that expensive and time-consuming fieldwork is unnecessary, and that a simple estimation – or to use the technical term, guess – is all that is required to meet this objective. A precise and appealing form of words can then be built up which expresses this guess in various ways, in as many ways as are required by the number and variation of subjects who might otherwise have to be recruited to any given study.
The second innovation is that of the approximation of meaning. Once again, given what is already known, detailed systematic analysis of transcripts is becoming less important. The researcher usually more or less knows what is both likely to be said in an interview, and whether this is likely to be acceptable to either the researcher or sponsor - this technique thus permits anticipated or desired meanings to be quickly and firmly located within the data. With existing data collected in empirical studies, or using estimated data that has been made up in the pub, the question of meaning may now be resolved by the application of entirely fictional frames, and theoretical connections made on an insubstantial, yet strangely compelling, basis.

The great merit of this perspective is that it means that qualitative research can become truly generalisable. This displaces conventional hermeneutic or phenomenological positions on carefully articulating the limits of research claims made by qualitative researchers. If there is no need for empirical data, or then for systematic analysis, then brute assertions about entirely fictitious ontological positions can quickly supersede reasoned interpretation. The authors of this book have therefore made an extraordinary contribution not simply to the hard fought terrain of research methods, but also to the foundations of contemporary political debate in the UK.

**Professor HR Savourie-Custard, European Sociopathic Institute, Berwick**

**Books available for review:**

Cobb M. 2001 *The Dying Soul: Spiritual Care at the End of Life* Buckingham: Open University Press

Daniels N, Sabin JE. 2002 *Setting Limits Fairly: Can we learn to share medical resources?* Oxford: Oxford University Press


Kerr A, Shakespeare T. 2002 Genetic Politics: from eugenics to genome Cheltenham: Clarion Press


Meyers RJ, Miller WR. (Eds.) 2001 A community Reinforcement Approach to Addiction Treatment Cambridge: Cambridge University Press


Watson NA, Wilkinson C. (eds.) 2001 Nursing in Primary Care: a handbook for students Hampshire: Palgrave

Williams C. 2002 Mothers, Young People and Chronic Illness Aldershot: Ashgate

If you would like to review any of the above books, please contact Geraldine Barrett via email (geraldine.barrett@lshtm.ac.uk), fax (020 7580 6507) or post (HPRU, London School of Hygiene and Tropical Medicine, Keppel Street, London WC1E 7HT).
Agony Aunt Marge

Confused of Aberdeen raises some issues about the Research Assessment Exercise that have been the subject of many dark mutterings among medical sociologists. Aunt Marge took a break from watching the world cup to prop up the bar with the college accountants, so she’s taking a distinctly hard-hearted approach to the issue. Alienated of London has a more sociological take on the issue - but will it cheer up Confused of Aberdeen? We’d be pleased to hear other thoughts on the RAE and how it has impacted on sociologists working in medical departments.

Dear Aunt Margery,

As everybody in my department is celebrating the RAE outcome: a fat 5! I’m left wondering whether or not I should be happy. On the one hand, it is good to be in a medical department with a very good research reputation. More money and glory is coming our way, we have been promised! Our department went for a low number high impact score strategy. In short, only Lancet papers counted. This strategy obviously had the desired effect.

On the other hand, I am not sure if I am really part of this rating, as I was not included, which defines me officially as ‘not research active’. Part of me feels that my five peer-reviewed papers with a reasonable impact score, a combined grant spent of over £100,000 and two edited books were a waste of time. Should I be happy?

Yours truly,

Confused in Aberdeen

Dear Confused in Aberdeen

Well, the problem for those of you in medical school departments is that it makes sense for institutions to submit all their staff under one of the medicine panels, as the ‘multiplier’ for each member of staff is then higher. So, even with a lower rating, you are worth more money to the institution classed as research active in ‘community medicine’ than you would be in ‘sociology’. There is no institutional
incentive to submit your undoubtedly 5* theoretical work in the Journal of Obscure Foucauldian Studies [that’s enough, Marge - ed] to a sociology panel. In fact, there is no incentive to include you at all if your work is not going to raise the average grade (ie, it isn’t a large multi-centre RCT published in the Lancet). My advice is to be happy in a qualified sort of way. With the upward drift, a 5 is not so good, but if it’s more than your department got last time, then there should be more resources around. But, if your department had a 5 last time round, there will probably be a drop in overall resources - and if you’re not contributing, it might be time to look my ‘Should I stay or should I go?’ questionnaire in the last issue.

Yours,
Aunt Marge

Dear Confused in Aberdeen

Being on the winning side is always a pleasant experience whatever the rules. With the RAE there is considerable reflected glory even when the rules seem to be unfair. It could be worse and the high score didn’t come in. Failing to achieve glory, or even falling back, brings with it fire brigade responses to make sure that next time such a calamity doesn’t reoccur. You might feel excluded now, but you could be blamed. The real problem isn’t the individual one of being included or not, but the structural one of seeing the RAE as a measure of intellectual activity. In the old days there used to be a sociological term for this - reification. Like a lot of good concepts it has fallen from our lexicon because it seems a bit too radical. Sociologists should be the first to see the operation of power when it happens. The whole purpose of the RAE is to divide and rule. It has been successful because most academics have redefined themselves in terms of its ever changing demands. My advice is that you should treat it as a game but not believe that it is anything more than “text inscribed within relations of power”.

Alienated of London
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