

Medical Sociology online

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The logo for Medical Sociology online (MSO) features the letters 'MSO' in a bold, black, sans-serif font. The letters are positioned in front of a stylized, 3D-rendered orange sphere that is partially obscured by the text.

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Editorial

Jacqueline Watts

Editor in Chief

Welcome to the first issue of MSo under the new editorial team from the Open University. One of the highlights in the MedSoc calendar is the BSA Annual MedSoc Conference, held this year in Chester, and we are delighted to feature in this issue papers given by the two plenary speakers, Alan Petersen of Monash University and Rose Barbour from the Open University. Other items from the conference also feature in this issue including a discussion paper drawing on the 'Author meets Critics' session that discussed the ethnography of Dr Jessica Mesman entitled *Uncertainty in Medical Innovation: Experienced Pioneers in Neonatal Care* (2008). A news item from Helen Busby entitled *Human Bodies in Biomedicine and Biomedical Research* reports on themed sessions and panel event held at the conference. The First Sociology of Diagnosis Symposium held in Boston in August 2011 is the subject of the piece by Tania Jenkins and the peer reviewed article authored by Pauline Osamor discusses the issue of hypertension in South West Nigeria.

The new website for MSo is now fully live and we are seeking research articles, news items, commentary pieces and conference announcements for forthcoming issues. Details of how to submit these are outlined on our web pages and we look forward to receiving your contributions.

Can And Should Sociology Save Bioethics?

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Sociology, like other disciplines, is inescapably normative. Despite efforts by many sociologists to avoid articulating their normative standpoint on issues or explicitly addressing normative questions, their work invariably reflects and reinforces particular values and outlooks. This is no less the case with sociology's engagements with bioethics, a field of growing interest to medical sociologists (especially in Britain) that is defined by its concern with moral questions. My question, 'can and should sociology save bioethics?' may at first seem odd. It may well be asked, does bioethics need 'saving'? And, what does sociology have to offer in this regard? However, in recent years, a number of sociologists have written articles that argue that bioethics suffers shortcomings in its approach and that sociology can lend a helping hand. The titles of the some of these articles are revealing. For example, DeVries (2003) raises the question, 'How can we help?: from "sociology in" to "sociology of" bioethics', signalling the need for a shift in sociological focus, while López (2002) announces 'How sociology can save bioethics...maybe', suggesting some doubt about sociology's ability to save the field.

According to these and a number of other sociologists, bioethics' contributions are limited by its adherence to so-called principlism; that is, the four principles of autonomy, beneficence, non-maleficence, and justice popularized by Beauchamp and Childress (1991). These principles, it has been pointed out, have been applied universally and mechanistically, without regard to the contextual factors that shape interactions and ethical assessments. Sociology, it is argued, can help 'save' bioethics, by overcoming its empirical deficits, especially through offering ethnographic studies of the contexts in which ethical deliberations occur (e.g. Fox and Swazey, 2008; Haimes, 2002; Haimes and Williams, 2007; Hedgecoe, 2004). That is, the claim is that sociology can somehow *improve* bioethics, to assist 'it' in *its* normative deliberations. This paper critically examines this assumption, and proposes an alternative direction for sociological work in the field of the biosciences and biotechnologies. To begin, I would like to contextualize this debate.

The Bio-economy And The Expectation Effect

As will be noted from the dates of publication of the above articles, sociologists' engagements with bioethics are relatively recent. In fact, most articles have appeared only since 2000. This is significant, as I will explain. It is a period in which a growing number of projects focusing on the biosciences and biotechnologies, and their 'ethical' implications, were funded by UK research councils, charities and, to some extent, the private sector. What occurred during this period? Why did sociologists seem to suddenly 'discover' bioethics and its shortcomings? And, what is wrong with sociologists lending a helping hand?

The opening decade of the 2000s can be characterized as one of high optimism in relation to the translational potential of the biosciences. The humane genome had been 'mapped' (announced in 2000), breakthroughs in human cloning had occurred (e.g. Dolly the sheep breakthrough, reported in 1997), and governments in many countries saw opportunities for building on this success in developing bio-based knowledge economies. Further,

nanotechnologies were seen as offering the basis for whole new fields, including nanomedicine, with expected applications in drug delivery, biosensors, implants and artificially created organs, and molecular imaging. The period of 'functional genomics' was seen to have arrived. It was believed that science had solved the 'riddle' of how we are 'made up', the remaining question was how genes 'worked' individually and in interaction with other genes and the environment to affect health and illness. And, authorities everywhere hoped to reap the expected benefits, through 'mainstreaming' genetics in healthcare (e.g. new genetic tests), and personalizing medicine, that is tailoring medicine to individual genetic profiles (and thus minimizing the adverse drug reactions that are common with the use of broad spectrum drugs). The benefits to societies with rapidly aging populations and burgeoning healthcare budgets associated with treating associated degenerative conditions were seen as obvious. The concept of regenerative medicine - to restore functioning and to replace damaged and diseased tissue through engineering body parts - has been highly seductive.

The last decade has seen the launching of a number of large-scale prospective research endeavours, based upon the expectation of future dividends for health and the economy. Genetics research and stem cell research have been the recipients of huge investment and much hype. Recent innovations include population-wide biobanks, which are being developed in many countries, including the UK, the US, Australia, Canada, Scandinavia, France, and Japan (Gottweis and Petersen, 2008), as well as large programs of stem cell research at the international level (Gottweis, et al., 2009). The high expectations surrounding the biosciences and biotechnologies have been clearly evident in popular culture, including news media.

A recent article in an Australian newspaper, 'Genome power is about to sweep the world: Nobel laureate' (Metherell, 2011: 3), reflects the high expectations surrounding this field. The article explains that a scientist (Barry Marshall) 'plans to become the first Australian to post his own full genetic code, or genome, on the Internet, even though it does reveal unnerving insights'. This includes the fact that he is 'three times higher life time risk of macular degeneration and double for testicular cancer and for Alzheimer's disease'. Another article, 'Curing cancer and other dreams', reports that 'It's hardly believable but in 20 years' time we will be able to stop most cancer in its tracks, according to John Shine, Professor and Head of Sydney's Garvin's Institute of Medical Research. As the father of "gene cloning", Shine is well placed to make such a prediction' (Margo, 2011).

There are a couple of points to note about both these articles, which are not untypical of those appearing in national newspapers in Australia, the UK, the US and other countries in recent years. Firstly, they reflect the high optimism surrounding biomedical science and technology. Note the confident tone of the above article ('*does reveal* unnerving insights', '*will be able to stop* most cancer in its tracks'). There is little doubt about the power and value of science. Further, there is an absence of reference to the environmental factors and gene-gene interactions that make it extremely difficult if not impossible to identify the genetic basis of most diseases (Holtzman and Marteau, 2000). Secondly, the articles rely heavily on the predictions of scientists themselves. Scientists have been found to be major sources in news stories on genetics, which allows them considerable scope to 'frame' issues, to highlight the significance and potential benefits of research (Conrad, 1999; Petersen, 2001, 2002). Through the use of public relations, scientists have sought to control public discourse and the science policy agenda. However, in reality, it has often proved difficult to 'stay on message', with optimistic, utopian portrayals competing with dystopian portrayals in coverage about issues such as cloning and stem cell technologies (Petersen, 2002; Petersen, et al., 2005).

Scientists sometimes 'overhype' the science, promising more than can be delivered – at least within foreseeable timeframes – with the danger that publics become disillusioned and lose confidence. Overly optimistic projections can have pernicious effects, including fraudulent behaviour among competing scientists, as seen in the case of the Korean scientist, Hwang, outlined by Gottweis and Kim (2010) and Kitzinger (2008). Sociologists such as Nick Brown (2003) and Adam Hedgecoe (2004, 2010) have highlighted the unintended consequences of overly optimistic predictions in relation to new biotechnologies. One danger that they point to is the onset of public disillusionment following unfulfilled expectations. An important, but unacknowledged danger is incautious decision-making, and extreme risk-taking, occasioned by belief in the expectations generated by scientists and those who stand to benefit from new technologies.

Some providers are already exploiting the opportunities that are seen as presented by new biomedical innovations. Genetic tests are readily available via the Internet, such as tests for BRCA1 and BRCA2 genes for breast cancer. And, there is evidence of consumers using the results of such tests to undergo treatments as a consequence. A recently reported case is that of a woman who had both her breasts removed as a prophylactic measure following a test for these genes (Phillips, 2010). Stem cell treatments available in a number of countries are currently marketed directly to consumers via the Internet, contributing to the phenomenon of so-called stem cell tourism. These treatments are marketed as offering hope to those who otherwise have little or no hope of achieving successful treatments in their own countries (Petersen and Seear, in press). Thus, *to some extent* the future has arrived – expectations are being realised – but is the reality as imagined? Are these early stage innovations as beneficial as providers claim?

The Narrow Focus Of Research And Debate

Bioethics, and sociologists who link themselves to bioethical agendas, have tended to adopt an overly narrow framing of their field of normative enquiry. As Hedgecoe (2010) notes, bioethics has tended to reflect the technological expectations of science. There has been little questioning of scientists' claims about the overall direction of science and forecasts in relation to resulting innovations. Despite bioethicists' claims to be able to scan the horizon of technological innovations, the horizon has already been scanned by scientists, and others; a definition of the relevant 'ethical' issues has occurred (Hedgecoe, 2010). A focus on 'technologies' in the abstract pervades the writings of bioethicists, sociologists and other social scientists who research and write about bioscience/technology issues, notwithstanding the growing influence of science and technology studies and its concepts such as 'co-construction' of science and society and of users and technologies (Oudshoorn and Pinch, 2003).

Most sociological investigations of 'bioethical' questions concern issues pertaining to the clinic ('clinical ethics'), or to single research projects of limited scope and duration ('research ethics'); for example, studies of decision-making processes pertaining to clinical trials, genetic testing, IVF, PGD, or ethics committees. These are sites and topics that have already been 'mapped' and 'colonised' by bioethicists, and others who have a declared stake in these issues. They mostly involve technologies that have already emerged and are in use. Sociologists have tended to overlook the applications of bioethics in programs of research such as those noted above that are *prospective* in character, that involve applications at the level of *populations*, and investment that is *long-term* and requires the participation and support of *diverse publics*. There has been little recognition and analysis of the politico-economic processes underlying technological innovations, including governments' commitments to bio-based knowledge economies.

Sociologists have failed to recognise the significance of bioethics' principlism in neo-liberal societies, and its impacts on thinking about health and healthcare. Further, they have been slow to explore the socio-political implications of research investment, of the social inequalities that arise or potentially arise from the development and use of specific innovations, and of moral questions posed by the commodification of life. These are all questions where sociologists may play a significant role – in drawing attention to and critically analysing issues neglected by principles-based bioethics – and in charting new terrain for sociologically based normative inquiry. However, sociologists' engagements with bioethics have been largely limited to the issues defined by bioethics itself and those who have declared an interest in the 'ethics' of the new biosciences/technologies.

Why This Sociological Neglect?

While there are a number of potential explanations for this sociological lacuna, the system of research support must take much of the blame. Sociological research undertaken in the field of the biosciences and biotechnologies during the last decade or so has been closely tied to government, private sector, and philanthropic agendas and funding. This includes bodies such as the Economic and Social Research Council (with its special initiatives such as the Innovative Health Technologies Program, e-Society Program, Genomics and Society Program (involving two, five-year tranches of allocated funds (coming to an end in 2012), and the Stem Cell Program); the Engineering and Physical Sciences Research Council (which, in recent years, has been receptive to social science involvement in its essentially technologically-driven research programs); the Medical Research Council; the European Commission Framework Programs; the Wellcome Trust research programs (including Bioethics and Public Engagement in Science programs); the Leverhulme Trust; and the US' National Institute of Health programs and Human Genome Project (HGP) ELSI (Ethical, Legal, and Social Issues) research program. The theme of 'Science in Society' has enjoyed popularity over the last decade, and in the UK has been sponsored by governments, charities, science and media bodies, and NGOs (Cullen, et al., 2007).

Some of this research is funded by initiatives that have an explicit focus on 'ethical' questions. This includes those of the HGP's ELSI research initiative, and the Wellcome Trust's Bioethics Program of the 1990s and its current Ethics and Society Program. In many cases, the 'ethical' questions and favoured perspectives or expertise have already been stipulated or assumed by the sponsors/funders. Those applying for funds via these initiatives need to demonstrate conformity to the funding guidelines and produce particular kinds of outputs and demonstrate that their work has 'policy relevance'. This works against the creation of critical, innovative work, which is likely to arise from interdisciplinary, 'blues-skies' investigation. Many of these initiatives, especially those of the Wellcome Trust - a 'big player' in this field - have tended to favour moral philosophy-based bioethics' perspectives and expertise.

Bioethics And The Politics Of Legitimation

Sociologists who have engaged with 'bioethical' questions then have tended to link their work closely to existing research initiatives, including those that are framed as 'ELSI'/bioethics' to begin with. Sociologists have seen and exploited opportunities and built research programs around the research agendas of others, and have often found receptive collaborators in science and bioethics' communities who recognize the missing 'social' dimension within the field. The arena of genomics/genetics is a clear case in point.

The launching of the ESRC's Genomics Network in 2002 created four large research centres (Cesagen, Egenis, Innogen and Genomics Forum) around the UK, which has created new careers and opportunities for many sociologists and other social scientists, and philosophers.

Many scholars moved into the field from other areas, such as science and technology studies, and the philosophy of biology. This initiative was a direct response to the UK Government's aim of furthering genomics/genetics research, and engendering collaborations between social scientists, philosophers and natural and medical scientists in order to address the social, economic and policy aspects of such research. There was never any effort to establish whether such research and the associated network structure was supported by 'the public' and was likely to deliver work of social value, and the model that was eventually adopted, involving a cluster of research centres, was actually rejected by the social scientists who were asked for their views. However, once established, the network generated and supported a thriving community of scholarship focusing on the social and ethical implications of genomics and genetics that was broadly aligned with the Government's objective to promote genetics-based healthcare (Department of Health, 2003).

In this context of support for biotechnology from the Government, and the private and charitable sectors, 'bio-ethically' interested groups, including philosophers, theologians, lawyers, medical practitioners and social scientists, have been called upon to help lend legitimacy and consent to particular policies and programs. As an already legitimated knowledge in the bioscience/technology arena, bioethics could easily lay claim to offering the appropriate expertise to help resolve the 'ethical' dilemmas arising from such innovations. As DeVries, et al. (2007) has argued, 'bioethics' is not a singular field dominated by one kind of expertise; indeed, research indicates that research committees deliberating on bioethics issues tend to be dominated by lawyers, theologians and medical professionals, rather than by self-identified 'bioethicists' (e.g. Salter and Salter, 2007). However, bioethics has developed a body of principles and frameworks, and ways of reasoning, that have found congruence with bureaucratic, formal procedures and the neo-liberal policies that dominate contemporary healthcare, and other spheres of life.

Principles such as 'respect for autonomy', the 'right to know', and 'informed choice' are those that support neo-liberal subjectivity where independence and an entrepreneurial approach to life are valued, indeed expected (Petersen, 1996; Petersen and Bunton, 2002). Bioethics has been valued because it offers a language that appears disinterested, 'context-less', and thus can be shared by different disciplines and constituencies with often very different perspectives and value standpoints. It appears to 'take the politics out' of decisions about inherently contentious issues, such as funding priorities, views on life, and who 'wins' and who 'loses' from policy decisions. And, it has served to restrict debate to 'safe issues' upon which there is already broad agreement – through a process of 'non-decision-making' (Bachrach and Baratz, 1963) - such as how to ensure that individuals who participate in research are 'fully informed' about the purposes of that research, what is expected of them, and their rights within that context.

In their effort to legitimize their own knowledge and social role, bioethicists have generated various 'origin stories' (Fox and Swazey, 2008). These include the technology-driven genesis, reference to key events (e.g. the Nuremberg trials) or organizational moments, or the coining of 'bioethics' (in 1970) (2008: 25-28). These are dominated by what Kim Little calls 'clean break' accounts (Little, 2002), that suggest that bioethics emerged suddenly and as a response to recognized earlier injustices, such as the Tuskegee research undertaken between the mid-1930 and early 1970s, where Black Americans with secondary syphilis remained untreated (Rothman, 2003: 183). These self-representations portray the field as progressive, as emerging as a defender of 'the public interest' and standing up for the rights of the individual against medical paternalism. Common to these accounts is their technology focus, reflecting rather than challenging the technological expectations of science. 'Technology' is reified, treated as a thing, rather than as a social product. There is little

reference to the contexts generating and supporting visions of technologies and their applications, let alone efforts to draw attention to and challenge the interests that promote these visions.

Technological expectations need to be sustained over the longer term, especially with many of the new genetic, stem cell, and nanotechnology innovations, which involve large research teams and significant financial investment, and call upon the participation and support of diverse publics. Therefore, the public representations of the science need to be supported through various reiterative practices, such as staged news releases, the extensive use of PR, and other means. With the strong 'translational ethos' that pertains to stem cell research and other contemporary areas of bioscience/technology (Maienschein, et al., 2008), scientists need to show 'up front' in their grant applications that their research will deliver health and social benefits. This leads them to frequently 'hype' the significance of their work, with the risk of promising more than can realistically be delivered, with the attendant dangers that I referred to earlier. There are numerous impediments to fulfilment of expectations - economic, political and socio-cultural. And, as the financial crisis of 2008-09 revealed with the rapid fall in biotech shares, the bubble of expectations may quickly deflate, leading shareholders to abandon the market, and leaving innovations without funding and support.

In the next and penultimate section, I wish to illustrate some of the ways in which bioethics and its knowledge have been deployed to help legitimize research agendas, making reference to some major fields of biomedical innovation; namely, biobanks, stem cell research, and nanotechnologies. I will then conclude by proposing a way forward for sociology *beyond* bioethics, which I believe is the direction in which sociologists should be moving.

Biobanks

The emergence of biobanks – or population-wide repositories of genetic, medical and lifestyle information – in many countries over the last decade has reflected the high optimism for 'post-genomic' medicine. Biobanks were seen to potentially deliver many benefits for the population. For governments and proponents of new genetics, these included the elimination of disease through predictive and 'personalised' medicine; reduced health care costs, which are expected to burgeon with the ageing of populations; improved risk management, through data that will assist individual lifestyle changes; and the empowerment of individual, the assumption being that those equipped with more information about their genetic susceptibility will have more options in healthcare. For the commercial sector, there was seen to be the potential for profitable new drugs through the field of pharmacogenomics/genetics and new diagnostic tests that will allow the prediction of risk for those with a range of genetic-based conditions. As noted, there has been much optimism concerning personalized medicine, and biobanks have been conceived as offering the research tools for disentangling the genetic and environmental factors that predispose to illness, and thus paving the way for the development of drugs tailored to the genetic profile of the individual or groups of individuals.

Many governments, scientists and industry groups have 'signed up' to this vision of genetics-based healthcare, as reflected in various national policy statements appearing during the last decade. The World Health Organization, too, shares this vision, seeing potential for genetic research to assist in eliminating communicable diseases, haemoglobin disorders, and other conditions (WHO, 2002). According to a recent publication, *Bioscience for Life?*, produced by GeneWatch UK, in Britain, the 'genomic revolution' in healthcare was promoted by a small group of influential government advisors, many of whom were working in medicine and/or had had close links to a range of commercial interests, such as the pharmaceutical industry (2010: 95-6) The idea of the biobank proved easy to sell to governments. National or

state/provincial biobank projects such as UK Biobank, Hunt 3 (Norway), the Health Sector Database (Iceland), Généthon (France), and the WA Human Genome Project (Australia) have been proudly promoted as national or regional 'flagship' projects, marketed on the basis of their uniqueness and potential to deliver future public benefits (see Gottweis and Petersen, 2008; Petersen, 2005).

Despite the numerous substantive issues raised by such collections – including whether they represent a good use of resources, the implied commodification of the body, the privatisation of what is arguably a shared community resource, and the potential for surveillance – 'bioethical' contributions have been limited. The main issue for bioethical deliberation has been informed consent – a concept originally developed with the context of single, short-duration research projects and the medical encounter – that is challenged by population-wide prospective collections such as these. Biobanks may hold genetic, medical and other personal information for many decades and the research purposes are mostly unspecified at the outset, creating considerable problems in relation to consent. Bioethicists and the social scientists who have assisted with deliberations on the ethics of such collections have agonised over how to reap the perceived benefits of biobanks while ensuring a form of consent that complies with established bioethical principles. It should be noted that not all biobanks encounter such ethical quandaries. In Japan, for example, Biobank Japan was established relatively quickly in the absence of any serious public consultation and any formal process of engaging with scientific and ethical communities (Triendl and Gottweis, 2008: 124-25). Where bioethics expertise and knowledge have been utilised, however, this has generally involved reference to a narrow set of principles that may be adopted or adapted in developing ethics and governance protocols. There has been little debate about substantive issues, such as whether such collections should be supported at all, how best to engage communities, and who will be the likely 'winners' and 'losers' from this genetics-based approach to healthcare. Bioethics and social science expertise has been largely used to help lend legitimacy and gain consent for projects, which have already achieved the support of governments, and influential scientists and industry groups (Petersen, 2007)

Stem Cell Research

The field of stem cell research is subject to similarly high expectations and has been the recipient of substantial government funding over the last decade. In 2009, the US' National Institutes of Health spent \$1 billion in this field, which was double the expenditure of 2006 (NIH, 2010). Applications of stem cells currently are limited to the use of bone marrow and cord blood for diseases of the immune and blood system (Strauss, 2010), with the progress from research to treatments being slow. While most research has involved adult stem cells rather than human embryonic stem cells – which are seen to have the greatest pluripotent potential – scientists remain divided about the most productive direction for research. This is a field marked by various conflicting pressures. On the one hand, there is a strong 'translational ethos' (Maienschein, et al., 2008), which demands that research be rapidly translated into new treatments. Some of the pernicious consequences of this pressure have been referred to; e.g. the Hwang case. On the other, scientists recognize that research will need to be long-term, and that the 'breakthroughs' will require ongoing public and policy support, and considerable funding and trust that benefits will in time accrue. However, opposition to the field – or at least what is widely seen to constitute the 'tampering of nature' (using and destroying 'spare' embryos) – remains widespread and strong. This opposition has shaped the field of stem cell research – with scientists seeking to overcome these moral objections by exploring alternative sources of stem cells – such as induced pluripotent stem cells (iPSC). And, it has shaped 'ethical' debates that have occurred over the last decade.

Where bioethicists have contributed to this field their discussions have been narrowly focused on the moral status of the embryo, as though this was the only or most important normative issue to consider. The agenda for debate has been established by the 'right-to-life' groups and by the Catholic Church who object to the destruction of human embryos during research. My analysis of articles on stem cell research appearing in the academic journals, *Bioethics*, and *The American Journal of Bioethics*, underlines this 'embryo-centric' focus of enquiry (Petersen, 2011). Social science and regulatory debates have been overly occupied with questions about how best to regulate the technologies so as to avoid the unnecessary destruction of life and to protect the health and wellbeing of women who may donate embryos. As with bioethicists, sociologists and other social scientists have tended to reify 'technology', and to overlook the social production of technologies. Broader questions such as those relating to the political economy of stem cell research, including research-funding priorities, relations between scientists, policymakers, and the bio-industries, and the politics of policy formation, have been largely ignored. Despite growing evidence of an early market in stem cell treatments in various countries – the stem cell tourism phenomenon, referred to earlier – there has been little analysis of the processes underlying the generation of the expectations that sustain this field, and the implications for patients and their families who are desperate for treatments.

Nanotechnologies

Finally, nanotechnologies are often described in terms of their 'revolutionary' potential, for 'enabling' new applications not just in medicine, but also in environmental sustainability and economic development. One Australian estimate is that nano-enhanced or –produced products will generate \$2.84 trillion by 2015 (Aust. Office of Nanotechnology, 2009). Scientists and policymakers in the UK see great potential in a range of fields in medicine and healthcare in coming years, as outlined in the landmark report, *Nanoscience and Nanotechnologies: Opportunities and Uncertainties*, produced jointly by The Royal Society and The Royal Academy of Engineering, in 2004. As the subtitle of this report reflects, this is a field characterised by uncertainties. These surround the science, the physical and environmental risks, and public responses. The latter have been a major concern in some jurisdictions, especially the UK, with frequent references to the potential for a 'GM-style backlash' in official communications in recent years (RS-RAE, 2004). There is a concern that public fears about the technologies and their impacts (described by some as a potential 'new asbestos') may lead publics to reject what are seen by many scientists, policymakers and industry groups as a highly promising set of technologies.

Despite the many uncertainties that surround this field, whose parameters and impacts will be defined by the convergence of technologies (e.g. genetic, digital, and neuroscience) much public discourse has focused on biophysical risk. In particular, in the UK and Australia, the issue of the safety of manufactured nanoparticles has dominated discussion. In the UK, soon after the launch of the RS-RAE report, *The Guardian* newspaper reported, 'Nanotechnology poses threat to health, says scientists' (Semple, 2004). The article noted that 'New laws are needed to ensure that vanishingly small particles made by the nanotechnology industry do not pose a threat to humans or the environment, experts said yesterday.' (2004). The report actually said that the risks were uncertain and that further research was needed. Similar concerns about nanoparticle safety, expressed particularly by the trade unions, have been subsequently voiced in Australia (e.g. Harrison, 2009). This narrow framing of 'the problem' posed by these technologies diverts attention from a broader range of issues posed by innovations in this field. This includes the extensive research funding in a field of high expectations and many uncertainties. In the UK, Europe and more recently Australia effort has been expended in 'public engagement' initiatives in relation to nanotechnologies, which

are seen as offering something of a 'test-bed' for a new kind of science-society relationship. The language of engagement suggests a more democratic, transparent approach to science communication, which has long been dominated by the so-called deficit model of public understanding. Social scientists, philosophers and bioethicists have contributed to these communication efforts, much of which has been funded by governments (e.g. in the UK, the Science-wise Program, and in Europe via the European Commission's 'Science in Society' Program).

Increasingly, bioethics' concepts and reasoning has entered deliberations about the normative implications of nanotechnologies. This is evident with the new journal *Nanoethics*, launched in 2007, where there has been much discussion about the applicability and utility of established bioethics, and the emergent field of nanobioethics, which focuses on the biomedical, biotechnological, and agrifood applications of nanotechnologies. In Europe, philosophers and bioethicists have helped develop 'tools' for assessing engagement/dialogue strategies and practices and tactics that can be used to 'engage' different audiences (European Commission, 2010). As with biotechnologies, ethical discussions have tended to reflect the technological expectations of science, so that there has been little effort to understand or challenge the forms of 'top-down', expert-driven approach to technological development and associated communication processes that have been developed. Despite evident shortcomings of these engagement efforts (e.g. Gavelin, et al., 2007), bioethicists and social scientists have not reflected on the role of engagement in the politics of technological innovation, or their own contributions to this process. Rather than offering a critical voice in relation to the expectations and visions that surround this field, they have lent their expertise to help legitimise policies that are supported by governments, industry, and science. The field of nanotechnologies provides another example of where bioethics has failed to offer critical perspectives and where sociologists and social scientists have been called upon to help engender public consent for technologies that are seen as self-evidently oriented to 'the public good'.

What Lessons For Sociology?

What lessons may one draw for sociology from this experience of its engagement with bioethics and 'bioethical' questions thus far? And, what might be a fruitful way forward for sociologists who believe that they have something useful to contribute to this field?

These case studies highlight that bioethics' principles and reasoning have been used in 'over-extended' ways. That is, a body of knowledge and related practices that developed in the context of clinical practice and single research projects of limited duration are now being applied in a very different context, to a set of research programs of long-term duration, that affect whole populations and that require the support of diverse publics. In its preoccupations, bioethics has reflected rather than investigated and challenged the technical expectations of science. There has been little questioning of these expectations; indeed, in many if not most instances, it is taken as given that technologies will evolve as predicted and that the technologies that have emerged are a consequence of some inherent scientific imperative; a reflection of modernist progress. Questions concerning politics and power have been framed out of consideration. Bioethics' technology focus has diverted attention from substantive questions such as, who decides what technologies get developed? Who exactly benefits and who is disadvantaged by innovations? Does the development of particular technologies represent a good use of public resources? And so on.

Abstract, moral philosophy-based bioethics is incapable of addressing such questions because the underlying epistemology of the field is blind to such questions. Bioethicists and those who are strongly influenced by bioethics' ideas and principles have a trained incapacity

to see the 'big picture' shaping technological innovations. Given this, it is hardly surprising that bioethics expertise is so influential within government and science communities. It offers no threat to dominant interests, and it serves as a useful tool of governance, in lending legitimacy to innovations for which there is considerable official support and momentum. Further, its principlism has served to restrict debate and action on substantive issues. The most important questions are never on the agenda for public debate and deliberation and remain in the sphere of 'non-decision-making'. Consequently, rather than seeking to 'save' bioethics, I propose that sociology unlink itself from bioethics' agendas, and move *beyond* bioethics, to develop its own normative approach to bio-knowledge, which includes bioethics itself as a topic of critical enquiry.

In developing such an approach, we need to begin by recognizing the point I raised at the outset; namely, that sociology is *always* normative. What this means is that sociologists should not just study norms but propose norms or seek to negate sociology proposing them (Szybel, 2009). Sociology, and the social sciences more broadly, need to recover value rationality, which has been lost or downplayed as a result of the dominance of technical rationality (Flyvbjerg, 2001). This technical rationality has arguably contributed to the discipline's disinclination to engage explicitly with normative questions, and to remain subservient to bioethics, which is seen as having a priori claim in the bioscience/technology field.

A normative sociology of bio-knowledge would focus centrally on the workings of politics, power, ideology, discrimination, social justice, and the promotion of human rights - areas of traditional sociological concern. In other words, it should study 'up' rather than 'down', which has been the tendency in much sociological study of 'bioethical' issues, and more generally. And, while this does not preclude the study of micro processes of ethical decision-making, such as occurs in the clinic and in relation to research, it calls for the conceptualization of the links between these micro concerns and macro structures and processes. It would encourage reflection on the ways of knowing associated with bioethics itself, and the social and personal impacts of 'ethicization' (Hisano, 2008) that increasingly pervades many spheres of life, as well as exploration of the scope for resisting this. Elements for such a sociology can be found in disparate work under way in fields such as feminist studies, especially feminist bioethics, which rejects principlism and seeks to build a human-rights' focused approach to the normative issues arising from the biosciences/technologies, from science and technology studies, and from the nascent sociology of human rights that is being developed by scholars such as Bryan Turner. Sociology has a rich tool kit of concepts with which to explore, make sense of, and offer responses to bio-knowledge. Sociologists should utilize these concepts to chart a new direction for their work, rather than being shackled by bioethics imperialism, which has limited their horizons and critical contributions to a field of potentially far reaching significance.

REFERENCES

- Australian Office of Nanotechnology (2009) *National Nanotechnology Strategy Annual Report 2008-09*. Australian Office of Nanotechnology: Canberra.
- Bachrach, P. and Baratz, M. S. (1963) 'Decisions and nondecisions: an analytic framework', *The American Political Science Review*, 57, 3: 632-642.
- Beauchamp, T. L. and Childress, J. F. (2001) *Principles of Biomedical Ethics*. 5th Edition. Oxford University Press: New York.
- Brown, N. (2003). Hope against hype: Accountability in biopasts, presents and futures, *Science Studies*, 16, 2: 3-21.
- Conrad, P. (1999) 'Uses of expertise: sources, quotes and voice in the reporting of genetics in the news', *Public Understanding of Science*, 8, 285-302.
- Cullen, J., Sullivan, F. and Jung, K. (2007) *Evaluating Science in Society Initiatives: A Framework for Evaluation*. Prepared for Department for Innovation, Universities and Skills Economic and Social Research Council. The Tavistock Institute: London.
(http://www.esrc.ac.uk/images/Evaluation_Framework_tcm8-4871.pdf) (Accessed 28 September 2011)
- Department of Health (2003) *Our Inheritance, Our Future: Realising the Potential of Genetics in the NHS*. HMSO: Norwich.
- De Vries, R. (2003) 'How can we help?: from 'Sociology in' to 'Sociology of' bioethics', *Journal of Law, Medicine & Ethics*, 32: 279-292.
- De Vries, R., Turner, L., Orfali, K., and Bosk, C. (eds) (2007) *The View From Here: Bioethics and the Social Sciences*. Blackwell Publishing: Malden, MA.
- European Commission (2010) *Communicating Nanotechnology: Why, To Whom, Saying What and How?* European Commission: Luxembourg
<http://www.eurosfairer.prd.fr/7pc/bibliotheque/consulter.php?id=1765> (Accessed 30 September 2011)
- Flyvbjerg, B. (2001) *Making Social Science Matter: Why Social Inquiry Fails and How It Can Succeed Again*. Cambridge University Press: Cambridge.
- Fox, R. and Swazey, J. P. (2008) *Observing Bioethics*. Oxford University Press: Oxford.
- Gavelin, K., Wilson, R. and Doubleday, R. (2007) *Democratic Technologies?: The Final Report of the Nanotechnology Engagement Group*. Involve: London.
- GeneWatch UK (2010) *Biosciences For Life? A Report By GeneWatch UK*. GeneWatch UK: Derbyshire.
- Gottweis, H. and Kim, B. (2010) 'Explaining Hwang-gate: South Korean identity politics between bionationalism and globalization', *Science, Technology and Human Values*, 35, 4: 501-524.
- Gottweis, H. and Petersen, A. (eds) (2008) *Biobanks: Governance in Comparative Perspective*. Routledge: London and New York.
- Gottweis, H., Salter, B. and Waldby, C. (2009) *The Global Politics of Human Embryonic Stem Cell Science: Regenerative Medicine in Transition*. Palgrave Macmillan: New York.
- Haimes E. (2002) '[What can the social sciences contribute to the study of ethics?: theoretical, empirical and substantive considerations](#)', *Bioethics*, 16, 2: 89-113.
- Haimes, E. and Williams, R. (2007) 'Sociology, ethics and the priority of the particular: learning from a case study of genetic deliberations', *The British Journal of Sociology*, 58, 3: 457-476.

- Harrison, D. (2009) 'Unions call for action to oversee nanotechnology', *The Age*, April 14.
- Hedgecoe, A. M. (2004) *The Politics of Personalised Medicine: Pharmacogenetics in the Clinic*. Cambridge University Press: Cambridge.
- Hedgecoe, A. (2010) 'Bioethics and the reinforcement of socio-technical expectations', *Social Studies of Science*, 40, 2: 163-186.
- Hisano, S. (2008) 'Ethicization of biotechnology, politicisation of biotechnology ethics', in G. Ruivenkamp, S. Hisano, and J. Jongerden (eds) *Reconstructing Biotechnologies: Critical Social Analyses*. Wageningen Academic Publishers.
- Holtzman, N. A. and Marteau, T. M. (2000) 'Will genetics revolutionize medicine?', *New England Journal of Medicine*, 34, 2: 141-144.
- Kitzinger, J. (2008) 'Questioning hype, rescuing hope?: The Hwang stem cell scandal and the reassertion of hopeful horizons', *Science As Culture*, 17, 417-434.
- Little, K. (2002) *Making History: Bioethics, Culture and the History of Moral Ideas*. Master's Thesis, submitted to School of Philosophy and Bioethics, Monash University.
- López, J. (2004) 'How sociology can save bioethics...maybe', *Sociology of Health and Illness*, 26, 7: 875-96.
- Maienschein, J., Sunderland, M., Ankeny, R. A. and Robert, J. S. (2008) 'The ethos and ethics of translational research', *The American Journal of Bioethics*, 8, 3: 43-51.
- Margo, J. (2011) 'Curing cancer, and other dreams', *The Australian Financial Review*, June 5.
- Metherell, M. (2011) 'Genome power is about to sweep world: Nobel Laureate', *The Age*, June 9, p.3.
- National Institutes of Health (2010) Research Portfolio Online Reporting Tools (RePORT) <http://report.nih.gov/index.aspx> (Accessed 30 September 2011)
- Oudshoorn, N. and Pinch, T. (eds) (2003) *How Users Matter: The Co-Construction of Users and Technologies*. The MIT Press: Cambridge, MA and London.
- Petersen, A. (1996) *The New Public Health: Health and Self in the Age of Risk*. Sage: London.
- Petersen, A. (2001) 'Biofantasies: genetics and medicine in the print news media', *Social Science and Medicine*, 52: 1255-1268.
- Petersen, A. (2002) 'Replicating our bodies, losing ourselves: news media portrayals of human cloning in the wake of Dolly', *Body and Society*, 8, 4: 71-90.
- Petersen, A. (2005) 'Securing our genetic health: engendering trust in UK Biobank', *Sociology of Health and Illness*, 27, 2: 271-92.
- Petersen, A. (2007) 'Biobanks' "engagements": engendering trust or engineering consent?', *Genomics, Society and Policy*, 3, 1: 31-43.
- Petersen, A. (2011) *The Politics of Bioethics*. Routledge: New York and London.
- Petersen, A., Anderson, A. and Allan, S. (2005) 'Science fiction/science fact: medical genetics in news stories', *New Genetics and Society*, 24, 3: 337-353.
- Petersen, A. and Bunton, R. (2002) *The New Genetics and the Public's Health*. Routledge: London and New York.
- Petersen, A. and Seear, K. (in press, 2011) 'Technologies of hope: techniques of the online advertising of stem cell treatments', *New Genetics and Society*.
- Phillips, N. (2010) 'Many lives changed by genome understanding', *The Age*, April 5.

- Rothman, D. J. (2003) *Strangers At the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making*. Aine De Gruyter: New York.
- Salter, B. and Salter, C. (2007) 'Bioethics and the global moral economy: the cultural politics of human embryonic stem cell science', *Science, Technology and Human Values*, 32: 554-581.
- Seale, C. (2008) 'Mapping the field of medical sociology: a comparative analysis of journals', *Sociology of Health and Illness*, 30, 5: 677-95.
- Semple, I. (2004) 'Nanotechnology poses threat to health, says scientists', *The Guardian*, 30 July.
- Strauss, S. (2010) 'Geron trial resumes, but standards for stem cell trials remain elusive', *Nature Biotechnology*, 28: 989-990.
- Sztybel, D. (2009) 'Normative sociology: the intuitionist crisis and animals as absent references. Part 1 of 2 essays on animals and normative sociology', *Journal for Critical Animal Studies*, 7, 2: 83-127.
- The Royal Society and The Royal Academy of Engineering (2004) *Nanoscience and Nanotechnologies: Opportunities and Uncertainties*. The Royal Society: London.
- Triendl, R. and Gottweis, H. (2008) 'Governance by stealth: large-scale pharmacogenomics and biobanking in Japan', in H. Gottweis and A. Petersen (eds) *Biobanks: Governance in Comparative Perspective*. Routledge: London and New York.
- World Health Organization (2002) *Genomics and World Health*. Report of the Advisory Committee on Health Research. World Health Organization: Geneva.

The Biographical Turn and the 'Sociolization' of Medicine

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I should perhaps begin by apologizing for the proof-reading problems engendered by my use of the term 'sociolization' and to attempt to define what I mean by this. It refers to what I wish to argue is the process through which sociology has come to shape the profession of medicine, partly, but not exclusively, through what I've called 'the biographical turn'.

I'm using the licence afforded by this plenary to take a biographical turn of my own and to revisit the thinking that informed my own PhD, carried out in the late 1970s. This was concerned with charting the professional socialization of social work students and drew on the literature relating to the sociology of the professions – particularly the work of Eliot Freidson (1970a), who published his influential book *Medical Dominance: The Social Structure of Medical Care* in 1970 (b) which, of course, built on the work of Everett Hughes (1958).

Freidson – and, indeed, other commentators - viewed medicine as the quintessential profession, deriving its authority through its claims to possession of a distinctive and complex body of knowledge; its control over selectivity with regard to admission; and the requirement of a lengthy training period – in other words, via its 'attributes'. Freidson's analysis introduced a conflict view of the acquisition and maintenance of professional power and acknowledged the power struggles both within medicine as the 'prototype' profession (Conrad, 2007) and with close contenders. Medicine was seen also as occupying a superior power position vis-à-vis other occupational groups concerned with providing health care. In the spirit of that time I, too, viewed social work as one of the semi-professions (Etzioni, 1969) and speculated as to whether it would ever become a fully fledged profession.

At this point in time social workers on the ground – if not their senior managers and associations - remained largely ambivalent with regard to attaining full professional status and sought to resist the all-pervasive drive to professionalization identified by theorists such as Wilensky (1964). I concluded in my PhD thesis that social work claimed legitimacy through appeals to a somewhat different cluster of attributes, which privileged the possession of 'people skills' and emphasized its value base. In a similar vein, Kleinman (1981) differentiated between professions which relied on an established skills set and those concerned with "making professionals into 'persons'". The arena of 'people skills', I argued, was not the terrain on which medicine deigned to wage battles for professional dominance, contenting itself with its manifest success in relation to fulfilling 'harder' and more easily observable claims as outlined earlier.

However, since that time both society and the medical profession itself have changed and, alongside a more generalized 'humanization' of society, medicine has, I would argue, sought to cultivate recognition in respect of these 'softer' skills, whilst retaining its traditional power base underpinned by its unchanging attributes. Rather than social work and other so-called semi-professions seeking to emulate medicine, it would appear that the movement has, at least some of the time and in some quarters, been in the opposite direction. Sociology – and, in particular, medical sociology – has also had a significant influence on the ways in which the medical profession, at least in some of its incarnations, has responded and sought to

move with the times in terms of developing its 'softer' face.

The late 1970s were also characterized by growing concerns with regard to the process of medicalization, which, it is argued, involved medicine in extending its influence, through turning social issues into conditions requiring medical treatment. This argument was, most notably, advanced in relation to pregnancy and childbirth. To sum up, these critiques of medicalization highlighted medicine's technical gaze; its episodic focus, its mechanistic rather than holistic approach and its concentration on the physical to the neglect of the psych-social. While such processes are undeniably still a feature of many encounters with the medical profession and other healthcare practitioners, society has moved on and so too has medicine. In particular, it is possible to trace the influence of and response to feminist critiques of maternity services in the changed content and tenor of many medical interactions around these issues. This shift has been associated with the ascendance of ideas regarding 'choice' and 'agency', with a new emphasis on partnerships with service users and the importance of informed decision-making.

Medicine – and, indeed, medical sociology - does not, of course, exist in a vacuum, and has been shaped by broader cultural shifts, including what I've termed 'the biographical turn'. Although biography has been an enduring feature of the literary scene, it is only relatively recently that we have witnessed the spread of the 'celebrity biography'. Some 'celebrities' are serial auto-biographers, so, for example, Jordan – a.k.a. Katie Price – has already produced at least three that I'm aware of. Given her relatively young age it is likely that more will follow. What is striking about this is the apparently new-found need to package – and, indeed, re-package – one's life; not at the culmination of someone's career, but as an ongoing reflexive project. In 2000 Simon Williams published a paper in SHI in which he somewhat mischievously reversed one of the premises of Bury's (1982) theory of 'biographical disruption'. Whereas Bury has argued that chronic illness gives rise to biographical disruption Williams asked whether, in fact, causation operates the other way around. Williams argued that biographical disruption, itself – i.e. the loss of the capacity to anticipate and package one's life according to a pre-existing template – can be experienced as a devastating rupture, which impacts negatively on an individual's psychological health and well-being.

The advertising industry, as always, has been quick to plug into the biographical zeitgeist, perhaps most notably in a recent John Lewis advert, which depicted a woman progressing through the various stages in her life (as an enduringly loyal John Lewis consumer). This advert, with a soundtrack by the Guillemots of Billy Joel's 'Always a Woman' was first aired during a break in Coronation Street on a Friday evening, and by the following week had had attracted over 120,000 hits on YouTube. Interestingly, this short sequence occasioned considerable controversy, with the chattering classes posting on the Guardian's website, where many deplores the anti-feminist take on a woman's role as reflected in an impoverished view of woman - as baby, toddler, child, teenager, bride, wife, mother and grandmother - whilst acknowledging that they had found the images and narrative surprisingly moving. Amidst this furore they seemed to have momentarily forgotten that this was, indeed, 'only an advert'.

'The Biographical Turn' certainly permeates health promotion rhetoric and interventions. The language of health promotion is that of deferred gratification, whereby we are urged to forego particular behaviours (many of which may be enjoyable) in order to maximize future health and well-being. Nowhere is this more evident than in relation, once again, to pregnancy. Together with some colleagues I was recently funded to carry out a research project investigating the reasons for 'low uptake' of folic acid by pregnant women (Barbour et al., in press). As medical sociologists we can find ourselves in rather difficult situations, when we

work on commissioned studies which uncritically echo current – but always provisional – evidence; in this case the study – at least in its early stages - reflected the medical preoccupation with the elimination of risk through scrupulous planning, or biographical anticipation. Women are currently advised to take folic acid prior to conceiving and for the first 12 weeks of pregnancy. This is somewhat unrealistic, given the high percentage of unplanned pregnancies and also the length of time it can take some women to conceive. Further discomfort was to follow, as focus group discussions and interviews revealed that service users had a more nuanced take on biography than the simplistic health promotion version:

Mel: I actually felt quite guilty – probably about half way through ... near the end of my (second) pregnancy - I actually started feeling quite guilty that I actually hadn't taken anything, but then

Rose: Right – because you'd taken folic acid with the first?

Mel: Aye – I think I was quite worried about it. I don't know if it's just me, but maybe later on, intelligence in later years and things like that, and I started thinking, 'Well, what if I've gave my first one a better start ...

(Joint Interview 200808)

Introducing the idea of looking ahead and maximizing benefits for one foetus inevitably leads to comparisons with behaviour in past pregnancies and health promotion injunctions have considerable potential to invoke feelings of guilt, as the quote above illustrates.

An earlier interview study of couples attending a fertility clinic showed that they, too, looked backwards, as well as forwards. The following two poignant quotes involve women castigating their past selves:

You know, I think it's just typical of me – to presume, you know, 'Well, I want to do this and that's when I'll have babies' and then you can't. All those years spent taking precautions ... (34 year old woman)

I keep kicking myself – no – thinking 'Well, why did we leave it so long? Maybe if we'd started 2 or 3 years earlier we'd have a baby by now ... (30 year old woman).

However, the picture was more complex, and, at times, the biographical focus simultaneously cast a forwards and backwards glance, as in the following quote where a woman anticipates her present self being castigated by a future self:

We would do IVF - we've talked about this long and hard. If we don't, I think, down the line in 10 ... 20 years' time, we'd say "Well, what if we'd tried IVF?"

(33 year old Woman)

Attending to one's biography, then, can be a demanding and unsettling business and is certainly not nearly as straightforward as current health promotion materials and approaches suggest.

In relation to maternity care and provision of fertility services, the new face of medicine now recognizes pregnancy and birth as social phenomena; embraces women's (and, indeed, partners' involvement in decision-making); focuses on the 'couple' as a unit; and emphasizes 'choice' – perhaps even to the point of reifying this last concept. However much 'choice' is championed it is, nevertheless, governed by often unexamined but powerful assumptions that serve to limit its exercise. 'Choice' is legitimated only within certain parameters – for example, at least in the popular media, individuals such as Victoria Beckham are disparaging labelled as 'too posh to push' – suggesting that 'choice' is fine, as long as women make the

'right choice'. Discussion about the impact of social class has been relatively muted, but some work, such as that of Nelson's in the US in the early 1980s has shown that perceptions and experience are contingent on social class position and associated values and expectations. In her study of American working class women giving birth she found that their wishes were at variance with those of the middle class women more commonly studied by researchers and whose views were more likely to be taken into account in shaping – or re-shaping maternity services. The women interviewed by Nelson (1983) did not aspire to the natural births favoured by their more affluent sisters; indeed they wanted to minimize pain and were keen to control this and shorten the duration of their labours by whatever means was available to them.

Despite the ascendance of the concept of 'choice' pregnancy and childbirth are frequently not experienced as being quite as straightforward as the rhetoric of 'choice' would suggest. Complications may arise to confound scrupulously delineated birth plans and there can be a considerable mismatch between women's expectations and the unfolding event of labour and delivery. Rachel Thomson and colleagues (2011) explore these tensions in their new book on their recently completed study of first time mothers. Closely related to the notion of 'choice' is that of 'control'. However in the event planning may turn out to be illusory. Conception, itself, is a relatively rare event and cannot be accurately predicted. Our study of young adults with cancer (Barbour et al., 2011), where we spoke to men and women at different stages in their reproductive careers highlighted the lack of conscious planning that often characterized childbearing. As one man told us:

(Our little girl was) "not planned as such but not.... You know we weren't trying as such but we weren't... (we were) not taking precautions ... it was something that we had been thinking about for some time but erm weren't actually putting an effort into having a planned.... but I mean it was something that we both wanted."

(23m -49 year old man with leukaemia).

A previous study (Barbour, 1999) highlighted that, even in the context of ongoing fertility treatment, women could, and sometimes did, become pregnant in between IVF cycles. Although sociology has undoubtedly led to valuable improvements in maternity and fertility provision, the widespread adoption of ideas surrounding 'choice' 'control' and 'agency' may have led to an over-socialized – ore, even, 'over-socialized' - perception of reproduction.

A further aspect of the 'sociolization' of medicine is fertility clinics' focus on the 'couple' as the treatment unit. At first glance this might appear an entirely benign approach, showing that clinical staff are cognizant of the huge social significance of fertility and the central role of biological offspring as the ultimate expression of a loving partnership. However, a closer and more critical examination of the way in which the notion of the 'couple' is invoked suggests that the picture is rather more complex. Fertility clinics are also delivering a product and it is striking to note the preponderance of photos of happy couples and healthy babies on clinic noticeboards, serving as a compelling – if somewhat misleading - advertisement. Nowhere are photos of happy childless couples to be seen, despite the uncomfortable reality that, even with the very best success rates achieved by clinics, failure to conceive remains the most common outcome of treatment. The pro-natalist stance of what could be termed the 'fertility industry' engenders muted discussion of other options open to couples. In particular, the insistence on focussing on the couple as a unit masks the other stark clinical observation that, frequently, only one partner has a fertility problem. In this context, constructing fertility problems as owned by the 'couple' raises the vexing question as to whether a 'couple' can, in any sense, be said to have a 'biography'. Counselling is commonly offered to couples, but,

certainly in our own study, we were surprised to find that none of the 24 couples we interviewed had, in fact, taken advantage of this service, perhaps preferring not to explore the potential of fertility problems to impact on their relationship. Couples sought to portray their partnerships as stable and distanced themselves from the stereotype of 'the neurotic infertile couple' who were viewed as being defined by their failure to conceive; being obsessive about having a baby; and unable to call a halt to treatment. We were repeatedly told of the fear that readiness to take up counselling opportunities might be construed as indicating that all was not well within their relationship (which, in turn, they alleged, could lead to them being denied NHS-funded treatment). Our interviewees, thus, challenged what they saw as a dominant social construction. From a sociological perspective this 'neurotic infertile couple' can be viewed as a lay version of biographical disruption.

In a more recent study of young adults with cancer and concerns about future fertility (see Barbour et al., 2011) the tension between the clinical (in the shape of cancer and arguments regarding the urgency of treatment) and the social (in respect of relationship formation, consolidation and reproductive decision-making) was thrown into sharp focus. Young adults who might be in a relatively new relationship were suddenly faced with having conversations about their reproductive intentions and found themselves subject to 'biographical acceleration' as they were plunged into hypothetical and sometimes actual decision-making as a couple. Even for young men, for whom storing semen might appear a relatively straightforward matter, the picture was complicated as soon as a partner appeared on the scene, necessitating joint form-filling and speculation about future wishes in the light of a range of potential scenarios. Given that this potentially difficult process inevitably followed hard on the heels of a cancer diagnosis, this led us to question whether this is always strictly necessary. Whilst I would not deny the importance of difficult ethical issues, this may not be the best time to address these. Rather than medicine straying into considering complex ethical issues, a more acceptable solution might be to re-institute an episodic approach, whereby samples are stored, pending in-depth discussion with ethics experts at a later point in the trajectory, when the question of use of stored semen is more likely to arise. Since most stored semen samples are never actually used, a staged process would appear more workable and, in the event, many such discussions may never need to arise.

Medicine's involvement in ethical – even philosophical - issues is, of course, nothing new, as is evident from the history of the profession and its alignments. However, as ever more complex ethical issues are raised by the development of new technologies, rather than being something practised at the periphery of the medical gaze (i.e. in terms of abstract discussions with other professional groups), medicine's ethical engagement has come to permeate everyday practices as part and parcel of the new requirements relating to patient involvement and informed decision-making.

However, there are some indications that, as it attempts to address these new demands, medicine is developing a new cultural repertoire. In this context, the relatively recent rise of the Medical Humanities is intriguing and is something that certainly merits further sociological attention. This new discipline - or sub-discipline - encompasses diverse strands, ranging from the study of established literary and artistic forms to cover more contemporary projects, such as graphic storytelling (with a Graphic Medicine Conference scheduled to take place in Leeds in November of this year). A key aspect of the Medical Humanities 'movement' is the embracing of patient narratives, following the recognition that subjective experience can be a legitimate source of knowledge. This marks a key shift in thinking, and challenges the conventional medical view of such pieces as anecdotal at best and, at worst, fundamentally flawed and unworthy of serious attention. However, rather than viewing accounts as talk that is both ideological and dilemmatic (as theorized by Radley & Billig, 1996), there has been a

tendency to privilege first-person stories and to take such accounts at face value, thereby risking 'romanticizing' (Atkinson, 1997) them. Such accounts veer from the 'misery' narrative to the 'transformational' (Rose, 1989) but, in the absence of the critical perspective advocated by Atkinson, remain essentially descriptive, are frequently condition-specific, and, thus, are ultimately analytically impoverished.

'Recovery narratives' form a distinct sub-genre and illustrate particularly vividly both the appeal and limitations of such accounts as presented and represented within the Medical Humanities and, one suspects, within the medical professional more generally. Recovery narratives set about embracing – even celebrating – misfortune with the often-repeated comment that the protagonist wouldn't change what has happened, since this adverse event has since (i.e. retrospectively) been re-evaluated in terms of its capacity to illuminate the individual's priorities and, thereby, to recast one's biography with the illness episode assuming the pivotal position. Recovery narratives are both persuasive and all-pervasive. They are everywhere – from newspapers, magazines, TV documentaries, soaps, through auto-biography, self-help books, novels, films and the theatre. Whilst frequently encompassing and floridly describing suffering, the tone of 'recovery narratives' remains fundamentally upbeat and positive. The injunction to be positive is frequently echoed in cancer narratives – particularly in relation to breast cancer, where skills in the "emotional labour of self-transformation" (Seale, 2002) are emphasized. As Seale (2001) has observed, the language of struggle predominates and a positive attitude is often held to be instrumental in accomplishing survival. The journalist Barbara Ehrenreich (2010) – herself a cancer survivor - takes issue with what she describes as the 'injunction to be positive' and her account provides a rare challenge to a rapidly accumulating body of cancer narratives which reiterate the dominant view of triumph against adversity, reflecting what Seale (2002) has described as "the media-orchestrated fantasy about human powers". There is otherwise little evidence of any dissenting voices and there appears to be scant potential for 'organized resistance' as theorized by Nikolas Rose (1989) – at least in relation to critiquing recovery and illness narratives.

As I highlighted earlier, perhaps the most significant challenge to medicalization, to date, was mounted via feminist critiques of maternity services. This development coincided with the 'baby boomers' reaching their childbearing years and reflected a whole raft of questioning with regard to personal relationships and political alignments. These self-same 'baby boomers' are now coming of age at a point where care of the rapidly expanding elderly population looks set to pose enormous financial and practical demands on an already struggling health and social care system. The French have a wonderful term for this phenomenon, referred to as 'Le Papy-Boum'. The baby-boomers – or more accurately 'papy-boumers' – have frequently been constructed as having re-defined every lifecourse stage as they have passed through these. Admittedly such valorization is often carried out by 'papy-boumers', themselves, but there is no denying their sheer force of numbers and associated purchasing power. Already the effect of this ageing population of consumers is evident in the proliferation of marketing directed at this segment of the American market, with websites courting the 'grey dollar' in the form of advertising for products such as customized walking sticks, including a fetching cowboy model. As an investment opportunity this may, indeed, be where the smart money is.

Some commentators have viewed this now ageing population as possessing considerable power to re-define society and public spending priorities. Huber & Skidmore, for example, in a book gloriously entitled *The New Old: Why Baby Boomers Won't be Pensioned Off*, argue:

'The baby boomer generation has the potential to rewrite the political agenda: around the

distribution of traditional forms of public spending; around the new politics, focusing more directly on 'quality of life' for individuals and communities; or with a generational clash of priorities around cultural values, cosmopolitanism and social equality. Far-sighted politicians and civic entrepreneurs should be turning their minds towards the issues that could act as mobilising flash points, with the potential to define political consciousness for a new generation'.(Huber & Skidmore, 2003)

This is rousing stuff, and it is tempting to envisage the happy conjunction of supply and demand. One of my all-time favourite Biff cartoons depicts an elderly man in a wheelchair being propelled by a nurse who is saying, "Come on, Ben, it's time for your Van Morrison". This conjures up a vision of personalized services with care homes pandering to the tastes and preoccupations of residents. I've long been trying to persuade the BSA to consider setting up a retirement home for medical sociologists. I envisage this as operating along the lines of a perpetual conference, where we might end up giving the same papers all the day, but this scenario, of course, is already not entirely unknown ... Before we get too carried away with this enticing possibility, it is important to critically examine the claims made with regard to the revolutionary potential of the 'papy-boomers'. Whereas the failings of the maternity services offered a convenient rallying cry for female baby-boomers, there is a lack of any identifiable concerns that characterize the experience of ageing and commonality of interests cannot be assumed. In theory, at least, care of the elderly and the shortcomings of the system might lead to such a challenge, but, in practice, there are likely to be important differences between what have been described as 'early' and 'late' boomers and social class differences are also likely to impact on experiences (Phillipson et al., 2008). Passage through the lifecourse may even have served to exacerbate such differences rather than acting as a unifying call to arms.

Notwithstanding the potential limitations to organized resistance on the part of an ageing cohort of baby-boomers, it is clear that the reach of health promotion is now extending beyond the early years. My Open University colleague, Carol Komaromy, recently remarked to me that, whilst previously women might have anticipated some respite from health promotion interventions upon reaching the menopause and leaving behind concerns about reproduction, we are now beset with advice about how to prevent Alzheimers. 'Biographical Anticipation' is very much part of the contemporary Zeitgeist. As we progress through one stage of life we are encouraged to maximize our health not just in the next anticipated stage, but beyond, with discussion about 'Living Wills' or Advance Directives', in the medical arena and, in the commercial arena, the appearance of persuasive publicity materials concerning funeral plans, where individuals can, if they so choose, seek to exert their preference beyond the grave. The 'papy-bouners' have certainly fuelled the demand for woodland burials, as perhaps the ultimate expression of green credentials and commitment. Taking this to its logical conclusion the reach of health promotion now – theoretically, at least - extends from pre-conception to the afterlife – from womb to wicker receptacle. Alongside such developments, medicine finds itself, increasingly involved in heated ethical debate around issues surrounding birth and death – particularly as new technologies and difficult ethical scenarios evolve apace.

There are other - perhaps less obvious, but nevertheless worrying - problems relating to medicine's 'Biographical Turn'. As shown by a few quotes I've presented we can see that this focus can, in fact, be detrimental for service users. The standardization, indeed reification of 'biography' can operate to mute dissenting voices and deny potentially liberating responses to adverse events and perceived health threats. The focus on the social – particularly when it privileges couples' experiences of reproduction and fertility services raises difficult questions around individual, intersecting, or diverging biographies. Medicine's 'biographical turn' is also

partial in that it emphasizes certain lifecourse trajectories at the expense of others – most notably via a markedly pro-natalist stance. The newly emergent patient accounts so readily embraced by the Medical Humanities and medical practitioners or various persuasions, are essentially over-simplistic and analytically impoverished. Undoubtedly we, as medical sociologists, have, at times, contributed to this skewed view of insights derived from research and are also at the mercy of funders who frequently encourage a condition-specific focus. I have been especially heartened at this conference to have heard several presentations which have taken a comparative focus to explore commonalities and differences across conditions. Both within the Medical Humanities and in health services research there is an over-attachment to ‘stage theories’ of progression through diagnosis, treatment and accommodation of illness, which fit well with a newly-adopted biographical focus, but which can lead to what Janice Morse (2000) has termed ‘theoretical congestion’. In the hands of service providers this can serve to over-ride a patient-centred focus with a view that emphasizes the universal. In effect, through focussing on those aspects which can be neatly summarized and presented, the resulting picture of the experience of illness may, like the much-criticized RCT, accurately describe the composite experience of a group whilst rendering inaccessible – and unaddressed – the experience of the individual. This version of biography over-simplifies and fails to treat biographies as unfolding and contingent.

I have, for the purposes of this argument, emphasized the novelty of medicine’s ‘biographical turn’. However, the medical profession has always claimed legitimacy with reference to guiding ethical principles, as outlined in the Hippocratic oath and the upholding of the confidentiality of the consultation in much the same way as does the clergy in relation to the confessional. Alongside the challenges thrown up by the emergence of ‘expert patients’ I would argue that we have witnessed the emergence – or perhaps re-emergence – of appeals to what I’ve called the ‘human doctor’. One of the most important functions of the Medical Humanities appears to be - at least according to the website of the Centre for Medical Humanities at the University of Durham (www.dur.ac.uk/cmh/medicalhumanities/) - is “to offer a richly-textured way of understanding medicine” where the object of enquiry is “medicine as a human practice” and the Medical Humanities provide an arena where the ‘humanized’ face of medicine can be explored and even constructed.

To return to my starting point in this talk, which was my own PhD thesis on professional socialization for social work, I concluded that social work students had to negotiate what I termed ‘transsituational demands’ (Barbour, 1985) whereby they had to align their emergent professional ‘selves’ with public perceptions and expectations and their personal value systems. I viewed social work as one of several ‘people processing’ occupations, which, in contrast to the archetypal professional of medicine (with its established body of clinical knowledge and technical/procedural expertise) had to make its claims to legitimacy and authenticity on the alternative grounds of the value positions and personal qualities of its practitioners. As the cultural repertoire of medicine has evolved and as the profession has had to respond to new challenges, it would appear that medical practitioners are also, at times, invoking similar claims to those advanced by social work and other occupations concerned with the business of counselling, teaching and engaging in therapeutic interventions – i.e. ‘talking cures’. In the case of the medical profession, these bids for authenticity along lines formerly appealed to by ‘people processing’ occupations have not supplanted traditional claims based on professional attributes; rather they afford access to yet another avenue – alongside tried and tested competence claims.

I have earlier suggested that new technologies throw ethical issues into particularly sharp focus, but it may simply be that medical practitioners are nowadays more willing to acknowledge the dilemmas that they face in practice. A few years ago I acted as a consultant

on a study of user and professional views and experiences of termination of pregnancy. This piece of research (The TOPAZ Study) was carried out in the West of Scotland – an area well-known within the UK for its conflicting religious affiliations, which frequently culminate in acts of sectarianism and violence (often associated with but not exclusive to football rivalries). Not surprisingly, in this context, terminations of pregnancy are often carried out in a climate of secrecy and shame, due to a particular constellation of cultural and religious factors, which affect not only the women undergoing the procedure, but also the professionals tasked with providing the service. Two types of procedure were available – medical terminations (which involved merely inserting a prostaglandin pessary and waiting for abortion to occur) and surgical terminations (which involved the removal, under general anaesthetic, of the foetus). Some, but not all, of the hospitals involved offered second trimester terminations and gestational limits also varied. Interviews with staff members highlighted a variety of individual responses, including that of a Specialist Registrar who opted not to carry out surgical terminations but was prepared to perform medical terminations, and a nurse who limited her involvement to inserting a prostaglandin pessary, but who was not willing to assist in any procedures after this point (Kennedy, 2002). These professionals recounted how they had devised individualized accommodations which allowed them to navigate this ethically difficult field whilst retaining their personal values. Surprisingly medical sociology has not really concerned itself with studying those processes whereby professionals weigh up and balance their personal beliefs with their commitment to treat patients and exercise empathy towards individuals who find themselves in difficulty. With regard to studying the professional of medicine, medical sociology, so far, has tended to privilege structure (i.e. focussing on the macro and the processes through which medicine exerts and maintains professional dominance) at the expense of agency (of individual practitioners), whereas the converse is the case with respect to research into patient experience, which abounds with studies of agency and accommodations to illness. The discipline could benefit enormously from redressing this balance and such studies could, I would argue, go some way towards further explicating the relationship between structure and agency – perhaps even addressing the important shortcoming of modernity identified by Margaret Archer (2003): that of dealing with the human person, and showing how the singularity of the individual is realized in practice, through such mechanisms as the internal conversations identified by Archer. Thus medical sociology could make a significant contribution to development of mainstream sociological theory.

To conclude then, there is much that is positive about the way in which the medical profession has embraced some sociological insights and its new-found willingness to listen to voices outside of its own ranks. However, this expanded and more permissive repertoire is not without its problems and, in some respects, it looks as if the pendulum may have swung too far, with medicine uncritically adopting some of the 'half truths' produced (or read into) accounts of medical sociologists whilst ignoring the all-important context and limitations placed around our findings. Medicine has started to embrace some of our concepts and insights, but does not have at its disposal the sophisticated analytical techniques associated with the scholarly activity of sociology and this leads to an impoverished and ultimately potential dangerous flirtations with compelling, but poorly understood arguments. We need, I think, to stop being automatically thrilled every time that someone invokes sociological ideas. Heartening though it is to see medicine embrace the 'biographical turn' this can be counter-productive and gives rise to a new set of problems. It is crucial that we – and, indeed, medical practitioners who partake of our research outputs – retain a critical perspective. As academics who often hold teaching appointments in medical schools we need to review our own role in encouraging and perpetuating some of the simplified understandings of complex

sociological ideas that we seek to convey to medical students. This, of course, presents considerable challenges, given the sort of timeframe involved and our frequently unspoken, but not unreasonable, conviction that some exposure to sociological thinking is better than none. The imperative to publish and the necessity of adhering to journal requirements (such as strict word limits) may also lead us to write in ways that, in turn, lend themselves to misinterpretation. When these accounts are perused by individuals unversed in the subtleties of sociological arguments, but who are, instead, seeking answers to a rather different practice-focussed set of questions, it is easy to see how the misleading but 'sexy soundbite' can prevail. We could also benefit from exploring the possibilities for engagement with the public – and, indeed, the professions – afforded by non-traditional media. Although I would stop short of advocating the approach followed by Alain Touraine (1981), whose 'epistemology of reception' approach involves harnessing the insights of members of the public in order to co-develop sociological theory and effect social change, I think we could do more in the way of encouraging our respondents (both patients and medical professionals) to 'problematize' alongside researchers, thereby, perhaps initiating the co-construction of new discourses. These would allow us to take a more critical look at developments such as medicine's 'biographical turn' and might even lead to the sort of organized resistance invoked by Nikolas Rose (1989).

REFERENCES

- Archer, M.S. (2003) *Structure, Agency and the Internal Conversation*, Cambridge: Cambridge University Press.
- Atkinson, P.A. (1997) "Narrative turn or blind alley?" *Qualitative Health Research*, 7(3): 325-344.
- Barbour, R.S. (1985) "Dealing with the transsituational demands of professional socialization", *Sociological Review*, 33(3): 495-531.
- Barbour, R.S. (1999) *Couples' Experiences of Sub-Fertility Services*, Research report to Northern & Yorkshire Regional Health Authority : York.
- Barbour, R.S., Porter, M., Peddie, V. & Bhattacharya, S. (2011) "Discourses about Future Fertility: Perceptions of Young Adults with Cancer and their Professional Carers", paper presented at 17th Qualitative Health Research Conference, held in Vancouver, October, 2011.
- Barbour, R.S., Macleod, M, Mires, G. & Anderson, A.S. (in press) "Uptake of folic acid supplements before and during pregnancy: focus group analysis of women's views and experiences". *Journal of Human Nutrition and Dietetics*.
- Bury, M. (1982) "Chronic illness as biographical disruption", *Sociology of Health and Illness*, 4(2): 167-182.
- Conrad, P. (2007) "Eliot Freidson's revolution in medical sociology", *Health*, 11(2): 141-144.
- Ehrenreich, B. (2010) "Smile! You've got cancer", *The Guardian*, Saturday 2nd January.
- Etzioni, A. (ed.) (1969) *The Semi-Professions and their Organization*, New York: Free Press.
- Freidson, E. (1970a) *Profession of Medicine: A Study of the Sociology of Applied Knowledge*. New York: Dodd, Mead.
- Freidson, E. (1970b) *Professional Dominance: The Social Structure of Medical Care*. Chicago: Atherton.
- Goffman, E. (1974) *Frame Analysis*, Harmondsworth: Penguin.

- Huber, J. & Skidmore, P. (2003) *The New Old: Why Baby Boomers Won't be Pensioned Off*, London: Demos.
- Hughes, E. (1958) *Men and Their Work*. London: Collier-Macmillan.
- Kennedy, A. (2002) *Living with a Secret: An Action Research Report on Women's and Service Providers' Views of the Termination of Pregnancy Services – Glasgow*, Glasgow: Family Planning Association, Scotland.
- Kleinman, S. (1981) "Making professionals into 'persons'", *Sociology of Work and Occupations*, 8(1): 61-87.
- Morse, J.M. (2000) "Theoretical congestion", *Qualitative Health Research*, 10(6): 715-716.
- Nelson, M.K. (1983) "Working-class women, middle-class women, and models of childbirth", *Social Problems*, 30(3): 2824-297.
- Phillipson, C., Leach, R., Money, A. & Biggs, S. (2008) "Social and cultural constructions of ageing: the case of the baby boomers", *Sociological Research Online*, 13(3) www.socresonline.org.uk/13/3/5.html
- Radley, A. & Billig, M. (1996) "Accounts of health and illness: Dilemmas and representations", *Sociology of Health & Illness*, 18(2): 220-240.
- Rose, N. (1989) *Governing the Soul: The Shaping of the Private Self*, London: Free Association Books.
- Seale, C. (2001) "Sporting cancer: Struggle language in news reports of people with cancer", *Sociology of Health & Illness*, 23(3): 308-329.
- Seale, C. (2002) "Cancer heroics: A study of news reports with particular reference to gender", *Sociology*, 36(1): 107-126.
- Thomson, R., Kehily, M.J., Hadfield, L. & Sharpe, S. (2011) *The Making of Modern Mothers*, Bristol: The Policy Press.
- Touraine, A. (1981) *The Voice and the Eye: An Analysis of Social Movements*, New York-Paris: Cambridge University Press-Éditions de la Maison des Sciences de l'Homme.
- Wilensky, H.L. (1964) "The professionalization of everyone?" *American Journal of Sociology*, 70: 137-158.
- Williams, S.J. (2000) "Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept", *Sociology of Health and Illness*, 22(1): 40-67.

Ethnography, Medical Innovation and Neonatal Care: A critical engagement

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The Neonatal Intensive Care Unit (NICU) is a unique medical site. Inherent within its walls and practices are the extremes of life's experiences. Life and death, celebration and mourning, hopes and loss are encountered in the bodies of children amongst the dizzying array of frontier medicines and technologies. In many senses it is a strange landscape, yet for those who work or inhabit that space - even if just for a while - the extremes can become familiar and a particular everyday ethics must be negotiated on a regular basis. Dr Jessica Mesman, a senior academic in the Department of Science and Technology, Maastricht University, has spent many years inhabiting this space in both the Netherlands and the United States. Her elegant ethnography, *Uncertainty in Medical Innovation: Experienced pioneers in neonatal care* (2008) provides a unique glimpse into this world and was awarded the 2009 Sociology of Health and Illness Foundation Book Prize¹. At the 2011 BSA Medical Sociology Conference, we celebrated this Award by hosting the inaugural 'Author meets Critics' session with Dr Mesman. Dr Alex Faulkner (Kings College London), Dr Dawn Goodwin (Lancaster University) and Dr Paul Martin (University of Nottingham) acted as critics to the book on this occasion.

What follows here are the papers by Dr Alex Faulkner and Dr Dawn Goodwin with a response by Dr Jessica Mesman. The following papers are brilliant expositions into the methodological, theoretical and empirical strengths and weaknesses of this text. They highlight the historical tradition of ethnographic work in medical sociology, the complexity of 'doing' and writing ethnography and they question methodological choices. They illustrate the complexity of the field of medical sociology by exploring the conceptual engagement with science and technology studies through discussions of policy, international case studies, medical devices and the lives of children. They challenge both the text and its' author, but also as we read and respond with Dr Mesman, they challenge each of us as we engage with our own research in our chosen branches of medical sociology.

¹ The BSA Sociology of Health and Illness Foundation Book Prize is now open for nominations for 2012. A prize of £1000 is awarded annually to the author(s) or editor(s) of the book making the most significant contribution to medical sociology and having been published over the three years preceding 1st January of the year in which the award is made.

Uncertainty in Medical Innovation: Experienced Pioneers in Neonatal Care by Jessica Mesman

A commentary by Alex Faulkner

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SOCIAL ORDER, DISRUPTION AND STRUCTURE IN TECHNOLOGICAL NEONATAL CARE SETTINGS

In the era of evidence-based medicine (EBM) and health technology assessment (HTA) medical sociology's traditional concern with how healthcare is actually accomplished by practitioners is given an even sharper edge. Bearing in mind our understandings of the informal, recipe-based, and repertoire-shaped ways with which health professionals do the work that they do, it becomes, in the context of EBM/HTA, of even greater concern to ask how healthcare professionals interact with each other and with patients and carers, in a world increasingly full of clinical guidelines, protocols, evidence-oriented practices, research representations, not to mention trends in commercialisation, privatisation and globalisation of medical technologies and healthcare knowledge.

Jessica Mesman's (JM) book is based on ethnographic fieldwork in two neonatal intensive care units (NICUs), one in the US and one in the Netherlands, and was conducted in the mid 1990s. We are told that it was updated in the mid-2000s and that observations would not have changed significantly.

Medical sociology has benefited from a line of classic hospital-based ethnographic fieldwork studies, much of which were originally focused upon work and the profession of medicine (Freidson, 1988) as well as doctor-patient interaction. One thinks amongst others of Glaser and Strauss's *Awareness of Dying* (1965) with its emphasis on the effects on work interaction of different modes of awareness amongst staff, Phil Strong's *Ceremonial Order of the Clinic*, Paul Atkinson's *Medical Talk and Medical Work* (1997), and Strauss et al's *Social Organisation of Medical Work* (1985), which is cited by JM, who adopts their 'trajectory' concept to describe the pathway taken by patients through the care process. The latter, with its identification of different types of work – sentimental work, machine work, comfort work, safety work, points to many of the same concerns that JM addresses in her data-rich book. It is worth noting also that Strauss claims that their book contributed to opening up the 'sociological study of technology', and interestingly it was published in the same year as the seminal 'social shaping of technology' volume on this topic edited by MacKenzie and Wajcman (1985), which marked the emergence of major debates and controversies about sociological approaches to understanding the human-made material world of technology, which, of course, has become an important strand of concern in social studies of medicine, and in terms of which JM's book is explicitly framed.

Apart from work, Glaser & Strauss were also concerned, of course, with the issue of the 'social order' of the hospital. Strauss et al's concept of the 'negotiated order' (in 'Psychiatric ideologies', 1964) is one that can be seen as underlying JM's own concern with the ongoing negotiation of decision-making in the NICUs that she has studied. These she formulates in terms of a variety of more recent theorists in the Science & Technology Studies (STS) field, referring to concepts such as centres of co-ordination, scripts, structuring device, and styles of ordering. Theoretically, JM claims that her approach is one of 'constructivist STS', arguing for example that 'case descriptions have consequences' (p11, referring to ch6 – pointing to

the constructive part played by texts in processes of social ordering). She takes an approach to sociomateriality, described in a footnote, which distances her approach from Actor Network Theory's conception of human and nonhuman actors as existing as ontological equivalents, in order in her own approach to preserve a view of human actors as agents who act with motivations such as responsibilities, accountabilities and normative and moral goals.

A frontier spirit runs through the actors conjured up in JM's book about the risky, uncertain, emotionally and morally challenging, technologically complex, and socially intense environment of modern neonatal care (encapsulated in her subtitle of 'experienced pioneers' and first chapter heading 'a permanent dynamic of change'). And this brings to mind a further reference point, though one not referenced directly by JM, which is Renee Fox's early work, especially *Experiment Perilous: Physicians and Patients Facing the Unknown* (1959), which, like JM's book, also started life as PhD research. Although *Experiment Perilous* was based on participant observation in a setting designed for research as well as therapy, the subject of this work implicitly informs one of the major themes of this book – that of professionals facing extreme clinical and moral uncertainty in settings of critical, life-threatening conditions. This is a classic topic of medical sociology's concern with life-threatening conditions and is an intellectual heritage which JM brings to the fore in this book, raising important issues of the intertwining of ethical and moral dilemmas with the practices of highly skilled, technologically mediated work. (Again, there are important predecessors for this more specific focus in intensive care, which JM cites in her introduction.

So JM's book in some senses at least joins a long tradition of important work that has shaped medical sociology as we know it today, where the ethnographic case study has been one of the main and most productive methodologies and the hospital the central location. JM's prime focus is upon the care process, with a particular subject emphasis on work and interaction, and the dynamic relationships between imperatives of moral and ethical decision-making in situations of uncertainty in critical neonatal healthcare settings where premature babies are cared for. In formulating what she calls the 'moral load' of critical care, JM describes her approach as being neither a normative ethnography, nor evaluative of healthcare work, and she takes a stance against 'rule-based' ethics as a description of how physicians make critical patient decisions. This position leads her to a starting assumption of a need for a 'situated morality' (what do ethicists themselves make of this concept?), and JM argues that this in turn leads to a requirement for empirical study of custom-made 'morality in the making' (echoing the so-called empirical turn in ethics) (p10-11). Thus the aim is to focus on how decisions are actually arrived at, and is the reason why her focus is on: 'the roles of actors, the meanings of data and the functions of devices'. Another formulation that we are given is that of the 'co-ordinative resources' that involve 'a high level of complexity and medical and ethical uncertainty' (p11). These terms resonate closely with Timmermans and Berg's work on standardisation in healthcare, where, for example, they discuss protocols of various types as 'co-ordinative devices'. So one of the difficult challenges that JM addresses is how to understand the production of 'sentimental work' and the negotiation of ethical and moral decisions in the context of an avowedly STS-based conceptual approach focused on day-to-day care processes, in two rather different healthcare and cultural settings.

In terms of epistemology, JM tells us that her book has a very specific focus that goes beyond mere (mere?) descriptive ethnography of life in neonatal care settings. Instead, or rather further, her aim is to understand 'how actors succeed in acting promptly and adequately in situations of uncertainty and doubt...' (p8). One can see that in this formulation a concern with the interactional maintenance of social order, reminiscent of ethnomethodology, is to the fore (Harold Garfinkel and David Sudnow are both referenced). In this context, one of the interesting stated aims of JM's book is the intention to pay attention

to the 'in-between zone' or 'intermediate zone', the 'hinge between the collective and the individual' (p6-7), where, by an analytic tactic that she terms 'exnovation', she intends to uncover the hidden competencies that clinical staff bring to bear in their working practices. However, this seems to me an approach quite typical of sociological and anthropological ethnography, and I will return to this 'micro' level focus on the objective of understanding 'how actors succeed in acting promptly and adequately in situations of uncertainty and doubt' (p8) in my concluding comments.

Let me now turn to consider in a little more detail two themes in JM's book in which I have a particular interest, namely material technology and law/regulation, in other words two forces strongly shaping contemporary health care processes, one deployed internally in the care process – technology- and one produced externally and implemented or adapted into care processes - regulation.

Technology

The advance of new technology is a ubiquitous feature of contemporary healthcare whether in primary care, general hospitals or specialist centres. There is an evident trend toward an intensification of expertise and technology in complex, critical care setting generally, and NICUs are clearly an example of this trend. NICUs are technology-rich environments, having developed from the early incubators of the late 19C. They have undoubtedly been instrumental in the lowering of premature death rates of very low birthweight infants during the 20C, as JM notes. However, the increasing use of technology to make life-saving interventions, as she also notes, has given rise to both public and medical concern since the 1970s about the ethics of preserving extremely fragile children often with the probability of severe disability and poor quality of life.

JM discusses technology primarily in the context of what she calls uncertain 'trajectories of care' (ch4). In terms of trying to understand how her two fieldwork settings in the US and Netherlands differ from each other (a comparative aim that I felt was not greatly to the fore in the book although some comparative analysis is made), we should notice that she states that the technological resources deployed in the two units are essentially the same. This includes a large battery of monitoring equipment such as for lung and cardiac function, incubators, tests, ultrasound, record-keeping forms, parenteral nutrition, surfactant and steroid therapies, and so on. So JM documents the wide variety of uncertainties that staff are faced with in an NICU, and the strategies used for dealing with it, one of which is to use the technological aids that are available. Because of the constant chance of a sudden unpredictable event, we are shown how staff pay close attention to the information and alarms coming from the monitoring equipment. In the context of critiques of advanced medical technology as a de-humanising phenomenon, JM argues that the social dimension of NICU care is such that the technology acts as a 'material passageway' between staff and child in which the technology is simply part of the care rather than a distraction. The contingent nature of the multi-skilled team process in the context of staff rotations is illustrated here, for example in a fieldnote extract describing the changing presence and absence of the lead physician, junior, anaesthesiologist and cardiologist viewing the blood monitoring display at the incubator of one child ('Robert', the Netherlands) who is both a neonate and a cardiac patient.

JM takes the respirator as an example to examine the role of technology in influencing how a child's treatment trajectory takes shape. Giving detailed description of how the respirator is used with a particular child, Tom, she shows how use of the device at least shapes but does not always determine the roles and specific tasks undertaken by staff, though at the same time frequently staff are described as having 'no choice' in responding to alarms in specified ways. The temporary nature of technology use is shown, where in Tom's case the respirator,

originally a benign influence, later becomes an impediment to the range of treatment options otherwise available. Overall, JM argues, the negotiable malleability of the care process is limited by biological and technological boundaries (which accords with a co-productionist STS perspective). JM also shows how technological skills e.g. with intubating may cut across formal disciplinary or organisational statuses in the informal working environment. She shows how the incubator 'constructs new categories of children' and helps define boundaries in the care decisions (p100). Here she uses one of the family of STS concepts that have developed to understand sociotechnical relations and the 'configuring of users', namely the concept of the 'script' (Akrich, 1992), and her approach can be seen to chime well with what Timmermans and Berg have subsequently called the 'technology-in-practice' approach (Timmermans & Berg 2003). Children themselves are also, appropriately, included amongst the range of 'users' of the technology.

Law and regulation

Neonatal medicine is one of the areas of medicine where a mis-diagnosis can have serious legal implications for practitioners. Although the Dutch and US law, regulation and professional guidance in the 1990s showed some systematic differences, it is clear from JM's introduction to this background that there was internal controversy in each country regarding the tension between case-by-case and rule-based philosophies.

In 'Northeastern', the US hospital setting, we learn, unsurprisingly, that there the over-riding principle is to intervene unless there is absolutely no hope of preserving a child's life, so for example JM quotes a nurse practitioner as saying: 'Once I treated a child that had very bad blood values. According to the books this child had to be doing very poorly. But the child was doing quite well....It only shows to tell that even medical knowledge is not fixed' (p24). And the nurse goes on to mention that she would go on trying to reanimate a child for 20 minutes even with no heart rate in evidence and says that this puts 'puts you in a stronger position in the case of a lawsuit'. So we can see here the acknowledged litigiousness of the wider society of the US entering into the considerations of actors in the NICU, especially in this instance following the famous 'Baby Doe' case. However, as JM states, illustrating the internal national controversy that I just mentioned, the Baby Doe Regulations were seen to contradict national professional guidelines that recommended case-by-case individualised decision-making. Thus we learn how a doctor can feel extremely uncomfortable asking parents to sign a 'Do Not Resuscitate' form because the US law requires it. Nevertheless, JM shows how in the case of the Dutch centre, the significance of external regulations are more matters of conflict and negotiation – e.g. providing extracts from discussion between different team members of the interpretation of an ultrasound scan (and the need for a radiologist or neurologist opinion). Here the analysis shows usefully how the use of case-oriented repertoires or 'situation' repertoires is not systematically tied to different disciplines or roles in the team.

Chapter 3 of *Uncertainty in Medical Innovation* identifies two sorts of performative vocabularies, also called 'social orders' – the juridical and psychosocial. Here JM points to systematic differences between the two NICUs, related to the legal context in each healthcare system. She argues that although both vocabularies are present in both settings, the 'institutional order' of the two settings is characterised by an ethic of individual responsibility on the one hand (US) and of shared responsibility on the other, in the Dutch approach. Here the account conveys a constructivist understanding of vocabularies (the Foucauldian 'discourse' is a term that JM doesn't appear to use) as structuring the way interactional care decisions are made. In the US setting the juridical style predominates, whereas in the Dutch case no vocabulary dominates; the use of the psychosocial vocabulary

allows the parents to be engaged emotionally in the decision process. If I understand the argument here, it is that although team members' responsibilities and perceptions may come into conflict, the aligning of different vocabularies, also enabling the emotional involvement of parents, tends to channel effort to the shared objective of the child's recovery or other decision, thus producing an orderly direction to the trajectory of care. (Here, I wonder about the conservativeness and the lack of serious disruptiveness to the care process that JM seems to assume in her focus on the maintenance of successfully acting promptly and adequately in the face of uncertainty and doubt').

Methodology

Now I turn to just one, but an important one, of JM's stated methodological principles, which really is the foundation of her research design. (Incidentally, the key details of this design are somewhat scattered in different parts of the book). It is important to note again here that her data come from hospitals in two contrasting healthcare systems and cultures, the US and the Netherlands. As an exponent and proponent of comparative case study methods, I was particularly interested to see JM's approach to case studies in her research. She states that she uses four case studies as the 'backbone to her argument' (p8). For JM here, in fact, a clinical case is also a sociological case. She chooses complex cases 'in which it is not exactly clear what is going on or what has to be done', in order to 'exnovate how treatment trajectories are preserved in uncertain circumstances' (p6) . (JM formulates the term 'exnovate' especially in terms of 'hidden competencies' of staff). The case studies chosen, therefore, can be described as follows: Tom, Esther, Maureen and Robert - in other words four very young children that have had the misfortune of encountering the very sharp end of intensive medical care in these neonatal intensive care units. (Other cases such as Ronald and Christine also make appearances). As JM notes these are 'real' (not her term) cases illustrating actual illness trajectories, not fictitious cases compiled by ethnographer's license from a variety of different individual actors.

It is common in writing up research based on case study approaches that the writing of descriptive narratives of the cases is at odds with other more generic authorial aims such as explaining, interpreting, theorising, referencing to existing disciplinary knowledge and so on, and it is not surprising that the written account hops from one child to another, sometimes without clear signalling. How are the children depicted in JM's account? The children, as written here, appear primarily through the lens of the staff and the ethnographer herself. I felt this was partly due to the writing and structuring of the book, though doubtless it is also due to the very dependent situation of the children themselves. Although they have names (unlike the staff) their parents, who make frequent, often ghostly appearances in the text, do not. The child-as-case approach, I believe therefore, somewhat downplays the visibility of the two different NICUs as distinct organisational settings themselves which the four children have passed through, and the broader dynamics of family networks which surely influence parents' involvement in the care decision process. The analysis is frequently presented in terms of 'the NICU', i.e. a generic, non-contextualised representation of the settings of concern. I was intrigued by this approach to defining cases, though this reaction may be conditioned by my own engagement in case studies of, for example, healthcare settings such as NHS units, or different types of medical technology (Faulkner, 2009). What is at issue here is both a 'unit of analysis' issue of research design and analysis, and a presentational one.

These thoughts about the design of the research underlying the book leads me to wonder if there is a tension here between the sorts of generic conclusions that JM draws (eg – p188-90) and the sorts of conclusions that might have been drawn had a different case study design been used. In common with some varieties of STS approaches focused on micro

processes of interactional ordering (leaving aside for the moment the controversy about micro/macro and validity of such 'levels' of analysis), such a focus can lead to a lessened focus on what many would regard as 'contextual' forces and power dynamics. Where, for example, are the hospital organisation and differences between medical and clinical specialities as analytic resources? We learn little about such structural differences in JM's account, such as the different expertises of neonatologists, paediatricians and subspecialisms of paediatrics, obstetricians, and different specialised nursing expertise. Therefore, I feel that the over-riding focus on the micro process level of the 'intermediate zone' as a hidden resource by which staff maintain an ongoing orderliness of the NICU plays down these other important features of the care setting and the innovations that might be brought into it via 'outside' forces such as changes to equipment caused by medical device producer innovation trends, or risk management training initiatives promulgated by hospital authorities or clinical specialities.

Concluding comments

Given the contemporary context of the advance of evidence-based medicine and health technology assessment (even taking into account its partly rhetorical character) it would be interesting to know how different JM's account would have been had it been based on more recent fieldwork, rather than at a time when this key healthcare movement was in its infancy. Would the account show a more significant impact of guidelines, protocols, standardisation and technology on care decisions, or would the depiction of the neonatal critical care process remain very similar? Even allowing for the well-known established sociological insights into the negotiable, flexible, contingent and creative character of professional health care, is the social order of the clinical care setting surely does show some signs of change.

With so much focus in healthcare policy on innovation as a good in itself (reflected in the UK in a current 2011 government consultation), JM's book raises challenging questions about different levels and different types of innovation. On the one hand, her account of NICUs shows the apparently irremediably negotiable nature of the care process at the micro level, but on the other, we know that care processes and pathways are the target of a wide range of powerful 'external' forces coming from the device and pharmaceutical industries, from patient safety and risk management reviews and policies, from the professional and policy exponents of EBM and HTA, and from the different structural patterns of healthcare delivery organisations, - in short the political economy of healthcare.

Of course, societies, cultures and the medical world have changed drastically since 1959 when *Experiment Perilous* was published, so one of the interesting questions raised by reading JM's book is the extent to which the deployment of more recently coined sociological concepts adds to our understanding of the conduct of medical practice. To what extent – and this is a question that applies to a great deal of work applying STS to medicine and healthcare, including my own - do the language and concepts of STS advance our conceptual and theoretical understanding beyond some of the classics that I mentioned at the beginning of this piece?

In conclusion, Jessica Mesman's book reminds us that clinical practice, professional medical work and medical technology are complex, evolving, multidimensional phenomena that continue to require correspondingly multi-faceted and methodologically diverse approaches, as we try to produce ever better understandings of how they work and what they mean in healthcare and society more broadly.

REFERENCES

- Akrich M. (1992) The de-scription of technical objects. In: Bijker W, Law J. (1992) (eds.) *Shaping Technology/Building Society*. MIT Press.
- Atkinson P. (1995) *Medical Talk and Medical Work*. Sage Publications.
- Faulkner A. (2009) *Medical Technology into Healthcare and Society: a sociology of devices, innovation and governance*. Palgrave Macmillan.
- Fox R.C. (1959) *Experiment Perilous: Physicians and Patients Facing the Unknown*. New York, Free Press.
- Freidson E. (1988) *Profession of medicine: a study of the sociology of applied knowledge*. University of Chicago Press.
- Glaser, B. and Strauss, A. (1965) *Awareness of Dying*. Chicago: Aldine Publishing Company.
- MacKenzie D, Wajcman J. (1985) *The social shaping of technology: how the refrigerator got its hum*. First edition. Open University Press
- Strauss A, Fagerhough S, Suczek B, Winder C. (1985) *Social Organization of Medical Work* University of Chicago Press.
- Strauss A, Schatzmann L, Bucher R, Ehrlich D, Sabshin M. (1964) *Psychiatric ideologies and institutions*. Free Press of Glencoe, NY.
- Strong P.M. (1979) *The Ceremonial Order of the Clinic: parents, doctors and medical bureaucracies*. Routledge & Kegan Paul, London.
- Timmermans S, Berg M. (2003) *The Gold Standard: the challenge of evidence-based medicine and standardization on health care*. Temple University Press, Philadelphia.
- Timmermans S. Berg M. (2003) The practice of medical technology. *Sociology of Health & Illness*, 25(3): 97-114.

Uncertainty in Medical Innovation: Experienced Pioneers in Neonatal Care by Jessica Mesman

A commentary by Dawn Goodwin

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INTRODUCTION

This book is a rich in insight into medical practice and the various disciplinary perspectives from which it may be studied. At the heart of this book are questions about knowledge (scientific and otherwise) and its limits (in various forms of uncertainty), the place of technology in contemporary health care, the constitution of ethical practice, and how these aspects relate to the actions of health care workers. It deals also with the web of relationships between doctors, nurses, parents, babies, and technology and how all of these must be made accountable to a wider juridical system, while in turn, the juridical system is insinuated into all of the above. All of these foci are also common, if not central, to both STS and Medical Sociology and Mesman elegantly combines insights from both of these fields. Yet the book speaks plainly, largely stripped of jargon and terminology, without losing any conceptual precision. The result is that it is a beautifully easy and engaging book to read, swept along as you are by gripping stories of the lives of a handful of neonatal babies and intricate (yet simple) explanations of what is involved in caring for them. But it is to the achievement of combining the insights of STS and Medical Sociology that I would like to address first.

Analytical perspectives on health care work

From an STS perspective, the field of medicine affords fertile ground for study. Lucy Suchman (2010: 203) has observed that medical practice comprises a site 'in which the boundary between bodies and machines comes into relief, only to be rendered more contingent'. And as Casper and Berg (1995: 396) suggest, for medical sociology 'the crucial role of technoscience in the shaping of medical work is more and more taken as a topic of investigation'. There is good reason, then, to combine analytical insights from STS and Medical Sociology in studies of health care work but it also presents some challenges, one of which is a divergence in analytical direction.

The emphasis in much of STS has been to explain the way things (organisations, relationships, practices, technologies, scientific facts) come to be, the way they are constructed. And in such stories of construction, contingencies and choice rather than forces of necessity are highlighted (Winner, 1993). Things, as they say, 'could be otherwise'. In this way, various forms of determinism (specifically scientific and technological) are undermined. 'Power' has also tended to be analysed from this perspective. Actor-Network Theory, an influential approach within STS, positions power as an 'effect' rather than a 'cause'. Hence, 'power' is not used to *explain* differences of privilege between one group and another, it is not a property belonging to individuals or groups, rather it is an *outcome* of social relations and therefore something that must *itself* be explained (see in particular, Latour, 1986).

However, such detailed explorations of the way things arise comes at the cost (for some) of a 'disregard for the social *consequences* of technical choice' (Winner, 1993: 368, my emphasis). As Winner observes of STS: 'the consequences of prevailing are seldom a focus of study'. The question of how to address this criticism has persistently dogged STS (Radder, 1998; Zuiderent-Jerak and Brunn Jenson, 2007). For example, STS researcher Vicky

Singleton, when articulating the indeterminacy and ambivalence ingrained at every stage of the cervical screening programme, was challenged to decisively answer the question of whether women *should* therefore have a cervical smear test (Singleton, 1996). More recently in 2004, Bruno Latour deliberated upon whether STS had disarmed itself in its endeavours to deconstruct scientific fact. And in 2010, STS researchers such as Teun Zuiderent-Jerak were still exploring ways in which to respond to constructivism's 'normative deficiency' (Zuiderent-Jerak, 2010).

Such criticism, of inattention to consequences, can hardly be levelled at Medical Sociology which has thoroughly explored, amongst other things, the pernicious effects of medical dominance. Exploring the various manifestations of such dominance – the manifold ways in which patients are rendered passive recipients of healthcare and their participation in decision making systematically diminished, not to mention how medicine's dominance pervades and structures doctor-nurse relationships – has been an important line of critique in medical sociology. In view of this and STS' perceived 'inattention to consequences', discussion of 'hierarchies of power' and strategies of resistance to these can be found more readily in Medical Sociology than in STS (see for example Griffiths, 2002).

In contrast to these criticisms of constructivist STS, Mesman does not shy away from discussing 'hierarchies of power' and its effects. However, by the time she uses this term 'power hierarchy' (on p168), she has already explored in detail what she terms the 'specificity of perspective'. By this she conveys how an individual's knowledge is born of the experiences they have access to. She takes, as her point of departure, Anspach's (1987) articulation of 'ecologies of knowledge' and advances this work in three important ways: first, she points out that by concentrating on professional position, parents are excluded as producers of prognostic knowledge; second, that the concentration on professional position obscures divergence of opinion within a professional group; and finally that a specific position within an ecology of knowledge, not only shapes 'what a person sees or knows, but also what they can do' (Mesman, 2008: 123). Mesman, therefore, silences the critics of constructivist STS by pointing to the effects of how the construction of knowledge relates to one's ability to act.

Mesman explains how sensory experiences contribute to specific prognostic knowledge. With sensitivity and compassion, Mesman describes the heartbreaking situation of Tom where every attempt to alleviate his suffering results only in increasing his distress; the respirator both delivers life saving oxygen but destroys the delicate structures of his immature lungs and consequently his chances of ever living independently of it; the diuretics produce kidney stones, the corticosteroids result in a stomach ulcer, every touch from the nurses agitates him to such a degree that he needs to be sedated and his oxygen levels increased; the roles of his parents are reduced to that of spectators. But it is impossible for nurses to care for Tom without touching him and so they unwillingly contribute to his anxiety.

By focusing on features like proximity, touching and observing, Mesman enables the reader to understand the particularity of experiences, how this fits within an ecology of knowledge, but further, how this explains differences within professional groups. The specificity detailed in these processes of knowledge construction mean that the concept of a 'hierarchy of power' is built on a rich understanding of how a particular knowledge perspective comes to be, the way this is deployed in negotiations, and to what effect. The charge of reconciling STS and Medical Sociology around the notion of power may have been challenging yet the result is particularly satisfying. Mesman (2008:169) concludes that 'These differences in power, access to preferred data and moral perspectives complicate the position of nurses in participating in end-of-life decision-making processes.' She also points out that whilst life

ending decisions may be shared, the burden of consequences 'ends up inordinately on the shoulders of some – the nurses' (Mesman, 2008: 175). Thus Mesman does not skirt around pointing out the disparities and inequities that arise from the hierarchies of power, however, intricately explaining how a power hierarchy is continually being remade in everyday practices allows her the flexibility to use such concepts without being deterministic about them.

One criticism that might be levelled at Medical Sociology from an STS perspective is that the analytical concentration on the extensive ways in which medical practice has undermined a patient's autonomy, control and self-determination risks positioning the patient as passive and docile. Some studies within STS have sought to tell a different story, for example, in the case of fertility treatment, Cussins suggests that patients might engage temporarily with their objectification if it advances movement towards their long-term goals of becoming a parent. A process she called 'ontological choreography' (Cussins, 1998). Another approach has been to focus on the limits of practitioner control, showing how even unconscious patients can call the shots, directing and constraining the actions of anaesthetists (Goodwin, 2009). Here again, Mesman artfully constructs a middle-ground; without adopting the nomenclature of STS (something I will discuss below) she still portrays parents as active participants, and when discussing the uncertain trajectories of these babies, she conveys the agency of the child in shaping its own trajectory. Following an intervention by the staff:

An experimental space is created in which it is not the staff's move but the child's. The staff has acted and subsequently it has to become clear how the child responds, if s/he will. (Mesman, 2008: 84)

Indeed, the multiple ways of managing uncertainty that Mesman details (for example, recourse to the future as a frequent reason for refraining from action, hedging language, and protocols) describe how medical staff meet, acknowledge, and struggle with the limits of their knowledge and control.

Normativity within STS

Having considered how Jessica reconciles potential tensions between Medical Sociology and STS leads me to reflect on what identifies a study as 'STS'. Earlier I mentioned the criticisms of STS that it is 'normatively deficient' in its arguments. However, there is perhaps another kind of normativity that affects STS and this relates to how such a study should look. I have said that the book is largely devoid of STS terminology without losing any of the conceptual clarity. To explain, in some forms of STS (most notably ANT and its various reincarnations) researchers are entreated to resist making assumptions about who or what are important and instead let differences (between, for example, humans and non-humans) be demonstrated empirically. By doing so it allows inscriptions (Latour and Woolgar, 1986), microbes (Latour, 1999a), scallops (Callon, 1986), and bush pumps (de Laet and Mol, 2000), to name an iconic few, to come to the fore. The aim of such symmetrical analyses is that, if we refrain from making such apriori distinctions, it allows us to appreciate the extent to which even mundane technologies structure practice or to recover and examine the contributions of those participants assumed not to have the ability to act (Goodwin, 2009). Another prominent trope of STS has been to explore the dense sociotechnical arrangements in which bodies and technologies are intricately enfolded within one another using the concepts of hybrids (Latour, 1999b) and cyborgs (Gray, 1995, Haraway, 1991). Cyborgs epitomise the mix of technological and organic necessary to extend and enhance life, and to generate new capacities, but they also represent a powerful blurring of boundaries and convey a sense of unpredictability (Goodwin, 2009). Given Mesman's subject area – neonatal intensive care – one might expect to find cyborgs. Mesman resists this temptation however – the descriptions in her book are elegant and simple distillations of what any outsider (rather than STS

scholars) might see if we entered, became familiar with, and learned to understand the NICU. There are no cyborgs (and to my count, only one hybrid) in this book.

But this is not the only way in which Mesman's book is distinct from the mainstay of STS. I'd like to discuss two further examples: i) the place of the monitoring technology, the numbers they derive and their value, and ii) the way diagnoses and prognoses are made.

First though, in relation to the monitoring technology, some alignments with STS: Mesman (2008:94) makes the beautifully subtle observation that 'The question of how the child is doing is mostly answered by a look on the screen of the monitor'. The monitor mediates between staff and child. Importantly, however, Mesman positions the technology not as a separate entity from the baby but an extension of the baby that amplifies articulation of its condition. Staff, she says, 'watch the monitor but see the child ... as if monitor and child are one' (Mesman, 2008: 94). A gentle invocation of the idea of a cyborg but without resorting to this (possibly insensitive) jargon.

Mesman explains how technology 'disciplines' practice, and so concedes agency to the technology. Respirators are inscribed with a 'program of actions' which determines the skills required and so the composition of the treatment team (Mesman, 2008: 100). Devices actively contribute to the way in which treatment trajectories evolve: with the poignant story of Tom, Mesman describes the escalation of intervention, here technology is an actor whose role it is difficult to contain. So, humans and machines as one, technology's scripts disciplining practice, technology shaping treatment trajectories – all insights central to STS.

In the discussing the role of numbers, however, Mesman somewhat defies expectations. Staff members, she acknowledges, collect numbers, they provide a common language used by doctors and nurses: they read HB values, saturation values and input and output quantities of the fluid balance, and they recount hours, weeks, days, frequencies, percentages, pressure, sizes, and assessments. Pointing to the connections between neonatal practice and legal frameworks, Mesman (2008: 105) highlights the preference for quantitative data: 'Because of its factual precision and comparability, a numerical transcription of the body is considered more reliable than its qualitative counterpart'. Yet, Mesman is quick to point out how numbers are not always considered hard facts: numbers can be a source of confusion when they contradict one another – implying different scenarios for action. Numbers can be persistently incomprehensible and are positioned, not as decisive, but as one of many sources of knowledge. However, Mesman (2008: 114, original emphasis) concludes that 'The NICU is a quantitative practice in which both man and machine contribute to the numerical edifice erected around the child.'

So to return to my point about expectations *within* STS, I find it interesting that, despite clear appreciation, and detailed discussion, of the qualitative practice of making numbers meaningful, Mesman does not attempt to flatten this hierarchy between the value of qualitative and quantitative knowledge. Flattened hierarchies are commonplace in STS (possibly another reason why STS has difficulties discussing 'power hierarchies?'); sometimes they are an inadvertent consequence of describing a network of actors (symmetrical analyses), but often they are a purposeful and politically motivated attempt to disturb the received view of what is important, for example, by making 'invisible work' visible – an abiding endeavour of Susan Leigh Star (eg Star and Strauss, 1999) or to recover (as did Shapin) the contributions assistants, technicians or operators have made towards scientific progress(Shapin, 1989).

My second example concerns the way diagnoses and prognoses are made. Throughout the book Mesman traces the processes by which treatment decisions are negotiated and

consensus constructed. In this she draws on with a significant body of literature in STS where decision making has been analysed as a process of alignment. However, attention within STS turned from looking at methods of closure to exploring the multiplicities, disunities and incoherences of bodies, objects and knowledges (see in particular, Berg and Mol, 1998, and Mol, 2002). Here, analyses have highlighted how differences are not necessarily resolved, they endure. So whilst attention has in recent times focused on multiplicity, incoherence, difference, ambivalence, Mesman talks of consensus (however difficult it may be to achieve) and alignment. And whilst Mesman does make clear what a convoluted process this is, in the end, however, consensus is achieved.

I wonder if Mesman's argument and end point are tied to the examples she draws on. When I looked at these issues in my own work (Goodwin, 2009), I found in routine situations a certain degree of incoherence could be carried by, for example, disregarding a certain reading after going through a series of routine checks which provided a sense of security. But when I examined critical situations, where the urgency of the case forced the hand of practitioners, the problem with incoherent bodies came into focus: bodies that offer multiple, plausible but incompatible explanations for their presentation do not provide a direction for action. Clinicians, therefore, must work overtly to legitimate and account, as far as is possible, for each step, action, or intervention. The development of understanding clinical practice as a process of distributed decision making, with decisions shared amongst humans, devices, and routine practices, and where multiplicities, differences and incoherences exist, has been an incisive analytical resource within STS, but it fails to acknowledge that practice may not necessarily be viewed this way when questions of professional accountability are raised. In these circumstances, practice is often scrutinised retrospectively, with actions decontextualised and contrasted against ideal models of practice inscribed into guidelines and codes of conduct.

I wonder whether Mesman and I are making similar points here – actions, decisions must be made accountable and the more critical or extreme the situation, the more likely that somewhere along the line those decisions are going to be scrutinised retrospectively. In these cases some form of coherence must be forged. So perhaps it is Mesman's care to incorporate the juridical consequences of NICU practice into her analysis along with the cases she selected – which she points out were purposely selected for their level of complexity and illuminative strength – that lead her to focus on the construction of consensus.

Methodology

This leads me into my two final points which focus on aspects of methodology. Firstly, following from the suggestion above, Mesman acknowledges that she focused on complex cases where it was unclear what was needed and in the case of the parents she concentrated on situations in which the staff/parent relationship was somehow challenged. Such situations are indeed analytically rich but I wonder how her analysis might have looked if she had concentrated on more routine situations and rather than moments of tension, she had looked at situations of cohesion. This question comes to mind in the light of Mesman's own methodological orientation towards patient safety. Mesman suggests a focus not on error, troubles or weaknesses but on the 'resources of strength' in a practice, 'things that go well and how they are supposed to be' (Mesman, 2009: 1706). Might a focus on cohesion, for example, have brought Mesman to different conclusions about the position of nurses when participating in decision-making processes?

And finally, I'm interested in Mesman's knowledge as an ethnographer. Without exception, the fieldnotes are beautiful, evocative, respectful descriptions of practice accompanied by

sensitive explanations of the different rationalities that inform participants' actions. The fieldnotes recount such clear, plain, incisive, simple descriptions of 'what is going on' even when those situations are characterised by extreme levels of ambiguity and uncertainty. I was struck again and again as I read through the stories described in the book about the work this took: the filtering of what gets included/excluded from the fieldnote stories, what is known at that time and how to avoid being wise retrospectively. Furthermore, all the different parties' prevailing rationales are so clearly presented and this understanding isn't weighted towards any particular group (nurses/ doctors/ parents). I think it was not the purpose of the book to make methodological arguments, but as an ethnographer, and one interested in the sociology of knowledge, the ethnographer's knowledge and its presentation here intrigues me.

REFERENCES

- Anspach, R. 1987. Prognostic conflict in life-and-death decisions: the organization as ecology of knowledge. *Journal of Health and Social Behaviour*, 28, 215-231.
- Atkinson, P. 2002. Reading the Body. In: Nettleton, S. & Gustafsson, U. (eds.) *The Sociology of Health and Illness Reader*. Cambridge: Polity Press.
- Berg, M. & Mol, A. (eds.) 1998. *Differences in Medicine: Unraveling Practices, Techniques, and Bodies*, Durham: Duke University Press.
- Callon, M. 1986. Some elements of a sociology of translation: domestication of the scallops and the fishermen of St Brieuc Bay. In: Law, J. (ed.) *Power, Action and Belief: A New Sociology of Knowledge?* London: Routledge.
- Casper, M. A. B., M 1995. Constructivist Perspectives on Medical Work: Medical Practices and Science and Technology Studies. *Science, Technology & Human Values*, 20, 395-407.
- Cussins, C. 1998. Ontological Choreography: Agency for Women Patients in an Infertility Clinic. In: Berg, M. & Mol, A. (eds.) *Differences in Medicine: Unraveling Practices, Techniques, and Bodies*. Durham: Duke University Press.
- De Laet, M. & Mol, A. 2000. The Zimbabwe Bush Pump: Mechanics of a Fluid Technology. *Social Studies of Science*, 30, 225-63.
- Goodwin, D. 2009. *Acting in Anaesthesia: Ethnographic Encounters with Patients, Practitioners and Medical Technologies*, New York, Cambridge University Press.
- Gray, C. (ed.) 1995. *The Cyborg Handbook*, New York: Routledge.
- Griffiths, L. 2002. Humour as Resistance to Professional Dominance in Community Mental Health Teams. In: Nettleton, S. & Gustafsson, U. (eds.) *The Sociology of Health and Illness Reader*. Cambridge, UK: Polity Press.
- Haraway, D. 1991. *Simians, Cyborgs and Women: The Reinvention of Nature*, London, Free Association Books.
- Latour, B. 1986. The powers of association. In: Law, J. (ed.) *Power, Action and Belief: A New Sociology of Knowledge?* . London: Routledge.
- Latour, B. 1999a. Give Me a Laboratory and I will Raise the World. In: Biagioli, M. (ed.) *The Science Studies Reader*. New York: Routledge.
- Latour, B. 1999b. *Pandora's Hope: Essays on the Reality of Science Studies*, Cambridge, MA, Harvard University Press.
- Latour, B. 2004. Why Has Critique Run out of Steam? From Matters of Fact to Matters of Concern. *Critical Inquiry*, 30, 225-248.

- Latour, B. & Woolgar, S. 1986. *Laboratory Life: The Construction of Scientific Facts*, Princeton, NJ, Princeton University Press.
- Mesman, J. 2008. *Uncertainty in Medical Innovation: Experienced Pioneers in Neonatal Care*, Basingstoke, Palgrave Macmillan.
- Mesman, J. 2009. The geography of patient safety: A topical analysis of sterility. *Social Science & Medicine*, 69, 1705-1712.
- Mol, A. 2002. *The body multiple: ontology in medical practice*, Durham, Duke University Press.
- Radder, H. 1998. The Politics of STS. *Social Studies of Science*, 28, 325-331.
- Shapin, S. 1989. The Invisible Technician. *American Scientist*, 77, 554-63.
- Singleton, V. 1996. Feminism, Sociology of Scientific Knowledge and Postmodernism: Politics, Theory and Me. *Social Studies of Science*, 26, 445-68.
- Star, S. L. & Strauss, A. 1999. Layers of Silence, Arenas of Voice: The Ecology of Visible and Invisible Work. *Computer Supported Cooperative Work*, 8, 9-30.
- Suchman, L. 2010. Moving Nature/Culture. In: Johnson, E. A. B., B (ed.) *Technology and Medical Practice: Blood, Guts and Machines*. Farnham, UK: Ashgate
- Winner, L. 1993. Upon Opening the Black Box and Finding It Empty: Social Constructivism and the Philosophy of Technology. *Science, Technology & Human Values*, 18, 362-378.
- Zuiderent-Jerak, T. 2010. Embodied Interventions—Interventions on Bodies: Experiments in Practices of Science and Technology Studies and Hemophilia Care. *Science, Technology & Human Values*, 35, 677-710.
- Zuiderent-Jerak, T. & Bruun Jensen, C. 2007. Editorial Introduction: Unpacking 'Intervention' in Science and Technology Studies. *Science as Culture*, 16, 227-235.

Uncertainty in Medical Innovation: Experienced Pioneers in Neonatal Care – an author's reply

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INTRODUCTION

First I would like to express my deep gratitude to Shirlene Badger for organizing this event. Participating in such an exercise has been a great honour and I have tremendously enjoyed the opportunity. I also wish to thank Dawn Goodwin, Alex Faulkner and Paul Martin for reading my book critically and presenting such lucid comments. Their detailed observations gave me new and valuable insights into many of the issues addressed in my work.

To organize my reply I have clustered the various comments thematically. Most of the issues put forward by the critics of my book on neonatal care and its practitioners are related to the implications of my methodological choices and their intended and unintended consequences. It is not my intention to present another general methodological treatise on 'doing ethnographic research'. Rather, I will merely try to account to my critics for my way of doing ethnographic research in this particular study. I will begin by addressing the critical commentary on the relationship between my case-study design and my conclusions. Next, I will discuss the remarks on the focus of my study, and finally, I will provide more detail regarding my handling of the context of this study.

The structure of the book

Collecting data on an intensive care unit for newborns for many months in both the Netherlands and the United States is not always easy, to say the least. On the two wards I studied I set out to track the performance and interactions of doctors, nurses and parents as closely as possible. I observed their activities, listened in on their conversations, attended their meetings, talked with them about their hopes and fears, their joys and worries. I asked them what kept them 'going', and asked them about their motivations and expectations. When I returned to the rather mundane world of university life, I had collected a pile of data large enough to write at least a five-volume book series about my findings. This abundance, of course, called for the need of careful data selection. After gaining a better grasp and a more comprehensive understanding of the issues covered by my data, I developed my main argument and was able to select four case studies whose protagonists would act as the main characters of my account: Tom, Esther, Robert and Maureen. Furthermore, by highlighting one child's NICU journey (Tom's), I hoped to provide a kind of sustained narrative line throughout the book in order that might act as a backbone to my argument. At times this approach proved a daunting balancing act between narrative and argument, requiring a careful distribution of events and analysis. However, my decision to foreground one case throughout the book also made it easier to select useful issues and elements from my other case studies and disperse them throughout the text.

Although data selection is a tricky research challenge in its own right, my critics zoomed in on the issue of data presentation: 'what are the effects of this specific case-study design for my conclusions?' In other words, would another presentation of data have yielded other conclusions? To address this valid concern I wish to describe my decision-making process for the case-study design as it is.

While struggling with the question of structure, I attempted different scenarios. In one scenario each child would have the lead role in a separate chapter: 'Tom', 'Esther', 'Robert', 'Maureen'. In another scenario I emphasised the geography of my two sites of fieldwork: the book was divided in two, with one part about the Dutch ward and the other about the American ward. Another option I considered was a book in which each chapter had a specific focus, like 'people', 'machines', 'paperwork', 'numbers' and so on. At one point it also seemed worthwhile to organise my research materials along disciplinary lines (philosophical reflections, anthropological insights, ethical considerations, and so on), or along the line of the medical activities involved: 'diagnosis', 'treatment' and 'prognosis'. In each of these scenarios, surely, my case materials would be presented in quite divergent ways.

Evidently, a choice had to be made, but what exactly would be its implications? What were the advantages and drawbacks of each of these scenarios for my argument? Which lines of argumentation would I block if selecting the first or second scenario or one of the other options? These were tough questions, during the early stages of my book project. While trying to piece things together and seeking to find good reasons for each option, I realized it also seemed interesting and perhaps possible to organise my fieldwork data and the issues I wanted to address around a metaphor, such as the theatre metaphor or the travel metaphor.

After weighing all the various concerns I decided pursue the travel metaphor. I believed it would allow me more space to describe the actions and interactions of NICU staff and parents in the face of all the medical and ethical uncertainties involved. It would give me the opportunity to discuss issues related to time and space, to past events (experience) and future events (expectations), and to the people and things that accompany NICU children during their entire admission or part thereof. The travel metaphor would help me to introduce the spatial elements of the setting and its boundaries, as well as its insiders and outsiders. It would provide me with a discourse to describe how doctors and nurses make decisions and take actions under highly difficult and uncertain circumstances and how working at the cutting-edge of medical science has turned them into 'experienced pioneers'. This specific approach would provide a structure that allowed me to present nearly all of the arguments I wanted to make. Importantly, the travel metaphor reflected my own experience of doing research and exploring a hitherto unknown and daunting domain. If anything, my fieldwork and research interests had involved an exciting and occasionally trying journey into the strange and brave new world of life in the NICU.

What then are the implications of this particular case-study design for my general conclusions? My initial response to this concern would be that a different presentation of my data would have changed neither the lives of the children I write about nor the conclusions of this book. After all, my conclusions in the book are based on their lives. At the same time, however, and as I also demonstrate in the book, every order or arrangement of data has implications for what becomes more or less visible, for what becomes important or relevant, or for what is at the centre or at the fringes. If I had favoured any one of the other ordering scenarios, some issues might not have come out as prominently. Some may not have been included at all. This particular concern needs more elaboration. In the book's conclusion I argue that case-descriptions have particular consequences - a rule to which my work is no exception of course. Following the reflexive turn in STS, I have no other option than to argue that any change in my case-study design would certainly have had implications for the kind of conclusions presented. What exactly they would have been, or how different, is hard to say. But one can imagine that the third scenario mentioned above (a topic-based structure: people, technology, paperwork and numbers) would have excluded many of the interactions and interdependencies between the ward's various dimensions. Likewise, the linear scenario of diagnosis, treatment and prognosis would have obscured the fact that in practice these

activities occur as part of one and the same process, rather than being sequential. Opting for the scenario of having separate accounts of my fieldwork in the Netherlands and the United States would have positioned my work in the corner of international comparative analyses. This would have required another ethnographic design (including other Dutch and American wards) and an explicit description of the specificity of, and the differences between American and Dutch cultures. Clearly, then, my answer here is yes, the thrust of my conclusions would have been different if I had designed a different study.

The focus of the book

The predominant focus of the study is on so-called hard cases: on patients with serious conditions, or on tensions between the involved people. As explained in the introduction of the book “[t]he exploration of complex cases (...) is not meant to give the impression that NICU life is totally caught up in doubts and uncertainties” (p.6). Instead this focus serves a methodological purpose. These kinds of cases served as a magnifying glass to the implicit and various strategies that are used on the NICU in order to deal with uncertainty. The question posed by the critics is how my analysis might have looked if I had concentrated more on routine cases instead of extreme cases and more on moments of cohesion instead of tension?

Responding to this, I think my analysis would not have been all that different. First, in my book I pay ample attention to styles of ordering on the level of reasoning (repertoires), talking (vocabularies) and acting (scripts). I describe how these styles are also used in routine practices such as in the use of a respiratory machine and in the daily conversations of staff about parents. However, in a study of routine practices – rather than complex and highly uncertain cases – it is possible to miss parts of practice and styles of ordering. Second, I address not only moments of tension, but also situations of cohesion (cf. Esther’s case). In this example I describe how both the staff and the parents of Esther use prescribed styles of ordering. I highlight how the distribution of power might be different in moments of cohesion, as the end-of-life decision considering Esther demonstrates. This focus on these moments of cohesion shows that while nurses do not necessarily have more power, they certainly experience less frustration.

There is also the question of how the book would have looked if I had focussed more on incoherence and differences instead of alignment and consensus. In the beginning of the book, when introducing the world of neonatology, I focus on routine cases and describe a particular example of the functionality of an incoherent reasoning about the use of numerical data. Likewise, for example in the fifth chapter, I account for the differences among actors regarding prognosis, and how this affected the decision-making process of stopping or prolonging treatment.

In order to follow Dutch professional guidelines regarding end-of-life decisions, the staff and parents on a Dutch ward have to arrive at a consensus before taking any further actions. Therefore the convergence of their different positions is the object of analysis for one of the chapters. Here I describe the performances that bring facts and values in line with each other to legitimate decisions. However, my analysis makes clear that this involves more than just ‘following the rules’. The staff members perform several activities at various moments, including testing the robustness of facts as well as the flexibility of moral categories; exploring the available maneuvering space; examining disciplinary boundaries and the distribution of responsibilities; searching for the right words; constructing a consensus; and learning to deal with the consequences of a decision. The challenges of NICU life, in other words, require a situated morality in which the distinction between a ‘general moral category’ and ‘the child’s unique situation’ is resolved. Staff generate a custom-made morality that fits

not only the patient, but also the staff and parents. Consensus involves a distribution of responsibility and this can provide a basis for sharing the moral burden of these kinds of decisions. What may happen without this consensus became clear in the case of Maureen, where doctors, nurses and parents felt responsible but without any power to decide and act.

Following the life of Tom and other NICU patients allowed me to focus on routine cases (Tom's initial status on the NICU) and complex cases (what Tom became), on difference (the prognosis of Tom after four months) and consensus (Tom's prognosis after five months), as well as on cohesion (Esther) and tension (Maureen). On the NICU all these various issues and concerns are part of everyday practice.

The context of the book

My critics put forward the claim that my study presents the NICU as an independent entity, as if there is no relationship with the socio-cultural context and health care organization of which the NICU is part. First, they suggested that in my analysis the hospital organisation, including its 'contextual forces and power dynamics', is virtually absent. Indeed, this is an omission in my book. I was aware of it at the time of data collection but feared that if I would open 'the door' and explicitly account for what would come in from the outside, I had to follow these multiple threads all the way outside the ward into the hospital and probably beyond. To be honest, the decision I made at the time was that data I collected within the walls of the NICU and for which I had to account was already overwhelming. In this respect, my current fieldwork has taught me that in today's health care practice the broader health care context is much harder to ignore. The rapid changes in health technology and the public and political attention to health care, its quality and safety in particular, has led to many new (mostly non-medical) activities on the ward (for example, formalizing indicators, incident reporting and crew resource management (CRM) training). For this reason, it has become more relevant than ever to address the specific hospital context of the NICU practice.

Secondly, the comments of my critics about the lack of context in my study also tie in with the fact that my fieldwork was conducted in the nineties. What, I was asked, would my conclusion have been if it would be based on more recent fieldwork? Based on my current fieldwork on a NICU I can confirm that the styles of ordering are still in place, a view also confirmed by the staff members with whom I discussed my book. Moreover, according to them the extreme cases I describe in my book are no exception anymore and have become a common factor in the patient population.

Thirdly, as one of the critics submitted, there is the invisibility of the difference between the socio-cultural contexts in which the two NICU's of my fieldwork are situated. Although in my study I link all empirical excerpts explicitly to either Northeastern General Hospital (United States) or the Academic Medical Centre (Netherlands), my critics observe that a thorough description of the specifics of the socio-political-historical culture in which these hospitals are located is missing: as if it would be irrelevant to me that one ward is located in the United States and the other in the Netherlands. My response is that of course it matters. Yet at the same time it doesn't. Let me explain this apparent contradiction.

First, if there are evident cultural differences between NICU practices in the Netherlands and the US, not everything that is done and said is typical for either American doctors, nurses and parents or their Dutch counterparts. Some aspects are more specific for neonatologists, or for female doctors, or for fathers, to mention but a few categories. At the same time, in some cases the cultural context is a decisive element and where this was the case, it featured in my argument (for example in the case of life-ending decision-making). In these kinds of situations the cultural norms and values proved very apparent. For one thing, it

caused American staff members to collect more numbers and Dutch staff members to go and sit around the table with each other. The first group did so in anticipation of a possible lawsuit and they made sure to have enough hard data to back up their decision. The second group did so in the light of professional guidelines that instruct them to discuss these decisions in a multidisciplinary meeting and to come out of it with a decision based on consensus (a typical example of the Dutch 'polder' consensus model).

So the role of cultural context can make a huge difference and as such it is highly relevant in general. But this fact was not always highly relevant to my overall argument. Moreover, from a methodological angle, familiarity with one ward in each country seems hardly a solid base for bold claims about American ways of acting or Dutch style decision-making. This absence of a solid base is certainly a problem when aiming for an international comparative study. However, as I explain in my study, my fieldwork in the US largely served a strategic purpose: to minimise 'cultural blindness' by using the contrast of another medical setting in another culture – yet with the same level of advanced technology and training standards. This allowed me to see more clearly how actors operated in the Dutch NICU, as well as what 'doing cutting-edge medicine' entailed. This methodological decision proved quite helpful indeed.

Although I neglected the way hospital dynamics and power structures find their way into the daily practice of the NICU, while also downplaying the role of the two different cultures for the reasons mentioned, I did not refrain from paying attention to outside factors altogether. On the contrary, such factors played a major role in explaining fears of lawsuits in the United States and the multidisciplinary meetings in the Netherlands. Additionally, in my study the wider world also entered the ward in the form of culturally specific data on the rate of premature babies and teenage-mothers, on parental expectations as based on popular television series like ER, or on the admission rate of other ICU's or surgical possibilities. In these various ways, my study accounts for the outside world and how it comes in and effects the things that go on inside the NICU.

Swimming against the tide

According to one of my critics, I tend to 'swim against the STS tide'. Although written from an STS perspective there are three issues in which the book, according to this critic, differs from current STS studies: language, the principle of symmetry and a focus on multiplicities and differences. Although this critic considers this a noteworthy observation rather than a weak point of the book, I would like to respond to its first two elements (I have already touched on the issue of differences).

First, to the issue of language. The field of Science and Technology Studies has developed an extensive set of concepts to express and explain the complexities of the practices it studies. If my book qualifies as an STS study, its text largely avoids STS jargon. The reason for this absence has to do with my audience and the sensitivity of the practice I study. From the very start my ambition was to open up my work to a larger public than just my academic peers. If possible, doctors, nurses, parents, medical students, social workers and scholars from other disciplines should be able to understand my observations, arguments and conclusions and their implications. This decision had huge implications for the words I chose. To be accessible for a wider public required not only a less scholarly style of writing, but also the proper empathic tone, given that the practice of neonatology involves many sensitive moments and actions. For example, when I discuss the intertwinement of the NICU patients with the technology that surrounds them, the notion of 'cyborg' may seem useful and appropriate from an academic vantage point. Most scholars will read 'cyborg' as a concept that is embedded in a nuanced debate. Parents, on the other hand, might relate it to bad

science fiction movies and as such consider the use of this term as insensitive.

Second, there is the issue of symmetry that is based on the observation that I do not attempt to flatten existing hierarchies, such as those between qualitative and quantitative knowledge. Although I foreground the qualitative process in which quantitative data is produced, on the NICU quantitative data is what staff members consider as more reliable, better to work with, easier to communicate, easier to measure, a potential strong defence in court, etc. It is here that doctors and nurses do not wear a stethoscope but a pocket calculator. It is the position of quantitative activities and data in their daily routines of work that makes me conclude that the NICU is a quantitative practice, despite the obvious qualitative process in which they are generated.

Finally, swimming against the tide might well be part of my nature. In my current project, which is on patient safety, I do not study the causes of medical incidents, as many researchers tend to do, but I look at the causes of medical safety. A major motivation for this is the rather surprising notion, at least in my view, that in medical practice more incidents do not occur. Considering the complexity of critical care I would expect more mistakes, errors and incidents. So besides following protocols and high levels of training, what is it that makes particular practices safe?

Let me conclude once again by thanking my critics for their insightful remarks, questions and criticisms. They are valuable not only for opening new perspectives on my own book, but also for my current research project. It would be wonderful if these comments would inspire others to reflect on their work as well. After all, most of the choices I had to make are not intrinsic to my individual research project; they are intrinsic to doing research in general.

Human Bodies In Biomedicine And Biomedical Research

Report on themed sessions and panel event
at the 2011 BSA Medical Sociology Annual Conference

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The use of human biological material in medicine and research has greatly increased over recent decades, and the range of tissues, cells and organs which can be 'put to use' in this way has been extended. Whilst the arguments put forward by one social scientist, Richard Titmuss, have been immensely influential in how policy makers think about blood and tissue donation, they also refer to an older model of blood banking prevalent in the 1960s (Titmuss, 1970). Catherine Waldby, whilst acknowledging the significance of Titmuss's work, has argued cogently for the importance of researching the ways in which '[contemporary] medical systems that exchange and circulate tissues are also social systems' (Waldby, 2002: 309, my brackets). Over the past ten years, many sociologists and social anthropologists have taken up this challenge. Five papers presented in this conference session chaired by Helen Eborall and Madeleine Murtagh were united by their interest in this theme, and each addressed different aspects of obtaining and deploying tissues and cells in biomedicine and in research. As well as having biological objects in mind, they were shaped by diverse theoretical interests, including the framing of risk, the conceptualisation of self, identity and reproductive labour, and standardisation in scientific practice. The sessions were organised by Helen Eborall, who along with Catherine Will had identified some common interests in these papers, albeit that they had originally been submitted with other themes in mind. I will briefly outline the papers, before moving to draw out some common themes from the presentations, discussions and the related Convenors event.

Patricia Mahon-Daly and Helen Busby both presented work about blood, a 'staple' of the supply of biological materials that underpin contemporary medical practice across most health systems. Whilst one focussed on donors' narratives, the other addressed the governance of risk in relation to receiving blood products. Mahon-Daly's analysis of narratives from interviewed blood donors developed the notion that the body has been made hierarchical to create a ranking order of parts of the self: 'The ranking represents the sense that some biological material is experienced as more closely with the concept of the Self rather than the body.' She concluded by suggesting that there might be a hierarchical dimension to how people conceptualise parts of self, with blood representing a kind of 'liquid self' that was relatively easy to give away.

Busby set out the paradox of blood safety, that new risks have emerged or been manufactured, even as progress is achieved, which resonates with sociological discussions about the nature of risk in modern societies. Yet it was suggested that the framing of risk in terms of a 'chaotically interacting risk society', following Beck, does not do justice to narrating risk and safety in blood services, which should, rather be layered with the complexity of experience in this field. Accordingly, the specificity of the use of blood amongst different groups was stressed, as was the shifting nature of ethical relations between actors in this field. Asymmetry of information about risks had in the past characterised the relationships between professionals, regulators, and patients with a stake in blood safety. Given this

troubled history, Busby and her colleagues aim to contribute to current discussions amongst practitioners and policy makers about information and consent for people receiving blood, drawing on this research.

Margaret Boulos and Catherine Waldby both presented papers relating to Australian studies on perceptions of eggs provision for stem cell research, drawing on empirical data from fertility patients, reproductive egg donors, and young women about their views on the provision of eggs for such research. Boulos showed how the invitation to donate eggs in a research context shifts the focus from one of baby-making in the 'here and now' to the more intangible process of developing scientific knowledge. In the course of this shift, issues about property rights become more explicit. In short, Boulos suggests that the donation of the same biological materials in a research context represents a 'significant reconfiguration of the relationships that exist in the reproductive paradigm'. Recommendations formulated from the project had been of interest to policy makers, IVF service providers, and bioethical bodies in Australia and elsewhere. Waldby's paper drew on the Australian study described above, as well as on a study by Ehrich, Williams and colleagues (2010). Together these studies provided interview data about willingness to donate fresh or frozen embryos to stem cell research (in the UK) and oocytes (in Australia). In these studies, it was reported, patients undergoing assisted reproduction were found to be unwilling to donate oocytes or fresh embryos. However in both study groups, women were willing to donate frozen embryos after their own fertility treatment had terminated. Waldby argued that this pattern points to the decisive role that tissue banking in the form of cryo-preservation plays in patient deliberation in this area as it creates 'a margin for deliberation which is not present in the case of fresh embryo or oocyte donation'.

Jessica Wright addressed the issue of standardisation in cancer tissue banking. For Wright et al, standardisation in (cancer) tissue banking is not simply a matter of technical specification, but is subject to structuring by institutional and organisational contexts and norms. Calls for standardisation of processes of collection, storage and transport of human tissue samples for research purposes frequently feature in higher level discussions about scientific cooperation in this field, in which it is argued that attention to 'better quality' (and more consistent) samples and data would allow larger, more powerful research projects to take place. This significance of this might be that opportunities for rarer cancers to be studied would be enhanced. However, diverse practices -exist in tissue banking, and Wright et al sought to explore tensions between practices of standardisation at a more local level and these ideals related standardisation, via ethnographic research in tissue banks in two NHS teaching hospitals. They locate non-cooperation with standardisation in the mundane practices of everyday organisational life, and in wider institutional battles about scientific collaboration.

Taking the papers together, several key themes emerged: the sense that the repeated calls for donation and statements of need for tissues might be shaping peoples sense of self, in such a way as to put a value on their blood, organs, regenerative cells, and in effect to calculate which they were prepared to give away, and which might be 'inalienable'. Then, a reminder of the specificity of requests to donate tissues across different contexts, which also underpins the view expressed earlier, that the ease or willingness with which such tissues are given varies greatly. This is not only a matter of the symbolic or affective dimensions of tissues, but equally of the material practices around tissue banking, that allow some things to be possible and others not. Drawing this out, attention to the ways in which new techniques and technologies allow us to think in certain ways about our tissues and what they might do for us- or for others in the future- should continue an important aspect of sociological work on tissues and cells. The emphasis on specificity (both of tissues and of context) that has

characterised much of this work is in contrast to the approach traditionally taken in bioethics.

A linked 'Convenors event', chaired by Catherine Will, drew together a panel to discuss 'Human bodies in medical sociology. Discussants Naomi Pfeffer, Richard Tutton, Madeleine Murtagh and Catherine Waldby addressed their comments to the current state of play in sociological work in this field. The panel kicked off with a talk by Pfeffer who gave an overview of the recent Nuffield Bioethics Council's working group on 'Human bodies: donation for medicine and research', chaired by renowned anthropologist Marilyn Strathern. As the report had not been released at this time, it was discussed in broad rather than specific terms. Pfeffer reported that the group had undertaken a wide-ranging exploration of ethical issues relating to the demand for biological material as diverse as whole organs, blood, tissues and gametes. In addition, volunteering in first in human clinical trials was considered to be within the scope of the inquiry as it could be conceptualised in terms of a 'loan of one's body' for the purpose of research. The discussants then reflected on the research undertaken to date by sociologists in this field - who it was argued have tended to privilege certain novel or iconic tissues for their research, whilst overlooking tissues that might seem more mundane. In relation to the problem of 'insufficient supply' of tissues and organs, the panel felt that more investigation of what money does is needed so that- to quote Waldby-' sociologists could investigate how money might put objects (tissues and cells) into circulation, rather than accepting prevailing assumptions about the incompatibility of money and 'altruistic donation'.

As became evident when the report was subsequently released, the Nuffield working group had also been taking an interest in looking more squarely at in what money does /might do in this context.

The Nuffield report sets out a scheme within which consideration of diverse forms of tissue and cell donation should be unified, a scheme described as a 'ladder of altruism', and recommends that particular ethical scrutiny should be given proposals for interventions that offer people incentives, benefits in kind, or financial payments (Nuffield Council, 2011). There is now a growing body of sociological and anthropological research about the transactions that take place within 'tissue economies', that might contribute to this call for scrutiny, and further work is envisaged or underway. The question of how 'demand' for tissue is made manifest was also seen to be an important one in the discussion amongst those present at the conference session, many of whom felt that the rhetorical framing of need for such tissues in terms of 'shortages' was to be questioned. In this sense, there is some shared ground between the sociologists undertaking work in this field and the bioethicists endeavouring to draw out current issues.

Pfeffer drew a comparison between the new report and the Council's previous work on 'human tissues' (Nuffield Council, 1995). Whereas the Nuffield Council's first report on these matters had centred on more abstract ethical and legal conceptualisations, the Council had moved to a more 'people centred' perspective in the new inquiry. The contrast between the two reports is substantial, signifying some of the ways that thinking about these issues has developed in recent years. The 1995 Nuffield report and recommendations pre-dated a swathe of legislation related to the governance of human tissues, including the Human Tissue Act (2004). It focussed on the need to clarify what professionals may do, and to facilitate the legitimate use of human tissues, and its guidance was welcomed by many working in the field of tissue banking. But it largely bypassed discussions about cases in which the procurement of human tissues was seen as contentious. In retrospect, the lack of consultation or research with people with a stake in these issues-other than the professionals involved, is striking. The approach taken by the working group for the recent report 'Human

bodies: donation for medicine and research' is more engaged with a range of evidence and hence makes references to in depth sociological and anthropological work on human tissues – in contrast to its predecessor report which had referred mainly to points of law, professional guidelines and the scientific literature.

Catherine Will concluded the panel by reflecting on the challenge for sociologists wishing to influence debates conceived in broad terms, such as the recent Nuffield Council inquiry into the donation of human bodies. As we saw in some of these papers, 'carrying over assumptions' from one domain to another can be problematic. As is often the case in medical sociology, work grounded in the specificity of experience challenges the ease with which theories might ascribe generality to human experience. And these papers testified to the extent to which researchers are doing public sociology, as they begin to address the implications of their findings for legislative reviews, policy debates, and governance processes.

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http://www.britsoc.co.uk/NR/rdonlyres/A3448432-EBF9-422D-9611-E2B1AEDE41B1/0/MedSoc11_Paper_Abstracts_310811.pdf

REFERENCES

- Boulos, M. (2011) 'Good eggs': ideal donors for stem cell research. BSA Medical Sociology Annual Conference, 14-16 September.
- Busby, H. and Kent, J. (2011) Risk and Safety in the Blood Supply in the 21st Century: Perspectives from Qualitative Research with Patients, Professionals and Regulators in England. BSA Medical Sociology Annual Conference, 14-16 September.
- Ehrich, K., Williams, C., Farsides, B. and Scott, R., (2010) Fresh or frozen? Classifying 'spare embryos' for donation to human embryonic stem cell research., *Social Science & Medicine* 71 (12-6) : 2204- 2211.
- Mahon-Daly, P. (2011) Donated Blood: towards a hierarchy of Self. BSA Medical Sociology Annual Conference, 14-16 September.
- Nuffield Council on Bioethics (1995) Human tissue: ethical and legal issues.
- Nuffield Council on Bioethics (2011) Human bodies: donation for medicine and research. : www.nuffieldbioethics.org/donation
- Titmuss, Richard (1970) *The Gift Relationship: From Human Blood to Social Policy*. London: LSE Books.
- Waldby, C. (2002) "Stem Cells, Tissue Cultures and the Production of Biovalue", *Health*, 6 (3), 305-323.
- Waldby, C. (2011) Deliberation and preservation: the role of tissue banking in the decision to donate eggs and embryos for stem cell research. BSA Medical Sociology Annual Conference, 14-16 September.
- Wright, J., Dixon-Woods, M. and Eborall, H. (2011) The Battle of the Standard: Competing standards for cancer tissue banking BSA Medical Sociology Annual Conference, 14-16 September.

Web-links

http://www.britsoc.co.uk/NR/rdonlyres/A3448432-EBF9-422D-9611-E2B1AEDE41B1/0/MedSoc11_Paper_Abstracts_310811.pdf

First Sociology of Diagnosis Symposium held in Boston this Summer

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21 participants gathered at the Sociology of Diagnosis symposium at Pine Manor College in Boston, Massachusetts this past August 16, 2011 to discuss the ins-and-outs of this emerging sub-discipline. The scholars in attendance ranged from doctoral students to senior faculty and came from a wide range of places, from Waltham, MA to Virginia, Wisconsin, Canada, the UK and even New Zealand. A variety of disciplines were also represented; while most attendees were sociologists, there were a few anthropologists, nurse practitioners and even physical therapists in attendance.

Indeed, this event only punctuates a recent surge in sociological interest on diagnosis in the past two years. In 2009, Annemarie Jutel published her review of the sociology of diagnosis in *Sociology of Health and Illness*. Two books were also recently published on diagnosis, with Jutel's book *Putting a name to it: Diagnosis in Contemporary Society* (Baltimore: Johns Hopkins University Press) and PJ McGann, David Hutson and Barbara Katz Rothman's edited volume, *Sociology of Diagnosis: Advances in Medical Sociology* both coming out in 2011. Finally, a special issue from *Social Science and Medicine* was also released in late summer 2011

The one-day symposium was divided into four main sessions; the first was led by Annemarie Jutel and addressed the question of what it means to be 'a sociology of something'. An animated discussion ensued about the importance of studying diagnosis from a sociological perspective. Is being a sociology of something more than simply insisting that something become an object of sociological study? Diagnosis fulfils many social roles but it also provides an analytic lens through which we can see many issues that are of concern to sociologists, such as professional and institutional boundaries, resource allocation, authority, negotiation, lay-professional disputes, and social relationships. In the end, it was agreed that the sociology of diagnosis serves as a prism which brings together such key medical sociology topics as institutionalization, professionalisation, medicalisation, and embodied knowledge.

The second session, facilitated by Phil Brown, discussed the various methods and research questions that can be posed through the lens of a sociology of diagnosis, particularly pertaining to contested diagnoses. There was a call for more media analysis, more links to narrative analysis, and more science-in-action and research in settings where people are getting diagnosed. A variety of research avenues were also discussed, such as better understanding the various sources of contestation in diagnosis, and finally, some of the framing concepts that could buttress the sociology of diagnosis, such as labelling theory, uncertainty and negotiation.

The third session, led by Mary Ebeling, specifically addressed the pharmaceutical industry and other neo-liberal imperatives to individualize health and the burden of care. Examples discussed of Pharma's reach included self-diagnosis, patient consumer groups, ghostwriting, public awareness campaigns and direct-to-consumer advertising. Other questions raised included lay responses to drug advertising, Pharma's contribution of funding to research, and the boundaries between the food and pharmaceutical industries.

Finally, the last session, facilitated by doctoral student Tania Jenkins, capped off the symposium by discussing her summer experience in teaching the sociology of diagnosis, and the reasons that scholars might want to do that. Such a course can serve as a good elective for sociology students, particularly those with a background in medical sociology. It could also be especially pertinent to clinicians, by helping them rethink their practice. The goals of such a course would include sparking the sociological imagination, as well as spurring critical thinking among students of sociology and medicine. A list of useful resources (such as books and articles) was devised, and is available to those interested by e-mailing tania_jenkins@brown.edu.

Overall, this symposium proved to be a great success and serves to underline the importance of this emerging sub-discipline. The group hopes to meet at regular intervals, perhaps at the next ASA, and is always open to increasing its membership. For those interested in getting involved in the sociology of diagnosis, please contact annemarie.jutel@vuw.ac.nz.

Health Care Seeking For Hypertension In South West Nigeria

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ABSTRACT

Hypertension, also known as high blood pressure, is one of the most common non-communicable diseases affecting adults all over the world. It is now being widely reported in Africa, posing a different kind of health care challenge from infectious diseases. As a chronic disease that has to be managed (not cured), affected people have a life-long challenge to have the condition under control so as to prevent complications. The current study aims to study care seeking behaviour for hypertension in an urban Nigerian community. The study was a community based cross-sectional study that included a survey of 440 community residents who have hypertension; these comprised 65.2% women, about half had had no formal education, and half were traders. Key informant interviews were conducted with 23 health care workers, patent medicine vendors and indigenous healers in the community. A large proportion (63.4%) of the respondents reported that they sought care for their condition from a hospital/health centre while 5% said they go to the patent medicine vendor (PMV). Remarkably, all respondents used a combination of two or more of these facilities. About 1 in 10 of the respondents who visited the hospital still made use of traditional medicine, while 7.3% used both the PMV and traditional medicine. Findings from the key informant interviews show that the preference of hypertensive subjects for these health care providers (in contrast to going to hospital) because of ease of access, time savings and reduced costs. In conclusion, hypertensive subjects seek health from a wide variety of sources beyond the formal health care system. These findings have potential implications for programmes and policies to control hypertension and reduce complications in this and other similar developing settings.

Keywords: Hypertension, Care Seeking Behaviour, Indigenous Medicine, Nigeria

INTRODUCTION

Hypertension (also known as high blood pressure) is one of the most common non-communicable diseases affecting adults all over the world. It is now being widely reported in Africa and is the most common cause of cardiovascular disease on the continent. It is also a major factor in the high mortality of adults in sub-Saharan Africa (WHO, 2003). Hypertension remains a major global public health challenge that has been identified as the leading risk factor for cardiovascular morbidity and mortality as well as all-cause mortality (WHO, 2004; Joint National Committee (JNC) 7, 2003; Kearney, Whelton, Reynolds, Muntner, Whelton, He 2004). By itself, hypertension has no early recognizable symptoms and, as a result, patients with hypertension often come to medical attention late when they already have developed complications such as strokes, heart attacks, heart failure and kidney failure, all of which are major causes of death in the adult population. For this reason, hypertension is often called a 'silent killer' (Hoel and Howard, 1997). The burden of Non-Communicable Diseases (NCD) is rising rapidly nationally and globally constituting a major challenge to development (WHO, 2007). An increasing number of studies suggest that NCD will soon be the most important

cause of morbidity and mortality in developing countries (Kadiri, 2005; Commission on Health Research for Development, 1990; Feachem, 1992; Manton, 1988; World Bank, 1993). At the beginning of the 20th century, cardiovascular disease (CVD) was responsible for fewer than 10% of all deaths worldwide. Today, that figure is about 30%, with ~80% of the burden now occurring in developing countries. So prevalent is hypertension in Sub-Saharan Africa today that hypertensive heart disease might in fact be the most common form of CVD in Africa (Bradshaw, Groenewald, Laubscher, Nannan, Nojilana, Norman, Pieterse, and Schneider 2003; Cruickshank, Mbanya, Wilks, Balkau, Forrester, Anderson, Mennen, Forhan, Riste, McFarlane-Anderson, 2001).

Care Seeking Behaviour

Care seeking behaviour can be defined as personal actions to promote optimal wellness, recovery, and rehabilitation (Iyalomhe and Iyalomhe, 2010). Health-seeking behaviour is a part and parcel of a family or community identity being the result of an evolving mix of personal, experiential and socio cultural factors. It varies for the same individuals or communities (Iyalomhe and Iyalomhe, 2010). Multiple channels of health care exist in most countries. Although homeopathic and other forms of alternative medicine (for example herbal medicine) are utilized in some industrialized countries, the major channels of health care in the developed countries are cosmopolitan, western-style health care institutions like clinics, general and specialist hospitals. This is in contrast to the situation in Nigeria and in other developing countries where the channels of care which are utilized are more varied, consisting of indigenous healers, spiritual churches, pharmacies, Patent Medicine Vendors (PMVs) and hospitals (Erinosho, 1998). Various factors such as ethnicity, class, gender and other aspects of people's backgrounds (including family factors) seem to have a strong influence on health care-seeking behaviour (Bucquet and Curtis, 1986). With regards to hypertension, failure to achieve blood pressure (BP) goals – the target of treatment - may be attributable to the poverty of patients' knowledge, perception, attitudes and life-style practices (Mari, Ukai, Yamamoto, 2006; Iyalomhe, 2007; Ong et al, 2007; Petrella, Merikle, Jones, 2007).

Case, Menendez, & Ardington, (2005) examined patterns of health seeking behaviour of individuals who lived in the Northern KwaZulu-Natal region in South Africa prior to their death. It was discovered that significant positive associations exist between individuals' socioeconomic status, measured using household ownership of a variety of durable goods, and their use of medical services. The researchers found out that asset ownership correlate significantly to health status and health seeking behaviour. Individuals with greater economic resources are significantly more likely to seek treatment from private doctors, and spend considerably more for all types of health services. Individuals who are ill for a longer period before death are reported to see a greater number of health providers. While almost everyone interacts with Western medicine, those who are ill longer also see traditional healers and take non-prescribed medication. According to Amod, Jimba, Murkami, Silwal, Wakai, Kuratsuji, (2002), when rural Nepalese feel sick, they seek healthcare only when the sickness is considered moderate or severe. Mild illnesses are treated at home. When the villagers seek health care, they preferred to visit traditional healers first, before visiting other health workers. Thus, studies from multiple countries have documented the utilization of multiple sources of health care and factors that influence these choices.

Traditional health practitioners and their role in health care systems are acknowledged world-wide (Mbwana, Mahunnah and Kayombo, 2007). Utilisation of traditional medicine is apparently on the increase globally and is being given recognition by health insurance providers in developed countries (Ritchie, 2007). In Nigeria, herbal medicine appears to be

strongly considered by hypertensive patients as one of the viable alternative for a cure for hypertension (Oke and Bamidele, 2004). The reported use of herbal medicine in the general population from different parts of the world include 40% in the United States (Esenberg, Davis, Ettner, Appel, Wilkey, Van Rompay, & Kassler, 1990-1997), 38.5% among the Indian community of Chatsworth in South Africa (Singh et al, 2004) and 48.5% in Australia (MacLennan et al, 1996). Specifically amongst hypertensive subjects, Shafiq, Gupta, Kumari, Pandhi, (2003), reported that as many as 63.9% of their hypertensive subjects in a clinic in India took herbal medicines, while in Morocco 80% of patients with hypertension and diabetes used medicine plants to treat their ailments (Eddouks Maghrani, Lemhadri, Ouahidi & Jouad,H, 2002).

Patent Medicine Vendors (PMVs) – vendors that sell medicines - are also a source of treatment in sub-Saharan Africa. The patent medicine vendor (PMV) or “patent medicine seller” can be defined as a person without formal pharmacy training, who sells orthodox pharmaceutical products on a retail basis for profit (Brieger, Osamor, Salami, Oladepo, Otusanya, 2004). Over-the-counter (OTC) drugs which include common drugs like pain relieving tablets, antimalarials, cough syrups and so forth are the only drugs authorized to be sold by the vendors, but they generally sell all types of drugs as determined by their financial capability (Erhun, Babalola, Erhun, 2001) and ordinarily the patent medicines should be sold in their original packs. Notwithstanding, PMVs in Nigeria often stock OTC, controlled drugs (e.g. antibiotics and steroids), and perform procedures that are outside the scope of their licensing (Osamor, 2001). Patent medicine selling in Nigeria predates Nigerian independence in 1960 (Aderuka, 1975). The Pharmacy Law of 1946 requires that PMV be licensed (Nigerian Pharm. Law 1946, Egboh, 1984), and there are grades of licenses. Holders of License C can sell only proprietary or patent medicines such as aspirin, paracetamol, Chloroquine, cough syrups, worm expellers, vitamin tablets, blood tonic and eye drops containing isotonic solutions. Those with ‘B’ may in addition sell selected ‘poisons’ contained in part IV of the first schedule of the Pharmacy Law such as disinfectants (Abiola, Adeyinka,, Alhassan, Famuyide, Nwaorgu, Olujohungbe, and Uche, 1983), while only Pharmacists receive license ‘A’ and sell the full range of medication. Therefore, a PMV could be defined operationally as one duly licensed by an appropriate body or authority to sell patent medicine and who holds a patent and proprietary medicine vendors license in the form B or C as contained in the Pharmacy Law of 1946.

In 1951, the PMVs in the former Western Region (Edo, Delta, Oyo, Ogun, Lagos, Osun and Ondo States) of Nigeria came together to form the Nigerian Association of Patent and Proprietary Medicine Dealers, headquartered at Ibadan. The Association received a certificate of incorporation in 1962, and associations in other states have joined in accordance with a 1978 national affiliation agreement (Adeosun, 1988). State, district and town branches have been formed. The Association serves as a mediator between members and local, state and federal government. One effect of the association at local level may be the relative uniformity in pricing. Another may be the speed by which information about drugs spread among PMVs.

It is possible to define the PMV by observing his/her practices. Van der Geest (1987) distinguishes five functional categories of PMVs in Southern Cameroon:

- General shop keepers who also sell patent medicines
- Traders in the periodic markets who sell medicines along with other merchandise
- Drug peddlers who go from village to village
- Merchants who specialize in the sale of medicine
- Health workers who sell the medicines obtained from their institutions

PMVs are not only one of the most viable alternatives for purely rural residents seeking health care (Brieger, Ramakrishna & Adeniyi, 1986), they also sometimes form the first port of call as noted by Abiola et al (1983) and Brieger, (1988). No other distinguishing requirements are written into the law. Apart from administrative regulations, eligibility requirement for obtaining a patent medicine license is contained in the Pharmacy Law is quite general and vague. The State stipulates that for one to be awarded a license one must attain the age of 21 years and that one's application should be supported by two referees (Nigerian Pharm. Law 1946). The law does not specify any minimal educational qualification; the PMV is expected to have completed primary school. No formal training is demanded or organized, although licensees are given a pamphlet outlining relevant aspects of the pharmacy law. Though their ethics and competence have been challenged (Iweze, 1987), the ability of PMVs to provide accessible services, even in remote areas cannot be doubted.

The current study aims to study care seeking behaviour for hypertension in an urban Nigerian community. Hypertension is a significant and growing public health problem in developing countries, such as Nigeria. As a chronic disease that has to be managed, it is critical to understand the broad sociological context in which hypertension is experienced by individuals, their health care providers and the community. This research addresses an important gap in the knowledge of key sociological aspects of hypertension (the most common non communicable adult disease) in Nigeria: patterns of care-seeking behaviour and what potential factors influence care-seeking behaviour.

METHODS

Study Settings

This study was conducted in the Idikan community, Ibadan, a city in the south western part of Nigeria, as part of a larger community based study of the sociological aspects of hypertension. Ethical approval for the study was obtained from the Joint University of Ibadan-University College Hospital Ethical Committee. Idikan is located in the indigenous part of the city of Ibadan and has a population of 15,042 (National Population Commission, 2009). The health facilities in the community include an outreach clinic run by the Department of Preventive Medicine and Primary Care of the University of Ibadan, four private clinics and a small dental clinic run by the Dental Centre of University College Hospital (UCH). There are 150 registered patent medicine stores in the area. There are three traditional healing homes, and they are all accessible to members of the community.

Research Design

The primary study population were adults (above 25 years of age) residents of Idikan who are known to have hypertension. The study was a community based cross-sectional study. The study collected primary data using a survey, focus group discussion (FGD) and key informant interviews (KIIs). The goal of the FGDs was to capture in-depth information that is complementary to the survey. Eight FGDs were carried out. Key informant interviews were

held with community members with specific roles or occupations that include providing health care to people who have hypertension, namely: clinic nurses, community health workers, Patent Medicine Vendors (PMVs) and indigenous healers. Overall, 23 KIIs were conducted.

Data Management

The author reviewed all open-ended portions of the questionnaire; codes were later developed for coding all open ended responses. Data entry and management was carried out using the *Statistical Package for Social Sciences (SPSS)* version 14.0 (SPSS Inc. Chicago, ILL). Frequency distribution and chi-square statistical techniques were adopted to analyse quantitative data in the questionnaire. Univariate analyses were employed in interpreting socio-demographic characteristics of the respondents, while a bivariate analysis was used in cross tabulating variables. Computer assisted qualitative data analysis (CAQDAS) was carried out using the software package *ATLAS.ti*. In addition, manual content analysis was added to accommodate verbatim quotation in support of ethnographic findings.

Results

A total number of 440 respondents were studied, comprising 287 women and 153 men. The ages of respondents ranged from 25 to 90 years, with a mean of 60 (SD 12) years. Most of the respondents (71%) were married, while 25%, 2%, 2% and 0.5% were widowed, single, divorced and separated, respectively. There was no significant relationship between the sex of respondents and their age distribution (Figure 1). Majority (61.4%) of respondents were Moslems, 38.4% were Christians and 0.7% was a traditional religion adherent. Respondents with no formal education constituting the highest cluster, representing 51.1% of the total respondents. Those with only primary education constituted 19.5% while those with higher national diploma or bachelor's degree constituted 17.5% and 11.1% for those with secondary school level. However, those with other types of education like Arabic school constituted only 0.7%. Majority (50%) of the respondents were traders, while those who have retired and not working constituted 25.7% (Table 1).

Figure 1: Relationship Between Sex Of Respondents And Their Age Distribution

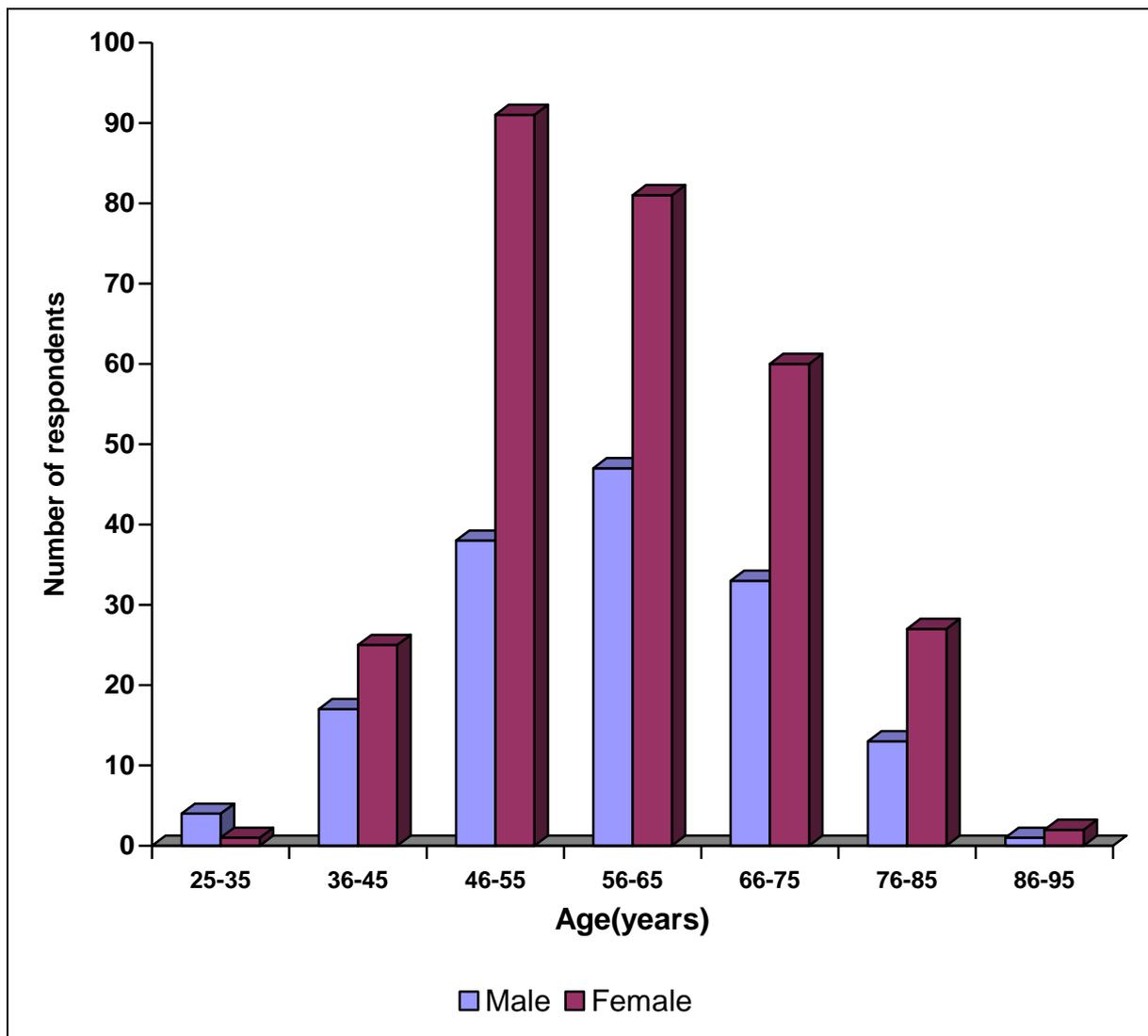


Table 1: Demographic Characteristics Of Respondents

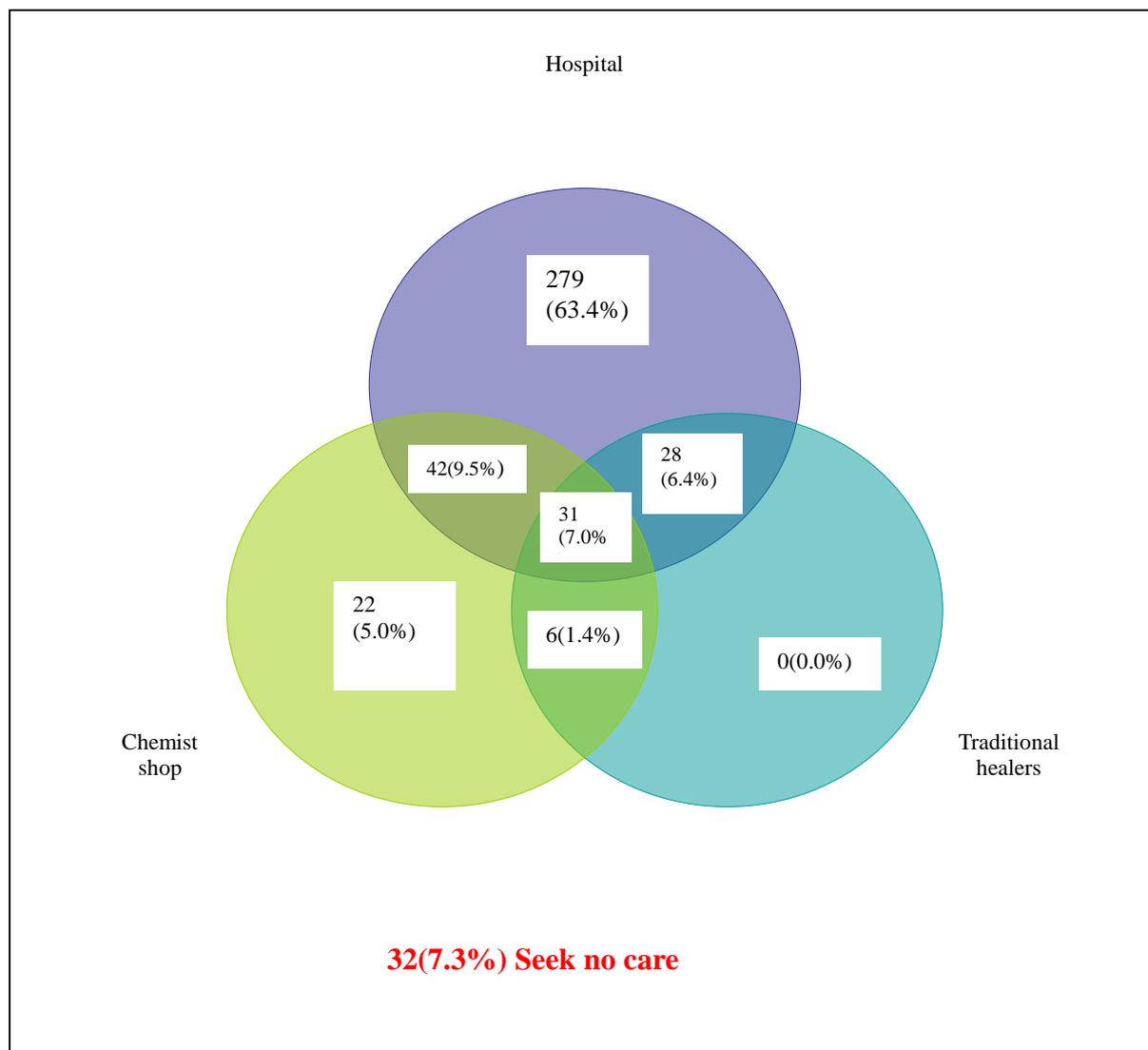
Characteristic	Number	Percentage
Religion		
Islam	270	61.4
Christianity	169	38.4
Traditional	1	0.2
Total	440	100
Ethnic Group		
Yoruba	434	98.6
Ibo	5	1.2
Isoko	1	0.2
Total	440	100
Educational Level		
No formal Education	225	51.1
Primary	86	19.5
Secondary	49	11.1
Post Secondary	77	17.5
Others (Arabic school)	3	0.7
Total	440	100
Occupation		
Trading	220	50.0
Artisan	49	11.1
Teaching/Civil Servant	43	9.8
Retired/not working	113	25.7
Religious Teachers	15	3.4
Total	440	100

Care Seeking Behaviour

In order to document the source of health facilities that respondents consulted for care for their hypertension, respondents were asked where they normally seek care for their hypertension. Figure 2 illustrates the different health facilities respondents consulted. A large proportion (63.4%) of the respondents reported that they sought care for their condition from the hospital/health centre (University College Hospital (UCH), community health centre and private hospital); while 5% said they go to PMVs. It was interesting to note that all

respondents used a combination of these facilities. Despite the fact that none of the respondent reported using indigenous healer exclusively, 9.5% of the respondents who visited the hospital still made use of traditional medicine, while 7.3% used both the PMV and traditional medicine.

Figure 2: Sources Of Health Care Facilities Utilised By Respondents



Some pertinent issues on the subject of choice of health care utilization were raised during the FGD session. One discussant said:

'I always rely on the research team. They give us free drugs. But since the project finished, some people go to UCH, only that the wahala (stress) to see doctor in UCH and the money to pay is too much. Sometimes, the nurses are shouting at you. As for me, since the research finished, I just go to the chemist (PMV) to buy my drug when I have the money.'

The moderator of the group session asked how he knew what drug to buy from the chemist and he said:

'I go to the chemist and tell them I want to buy drug for hypertension and show them the type they gave us in research clinic. I also know the shape and colour. Some people take their old prescription to the chemist to buy what they can afford'

A discussant from another group session had this to say:

'If you are told that you have hypertension, you can take traditional medicine and it will be cured. After the research team left, I use herbal medicine when I cannot buy the recommended drug. Traditional medicine is cheaper and if you do not have money, you can always go back and pay later. Nobody will give you medicine in the hospital on credit. Many people go to the chemist and babalawo (traditional healer) to complain and get help. It is faster and cheaper'

Another discussant from the same group session stated:

'I believe in prayers. I normally go to pray on the mountain because hypertension is from the devil and only God can deliver us. We have been going to the hospital for years and it is still there. Many people have died. Don't you see we can only ask God for help?'

Respondents were further asked if they used other methods of treatment other than western medicine. The finding showed that 70% said 'No', while 29.1% said 'Yes'. Table 2 represents the different methods used by respondents in addition to western medicine.

Table 2: Distribution of Respondents by their use of Non-Western forms of Treatment

Other methods used	Number	Percent
Traditional method (Herbs/concoctions)	83	18.9
Garlic	27	6.1
Herbs and Prayers	10	2.3
Prayers	5	1.1
Urine concoction	2	0.5

Interviews With Health Workers, PMVs And Indigenous Healers

Interviews with the community health care workers revealed that some of their patients do not like going to the nearest university teaching hospital (the University College Hospital, Ibadan) because the hospital visits are too stressful, including having to arrive early, waiting for hours before seeing the doctor and often not being able to go to work or attend to their trade for that day. They also said that they are made to do a lot of tests, which they often cannot afford. Often, they do not have enough money to buy their drugs and transport themselves back home. For these reasons, they prefer visiting the community health clinic to check their blood pressure (especially when they know when the doctor will be around) because the clinic visit is free, it is less crowded and they get attended to quickly so they can go to their place of trade or rest for the day. They then go to one of the PMV shops to buy as little antihypertensive medicine they can afford.

The interviews also revealed that some of these patients do not understand how serious hypertension is. When they feel better, they do not bother to go for their clinic appointments or even use their drugs.

One of the nurses interviewed said:

'Most people do not keep to their clinic appointment for two major reasons: Firstly, when they feel better, they do not see the need to go back for their appointment or go to see the doctor. They believe that the illness is cured. The second reason why there is poor utilization by hypertensive patients is money. Many people cannot afford to be going to the hospital every month and be collecting prescription to buy drugs. These things cost money. I also think that some people do not use health facilities because they forget or they traveled.'

Another nurse from the private clinic stated:

'Hypertension is not like many other sicknesses like malaria that is easy to manage and cure. You just take your medicine for a couple of days and you feel better. It is not easy to be going to hospital all the time and also swallowing medicine. When the research clinic was still going on, these people keep appointment because they are given free drugs and treatment free of charge.'

Interviews with the PMVs revealed that many hypertensive patients do not like going to the hospital and that is the reason they go to the PMV with old prescriptions to buy drugs when they feel sick. The PMVs also said that some of these people with hypertension believe that once they take their medication for some days, the hypertension will go away. But when they are sick, they come to the PMV to buy drugs and start again. As stated by one of the interviewed PMVs:

'People go to the hospital only when they are very sick and have no choice. In this Idikan, most people use the community health centre or private hospitals. Some others use traditional medicine. It is mostly when the case is serious that they go to the hospitals. Not many people comply with their clinic appointment. Once they have an old prescription, they just come to the chemist [PMV] to buy the medicine.'

The PMVs mentioned that there are times they ask their clients to go see a doctor because of the nature of some of their complaints. These people often refuse to go to the doctor because they claim they will still be given the same medicine in the hospital. So instead of (in their view) wasting time and money, they go to the PMV to buy their medications. In another interview, a PMV indicated that some of their customers use the health facilities and keep to their clinic appointment because they always come with new prescriptions from the hospital. The only problem is the fact that they do not always buy full medication dosage written on the prescription sheet because of lack of cash.

The indigenous healers on their part stated that many people do not like going to the hospital because it is expensive, and to see the doctor takes a long time. Even when they write the prescriptions for the drugs, the clients cannot afford to buy all, hence they prefer to go to the indigenous healer.

One of the indigenous healers interviewed said:

'Since the research where they were giving people free drugs finished, it is difficult for people to go to the hospital, hence they come to us. Even if they do not have money, we give them medicine and they can always come back to pay later. After all, we are all in this community and we know ourselves.'

The researcher wanted to know how often these community health care workers, PMVs and indigenous healers refer patients to the hospital. The nurses from the community health centre said they occasionally refer patients that are very sick and their blood pressure very high to the hospital. The community health centre is a clinic run by the Department of

Community Medicine, UCH, as a community outreach and it does not have facilities for admissions. On the other hand, a nurse from the private clinic said they do not often refer patients with hypertension to other hospitals because they have admission facilities and doctors. It is only when the patient is very sick that they refer them to UCH. Likewise, two of the indigenous healers said they do not send their customers away or refer them to hospitals for treatment. They only send them to the health centre to go and check their blood pressure.

One of the healers said:

'I do not send them away or anywhere. They come to me for help and I give them medicine. Why should I refer them to another place?'

Another indigenous healer has this to say:

'When I give them medicine, I ask them to go to the community health centre once in a while to check their blood pressure. I do not refer them. I treat them myself and some are well and cured.'

Yet another indigenous healer interviewed had a slightly different opinion about referral:

'When they are too sick, I ask them to go to the hospital so that nobody will die in my place. But when they can still walk around, I do not refer them or send them away.'

All the PMVs interviewed indicated that they do not have to refer anybody because the patients only come to buy drugs and not to be treated. The PMVs claimed they are not doctors and so cannot refer anyone. On the other hand, a couple of them said if they see any of their patients who look very sick, they just ask them to go and see the doctor.

DISCUSSION

Today it is recognized that, instead of being presented to health professionals, many symptoms are ignored, tolerated or self treated: a phenomenon known as the "symptom iceberg" (Hannay, 1979). Health seeking is worse for illnesses that are asymptomatic like hypertension. A feature of contemporary health care is the diversity in sources of help available. For example, an individual who feels unwell may consider contacting a hospital (formal or private), over-the-counter consultation (patent medicine vendors), indigenous healers or do nothing at all. In Nigeria, and in other developing countries, channels of care which are utilized are more varied, including indigenous healers, spiritual churches and pharmacies (Erinosho, 1998). Results from this study show the use of a combination of health care facilities among respondents. Despite the fact that none of the respondents reported using indigenous healers exclusively as a primary source of health care, 9.5% of the respondents who visited the hospital still made use of traditional medicine, while 7.3% used the PMV and traditional medicine. In a recent study (Harding and Taylor, 2002), of over 1,000 adults in Britain, 32% used an over-the-counter product or previously prescribed medication, 9% used home remedy or alternative medicine while under half (46%) dealt with their illness by taking no action. The present study and others show that various factors, such as previous experience with the medical system and financial burden were crucial to whether or not respondents choose to consult their doctors. According to Chuma, Thiede, & Molyneux, (2006), an important influence over treatment seeking behaviour is household ability to pay for health care. Other findings from a household survey conducted in Tblisi, Georgia, in 2000 reported that health care services are a financial burden. Members of the poorer households are less likely to seek care than people from more affluent households, and devote a higher share of household monthly expenditure to health care. According to Amod, Jimba, et al (2002), when rural Nepalese feel sick, they seek healthcare only when

the sickness is moderate and severe. Mild illnesses are treated at home. When the villagers seek health care, they preferred to visit indigenous healers first, before visiting other health workers. Thus, studies from multiple countries have documented the utilization of multiple sources of health care and factors that influence these choices.

The present study also revealed that patent medicine sellers were another main source of health care for the respondents. Patent medicine sellers or vendors (PMV) have become widespread sources of obtaining medications for various conditions and even for health care in many sub Saharan countries. Originally meant to sell only over-the-counter and non-prescription medications, their role has evolved to include the sale of prescription medications for multiple diseases (Ongore and Nyabela, 1996; Werner, 1981). In the present study, the reasons for the use of PMVs by respondents are practical: the patient saves time (no long waiting lines to see the doctor or at the pharmacy) and they can purchase any quantity based on the amount of money he/she has (does not have to “fill a prescription”). The downside is that they miss professional evaluation of their hypertension and the often-needed time to time adjustment of their medication types and dosages, which may make them more prone to poor control and complications.

It is important to highlight the importance of indigenous or traditional medicine in many sub Saharan African societies. This study identifies some of the factors that may be helpful to understand respondents' motive to use other method of treatment outside the orthodox treatment. The result suggests that the decision to use indigenous healers is influenced by perception of their effectiveness, barriers regarding visiting the hospital and availability of affordable medicine. In support of this, Oke and Bamidele (2004) in a survey on misconceptions about hypertension amongst 1365 Nigerians hypertensives, noted that 21% of the respondents were of the opinion that they would achieve a permanent cure of hypertension only from alternative medicine practitioners. Our findings were also similar to other studies where patients' perception of the therapeutic efficacy of alternative medicines were assessed. In these studies, more than half of these alternative medicine users perceived that the alternative health care was responsible for some noticeable improvement in physical or psychological well being (Kappauf et al, 2000; Harnack et al, 2001).

Findings In The Context Of Health Care Providers

This study used qualitative methods to gain a better understanding of key informants (community health workers, indigenous healers and PMVs) as they have interacted with and cared for people with hypertension in the community. Understanding their perception of hypertension in the community and other recurrent issues is necessary as they are a link between the community they serve and the health sector. These key informants seemed to have insufficient knowledge and health information on the cause and curability of hypertension and, similarly to the hypertensive respondents, attributed stress as the cause of hypertension. A recurring theme is that of combining medical treatment with other remedies including traditional and use of over-the-counter medication. The respondents used the non-Western indigenous medications alongside the prescription medication in contrast to the findings of another Nigerian study (Olisa & Oyelola 2009) who found that patients discontinue prescribed medication in favour of traditional medicines. Data from the study revealed that people fail to understand why they should continue with hypertension treatment for life, especially when they do not experience pain. Therefore, they conclude that the western medicine is not very effective, and start looking around for the cure for the condition. The data with these key informants confirm that respondents often combine treatment from various sources, sometimes because they believe they will get cured using indigenous medicine.

Interesting group-specific findings emerged from the key informant interviews. As a group, indigenous healers strongly believed they could cure hypertension in contrast to the nurses in the community who said hypertension can only be controlled, not cured. PMVs saw their role as the sale of medicine and not that of treating patients, in contrast to the other two groups who saw themselves as health care providers. A noteworthy finding from this component of the study is that these health workers have developed ideas about hypertension from long-term observation of their client's behaviours and interaction with their clients. Illustrative of this is the indigenous healer who stated that he does not think hypertension can be cured because he has clients who still have hypertension despite being treated for a long time with both indigenous and Western medication. It was instructive how frequently during the key informant interviews that the community health workers, indigenous healers and PMVs cite or quote their clients. This implies that these key informants have a view of the experiences of people with hypertension that the health professionals in hospitals and medical centres do not see. In summary, the findings from the key informant interviews confirm and extend many of the findings from the survey of hypertensive respondents.

There are some limitations to this work. While this study generated a wealth of useful data on sociological aspects of hypertension, it is not certain how generalizable these findings are to other communities, which may have different demographic, cultural and other characteristics. Therefore, the findings should be regarded as reflecting primarily this study community and may be generalizable to other southwest Nigerian communities only to the extent that they resemble the study community. Given the known differences between men and women in health care seeking behaviour, it would have been useful to enroll equal number of men and women. This is a limitation of this study.

More studies of the sociological aspects of hypertension are needed. However, because hypertension does not display any major symptoms, there is the need for community screening in order to detect the condition and improve awareness in the community. Without these preliminary steps, it may be quite difficult designing and conducting sociological studies of hypertension because the lack of awareness means no experience of care-seeking, treatment or living with the disease. Therefore, community screening is an essential step that will facilitate future sociological studies. A key finding in this study, in common with several such studies from developing countries, is the role of multiple community based care providers (clinic nurses, PMVs, indigenous healers) in the treatment of hypertension. In contrast, hypertension care is hospital/clinic based and access to health care is near-universal in most industrialized nations. These differences (as well as others) suggest that it would be desirable to develop and evaluate models of community based management of hypertension in our environment. Such studies would link sociological research with action to control hypertension in the community.

In conclusion, this work has produced both quantitative and qualitative data on care seeking behaviour, a key sociological aspect of hypertension as experienced in a Nigerian community by people who have hypertension and their health care providers in the community. The findings provide a resource for understanding the context of hypertension care-seeking behaviour in this urban Nigerian environment and could serve as input into health policies and programmes designed to control hypertension.

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REFERENCES

Abiola, AB, Adeyinka, AF, Alhassan, MR, Famuyide, AO, Nwaorgu, OGB, Olujohungbe, ABK and Uche, FN, 1983, 'A Qualitative Assessment of Medicine Sellers in Igbo Ora' Project report (A' 87V), Ibarapa Posting, Department of Preventive and Social medicine, University of Ibadan

Adenika, FB 1975, 'Pharmacy Practice Management in Developing Communities', Literamed Limited, Ikeja, Lagos. pp. 25-37, 96-102, 241-245.

Adeosun, P, 1988, 'Brief history of the National Association of Patent/Proprietary Medicine Dealers' Presented at the Silver Jubilee Celebration of the National Association of P/P MD, Lagos, Nigeria, 11 May.

Amod, K Jimba, M Murkami, I Silwal, RC Wakai, S Kuratsuji, T 2002, 'A indigenous healers' training model in rural Nepal. Strengthening their roles in community health'. *Tropical Med and Int. Health*. Vol. 8, no.10, pp 956.

Beaglehole, R & Yach, D 2003 'Globalisation and the Prevention and Control of Non-Communicable Disease: The Neglected Chronic Diseases of Adults'. *Lancet*. 362:pp.903-8.

Brieger, RW Osamor, PE Salami, K Oladepo, O & Otusanya, SA 2004, 'Interactions between patent medicine vendors and customers in urban and rural Nigeria' *Health policy and planning*; vol 19, no. 3, p. 177-182

Brieger, WR Ramakrishna, J & Adeniyi, JD, 1986, 'Self-treatment in rural Nigeria, a community health education diagnosis' *Hygie* vol.5, no.2, pp. 41-46.

Brieger, WR 1988, 'Drugs too freely available' *A.R.I. News* No. 11, August 1988, AHRTAG, London.

Buquet & Curtis 1986, 'Socio-demographic variation in perceived illness and the use of primary care: The value of community survey data for primary care service planning' *Soc. Sci. and Med*. Vol.23, No7, pp.737-44

Case Menendez, A & Ardington, C 2005 'Health seeking behaviour in Northern KwaZulu-Natal' CSSR Working Paper 05/116 (submitted to *Social Science and Medicine*)

Chuma, J Thiede, M & Molyneux, C 2006, 'Rethinking the economic costs of malaria at the household level: Evidence from applying a new Analytical Framework in Rural Kenya' *Malaria Journal*, vol. 5, pp. 76-90

Commission on Health Research for Development Health Research. Essential link to equality in development. New York. Oxford University Press, 1990

Cruickshank, JK Mbanya, JC Wilks, R Balkau, B Forrester, T Anderson, SG Mennen, L Forhan, A Riste, L McFarlane-Anderson, N 2001, 'Hypertension in Four African-Origin Populations: Current 'Rule of Halves,' Quality of Blood Pressure Control and Attributable Risk of Cardiovascular Disease' *Journal of Hypertension*, vol.19, pp. 41-46

Eddouks, M.; Maghrani, M Lemhadri, A Ouahidi, ML & Jouad, H 2002 'Ethnopharmacological survey of medicinal plants used for the treatment of diabetes mellitus, hypertension and cardiac diseases in the south-east region of Morocco (Tafilalet)' *J. Ethnopharmacol*, vol 81, no.1, p. 81 - 100.

Egboh, AA 1984. Pharmacy Laws and Practice in Nigeria. Literamed Publications, Ikeja.

Eisenberg, DM Davis, RB Ettner, SL Appel, S Wilkey, S Van Rompay, M & Kassler, RC 1998, 'Trends in alternative medicine use in the United States, 1990-1997: Results of a follow-up National Survey' *JAMA*, vol. 280, pp. 1569-1575

- Erhun, WO Babalola, OO Erhun, MO 2001, 'Drug Regulation and Control in Nigeria: The Challenge of Counterfeit Drugs', *Journal of Health & Population in Developing Countries*, vol 4, no.2, pp. 23-34
- Erinosho, OA 1998, 'Health Sociology for Universities, Colleges and Health-Related Institutions' Bookman Social Science Series
- Feachem, FGA Kjeflstrom, CJC Murray, M & Phillips, MA (eds) 1992, 'The Health of Adults in the Developing World', New York; Oxford University Press
- Hannay, R 1979, 'The Symptom iceberg: A study in Community Health. London', Routledge and Kegan Paul.
- Harding, G & Taylor, K 2002, 'Social dimensions of pharmacy: (2) power, status and pharmacy', *Pharmaceutical Journal*, Vol. 269 pp.440-2.
- Harnack, LJ Rydell, SA & Stang, J 2001, 'Prevalence of use of herbal products by adults in the Minneapolis/St. Paul, Minn, metropolitan area', *Mayo Clin Proc.* Vol. 76, no.7, pp. 688-694
- Hoel, D. & Howard, RB 1997, 'Hypertension – Stalking the Silent Killer' *Postgrad Med. J.*, vol. 101, pp.116-121.
- Iweze, EA 1987, 'The patent medicine store: Hospital for the urban poor. In the urban poor in Nigeria' (Edited by Makinwa P. K. and Ozo O. A.), pp. 317-322.
- Iyalomhe, GBS 2007, 'Compliance to antihypertensive therapy', *Nig. Clin. Rev. J.* vol. 63, pp 12-16.
- Iyalomhe, GBS & Iyalomhe, SI 2010, 'Hypertension-related knowledge, attitudes and life-style practices among hypertensive patients in a sub-urban Nigerian community', *Journal of Public health and Epidemiology*, Vol. 2, no.4, pp. 71-77
- Joint National Committee (JNC) on Prevention, Detection, Evaluation and Treatment of High Blood Pressure: The JNC 7th Report (2003). *JAMA* vol. 289, pp. 2560-2572.
- Kappauf, H Leykauf-Ammon, D Bruntsh, U Horneber, M Kaiser, G Buschel, G & Gallimeier, WM 2000, 'Use of and attitudes held towards conventional medicine by patients in a Department of Internal Medicine/Oncology and Haematology', *Support Care Cancer*, vol. 8, no.4, pp.314-322
- Kearney, PM Whelton, M Reynolds, K Muntner, P Whelton, PK He, J 2004, 'Global burden of hypertension', *J. Hypertens*, vol. 22, no.1, p. 140.
- MacLennan, AH Wilson, DH & Taylor, AW 1996, 'Prevalence and cost of alternative medicine in Australia', *lancet*, vol. 347, pp.569-573.
- Manton, KG 1988, 'A longitudinal study of functional change and mortality in the United States' *Journal of Gerontology: Social Sciences* vol. 43, S153-S161
- Mari, H Ukai, H Yamamoto, H 2006, 'Current status of antihypertensive prescription and associated blood pressure control in Japan', *Hypertens. Res.* Vol. 29, pp 143-151.
- Mbwambo, ZH Mahunnah, RLA. & Kayombo, EJ 2007, 'Traditional health practitioner and scientist: Bridging the gap in contemporary health research in Tanzania', *Tanzania Journal of Health Research.* Vol. 9, no.2, pp 115-120
- Nigerian Pharmacy Law, Chap 92. Federal Ministry of Health, Lagos,.Nigeria. 1946.
- National Population Commission, Nigeria Demographic and Health Survey, 2009
- Oke, DA & Bamidele, EO 2004, 'Misconceptions of hypertension' *Journal of the National Medical Assoc.* Vol. 96. no. pp.1221-4.

Olisa, NS & Oyelola, FT 2009, 'Evaluation of use of herbal medicines among ambulatory hypertensive patients attending a secondary health care facility in Nigeria', *Int J Pharm Pract.* Vol.17, no.2, pp.101-5.

Ongore, D. & Nyabele, L 1996, 'Role of shops and shopkeepers in malaria control', *East African Medical Journal*, Vol. 73, p.6

Ong, KL Cheung, BM Man, YB Lau, CP Lam, KSL 2007, 'Prevalence, awareness, treatment, and control of hypertension among United States adults 1999-2004', *Hypertension*, vol. 49, pp. 69-75.

Onwujekwe, O & Uzochukwu, B 2005, 'Socio-economic and geographic differentials in cost and payment strategies for primary health care services in Southeast Nigeria', *Health Policy*, Vol. 71, pp.383-397

Osamor, PE 2001, 'Knowledge and selling practice of patent medicine vendors (PMV) regarding the treatment of malaria in Idikan community, Ibadan, Oyo State', University of Ibadan: A dissertation in the Department of Health promotion and Education, College of Medicine, 2001

Petrella, RJ Merikle, EP Jones, J 2007, 'Prevalence, treatment and control of hypertension in primary care: Gaps, trends and opportunities', *J. Clin. Hypertens*, Vol.9, no.1, pp.28-35.

Ritchie, MR 2007, 'Use of herbal supplements and nutritional supplements in the UK: what do we know about their pattern of usage?', *Proc Nutr Soc.* Nov, vol. 66, no.4, pp.479-82.

Shafiq, N Gupta, M Kumari, S Pandhi, P 2003, 'Prevalence and pattern of use of complementary and alternative medicine (CAM) in hypertensive patients of a tertiary care center in India', *Int J Clin Pharmacol Ther*, vol.41, no.7, pp.294-298.

Singh, VL Raidoo, DM Harries, CS. 2004, 'The prevalence, patterns of usage and people's attitude towards complementary and alternative medicine (CAM) among the Indian community in Chatsworth, South Africa', *BMC Complementary and Alternative Medicine*, 4:3

SPSS for Windows (version 11). Chicago: SPSS Inc; 1999

Van Der Guest, S 1987, 'Self -care and the informal sale of drugs in South Cameroon'. *Social Science Medicine*. Vol.25, No.3, pp 293-305.

Werner, D 1981, 'Where there is no Doctor'. A village health care handbook. Macmillan London.

WHO. Prevention and control of noncommunicable diseases: implementation of the global strategy Report by the Secretariat. Document EB120/22, WHO, 2007

WHO/ International Society of Hypertension 2004, 'WHO/ISH statement on management of hypertension' *J. Hypertens*. Vol. 21, pp. 1983-1992.

World Health Organization. 2003, 'Journal of Hypertension', Nov, vol. 21, no.11, pp. 1983-1992

World Bank. World Development Report, 1993, Investing in Health, New York: Oxford University Press.

BSA MedSoc Regional Groups

There are a number of BSA Medical Sociology Regional Groups around the UK which regularly organise local events. Joining one is a great way to meet colleagues in your area and stay linked in to the MedSoc community throughout the year. Existing Regional Groups are:

- London
- East Midlands
- West Midlands
- North West
- South West
- Wales

See the MedSoc Regional Groups page on the BSA website for contact details:
<http://www.britsoc.co.uk/medsoc/MedSocRegionalGroups.htm>

IF THERE ISN'T ONE NEAR YOU, WHY NOT START ONE?

The BSA Medical Sociology Group Committee is keen to support the establishment of new Regional Groups in areas that are not covered. For example, currently there is no Scottish group and we encourage interested volunteers to set one up. Funding is available on an annual basis to support events and networking.

For further details please contact Graham Martin (gpm7@le.ac.uk).