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## **EDITORIAL FOREWORD**

Our team based at the University of Liverpool has been editing the newly named journal Medical Sociology online for four years, carrying on the 41 year tradition in the UK, of a publication associated with the British Sociological Association's (BSA) Medical Sociology group, or MedSoc as it is more commonly known by its members. When putting together this edition, we have been impressed by the variety of submissions that have been sent to us for review: from epidemiological studies to auto-ethnographic accounts, all employing a variety of methodological approaches and drawing on different literatures.

We have included two papers in this edition: the first is ME: The rise and fall of a media sensation, where Patricia de Wolfe explores the natural history of the controversial and influential media coverage of Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS). In her analysis, de Wolf draws attention to the different constructions of this illness which delineated and divided medical practitioners and sufferers alike. While many people with ME/CFS favoured an organic explanation of ME/CFS as a 'disease', and actively sought social recognition as people experiencing a chronic illness, others, usually from bio-medical sciences, including doctors, tended to favour the explanation of ME/CFS as a mental health disorder, manifesting itself as a collection of apparently physical symptoms. By locating the roots of the disease in documented cases of 'female hysteria', these gendered biomedical explanations were picked up and turned over by the media, leading to new constructions of the illness over time. Similarly the class/ occupation influenced designation of 'Yuppie 'Flu' reflected contemporary preoccupations with new working practices and upward social mobility.

In contrast to this exploration of the media, Lorraine Ritchie's article; Wearing two hats: interviewing older people as a nurse researcher, is a personal reflexive account of her experience of interviewing older people as a nurse and also as a researcher. Through an exploration of these two roles, Ritchie draws our attention to the dilemmas a number of people with occupational identities experience once they start to conduct research, which in other research disciplines are not always fully explored. Hannah Bradby's opinion piece, is a similarly personal account, reflecting and analysing how it 'felt' to experience a major lifeevent (surgery), without at the time meeting the person who conducted the surgery. While Sarah Collins in her response argues that this not usual, both writers highlight the need for personal communication between doctors and the people who for a time, become patients in their care.

If you have any comments about this edition or would like to contribute to the publication, please email the editorial team on MSo@liverpool.ac.uk. If you would like to submit an Medical Sociology please peer-review to online, http://www.medicalsociologyonline.org/submissions.html

## The University of Liverpool Editorial Team

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# ME: The rise and fall of a media sensation

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#### **ABSTRACT**

ME (also known as chronic fatigue syndrome), a medical disorder of unknown aetiology, generated considerable media attention in the late 1980s and during the 1990s. Patients insisted they suffered from an organic disease, while certain lay and medical commentators construed the condition variously as an effect of female hysteria; as a form of depression manifesting itself in physical form; and most famously, as 'yuppie flu', an affliction of stressed young professionals. This article documents the origins of the controversy, explores the principal constructions of ME that arose amongst commentators and the assumptions that underlay them, and traces the differing fate of the diverse constructions in subsequent years.

#### Introduction

The late 1980s saw the very public commencement of a controversy about the nature of a contested medical condition, ME. Patients vehemently insisted that they were the innocent victims of an unexplained incapacitating organic disease, while many medical practitioners and social commentators interpreted the symptoms, from a variety of perspectives, as psychological or self-inflicted. The disorder was widely termed 'yuppie flu'. Twenty years on, however, ME, though still prevalent and still controversial, no longer hits the headlines; and, notably, it is no longer construed as a symptom of a pathogenic society.

This retrospective was prompted by the realisation of how media coverage of the condition has altered, and how certain constructions have waned. However, the reasons for this change are not obvious. In particular, recent economic events have highlighted the extent to which greedy city high-fliers, formerly seen as prime candidates for ME, still abound. Concerns about combining motherhood with work - apparent in some discourses on ME endure (Carvel, 2008). A diagnostic marker for the disorder continues to elude researchers (ME Association, 2007). The preconditions for much of the furore about ME thus still appear to be in place – but certain aspects of the furore have subsided. These considerations led me to ask why the debate arose when it did, in the form it did, and in what respects it has since been transformed.

In an attempt to throw some light on these issues, I examine the various constructions of ME at the height of the controversy, and the assumptions underlying them. I focus on the pronouncements of those who construed the condition in ways not envisaged or favoured by many patients, rather than those of patients and their sympathisers; it is the constructions propounded by the former, rather than the latter, that, after an initial period, dominated the media coverage. The pervasive 'yuppie flu' construction plainly arose from its social context, and I go on to consider what, socially, may have changed as it ceased to be prevalent. I begin with a brief account of the way in which ME first entered the public domain.

### The emergence of ME

On 1 June, 1986, the *Observer* newspaper carried a feature entitled 'A disease doctors don't recognise'. The author, Sue Finlay, wrote of her disabling illness, which she named as Myalgic Encephalomyelitis (ME) or post-viral fatigue syndrome. (It is now also widely

known as chronic fatigue syndrome, or CFS.) She described her symptoms - exhaustion, extreme muscle weakness, joint pains, mood disturbances, deteriorating eyesight, vague stomach problems - and related her long and frustrating search for a diagnosis, and thereafter for medical help. She claimed that thousands of people in Britain shared her predicament, enduring years of physical misery while doctors ascribed their problems to 'nerves'. Readers were invited to write to the Observer for a factsheet; over 14,000 people responded, and a year later, Sue Finlay was receiving over 200 enquiries a week (*Observer*, 2 August, 1987). It was the beginning of a publicity campaign which would make ME a household name, and in the course of which it would become the subject of heated controversy about its nature and significance.

The debate about ME in this country was not new, although the issue had attracted little attention for many years. In 1955, an epidemic swept through the Royal Free Hospital in north London, affecting nearly 300 people, mainly nursing staff, some of whom appear never to have fully recovered (Ramsay, 1986). Although they could not isolate the organism causing the symptoms, doctors were certain that they were dealing with an infectious disease.

A subsequent editorial in the Lancet (1956) reviewed a number of apparently similar outbreaks, distinguishing the symptoms from those of known viral conditions such as poliomyelitis, as well as from those of hysteria. It proposed the name 'benign myalgic encephalomyelitis' ('benign' denoting absence of fatalities) for the newly identified syndrome. In a comparison of 14 episodes of paralytic illness in various parts of the world, beginning with an outbreak in Los Angeles in 1934, Acheson (1959) provisionally endorsed the Lancet's He considered at some length (ibid.: 589-591) the possibility that these epidemics might be due to hysteria, but dismissed this as improbable on a number of grounds, including similarities in the symptomatology and course of the illness across many types of community.

However, two British psychiatrists later reviewed the records of the Royal Free patients, and in 1970 published two papers in the British Medical Journal arguing that the supposed viral epidemic was in fact an episode of mass hysteria (McEvedy and Beard, 1970a; 1970b). Pointing to the high proportion of female nurses amongst those affected, they suggested that this type of condition often proliferated when large numbers of women were cloistered together. This view rapidly became medical orthodoxy. Despite the foundation in 1976 of the ME Association, a charity for the support of sufferers, and despite apparently similar outbreaks in the UK in 1974 and 1980 (Bell, 1991: 96), the disorder lapsed into obscurity.

Within months of Sue Finlay's 1986 article, however, publicity about ME began to abound. A new patients' pressure group (the ME Action Campaign, later renamed Action for ME) was formed, with Sue Finlay as one of the trustees, and the navigator Clare Francis, herself diagnosed with ME, as president. The ME Association - despite its lack of involvement in the publicity drive - reported a trebling of its membership within a year (Blackman, 1988).

At first, much of the media coverage was sympathetic, with ME reported as a serious, neglected disease caused by the persistence of a virus in the body. Before long, however, medical practitioners and journalists began to propose explanations of ME in terms of the personality of the sufferer. The term 'yuppie flu' became widespread - linking the condition no longer to gender, but to class. (This term originated in the USA, where an epidemic in an opulent area of Nevada in 1985 provoked a similar debate about the aetiology of the symptoms (Bell, 1991: 7)). The disagreements in the mass media were mirrored by those in medical publications; indeed, some of them involved the same protagonists using the same arguments.

In the controversy of the 1980s and '90s, the topic of epidemics of ME was often sidelined. Broadly, two types of account of the genesis of ME as organic disorder have prevailed (Cooper, 1997: 189). The first attributes the condition to persistent viral infection: it is considered an endemic disease subject to outbreaks of epidemic prevalence (Ramsay,

1986: 28). A contending account is that, although ME may be triggered by a virus, its underlying cause is a damaged immune system. The latter explanation allows for the preponderance of sporadic cases, which later came to constitute the majority of those diagnosed with the condition (Aronowitz, 1992: 161), and it underlies many of the constructions of ME widespread in the media in the 1980s and 1990s. However, Dr Melvin Ramsay (1989: 20), who treated the victims of the 1955 outbreak, inveighed against immunological views of ME, demanding to know how 200 nurses at the Royal Free Hospital could have developed abnormalities of their immune system within three months. Whether the Royal Free nurses of the 1950s were afflicted by a disorder of the same aetiology as the patients of the 1980s, 1990s and 2000s - or indeed, whether the symptoms of the latter all result from the same underlying pathology - remains uncertain.

### Background and identification of data

My interest in constructions of ME stems from my experiences as a sufferer, diagnosed in 1987. Since then, I have participated in patients' self-help groups, and I have been a member of two principal ME charities: Action for ME, and the ME Association.

From 1989, Action for ME collected press reports through a press cuttings agency, Durrant's, their search term being 'ME'. They offered a selection of these to members, and this has been my main source in documenting press coverage between 1986 and 1993. (My recent attempts to ascertain the proportion of their collection distributed, and their selection criteria, failed after such a long interval of time.) I added cuttings that I gathered myself, or that were donated by friends. 164 cuttings were consulted covering the period 1986 to 1993, 153 of which relate to the period 1988 to 1993 – by which date the main constructions of ME were well established. I collected later press reports less consistently. I have further relied on the videotape, again provided by Action for ME, of television programmes transmitted during 1988; subsequent programmes are also referred to in the text. All material relates to the United Kingdom only.

This material cannot be claimed as comprehensive or strictly representative. However, I believe that it covers the range of popular discourses surrounding ME in the UK - a view supported by my contacts with patients' groups and my perusal of the ME charities' literature: the journal of Action for ME carried frequent reviews of press reporting of ME.

I occasionally refer to writings on the disorder in the medical press and in academic contexts where these had a clear influence on popular constructions of the condition in the UK. Notably, in describing and discussing the assumptions underlying influential psychiatric constructions of ME, I have drawn on accounts in the medical press (e.g. Butler et al. 1991) and in the ME charities' journals (Chalder and Butler, 1989). While these do surface in press reports, their basis is clarified more fully elsewhere.

I have excluded the contentious issue of children believed by their parents to have ME, but diagnosed by health professionals as suffering from psychoneurotic disorders. ensuing debate generated discrete discourses, with stigmatising constructions of parents as well as patients, which require separate examination.

Finally, even with more comprehensive documentation of reporting in the early years, it would be difficult to measure past against present media interest. The spread of the internet makes comparisons between the extent of coverage now and 20 years ago extremely problematic, and arguably meaningless. There are now online versions of newspapers that differ from the printed versions, and that incorporate readers' comments, as well as an untold amount of information with no printed equivalent.

This reservation will become relevant when I discuss the fate of constructions of ME later in the paper. But I first proceed to examine these constructions as they arose in the late 1980s and early 1990s.

#### Constructions of ME after 1986

Discourses on ME are diverse, and sometimes mutually contradictory. Preoccupations about the robustness of the human frame, and its fitness for lifestyles characteristic of the (changing) modern world co-exist with others relating to specifically feminine frailty and invalidism. But there are similarities of theme. Certainly, some issues are conspicuously absent from all the discourses on ME. Amongst these are sexuality and the fear of contagion<sup>11</sup> - the latter perhaps surprisingly since ME was originally specified as a disease occurring principally in epidemics. While the reason for these absences can only be surmised, it seems possible that the AIDS pandemic, a matter of intense concern at the time, had so completely appropriated all available meanings surrounding these two topics that other medical conditions were bound to be construed in different terms, expressing other social anxieties.

# ME personality - a gender issue?

Accounts of ME, in the 1980s and 1990s as later, consistently stress the preponderance of women sufferers (e.g. Dawes and Downing, 1989: 20; Hall, 1991; Cooper, 1997: 192-194; CFS/ME Working Group, 2002, Annex 5). However, estimates of the ratio of women to men vary, and difficulties bedevil attempts to ascertain it (Mechanic, 1993: 329-332). It is clearly impossible to specify the true gender distribution of a condition for which no firm diagnostic criteria exist. Further, men and women who experience the same symptoms may react to them and describe them differently; and even similar reports may not elicit the same response or diagnosis. Whatever the 'true' gender distribution of ME, however, certain dominant discourses have construed it as a disorder of femininity. As already noted, the first wellpublicised theory about ME personality was propounded by psychiatrists McEvedy and Beard (1970a; 1970b). For them, being a woman is a sufficient condition for having an ME personality; particularly vulnerable are those living at close quarters with other women.

The characterisation of ME as hysteria did not endure (David, 1991: 981), and it is, in any case, difficult to see how an account in terms of mass hysteria could apply in a situation where most sufferers did not become ill in the course of an epidemic. However, McEvedy repeated his views, virtually unchanged, in a television programme in 1988 (Horizon, BBC2, 27 June, 1988). Women, he argued, have a tendency to identify with other sick women, and a lower threshold for feeling ill and manifesting symptoms than do men.

Other accounts also construe ME in terms of a pathogenic femininity. Richmond (1989), in an article entitled 'Myalgic encephalomyelitis, Princess Aurora, and the wandering womb' places ME in a long line of supposedly organic, but actually fictitious, diseases of the past. As is apparent from the title, images of female invalidism and hypochondria abound in her account of ME, which she sees as a construct enabling patients to avail themselves of a

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<sup>&</sup>lt;sup>1</sup>An exception is a press report in *Today* (Pope 1990) entitled 'Yuppie flu from single handshake' - the only 'scare story' about contagion (from a supposed viral infection) I have found.

glamorous diagnosis, and private doctors to make a profit. 'Then as now,' she states, after a foray into the bile and vapours of the eighteenth century, 'ladies suffering from the vapours retired to their boudoirs. Taken from the French word bouder, to sulk, a boudoir is a lady's sulking room... A typically environmentally sensitive princess could not sleep when a pea was placed under 15 mattresses...' (ibid.: 1296). It beggars belief that Richmond is an influential medical journalist, and this contribution to the debate is scientifically legitimated by its publication in the *British Medical Journal*. Richmond (1992) repeats her views in the popular press, though in somewhat less flowery terms.

A further 'scientific' opinion is that of neurologist Peter Hudgson, who claimed in a television interview (in a tone of contempt for his ME patients of both sexes that cannot be conveyed in writing) that four fifths or more of the ME sufferers who consulted him were women with unsatisfactory marriages and difficult children with thwarted ambitions (Frontline, Channel 4, 25 July, 1993). Hudgson did not explain why similarly frustrated men might be less likely to develop similar symptoms. The same omission is evident in many more sober accounts of ME reporting the high proportion of female patients. One account which does attempt to explain the preponderance of women is that of American medical anthropologist Norma Ware (1993: 66), cited in the British press (Woodham, 1993), who argues that women under the influence of feminism have sought to 'have it all', and have overcommitted themselves in the effort to achieve a successful career and a fulfilling family life.

However, not all discourses on ME construe it as an effect of a pathogenic femininity. Indeed, certain constructions of the disorder as an outcome of overactivity actually seem to posit what might be thought of as a type of feminisation as a remedy for its symptoms. Within such discourses, excessive ambition needs to be tempered by gentleness and patience, conventionally feminine qualities. I now turn to these discourses, and to the assumptions implicit within them.

# ME as 'yuppie flu'

The construction of ME as an affliction of busy and ambitious people in a work-obsessed society is - or was during the period under review - perhaps the best-known popular understanding of the condition. It may have been fuelled by the accounts of patients themselves, anxious to rebut aspersions of malingering by emphasising their dynamism before the onset of illness. It is particularly evident in the press coverage in the early years of reporting. Walsh (1987), writing in the Sunday Express, refers to 'twentieth century burnout'; in a six-page article in the Telegraph magazine, Askwith (1989) quotes Dr Audrey Livingstone-Booth, director of the Stress Syndrome Foundation, as claiming that people are 'becoming immunosuppressed as a result of an obsession with achievement, work and material advancement', with their stressed bodies producing a noxious admixture of adrenaline and various steroids. A similar length feature in the Observer magazine (Bryan and Melville, 1989), on the following day, suggests that many people with ME were previously high achievers. An article in the magazine *Here's Health* (McKenna, 1990: 14) states that 'sufferers seem to be 'achievers' who have run down their immune system by overwork and stress, allowing viruses to take hold'. While it is occasionally specified that busy people of all classes and ages are at risk (e.g. Walsh, 1987), most accounts emphasise the dangers to professional people. Thus, in the Daily Telegraph, Wookey (1988) tells us that 'young energetic executives seem to suffer severely', and Rowe (1989) refers in Today to 'stressed city high-fliers'. The other category of people singled out as prone to ME are athletes (e.g. Harris, 1989). While many of these accounts are sympathetic to ME sufferers, presenting them as hard-working people afflicted by serious disabling symptoms of organic aetiology, it may be that some journalists are expressing, or at least relying on in their readership, a degree of *Schadenfreude*, a desire to see city high-fliers fall flat on their faces.

This characterisation of ME personality and lifestyle is also apparent in the theory that ME is an effect of hyperventilation, or overbreathing. In this version of the 'yuppie flu' construction, sympathy for the sufferer morphs into contempt. The theory, based on the claim that a change in breathing lowers the level of carbon dioxide in the blood, inducing malfunction in muscles and other organs, was publicised in an article on the front page of the Sunday Times (Hodgkinson, 1988); the title, predictably maddening to sufferers, was 'Yuppie flu' is all in the mind, say doctors'. The doctors concerned were cardiologists Peter Nixon and Stuart Rosen, who expounded their views in the same issue of the Sunday Times, and whose proposed method of treatment was a period of sleep induced by heavy sedation, followed by breathing retraining.

The notion that the symptoms of ME result from hyperventilation produced by anxiety originates in the writings of McEvedy and Beard (1970b: 13). The essentials of this new version of an old idea emerge from the press report just mentioned. 'All the (ME patients) we have seen here,' explains Rosen, 'have four-star abilities with five-star ambitions. They have above-average intelligence, high levels of drive, lots of enthusiasm; but they are not quite the superman or superwoman they need to be to achieve their ambition.' A severe viral infection, he believes, can trigger the health crisis, but it is not the root cause. With the disregard for logic and coherence that characterises so many pronouncements about ME, Rosen adds that his patients have ranged from an old lady whose illness began when she was pushed out of a bus queue, to a woman who survived torture in a South American prison, but became ill when she learned that her daughter had married a fascist. How either of these cases fits the specification of five-star ambitions hampered by four-star abilities is not clear.

Rosen's colleague, Peter Nixon, adds more soberly that 'overbreathing is a symptom of fear or panic, that can be experienced when people who demand a lot of themselves are falling short in their achievements'. A subsequent paper in the medical press, of which Rosen and Nixon are amongst the co-authors, draws analogies between alleged stages of ME and those of battle-weariness, and speculates as to whether hyperventilation due to anxiety and effort may be the natural penalty for violating the boundaries of physiological tolerance (Rosen et al. 1990: 763-764).

In a later television interview, Hodgkinson (Frontline, Channel 4, 25 July, 1993) defended his use of the term 'yuppie flu' in his Sunday Times report. He explained that yuppies in the 1980s went all out for material success, becoming ill when their goals were frustrated; they had 'one foot on the accelerator and one foot on the brake', and suffered a crisis leading to deep exhaustion and despair. As suggested above, there is an implication, albeit unstated, that ME sufferers are unpleasant, pushy people, who have got their just deserts. preponderance of female sufferers appears to be forgotten here: it is not plausible that most of the high-powered people to whom Hodgkinson refers were women.

### 'Yuppie flu': social or individual pathology?

In considering the account of ME as the outcome of 1980s ambition and overactivity, the issue arises of whether this construction attributes blame to individual 'yuppies', or to economic and social conditions that promote a pathogenic lifestyle. In addressing this question in relation to ME, it is interesting to draw parallels with another disorder at one time constituted (also by cardiologists) as uncertainly poised between a driven personality and an achievement-orientated society, namely coronary heart disease (CHD).

Studies conducted in the USA from the late 1950s (fallaciously) present the typical CHD victim as characterised by the 'type A behaviour pattern' (TABP). The features of this pattern include competitiveness and addiction to high stress careers (Helman, 1992: 31-32). CHD is, then, like Hodgkinson's account of ME, construed as a disease of overambitious, middle-class people ultimately defeated by the pressures of a fast-moving, achievement-obsessed society (ibid.: 35). Considerable ambiguity exists in the literature on CHD as to whether TABP is a response to a social environment, or a personality trait which inheres in the individual irrespective of life situations.

In the literature, heart disease comes as nemesis, as a punishment for overconformity to the norms of competitive capitalism (ibid.: 52). The same fate, according to the model of Hodgkinson, Nixon and Rosen, befalls the overbreathing yuppie flu victim of the Thatcherite The analogy between the construction of the two diseases is reinforced by the accounts of the subsequent fate of the sufferer: the type A heart attack survivor returns to the community chastened, and is thereafter encouraged to be less competitive and impatient (ibid.: 50). This prescription is similar to that sometimes advocated for the recovering ME patient. Ware (1993: 67) argues that the illness frequently acts as a catalyst for an ultimately beneficial change of lifestyle, in which 'perpetual motion' is replaced by relaxation, caring for others, simplicity and calm - a view echoed by Woodham (1993) in the Independent on Sunday. Jacques (1996) – a former ME sufferer - concurs with Ware in attributing ME to an increasingly pressurised lifestyle - and moreover, implicitly characterises his solution as a kind of feminisation in his description of 1980s attitudes to work as 'machismo'.

As with CHD, the emphasis in this construction appears to fall more on the sufferer's state of mind than on social factors. Indeed, it appears to be ambition and addiction to work (largely the preserve, of course, of middle-class people with interesting jobs and good career prospects), rather than hard work itself, which is deemed pathogenic. The proposed remedy for both disorders is not social transformation (the abolition or modification of capitalism), but the moral re-education of the sick person.

However, the construction of the CHD sufferer differs from that of the ME sufferer in one important respect: the latter emerges as meriting ridicule. First, ME patients are often depicted as failures in terms of worldly success as well as health: they lack the capacity to make good despite all efforts, whereas no such slur is cast on the abilities of type A personalities with CHD. Second, their illness is only apparently serious: the incapacitating nature of the symptoms belies the triviality of the cause. By contrast, CHD victims have a life-threatening disease. Analogies between ME and the 'effort syndrome' found in wartime exhaustion (Rosen et al., 1990: 763) further highlight the silliness of patients whose panic and hyperventilation has been induced not by the terrors of battle, but by everyday stresses. Indeed, according to this construction, ME scarcely qualifies as an illness at all: sound sleep will bring recovery.

### ME as learned helplessness

Meanwhile, again to the displeasure of patient groups, psychiatrists were propounding views of ME – or chronic fatigue syndrome, as they preferred to call it - as depression manifesting itself in physical form (Stuttaford, 1993; Wessely, 1993). Wessely, a controversial and influential figure who today remains the bugbear of many patients, construes ME primarily as learned helplessness. He and his adherents argue that, although a virus may trigger the disorder, persistent symptoms are due to cognitive distortions and lack of activity. In the course of an initial minor illness, patients are said to develop dysfunctional beliefs about the nature of their condition and the dangers of taking exercise - beliefs reinforced by the fact that physical deterioration resulting from excessive rest makes any sporadic attempts at activity The result is 'a vicious circle of symptoms, avoidance, fatigue, tiring and painful. demoralisation and depression' (Butler et al.,1991). Treatment - cognitive behaviour therapy (CBT), sometimes accompanied by antidepressants - is aimed at modifying unhelpful cognitions (Chalder and Butler, 1989: 17), while activity is slowly increased by means of graded exercise therapy (GET), strengthening muscles weakened by prolonged disuse.

Accounts of this treatment offered by its proponents are striking in the emphasis placed on introducing predictability into the pattern of rest and activity – as though disordered bodies, predominantly female, need to be disciplined. Thus, long intervals of rest may be allowed, at least initially, but these must be for a set period, and at set times (Chalder and Butler, 1989: 17; Butler et al., 1991: 154). Emphasis is also placed on the importance of completing a preplanned activity regardless of symptoms. This regulation of activity stands in stark contrast to that proposed by ME patients and their organisations, who advise sufferers to avoid straining at their limits; to 'listen to their bodies'; and to tailor their lifestyle to their reduced capacity. According to the advocates of CBT, however, the belief that the illness is long-term, and requires an adaptation of lifestyle, needs to be countered.

Wessely further speculates about the social context of ME. In a well-known paper, Old wine in new bottles: neurasthenia and 'ME' (1990), as well as in the press (Wessely, 1993), he draws analogies between neurasthenia patients in the late nineteenth century and ME patients in the 1980s. (Richmond (1992) makes the same comparison.) Both conditions, he argues, are characterised by fatiguability, with a host of other mental and physical symptoms (Wessely, 1990: 36-37); and neurasthenia was, like ME, regarded as an outcome of the pace of modern life and of the drive to succeed, rather than of work itself (ibid.: 43). Like ME patients, neurasthenics allegedly claimed lack of sympathy from the medical profession and by contrast with hysterics - stressed their eagerness to collaborate with their medical advisers, and to return to normality (ibid.: 39-40).

For Wessely, the long interval between the demise of neurasthenia and the emergence of ME denotes neither a relaxation in the pace of life during that period, nor changes in the classification of symptoms at different times. Instead, he claims that what in the psychiatric literature is termed 'distress' (Wessely, 1990: 43; David, 1991: 181) manifests itself in culturally sanctioned ways, varying with changes in attitudes to work and material success (Wessely, 1990: 50). He concedes that his account is incomplete in that the social processes governing what he terms the 'creation' of such illnesses remain obscure.

But it is not only social processes that Wessely's account leaves untheorised: the individual's distress also remains unexplained, and in particular, there is no suggestion that certain social attitudes or arrangements might give rise to more distress than others. While the 'yuppie flu' construction of ME does, however ambivalently, link the prevalence of the condition to its social context, the construction of ME as psychiatric illness construes it as social only in the form it takes.

### What became of the headlines?

ME first made news in the late 1980s because activists worked hard to ensure its prominence. In particular, Clare Francis, president of Action for ME, campaigned unremittingly for recognition of the disease, securing repeated media interviews (e.g. Francis, 1988a; 1988b; Right to Reply, Channel 4, 11 June, 1988). But, albeit with exceptions (e.g. Hawkes, 1992), the reportage soon took a turn they neither expected nor welcomed. It appears that a determined and initially successful publicity campaign by sufferers was hijacked by a variety of parties with their own agenda. In an exploration of their waxing and waning, the various discourses on ME require separate examination.

The involvement of psychiatrists and psychologists, once the debate was underway, can arguably be explained by professional self-interest, given the high profile of the condition and the large number of sufferers. (The same could be claimed of Drs Nixon and Rosen.) The psychiatric construction has changed little over time; its associated treatments, CBT and GET, are offered in various hospital departments and claimed as effective by their adherents (e.g. Quarmby et al., 2006). They remain bitterly contested, with some patients claiming that GET can be harmful, and many demanding that efforts focus instead on discovering the organic basis of their symptoms (ME and CBT, BBC Radio 4, 7 November, 2007; ME Association, 2009).

The discourses of the late 1980s foregrounding women's proneness to pathology display an inconsistent mixture of the old and the new, legitimated by the preponderance of women amongst diagnosed ME patients. These do appear to have undergone a change. Wellestablished constructions of women as hysterical, suggestible, and vulnerable to psychosomatic symptoms have hopefully now become less common; they are not in evidence in the current psychiatric literature on ME. And while discussion continues about women's increased representation in the workforce, and their attempts to 'have it all', anxieties now centre on the possible ill-effects on family life where long and inflexible hours are the norm, and fathers do not share responsibility equally (Carvel, 2008). So far as I am aware, concerns about working mothers are - for unknown reasons - no longer linked to their supposed propensity to become ill with ME or any other condition.

In considering the reasons for the rise – and subsequent fall – of 'yuppie flu' constructions, it is useful to examine the account offered by Martin Jacques (1996), former editor of Marxism Today. This was late for a construction of this particular kind – although 1996 saw heated debate about ME with the transmission of an angry television programme (Rantzen Report - ME: The Secret Epidemic, BBC 1, 5 August, 1996) and the publication of a psychiatrically-dominated report (Royal Colleges of Physicians, Psychiatrists and General Practitioners, 1996). In a long Guardian feature, Jacques relates his own experiences of suffering and recovery from the disorder. He spells out what he sees as the pathogenic features of the 1980s, citing increased intensity of work, decline of certainty and rise of insecurity, and the transformed condition of the middle class. He argues that it was not surprising that under these circumstances new diseases that were simultaneously stress-related and physical should emerge.

Admittedly, social inequality – a growing feature of the 1980s – may impair health (Wilkinson and Pickett, 2009). Nonetheless, Jacques's claim seems vastly overblown. Within living memory, for instance, sections of Europe were devastated and British cities blitzed. One might ask why the victims of these events did not develop ME. What about concentration camp survivors? The inhabitants of Darfur? In the light of these catastrophes, it appears implausible that life in peacetime for prosperous young people should have been so unprecedentedly stressful as to generate a new disease. One wonders why those who reflected and reported on the lifestyle and health of their contemporaries were so panicstricken and, in a sense, so self-pitying.

It is beyond the scope of this article to explore the preconditions for 'moral panics' and other forms of social disquiet, and why these may sometimes express themselves as fear of specific illnesses. But it is not inconceivable that social disruption in supposedly 'normal' times might on occasion cause almost as much disorientation as upheaval at times when normality is no longer expected. Certainly, British society under Thatcher underwent radical and rapid change - although there is no objective evidence of a resulting increase in the incidence of ME. Journalists, both reflecting and generating unease, may have been particularly conscious of the shifting culture: Rupert Murdoch's confrontational move of his titles to Wapping in 1986, soon followed by most of the press, would - though aimed at the printing unions rather than themselves - have made them sharply aware of a more ruthless ethos. By linking their concerns to the proliferation of an allegedly new physical disorder, these commentators could claim emerging social changes not just as distasteful, but also as pathogenic. 1986 also saw the Big Bang, the deregulation of the stock exchange. This was, of course, also the year of Sue Finlay's *Observer* article that brought ME to prominence.

Legacies of Thatcherism persist: large numbers of City (and Canary Wharf) high-fliers remain. But attitudes towards them soon altered dramatically. Peter Mandelson famously stated after New Labour's accession to power in 1997 that the new government was 'seriously relaxed about people getting very, very rich'. Forms of competitiveness and greed that arose with the advent of Thatcher in 1979, and that evoked alarm in the years that followed, ceased to attract much comment. The economic crisis that began in 2008 has raised fresh questions about their desirability, but 'yuppies' - a term now more or less fallen into disuse - are no longer thought to embody an unnatural lifestyle deemed to generate bodily disorder.

#### Conclusion

By 1998, the ME charities were welcoming - Action for ME warmly (Tolley, 1998); the ME Association (1998) with more caution – of a widely reported statement by the Chief Medical Officer describing ME as a debilitating and distressing 'real medical condition'. An ensuing report (CFS/ME Working Group, 2002) gave a voice to patients, acknowledged the contribution of their organisations, and highlighted the prevalence, severity and chronicity of ME It disappointed some patients by its alleged failure to sufficiently stress the need for research into the aetiology and pathogenesis of the disorder, as well as by its endorsement of CBT as a useful, if not curative, strategy; but constructions of ME in terms of feminine hysteria or Thatcherite hyperactivity had clearly been relegated to the past.

With the reservations noted earlier, it seems fair to suggest that media interest in ME has waned. Reports and sufferers' accounts still occasionally appear, usually taking the organicity and seriousness of the disorder for granted (e.g. Gould, 2008; Kahn-Harris, 2008). Notably, the Mail Online produces a fairly steady stream of (often confused and ill-informed) reportage (e.g. Lantin, 2007; Edwards, 2008). But an unsubstantiated theory about the aetiology of ME would not now occupy the front page and an entire inside page of a major newspaper (Hodgkinson, 1988); nor would ME now be the subject of six-page weekend colour supplement features (Askwith, 1989; Bryan and Melville, 1989).

Sontag (1991: 5) suggests in relation to TB and cancer that illnesses will be encumbered by the trappings of metaphor for as long as they are not understood and not curable. It seems, however, that ME, once so powerfully construed as a symbol of the social ills of its age, has shed its metaphoric connotations. It is regarded either as a predominantly psychiatric condition to be addressed by management techniques; or, perhaps increasingly, as a poorly understood organic complaint that is just one more dreary and meaningless chronic illness amongst others.

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# Wearing two hats: interviewing older people as a nurse researcher

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#### **ABSTRACT**

Interviewing older people is a common practice in qualitative research. Interviewing older people as a nurse who is a researcher is also not uncommon. But what is the relationship between the two roles of nurse and researcher and is there a 'correct' approach? Researchers listen to people in an interview setting in order to collect data; nurses listen to people to take a history, a clinical assessment towards a plan for the delivery of care. How compatible are these two approaches to interviewing?

In this paper I explore the process, potential and actual tensions and particular challenges presented by the nurse-as-researcher interview with older people, using secondary analytic techniques to revisit and critique interview data collected as part of a doctoral research study exploring older people's medication beliefs. The central themes I identify from these 'double duty' interviews relate to older people's perceptions and expectations of the interview process, as much as to the interviewer's conduct. I go on to consider the contextual features of the older person/interviewer interface which may impact on the interview: notably gender, age, commonalities and cognitive and physical abilities. Finally, I reflect upon how these role complexities which are inherent in the qualitative interview serve to strengthen my approach as a novice interviewer thus confirming the value of reflection.

### Introduction

In this paper, I reflect on the process and particular exchanges within the clinician-asresearcher interview. The data on which the paper is based are taken from a wider research study into the medication-taking beliefs and practices of twenty older people in two small New Zealand towns. The current paper focuses on a secondary analysis of these data, where the role of the researcher as nurse is closely examined within the interview. As I am a registered nurse with a clinical background which consists primarily of nursing older people, I stepped into research interviewing (as opposed to clinical interviewing) as a relative novice in common with many postgraduate students. In this paper I share some of the reflections which this transition raised for me, and which are likely to have resonance for other clinicians in similar 'first time' situations.

### **Background**

The primary research on which this paper is based emanates from my doctoral research into geriatric comprehensive assessment with a special focus on medication narratives. In the main study, twenty older New Zealanders (aged 67-92 years) were recruited from a larger local District Health Board study which was trialling the use of the InterRAI Minimum Data Set – Home Care (MDS-HC) assessment tool with older people living in the community (Keeling et al. 2005). Medication is one of the domains of this tool and as I have an interest in beliefs around medication-taking, I interviewed all twenty participants in their homes about their medication within a fortnight of their initial assessment interview. My main interest was in asking the participants how they felt about taking medication; what it meant to them, and how they incorporated medication-taking into their everyday routines. This interest arose from previous home visits to older people where I had observed indifference, nonchalance and chaotic medication-taking routines and because in existing research emphasis has been placed less on patient beliefs in taking medicines (Britten, 1994), than on the 'problems' of non-compliance and polypharmacy in older people. I felt that asking people about their underlying feelings and attitudes towards taking medication might be of benefit in understanding their medication use.

## Research approach and interviewing

The wider research study, and indeed the smaller reflection-focussed study presented in this paper, employed a qualitative narrative approach. Qualitative research encompasses a range of methodological techniques with no one underpinning philosophy or perspective, although the subjective lived experience of participants is always valued. My research is underpinned by the philosophical position that knowledge is socially co-constructed through relationships with others. The constructionist-interpretive paradigm recognises multiple meanings and subjective realities (Finlay and Ballinger, 2006). Therefore with a philosophical position of valuing subjectivity, stories and the lived experience of older people, I employed a narrative approach to collection and analysis. In narrative studies, participants' stories are particularly valued, and interviewing is the vehicle to obtaining the narratives (Riessman, 2008).

Qualitative interviewing emphasises depth and richness of response rather than the ability to compare and measure responses (Elliott, 2006). Standardisation and the same information were not being sought from each respondent, but rather 'representations' (Opie, 2003). My interview style was 'semi-structured' in that I had a question guide which I hoped to cover, but did not mind if the interviewee's narrative digressed from this, as a narrative approach assumes that all narrative which arises from the interview is worthy in itself. In support of this theory and as an extension of this idea, Oakley (1981), in her classic paper, 'Interviewing

<sup>2</sup> InterRAI is an international network of researchers and health and social care professionals who promote the use of evidence-based practice in the care of older people: http://www.interrai.org/section/view/.

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Women: a contradiction in terms', dismissed the objective, value-free, researcher-distanced style of interview. She claimed that researchers cannot arbitrarily remove themselves from the interview context, and indeed ought not to. Holstein and Gubrium (2003: 4) agree that interviewers 'are deeply and unavoidably implicated in creating meanings that ostensibly reside within respondents'.

Further, Oakley (1981: 58) does not see 'personal involvement' in the interview as a 'dangerous bias' but as a 'condition under which people come to know each other and admit others into their lives'. As well as becoming involved in some of the clinical/health aspects of interviewees' lives, which is the focus of this paper, at times I disclosed details of my own life with interviewees such as my job, what my research study was about and alluded to parallels with my ageing parents, where I thought this appropriate. Despite having provided a detailed Information Sheet, only one participant asked me further questions about what the study entailed. I was surprised at this and spent some time in the interview explaining this as this participant seemed to have a genuine interest which I hadn't come across before. Another of my participants asked me 'is this the sort of thing you want?'. Van Hoonaard (2005) describes a similar experience in her paper titled: "Am I doing it right?": Older widows as interview participants in qualitative research'. Van Hoonaard found that participants were very concerned that they were giving her the 'right' information, even while telling her their own personal story about the experience of being a widow.

Interviews will always vary according to the profile of the participant group: their background, education level, gender, knowledge of research will all influence their responses and the relationship which ensues between researcher and participant (amount of shared story, disclosure). In particular, having something in common (such as coming from the same town or country or having shared similar life experiences or interests) can influence the direction and tone of an interview. For example, as a nurse I have recently interviewed a group of peers in an unrelated study - other nurse academics. We speak the same language; we are similarly acculturated into the world of professional nursing and the values and attitudes that lie therein (often invisible to outsiders). The interviews I conducted with these men and women had a different starting platform to those which I analyse in this paper where the participants were older people, strangers in the sense that I had not met them before. Despite this, I still found some common ground with two participants in the doctoral interviews: with one who had been a nurse and another who had been a general practitioner. I found that this commonality of medical backgrounds influenced the way we spoke to and understood each other, particularly about medication. Conversely, there were participants with whom I felt I had very little in common, interestingly, due to their life circumstances and outlook more than their age or gender.

As the 'underlying rules' (Cunningham-Burley, 1985: 67) of the research interview have evolved, how researchers position themselves is now being accepted in large part as fluid and contextual, although proper ethical boundaries and principles such as confidentiality, informed consent and so on must always be maintained (MoH, 2006). For a novice researcher/interviewer, appropriate ways to interview are not always clear, despite conducting pilot interviews and discussing the process with supervisors. In a sense, an important way to learn 'how' to interview and to feel at ease doing it, is by doing it. Many textbooks give advice as to the mechanics of the interview, but there is less written on the dynamics which take place in the interview. Robertson and Hale (2007) have written about distress in interviewing older people as painful topics may emerge. However, my doctoral interviews were about taking medication, which I felt was a relatively 'safe' topic as my questions were not about highly personal aspects of the participants' lives, although I recognised that a researcher can never anticipate precisely what the conversation may bring up for people. In this paper I explore the tension for the researcher between being a clinician and a researcher, and the events and exchanges that are played out on this role boundary. It is acknowledged that related tensions around wanting to help, inform, reassure, sympathise, advise and advocate for people may also occur for the non-clinical researcher. However, the clinicianresearcher learns these features as an inherent and embedded part of their professional responsibility and duty. It is part of their training to administer help and so any role tension may therefore be a more acute one. Part of the learning and reorientation involved in doing qualitative research is to see the interviewee as person before patient.

### Interviewing older people

In New Zealand, official government documents such as the Health of Older People Strategy (MoH, 2002) consider that 'older people' are those aged 65 years and over, which is the population group of this research. The question arises as to whether interviewing older people is any different to interviewing people of other age groups? Truglio-Londrigan (2006) writes of the challenge of establishing trust with older people due to their vulnerability, although vulnerability is not exclusive to older people and many groups could be considered vulnerable such as children, people with physical or intellectual disability.

Potential vulnerabilities of old age include sensory deficits such as hearing loss or visual impairment and other possible challenges such as dependence on others, social isolation, illness, institutionalisation and being at risk for functional decline (Wenger, 2003). Jonkinen et al. (2002) suggest that some older vulnerable people may need 'extra protection' around ethical issues such as consent, particularly if cognitive changes are apparent. While these particularities and cautions of interviewing older people are valid and have been well documented, it is important not to patronise older people and expect that all will require special attention, as not all older people are the same, and as Wenger (2003: 113) writes 'there is no one recommended approach to interviewing older people across such differences'. For some older people the interview may be a welcome social occasion - a situation where they feel they are making a contribution, and that their knowledge and opinion is being listened to and valued. Manderson et al. (2006: 1322) write that the age of both the interviewee and the interviewer is significant and can influence the shape of the interview. In their study on the social dynamics of the interview, they found that 'older interviewers often drew on life experiences to frame tentative or complex questions' and 'adopted a more conversational style' than younger interviewers.

The results of this secondary analysis of my research did not indicate that my age, gender or social background might have impacted upon participants. However, the data below do indicate that my professional persona of nurse had some influence on the interview relationship. There is also the possibility that my being overt about my clinical background (through the wording of the Information Sheet for example) could have hindered and limited the scope of the research in some way, and I may have gained different data had I not gone into 'nurse mode' at times. Although it is not possible to know the answers to these reflexive ponderings, they contribute to robust debate and a deeper consideration of issues before moving on to future research projects which involve the use of interviews.

#### Researcher as a nurse or nurse as a researcher?

The relationship between the interviewer/researcher who is a nurse/clinician and the older person as interviewee is not a clear one. A nurse's primary role is to deliver clinical and holistic care and to advocate for her patient. A researcher's primary role is to answer research questions through exploration of a phenomenon which involves collecting and interpreting data. In colloquial English, acting in a particular way that is commensurate with a particular role, is sometimes referred to as 'putting on a hat', a somewhat archaic reference to a time when many people in the UK wore hats, many of which were unique to particular occupations and/ or denoted social status (fire fighters helmets, workers flat caps, railway workers' peaked caps, gentlemen's top hats). I suggest that the novice nurse-researcher can feel like they are, metaphorically speaking, 'wearing two hats', in the sense of carrying out two potentially conflicting roles and responsibilities at the same time – a nurse's 'hat' and a 'hat' for the researcher. This gives them a sense of having a 'double duty'.

Others have written of 'role conflict' and the feeling of having 'split personalities' when these two roles come together in the one person. In their paper on this subject, Colbourne and Sque, (2004: 297), write that Sque had 'no idea how difficult letting go [her] clinical hands-on role and embracing that of a full-time researcher' would be. She uses reflexivity (guided by Finlay's (2002) definition of this as 'thoughtful, conscious self-awareness') to make sense of the conflict and move on. Colbourne and Sque (2004: 298) acknowledge that it is not only in the actual interview where one has role tension, but also in the analysis of the data: they write that professional socialisation could 'get in the way'. This observation raises the question: once having become a nurse, can one ever step outside the role? Nurses are socialised into keen observation, assessment and concern for people and this professional hat cannot be taken off easily, even when analysing and interpreting the participants' own words. Further questions relevant to this research are: Should a nurse ever leave their role behind, even when conducting research? Do nurses' moral obligations remain when wearing a 'researcher's hat'?

Even the nomenclature can be difficult as Deave (2005) points out: Should we be called 'research nurse' or 'nurse researcher'? Role confusion is inevitable as dual roles of being a nurse and a researcher are carried out (Truglio-Londrigan, 2006). In their paper on the challenge of multiple roles in the qualitative clinician researcher-participant relationship, Cartwright and Limandri (1997) noted that the relationship is a multi-dimensional one and that both parties move in and out of different roles throughout the interview encounter. They offer a useful framework which identifies five potential relationships within the interview: 1. stranger-stranger; 2. researcher-participant; 3. friend-friend; 4. nurse-client; 5. guest-host. As mentioned above, it is the relationship between the second and fourth relationships that I am particularly focusing on in the current discussion.

### Reflexivity

Gerrish and Lacey (2006: 15) argue that as qualitative research employs an approach 'where the researcher and the research are closely intertwined', problems can arise and which render reflexivity a necessary and inherent part of the research.

Finlay and Ballinger (2006: 21) define reflexivity as involving 'critical self-reflection, focusing on the ways a researcher's social background, assumptions, positioning and behaviour affect the research process'. The authors go on to emphasise that the 'purpose of reflexivity is not to achieve neutrality but to achieve a far more intense insight'.

Several authors write on the issue of reflexivity within the process of interviewing where the interview itself becomes the focus of examination. Chesney (2001: 131) writes that she is interested in the use of 'self', or as she calls it the 'me in the research', and similarly, Watt (2007: 82) hopes to 'demystify' the research process through reflexivity. Mruck and Breuer (2003: 1) attempt to 'achieve new levels of understanding', and as novice researchers, Colbourne and Sque (2004: 297) use reflexivity to explore role conflict and 'difficulties in the transition from a clinical post to a nurse researcher role'. All of these support my own intentions in critiquing my role as both nurse and researcher in this paper. The secondary analysis gave me an opportunity to focus on and critique the process or the 'how to' of my interviewing technique and exchanges with participants, rather than the content or the 'what' of data. Thus I hoped to achieve greater insight into my performance and positioning as a research interviewer.

#### Method

For the doctoral study, each of the two sets of twenty interviews with the twenty participants were analysed in two ways: firstly using a conventional thematic analysis and secondly using a narrative/discourse analysis. The findings from these two analytical approaches were synthesised to develop a global account of the data.

The secondary analysis involved identifying and scrutinising those places in the interview transcripts where I was 'wearing my nurse's hat', for example, situations where I was asked to explain what certain drugs were for or what quantity to take or if they were necessary. The analysis identified specific themes derived from these micro-portions of the interviews. These themes are presented and discussed in the section below.

The twenty interviews were read and closely scrutinised for any researcher-interviewee interaction or exchange where I considered that I was acting in a predominantly 'nurse role', rather than 'researcher role'. I was able to code or mark these portions by my change in tone, language and the type of questions I was asking or being asked. Using a model of general thematic analysis (Finlay and Ballinger, 2006), five major themes were identified: advice, assessment, referral, education and reassurance. These themes are discussed with illustrative excerpts below. All names used here are pseudonyms.

### **Findings**

#### Advice

Advice-giving was one of the main features of the interview portions identified in the analysis. Sometimes this advice was solicited by a participant such as Hazel who invited me to have a look at the wound on her leg. In the middle of discussion about over-the-counter medication, she asked 'I would like someone else's opinion, what do you think?' This advice turned into assessment (the next theme) as well. I was quite cautious as Hazel had spent quite some time criticising her doctor and did not always seem to be trusting of his judgements, so I responded:

- LR: Sure yes, have you shown it to the nurse at the doctor's place?
- No I haven't. I'm not going back [for a while]...
- LR: Oh, which one are you talking about...this area here?
- Well, that's where it all blew up into bubbles, underneath the waterproof dressing that H: she put on...
- LR: It's not hot. You know, I think it might have been an allergy to that dressing
- Yes, I thought that's what it was. H:
- LR: Has it improved?
- Oh yes, you should have seen it before, it was all leaking H:
- LR: It's not sore?
- H:
- LR: It's not hot and it's not sore, it doesn't feel inflamed...
- It was redder than that before I put the arnica on H:
- LR: It's not red and angry and swollen and painful. They are all signs of infection, but still the next time you go to your doctor...
- H: Yes, I've got to go next month
- LR: Yes, I think I would show it to him, or maybe the practice nurse. Is there a practice nurse there?
- H: Oh yes, a couple of them and three doctors.

Sometimes the advice was initiated by me. For example on two or three occasions I advised participants to return their unused medication to the pharmacy. In these situations I tried to suggest rather than tell people what to do.

- LR: [to George's caregiver who managed his medications] So in that bag there, that's the ones he's no longer taking?
- C: Yes, he doesn't take these anymore
- LR: One day it might be an idea to take them back so you haven't just got them lying around, but that's just a thought.

#### Assessment

The illustration of an 'advice exchange' with Hazel above was the only circumstance where I was directly asked to assess a situation. I initiated several other assessment conversations, however, secondary to observing symptoms which I considered distressing or unresolved for the participant, as in the case of Alison's cough:

- Have you had anything for your recent chest infection? Did they give you anything for that?
- No. A:
- LR: Did you go to the doctor?
- I went to the doctor last week for a re-fill of the tablets.
- And did they listen to your chest? LR:
- A:
- You didn't mention it? You weren't worried about it enough? LR:
- A: It's come on this last day or two again, the chest like, you know. Always a cough, well not a cough, but......
- LR: You don't feel unwell?
- No, but I wish I was a bit brighter. A:
- Right. Do you feel a bit sleepy? LR:
- A: Yes, dopey, but I'm dopey at the best of times (cough, cough, cough)
- Oh, you might have to go back if that doesn't go away.
- Oh, I've had that on and off for ages. I used to live and work on the Main Road, in A: Birmingham, and I think all the traffic, you know, in your eyes up to it.
- So you've had that cough for a long time? LR:
- A long, long time, yes. A:
- LR: It comes and goes, does it?
- That's it.

On listening to the tape and reading the transcript after this interview, I realised I had slipped into nursing assessment mode. I was viewing the participant primarily as patient at this point of her interview.

#### Referral

The majority of times where I assumed 'nurse' role was when I referred the participant back to their GP or practice nurse as I have shown above. This was particularly when I felt I couldn't answer a question safely or responsibly, in the sense that I didn't know their medical history or why they were taking particular medications. After the first two interviews I went out and bought an up-to-date nursing Saunders Nursing Drug Handbook (2006) as I felt that if I am going to answer questions, I wanted to be accurate and look drugs up when participants asked me questions about their medications. Referral was also one way of closing a discussion down if I felt the nurse role was becoming too dominant and we needed to return to the research agenda.

### Education

Education took the form of giving information (usually about medications, their action or purpose or how and when to take them); 'checking out' with participants as to whether they knew the right thing to do; imparting knowledge and answering questions. For example, Rosemary had been in hospital several times for major heart surgery and her medications had been altered constantly and recently reduced:

So do you know what all your medications are for?

It's all to do with..... R:

LR: It's all cardiac.

- My rhythm is not good in the heart and some of those might be for that. This Digoxin, R: you don't know what they are either?
- Yes, I do, Digoxin slows and strengthens your heart, so that regulates your heart-beat, LR: slows it down.
- I only take one of those at breakfast time, and I take the Cardizem, one at breakfast. R:
- LR: That's this one.
- And then I take Enalapril, that's a heart tablet isn't it? R:
- LR: It's an antihypertensive, Enalapril. Yes.
- R: Well I take.....
- LR: That at breakfast?
- R: Yes. It's a funny thing, I thought I took two of those, but no.
- It should be down on here.
- It looks good, just seeing these few now, to what I had. R:
- LR: It must do.

This conversation turned into reassuring Rosemary which leads to the final theme.

#### Reassurance

On several occasions, I found myself giving reassurance and encouragement wearing my 'nurse's hat'. As already mentioned many of the participants were still recovering from surgery in hospital or major medical events and were learning to re-manage their lives in their own homes. Many of them shared narratives of 'improvement', although not all. On reflection, I was also giving them a kind of feedback as a representative from 'the system' that they were doing well. Sheila was very anxious at not having heard about her cancer pathology results:

- LR: And did you have just one breast off?
- S:
- LR: Right okay. That was in December?
- S: November.
- LR: And you followed up with your doctor, just to find out what's....?
- S: That's what I wanted to see, with you know.....
- What about your own GP, were they.... LR:
- Oh, he seems to be perfectly organised, there was um... S:
- LR: Perfectly?
- He's given me the phone number to ring at the hospital. S:
- LR: Oh I see what you mean. He hasn't heard though himself?
- I haven't heard yet. I wrote, when was it last week, I rang him because I thought it has S: been long enough now, but she said they are behind, and I know there are waiting lists for everything, and I thought well perhaps I'm hopefully thinking there's nothing else, because she said it was a very tiny cancer that was there.
- You would think if it was serious you would have heard by now. It's six months now. If it's urgent they usually get on to it pretty quickly.
- S: Yes, pretty quickly.
- You could try phoning again... So how are you feeling in yourself? LR:
- Oh fine, I got over the operation quite well. I can get my arm right up now. S:
- LR: Oh well done.
- I did all my exercises. S:
- LR: Oh good on you.
- DW: And I did that quite well.
- LR: That's great.

#### **Discussion**

This paper adopts the viewpoint that the interview is a co-constructed entity, where interviewer and interviewee together create an end product through conversation. The conversation generated is dependent on many factors such as age, gender, context of both parties. Power rests with the interviewer as the initiator, designer of the interview format and seeker of data. Power also rests with the interviewee as the site of the interview is in their domain and they can choose to tell what they want to tell and exhibit the 'self' that they choose to present (Goffman, 1981). Shared power however assumes that the two parties are equal and this is often not the case. Older interviewees may be vulnerable due to illness, disability or impaired cognition not just age per se (Wenger, 2003).

In the current research, another kind of power difference manifested itself in the form of the interviewer wearing two professional hats: that of nurse and that of researcher. The literature offers no 'right' way to manage this tension along a 'subjectivity-objectivity continuum', although various authors have explained their approach and rationale (Colbourne and Sque, 2004; Chesney, 2001).

I made it clear to all interviewees from the outset that I was a nurse, in addition to wearing my badge ('Lecturer, Centre for Postgraduate Nursing Studies'). I felt that it was important to deliberately identify myself and where I came from as the participants had never met me before apart from a brief phone call arranging the time and venue for the interview. One reason I was deliberate in my declaration that I was a nurse was that I felt this gave me some status and authority to be in strangers' homes. So I initiated and set the scene for a 'mixed' (nurse and researcher) relationship. I was seeking legitimacy and this was how I positioned myself (Davies and Harré, 1999). I also felt comfortable and 'at ease' in a familiar role and undoubtedly generated this comfort, which I believe is a requisite for establishing rapport and a successful interview.

In stark contrast to my approach, Colbourne used devices (Colbourne and Sque, 2004) to make explicit her primarily researcher role, via both written information and verbal reinforcement. She did this in order to avoid bias and to remain true to the participant's story. Even though I too had 'researcher authority' via ethical approval, (a clear information sheet and a signed consent form) which gave me legitimate and formal access, I felt that as I was to be asking participants about health-related matters (medications), I might put them more at ease if they knew that I had some professional knowledge and insight into the topic. As researchers, we are ethically obliged to encourage respect and trust in interview relationships. My experience of trust is that it is not assumed, but earned. Both consciously and unconsciously, I was offering myself as a nurse (with all that the role implies: advice, assessment, knowledge, education, reassurance) as a way of saying 'Trust me'; 'I am trustworthy' (not that all nurses or health professionals necessarily are).

I was also concerned about reciprocity. I felt that, although consenting to be interviewed, participants were doing me a favour. They were not at all obliged to have me come and ask them lots of questions When I thanked participants at the end, many said 'Oh well, as long as it has been of help', when a more pressing concern for them (as recently incapacitated) surely must have been obtaining home help which my District Health Board colleague had assessed them for the week before.

The information sheet was 3 pages long (necessarily to meet all the requirements of the Ethics Committee), and although written in lay language, it was still the language of research. In other words, the core purpose of the interview and research in general was mine, not theirs. I was in the domain of their house but they were in the domain of my research. By making it clear that I was a nurse, I felt I was giving them reason to trust me, to know I was genuine and that through advice, concern and information, I could give them something back.

I believed the interviews were strengthened by the approach I took at the time. I am not sure that I would emphasise my nurse's role to the same extent in the future as I think this reflection has led me to conclude that this was due to my own role transition and developing confidence as a researcher. I set my terms and conditions out clearly from the beginning by saying I was a nurse and a researcher who had come to ask them about their medication. In a sense, both roles were carried out in tandem. The compatibility of the two roles rests within my 'presented self' (Goffman, 1981) as an individual interviewer and it would be perhaps impossible to untangle them. The wider question of compatibility between the dominant discourse of nursing (to help, advise, refer, give information, form relationships) and the dominant discourse of research (to seek information, contribute to useful knowledge, to form relationships) depends on where one stands on the subjectivity-objectivity continuum. Both discourses have much in common if the researcher initiates an involved, subjective, partnership stance and a climate of trust and reciprocity is fostered. This is the stance I tried to take in the case of the current research. It did not extend to friendship and ongoing relationship, nor did it 'stick to its core objective business' at all times. It is probably half way along the continuum. I believe that an ease in weaving in and out of both roles was achieved. Participants had their questions and concerns answered by information and referral and as researcher I was able to collect much rich data for my doctoral thesis. It would have most likely been helpful to have a set of strategies in place to manage clinical questions, such as stating that I could answer any questions about treatment, medication and so on at the end of the interview. I could have deflected, delayed and denied offering immediate help or answers and focused on the job of interviewing. This approach might have been legitimate as a researcher but it did not occur to me to have strategies other than to switch intuitively to an ingrained nursing role.

Prior consideration and discussion and reading about the mechanics of interviewing skills can be useful, but in my case the dual tension I experienced was unexpected. Reflection on the interview process as a final but necessary step in the analysis of data has been a useful tool in retrospectively exploring the metaphorical phenomenon of 'wearing two hats'. Perhaps the truth of the matter is that several hats (at least two) are being worn at once throughout the interview. The important thing is to acknowledge one's behaviour as a researcher by reflecting on each interview/research project and thus gaining greater self-awareness and clarity for future projects.

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## OPINION PIECE

# Efficiency, equity and humanity – can we have it all?



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Here's a familiar dilemma that my twenty years of reading, writing and teaching medical sociology hasn't yet answered. How does an efficient and equitable health service also treat patients with humanity and take their concerns seriously?

We live in a confessional age. Here comes mine, so look away if you're afraid of too much information. After the one major surgery that I've had, I was horrified. Not the brute fact of being opened up and fiddled around with, although that was quite odd. Nor the peculiar feeling of being an extra in a medical soap opera: I had an emergency procedure and professionals in blue scrubs pushed me down a corridor on a trolley, reassuring me that everything would be fine. Nor was it the strange way that the ordered rush suddenly paused as the surgeon absented himself from the theatre - 'In the army we call this 'hurry up and keep waiting" pronounced the anaesthetist behind my head. It wasn't even the bizarre sensation of waking up and finding a smiling lady wiping down my stomach with a warm J-cloth, nor the discovery that I had gained 3 plastic tubes delivering and removing various fluids. What really shocked me was that the double-barrelled surgeon who cut through my stomach wall and had his hands in my entrails never saw or addressed me again. When I was on the postoperative ward he sent a fragrant, over-worked registrar to inspect the wound and go through a recovery checklist. She couldn't make eye contact because she was too busy processing me, and no, she replied, while still writing, she hadn't attended my operation. The closest I've come to encountering the man who saw my insides was five years later, when visiting the same hospital for a routine appointment with another hearty doctor. He admired my scar and confirmed that Mr Double-Barrel was a very fine doctor indeed.

I really wanted to hear an account of the operation from the man who had taken the scalpel to me. Was I reluctant to undergo 'narrative surrender' to the medical professionals (Frank, 1995) or keen to immerse myself in it? Certainly I wanted answers to the questions of order and control: 'Why me? Why now?' The imperative of re-making the narrative to accommodate the shock of a pathology is, we know, compelling (Farmer, 2004). I felt that if only the surgeon himself had come to speak to me, then my recovery would have been easier: I could have made sense of the physical rupturing of my boundaries and therefore knitted up some scar tissue quicker. I wanted to ask him 'What would have happened if you hadn't operated?' and, of course, 'What did my entrails look like?'

My desire to hear the story of my operation from the man holding the knife was strong. But if Mr Double-Barrel had been tending to my narrative needs, would his steady hand and confident manner have been well deployed? Was not he best kept in theatre tending to people in urgent want of his speedy removal services? Of course, his absence from my bedside when I wanted to hear about my innards might have been a function of his private practice, rather than his enormous NHS workload. (Perhaps 'consumer choice' in the NHS will one day extend to booking a surgeon who refutes private practice on ideological grounds.)

The tension between efficiency and humanity in medical services is an aspect of medical practice that the medical students I have taught cannot easily see. In their early years of training, medical students describe their motivation in beneficent and altruistic terms. They have not yet encountered the professional and bureaucratic systems that will constrain their ability to do the best for each patient, nor have they met the inherent uncertainty of disease which can undermine faith in medical methods. The students report feeling themselves to be powerless in the face of testing exams, competition for training places and clinical experience. Since students' main concern is getting into the profession, criticism of medical dominance, narrative denial or reductionist epistemology are not readily received. As a teacher I reassure myself that my pearls of wisdom and nuggets of insight into the doctor-patient encounter are lodged deep in the students' minds and will re-surface later in their careers. In a pastoral capacity I suspect that medical students need a certain insensitivity to patients' perspectives in order to survive the exigencies of medical training and the frustrations of NHS work without experiencing nervous collapse. This is, of course, at odds with my desire to be treated by compassionate, sensitive clinicians.

Sociology is an analytic discipline that apprehends the medical encounter in terms of systems, organisations, professions and power. Sociological approaches show us how professional, gendered or ethnic groups deny the humanity of others by developing particular meaning systems and by having the power to impose them. So what does a responsible medical sociologist recommend as a means of improving the humanity of medical practice in a world of finite resources? This was the question I faced in writing an introductory text for medical students (Bradby, 2009): what practical means can students adopt to develop a humane practice that attends to patients' concerns? Alongside their other medical competencies I hope that students learn to treat each person they encounter day-to-day with respect. While colleagues should be treated with respect and care too, I particularly urge students to address patients in a manner that recognises their humanity, erring in favour of polite formality until invited to do otherwise. Why does this quaint insistence on good manners matter? Perhaps if students' communication recognises the humanity of others, it is harder to deny it through the processes of decision-making, care and treatment. Students and doctors need to remain open to recognising the subjective frailty of people faced with medicine's methods, while the adoption of a professional manner should prevent them from becoming overwhelmed by others' suffering. Holding this contradiction together, tolerating its uncertainty, is part of what makes for an excellent clinician.

Emphasising a careful and respectful style of communication does not encapsulate the full range of sociological criticism of medicine. But it does offer a means whereby a practitioner might continue to elicit patients' views, which is an essential first step if real (rather than rhetorical) patient-centred care is to develop. The puzzle of sociology's sometime aversion to offering solutions to the problems that it diagnoses so incisively is a question that I'm leaving for my next book.

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# How does an efficient and equitable health service also treat patients with humanity and take their concerns seriously? A response to Hannah Bradby



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As many of us on the receiving end of healthcare know to our cost, poor communication (or the absence of communication), whether in hospital, general practice or in the community, is detrimental. Hannah Bradby's experience was clearly a distressing one. Like other patients' anecdotal reports, and numerous studies (e.g. Wright et al., 2004; Mercer and Howie, 2006), it highlights the therapeutic value of communication.

Hannah's experience was also unfortunate. It is unusual for the surgeon who performs the operation not to see that patient again, and the registrar's overworked condition does not excuse an apparent inability to communicate. But emergency surgery removes much of the scope for planning, discussion and getting to know the team. Perhaps the surgeon was caught in a series of urgent cases; or perhaps he disappeared to go on holiday. Might another surgeon, who understood and could explain the procedure, have taken his place? Could the registrar have returned when she was less busy?

Was Hannah given any explanation at all? Clinical guidelines (RCSE, 2008) state that 'all surgeons must... listen to and respect the views of patients ... insist that time is available for detailed explanation', and 'fully inform the patient...of progress during treatment'. Anecdotally, surgeons express reliance on patients' narratives to guide surgery, and respect the patient's need to be listened to throughout: as one surgeon reported (personal communication), 'I imagine they are my own mother or father and how I would want them to be treated'. If Hannah had decided to register her complaint, it would have been taken seriously.

There is another side to the story. Not only do doctors need to remain responsive to individuals. They also need to spread themselves across the remit of their patients and the length of their working week. This is all the more challenging in a target driven culture and in the context of the European Working Time Directive (EWTD), introduced to limit doctors' hours to 48 per week. This ruling is proving insufficient for junior surgeons to develop skills, and disruptive to continuity of care. Consultants are taking on more emergency work and patients may not see the same doctor twice (Oliver, 2009).

Contrary to the opinion expressed by Hannah Bradby, my experience indicates that medical students know the tensions between humanity and efficiency only too well. On clinical placement they deal with these on an everyday basis and discuss them with senior colleagues. Far from being insensitive to patients' perspectives or developing immunity in order to survive, they centre their learning on what the patient has to say. The maturity of their outlook extends to redressing some of the miscommunications they encounter.

What does their training teach them? Reflective skills, critical appraisal, person-centred care, communication with colleagues, dealing with uncertainty, professionalism, empathy, self-care, and the everyday demands of the NHS. Their survival technique is one of balancing their own needs and professional boundaries alongside their capacity to care for patients. Their main concern may be 'getting into the profession'; but what does that mean to them? They equate becoming a doctor with being safe and being competent (not with medical dominance or narrative denial). As medical students themselves said:

'Placement-based medical teaching gives me the opportunity to see good practice by good clinicians who have enormous respect for patients and inspire more consideration than any simulated session. As for the rarer instances when you witness a bad patient-doctor relationship, the consensus among medical students is that this works as a deterrent very effectively. Nobody wants to be the cocky 'so-and-so' whom the nurses hate and who makes the patients feel small.'

'I hope myself and my colleagues will be much different doctors from those qualifying a generation ago. It was enlightening to read her experience, and if I were a patient I can really understand where she is coming from. That surgeon shared a part of her that she will never know herself, and she never even got to know who he was until years later, let alone talk with him. But in the 'real world', her expectations may be unrealistic, even though they shouldn't be.'

'In the final years of medicine when the 'exigencies of medical training and the frustrations of NHS work' kick in, we are more keen to hear the patient's story. It makes us re-realise why we came into the profession, to regenerate the altruism we all once felt. The more we have interacted with the patient and the more we care, the better able we are to pin that learning in place.'

'We have all had 20+ years of practice at being human, and far less at developing the biomedical skills needed to make accurate diagnoses. But our placements still reinforce the important. For example even orthopaedic surgeons, often stereotyped as scalpel-happy and completely uncaring, ask the patient to what extent their problem is affecting their life and for their own views and these are definitely considered in determining if/when to intervene surgically.'

To answer the question, then, we need more than sociology: we also need a doctor's understanding and application of sociology in practice. We need to understand how medicine blends social with biomedical sciences. We need an integrated approach, with debate to bring different disciplines and perspectives together. We could make greater use of medical students' experiences to inform how we employ sociology and situate it within the undergraduate curriculum. On clinical placement, students see organisations in action, experience tensions between efficiency and humanity, play out learning acquired through lectures and simulated scenarios, and live through a doctor's day and all it entails.

Within sociology, we need to explore a number of dimensions, including: effects of policy directives; clinicians' everyday experiences; patients' views concerning how, and whether, their needs can be met.

The question of how to remain patient-centred may appear harder to answer in hospital than, perhaps, in community psychiatry or general practice. But it is gaining increasing recognition in all areas of medicine, at undergraduate, foundation and continuing professional development levels. One solution, currently being proposed and explored across different clinical settings, is to equate efficiency with listening to patients' concerns, e.g. by marrying process and content in history-taking and physical examination (Silverman et al., 2003).

Maintaining a careful and respectful communication approach requires a composite understanding that extends beyond single disciplines: one engendered through sociology, psychology, arts and humanities, ethics and linguistics, along with medicine.

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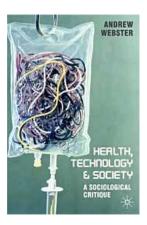
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## **BOOK REVIEWS**



Andrew Webster

Health, Technology, and Society: A Sociological Critique

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## Reviewed by Kelly Joyce, College of William and Mary, Virginia, USA

Andrew Webster, a prolific sociologist of science and technology, outlines a sociological approach to the study of technological innovation and applies that approach to specific cases such as genetic diagnostic tests and tissue engineering. The sociological approach presented emphasises a co-construction framework. That is, Webster examines how various actors, institutions, scientific knowledge, and policies interact to produce health technology use and dissemination. For Webster, it is crucial to trace the traffic between groups, diagnostic categories, economic investments, and health care policies to better understand how and why some technologies are accepted as well as how patients, health care professionals, and caregivers simultaneously give meaning to and shape technological innovation. To build his theoretical approach, Webster synthesises an array of medical sociological literatures and ideas (e.g. sociology of bodies, illness narratives, the sick role). The amount of material covered is impressive, and Webster's ability to build connections between various works is remarkable.

Technology, according to Webster, must be understood through social relationships and contexts or what he calls 'the social matrix'. A sociological critique of innovation should trace the factors that contribute to a technology's introduction. It should also examine the effects a technology has on our identities, relationships, and perceptions of health once it is used in health care. Webster pays particular attention to how private and public institutions invest, support, or control technological innovation. Charting transformations in medical practice over the last five decades, Webster argues that the state and the private sector have overtaken the importance of the clinicians 'as drivers of new technology' (49). Clinicians, however, still play an important role as gatekeepers; they help manage the way new techniques are integrated into clinical care.

Central to Webster's understanding of the social matrix of technological innovation is a reconsideration of the concept of the sick role. Developed by Talcott Parsons in the 1950s, sociologists have expanded, critiqued and refined the concept in subsequent decades. Webster develops what he calls 'the new sick role,' which extends the concept to include how individuals or groups mobilise, contest, and define the sick role in arenas (e.g., internet sites, media accounts) outside of or on the border of health care agencies. Webster outlines four ways individuals or groups actively contribute to the sick role. They can: (1) collectively research and define an illness to marshal additional health care resources; (2) argue for an illness's acknowledgement by mainstream health care professionals; (3) challenge the meaning of an illness; and/or (4) dispute a medicalised definition of an illness. Focusing on these processes emphasises the actions of patients, caregivers, and patient advocate groups. This move builds on scholarship by sociologists and science and technology studies scholars, and displaces the privileged status of health care professionals in sick role formulations.

Beyond emphasising how individuals reconfigure the sick role, Webster also begins to formulate a health role. Webster (95) writes, 'It [health] is, like sickness, more than simply a reflection or expression of the biophysical state of the body... health in this sense is anchored in socio-psychological beliefs and emotions, thereby dependent, as is the sick role, for its affirmation and confirmation by others.' Paying attention to the social definitions and expectations of 'health' is a productive new direction for scholarship. Although Webster briefly addresses this topic, the moral obligation to pursue health behaviours (e.g., exercise, eating plans, quit smoking); the relations between gender, race, class, nation, and changing definitions of health; and the linkages between interest groups and definitions of health require sustained sociological analysis.

The cultural dimension of innovation and dissemination is another topic that could be more thoroughly discussed. Webster thoughtfully attends to the identity-body-technology nexus, but the relations between medical technology innovation and cultural values, beliefs, and practices are not highlighted. Such a perspective could ask, for example, why are some technologies (e.g. medical imaging machines) appealing while others (e.g. male contraception pills) are not? In The Male Pill: A Biography of a Technology in the Making, science and studies scholar Nelly Oudshoorn (2003) calls for analysis of the cultural construction of technology. A sociological critique that integrates analysis of cultural belief systems, contexts, and conventions will provide insight into why some technologies are adopted and why others are not.

Ultimately, Health, Technology and Society is a call for research. It presents a conceptual framework that can be taken up by social scientists. As such, the book will be useful in undergraduate and graduate courses; it will inspire new research on the technology, science, and innovation junction. Promoting sociological scepticism, Webster's work challenges the celebration and fetishisation of technological innovation in popular culture and health care.

#### Reference

Oudshoorn, N. (2003) The Male Pill: A Biography of a Technology in the Making. Durham, NC: Duke University Press



Alison Hann (ed)

### **Health Policy and Politics**

Ashgate, 2007

ISBN: 9780754670643

206 pages, £55.00 (hbk)

## Reviewed by François Briatte, University of Grenoble, France

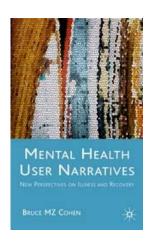
The topic of health policy-making in Britain seems inextinguishable, constantly renewed by shifts in the balance of power between its main players – the state, the medical profession and civil society. In that context, the papers collected in Health Policy and Politics examine the political factors that currently shape the making of health policy in the National Health Service (NHS). Its fourteen chapters cover a wide array of overarching issues that affect virtually all forms of treatment within the health care sector, except for two more specific case studies (Chapter 10 on 'protracted waiting for orthopaedic services' and Chapter 12 on immunisation policy). Most chapters are drawn from conference papers given by members of the Health Politics Group between 2005 and 2006.

An important transversal theme of the book relates to the design and reform of structural, system-level aspects of the NHS, which Alison Hann introduces as the 'macro' level of British health policy-making. Chapter 2 explores the mechanisms that help to explain a characteristic paradox of the NHS, or as Rudolf Klein once put it, a paradox of famine among plenty: 'how did a creditable record on NHS expenditure after 2002... come to co-exist with record deficits?' (14). Chapters 3 and 4 address the parallel issues of decentralisation and modernisation within the institutional framework of health services, both observing that reform is driven by sets of dual dynamics which often contradict, between centralist and decentralist tendencies or between competing models of modernised policy-making. Such ambiguity and complexity affects all instances of NHS reform, as illustrated by the Quality Outcomes Framework recently introduced in primary care (Chapter 14).

Another common line of inquiry addresses legitimacy and accountability in health services, which forms the backbone of Chapter 6. The historically persistent trend towards a consumerist model of health care, as described in Chapter 5, emphasises responsiveness as an organisational imperative for the NHS, insisting on the need for 'a more flexible mode of health provision' (66) that considers the patient as an active figure in his/her care. For that reason, patient and public involvement in health services (PPI) has provided a recurrent motive for reform and a long history of unsolved issues, as presented in Chapter 8. In parallel to the forums dedicated to 'expressing the patient's voice,' new institutions such as the National Institute for Health and Clinical Excellence (NICE) face a different challenge as they strive to establish themselves as legitimate decision-making bodies in the NHS, a task that blame-avoiding governments tend to avoid handling themselves because of, as shown in Chapter 7, 'the high political profile enjoyed by the NHS, leading to the prospect of lost votes for any party seen to damage it' (93).

The book inevitably leads the reader to look forward to the most important factors that might guide future developments in health policy. Alongside mentions of European regulatory convergence over particular aspects of health care, such as drug licensing (Chapter 13: 174), two chapters are particularly interesting in that respect. Chapter 1 provides a brief survey of the impact of European regulations, derived mostly from common market agreements, on public health policy—a trend, one may hint, which is set to increase in the coming years. A parallel source of influence over health policy-making stems from the rise of a 'New Public Health' ideology described in minute detail and through a careful examination of its historical lineage in Chapter 9. Both factors provide an institutional and ideational impetus that, when operating in conjunction with other social factors, may contribute to the introduction of important changes in the public health policies of European Member States, as already shown in the past with the adoption of new measures in tobacco control policy (115).

The texts collected in *Health Policy and Politics* provide an informative as well as critical vision of British health policy, which will prove especially useful to students of the NHS under New Labour. The only immediate regret that the reader might feel concerns some important aspects of health care that do not clearly appear in either the structure or the substance of the book, such as the evolution of clinical autonomy within clinical pathways built on networked models of care, the role of the third sector in supporting state-led treatment facilities and biomedical research, or the governance of the nursing profession in the NHS, all topics which become even more salient when observed in comparative settings.



Bruce M.Z. Cohen

# Mental Health User Narratives: New Perspectives on **Illness and Recovery**

Palgrave Macmillan 2008

ISBN: 9781403945365

232 pages, £53.00 (hbk)

#### Reviewed by Amy Chandler, University of Edinburgh, UK

In Mental Health User Narratives: New Perspectives on Illness and Recovery, Bruce Cohen has several related aims: to investigate the narratives of acute and severe mental health users; to compare those who have received in-patient psychiatric treatment with those who received a new home treatment service; and to demonstrate the usefulness of taking a 'narrative approach' in researching mental illnesses. Cohen also has a clear political project throughout the book: to expose and problematise the dominance of biomedical psychiatry in the treatment of people with mental illnesses. This project clearly informs his research methods, analyses and conclusions.

The research Cohen presents leads from his evaluation of a novel home based treatment approach to the care of people diagnosed with mental illnesses, which ran in Bradford, UK, between 1993 and 2003 (60-1). That the Bradford Home Treatment Service (BHTS) no longer exists in the form described by the participants of Cohen's research makes the positive discussion of the service somewhat bittersweet, as the reader is aware that the service is now largely disbanded. This evidently informs the political sub-plot of the book, as Cohen seeks to demonstrate the ways in which psychiatric practice is mediated by politics and governance, as well as medical 'knowledge'.

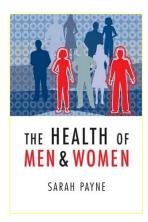
The book is useful on a number of levels, and thus will appeal to a variety of audiences. The early chapters provide interesting, concise and useful summaries which will aid students and readers new to either sociological perspectives on mental illnesses, or narrative research. Chapter 1 provides a review of the historical development of social scientific theories of mental illness, with a clear slant in favour of those critical to biomedical psychiatry. Chapter 2 summarises existing work in narrative research, focusing particularly on work on illness narratives and introducing Kleinman, Estroff and Palombo. Chapter 3 provides political and contextual information on the development, running of, and eventual disbanding of the BHTS.

The chapter on methods provides a fascinating discussion of the practicalities of actually 'doing' narrative research. Such reflexive and reflective discussions are often sorely lacking in existing narrative health research, and thus will prove interesting to both students and researchers alike. In particular, Cohen sets out solutions to some of the problems commonly faced by those of us attempting to 'do' narrative research – such as balancing ethical concerns about preserving narrative coherence with practical considerations regarding how best to present data.

Perhaps the most widely appealing sections of the book are the chapters of data, where Cohen presents the narratives of the people he spoke to in two distinct, but equally engaging, manners. Chapter 5 presents the narratives of 8 of the 49 interviewees in some detail. Large sections of transcribed text are presented, encouraging the reader to 'contemplate new and alternative 'readings' of the accounts' (91). Chapters 6 and 7, in contrast, give a more 'traditional' analysis of the whole data set, focusing on common themes from the crosssection of interviews. This two-pronged approach represents part of Cohen's solution to a common problem in presenting narrative research – how to preserve the coherence of a narrative 'as heard', without 'merely representing'. In attempting to do this, I would suggest Cohen has been largely successful. Chapter 5 gives the reader a good sense of the diversity of stories which Cohen heard, and also some idea of the variation in the ways in which these were told, whilst chapters 6 and 7 provide a broader view of some common narrative themes.

Chapter 6 focuses on the ways in which participants talked about their 'descent' into psychiatric illness and their experiences with services. Chapter 7 examines the different ways that participants talked about their recovery. Each of these chapters successfully illustrates the diverse ways in which these different aspects of being diagnosed with a psychiatric illness might be experienced. Supporting Cohen's political project, these accounts are presented as correlating closely with the type of psychiatric intervention the patients experienced. Thus, those patients who had been cared for at home through the BHTS reported generally favourable experiences, and appeared to frame their illness as something they were now able to cope with, or had even recovered from. Conversely, patients who had only experienced inpatient psychiatric care were more likely to talk about negative experiences, and appeared more liable to view their illness as more permanent and debilitating. It is of course possible that these findings reflect the type of person more likely to be referred to BHTS (less 'severe' cases perhaps), or that Cohen's political leanings led him to read more positive outcomes into the narratives of the BHTS patients. However, as no patients receive care from the BHTS now, this still leaves the discouraging possibility that whatever the reasons for the positive outcomes, they will be much less common now that the BHTS no longer exits.

The final chapter draws together Cohen's arguments and data, making some challenging and sobering conclusions with regard to the state of mental health care in general, and psychiatric practice in particular. Here Cohen is clear about the limits of the BHTS approach, and the unlikelihood of this type of approach to mental health care successfully operating permanently in the current socio-political climate. Cohen argues cogently for the importance of taking into account 'social and economic life factors' (178) in the development and treatment of mental illnesses, a stance which clearly demonstrates the importance of sociological perspectives on this area of medicine. However, he also acknowledges that such an approach is greatly hampered by the continued preference for biological psychiatric approaches, not only in medical discourse, but also in the eyes of many patients (174). Overall, Cohen presents an engaging critical study of the development and treatments of mental illnesses, which successfully demonstrates both the importance and relevance of social scientific approaches to the study of this area of medicine.



Sarah Payne

The Health of Men and Women

Polity Press, 2006

ISBN: 9780745634548

240 pages, £16.99 (pbk)

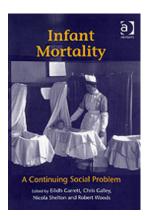
### Reviewed by Anna Gruszczynska, Aston University, Birmingham, UK

The strength of Sarah Payne's book, 'The Health of Men and Women' lies in her inclusive approach to gender and health, which combines two previously usually separated areas of enquiry and health policy, that is, women's health theory and the study of men's health and gender, where the author adopts quite a strong and comparative international focus, both in industrialised and in developing countries.

The author starts by outlining her idea for a comprehensive model, which reviews similarities and differences in women's and men's physical and mental health as shaped by both gender and sex-linked biology, and also by outcome and by age, class, race/ethnicity, sexuality and global region. She starts by applying this model to health-related behaviours such as exercise, alcohol, smoking and drug use. She also provides a very timely discussion on the multi-factorial nature of obesity and related issues such as dieting and exercise. The main body of the book focuses on three themes, that is, mental health, reproduction and mortality where she illustrates the working of her theoretical framework on specific examples. The author's choice to focus on case studies within each theme is a very good decision, which shows specificities and allows for a more in-depth understanding of complex factors connected with women's and men's health. Her discussion of mental health issues focuses on issues of eating disorders, depression and suicide. She then goes on to discuss issues connected with reproduction by focusing on sexual health, pregnancy and childbirths and HIV/ADIS. Finally, she examines issues of mortality, and looks at causes of both accidental and non-accidental death, and the factors behind healthy life expectancy. All of the case studies are examined in-depth in the context of her conceptual integrative framework - for instance, while looking at issues of mortality, she critiques gender differences in terms of healthy life expectancy and looks at the complex factors involved in the 'gender paradox' (i.e. the suggestion that women live longer in comparison with men but suffer poorer health). Finally, she returns to her model in the conclusion and argues for inclusivity in health-related research and the adoption of a framework that would include a critique of biological factors, material factors, gender discourses and gendered dimensions of treatment and research.

Paradoxically, the biggest strength of the book - the comprehensive model of sex and gender as elements of a larger theoretical framework in which class ethnicity and sexuality are also relevant - becomes the book's weakness. Throughout the main body of the book the author quite often starts the analysis of case studies by focusing on women's and men's health in general, and only then goes on to mention specific issues concerning, for instance, sexual and ethnic minorities. This way, she effectively contributes to the othering of men and women who do not fall under the default option of a white, heterosexual and middle-class option. Furthermore, while the author's attention to issues regarding gay and lesbian health is commendable, she chooses to omit transsexuality or intersexuality, which would provide a great opportunity to critique the normative notions of sex and the social construction of biology in relationship to health research.

Nevertheless, the book provides a thorough, quite exhaustive synthesis of research evidence on the relationship between gender and health that problematises a focus on women's or men's health alone. It should certainly be recommended as a reference book for both students and scholars of sociology of health and illness, and the publication will also be highly relevant for courses on gender, race and ethnicity as a good starting point for introducing the complex issues surrounding men's and women's health.



Garrett, E., Galley, C., Shelton, N. & Woods, R. (Eds)

#### Infant Mortality: A Continuing Social Problem

Ashgate, 2007

ISBN: 9780754645931

312 pages, £65.00 (hbk)

# Reviewed by Valerie M Sheach Leith, The Robert Gordon University, Aberdeen,

At the turn of the 20th Century, whilst health had improved for some sections of the population, infant mortality rates remained high, being over 150 (number of deaths under the age of one per 1,000 live births) in England and Wales. Through the publication of Infant Mortality: A Social Problem (1906) Sir George Newman, then Medical Officer of Health for the London Borough of Finsbury, increased awareness of this blight on the nation's health and advocated a range of policies for reducing the loss of so many young lives. Crucially, Newman believed the causes of high infant mortality to lie in the realm of the social rather than the medical sphere.

Garrett et al.'s (2006) edited collection commemorates the publication of *Infant Mortality*: A Social Problem, which in retrospect can be understood as a landmark text in the struggle to reduce infant mortality rates. Bringing Newman's work to a modern audience the editors' aim is to 'excite and inspire further research' (14) in a topic which has been historically complex and, as their title notes, continues to be so. Divided into three parts, the first section explores Newman's life and the impact of his work. The second and most substantial section is comprised of historically based research which rigorously examines aspects of the different factors that Newman believed contributed to infant mortality, namely the mother, the child and the environment. The concluding chapters highlight the huge strides made in reducing infant mortality rates since the early 20<sup>th</sup> Century but also provide a sobering commentary on the inequalities that remain.

The text has a number of real strengths. It is an excellent resource for those undertaking or planning research into historical aspects of infant mortality. Reading the central chapters, I was struck by the specific challenges facing researchers in grappling with the intricacies of historical sources, e.g. parish registers (Smith and Oeppen, Chapter 4), as well as the difficulties in using data to make comparisons between different geographical areas, which could, for example, be influenced at the micro level by the individual preferences of doctors when certifying cause of death (Garrett, Chapter 7). The text also provides fascinating insights into the intricacies of teasing out the different factors which may have contributed to the high infant mortality rates. To take just one example, Sneddon in his study of the Lincolnshire Fens, 1870-1900 (Chapter 5) explores why the rural-agricultural region of the Fens 'suffered from an infant mortality regime that was more akin to that of urban-industrial Revealing the need to rigorously interrogate data and to recognise its limitations, as well as emphasising the pitfalls of neglecting the nuances of class, ethnicity and geographic area, the text would also prove to be an excellent teaching resource not only in the public health arena but in the social sciences also.

To leave it there, however, would be to omit some of the most interesting aspects of the text. Newman (1906: 257-58 c/f Garrett et al 2006: 42) was clear that the key to reducing infant mortality lay in improving the state of motherhood. He believed that, 'the child...depends for its life in the first twelve months, not upon the State or the municipality, nor yet upon this or that system of crèche or milk-feeding, but upon the health, the intelligence, the devotion and maternal instinct of the mother'. Thus, mothers and the efficacy of their mothering were brought to the fore. Whilst this led to recommendations focused on the improvement of ante-natal and post-natal care, the education of mothers, particularly in relation to infant feeding, and consideration of the impact of maternal occupation (Reid, Chapter 10), it also meant that certain groups of mothers were identified as 'ignorant and careless'. From Newman's perspective some mothers were as much to blame for the death of their infants as was social and economic disadvantage. In the concluding chapter Shelton (257) considers the ways in which Newman's concerns about mothering are reflected in contemporary policy initiatives (e.g. the 'Healthy Start' scheme) which it is argued still imply that 'ignorance remains in the lower social classes'. Newman's focus on infant feeding also resonates with contemporary concerns about the impact of social grouping on breastfeeding initiation and continuation rates (Kelly, Chapter 12). The final chapters also draw attention to current inequalities which still impact on infant mortality rates. To give a stark example, in the years 2002-2004 Birmingham experienced 449 infant deaths, whilst Eastleigh had 6 (Review of the Health Inequalities Infant Mortality PSA Target 2007: 14). This linking of past and present in an insightful and thought provoking manner is a notable feature of the text.

A small quibble is the presentation of some of the illustrations which challenged my eyesight. This, however, was a book which rewarded close reading and which it is hoped will indeed fulfil the hope of the editors in inspiring further research. Although Newman could in all likelihood not have envisaged infant mortality rates falling to single figures, inequalities remain and complacency is not an option.

#### Reference

Healthy Inequalities Unit, DH. (2007) Review of the Health Inequalities Infant Mortality PSA Target, Department of Health. Available online <a href="http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGu">http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGu</a> idance/DH 065544> Accessed 1st September 2008.



Margaret Voysey Paun

A Constant Burden: The Reconstitution of Family Life

Ashgate, 2006

ISBN: 9780754644705

254 pages, £60 (hbk)

#### Reviewed by Paul ten Have, University of Amsterdam, The Netherlands

This is a re-edition, or rather a reprint, of a book originally published in 1975 by Routledge. The original text is preceded by a short preface by the series editor Robert Dingwall, and a 'New Introduction' by the author. As far as I can see, the basic text has been re-set, but not revised. The book certainly deserves its status as a 'classic', not only in medical sociology, but also in qualitative research more generally. Its original impact, however, seems to be mostly limited to the U.K., where it was especially noted by authors like David Silverman who were, or became, rather sceptical of the conventional usage of interview-based research. Its significance, then, transcends its substantive topic of the study of the impact of having a disabled child on family life. The core data-base of the study consists of interviews with parents, mostly the mothers, of families with such a child, who were seen 4 times. Inspired by a wide reading of the then current literature on 'deviance' and related subjects, the author struggled to come to grips analytically with what the parents told her about their experiences. Rather than as 'reports', she came to see these expressions as 'performances' or 'accounts'. Talking to a stranger, vaguely associated with medical institutions, they presented a picture of their experiences in terms of a public morality of family life, relevant even in their exceptional circumstances.

Providing adequate care for one's child is one of strongest moral obligations one can have. One of its upshots is that one has to understand what a child needs. When 'something' seems to be 'wrong' with a child, this becomes especially difficult. In those cases, what one can observe is a complex and differentiated pattern of interaction between common sense knowledge derived from various sources and expert knowledge offered by, or sought from, professionals such as doctors. Differentiating aspects are onset (sudden or gradual), diagnosis (clear or not), and prognosis (certain or not). The author describes and illustrates some typical ways of, and developments in, seeing the child, depending on variations in these aspects.

Parenting a disabled child creates specific problems in contacts with the outside world. It makes the 'ordinary' task of demonstrating one's adequacy as a parent more difficult than it already is for 'normal' parents. One issue is whether and how to make the fact of the child's disability available to outsiders. One may try to hide it, tell it outright, or reveal it gradually, each of these alternatives having its problems of strategy and tactics, depending on various circumstances. Another set of difficulties has to do with the extent to which, and the ways in which, a parent may depart from how a normal child would be handled, because of the disability. Overall, parents do present their choices in these matters as accountably adequate, as 'normal' in the given circumstances. Two aspects of parental adequacy are especially relevant, their 'responsibility' for the child's condition and their 'power' to do something about it. By treating these components as dichotomous, the author distinguishes 4 combinations as typical conditions.

Raising a disabled child places an enormous burden on the parents' capacities to accept the

child's condition and all that it entails, and to present an image of parental adequacy and normality-in-the circumstances to the outside world. They do not have to face this hardship 'alone'. The author discusses various cultural resources, derived from religion, medicine, psychiatry and/or sociology, and institutional agents, such as medical ones, social workers, voluntary associations and/or press publications, that can be seen to 'assist' them in making sense of their unexpected burden. Taken together the parents are encouraged to accept their fate and make the best of it, and follow the assistance and advice of the relevant experts and agencies. In short, the parents are induced to 'accept and adjust' by a generally expressed or implied positive ideology. As the author writes: '[i]n general it can be seen that the ideology acts to define the situation of parents with a disabled child in such a way that it appears congruent with the normal order of child-rearing. Evident discrepancies between the parent's situation and that of normal parents are symbolically transformed so that, far from far from constituting a challenge to, they appear to affirm the validity of that order.' (195)

Voysey's achievement was to use a wide range of theoretical insights, developed during the 1960s and early 70s, to carefully 'dissect' the actually used methods of making sense. However, the analysis could have been brought 'up to date'. One could imagine, for instance, a parallel analysis along Foucaultian lines: would that be equally sensible and/or relevant? It may also be that aspects of the 'ideology' as expressed or implied by various professional bodies may have changed during the intervening 40 years. At least some of the terms used have, such as 'mongol'. But I do not hesitate to recommend the book, both as an exemplary methodological exercise and as deeply informative about sense-making practices regarding disability and parental accountability.



Jonathan Ablard

Madness in Buenos Aires: Patients, Psychiatrists, and the Argentine State, 1880-1983

University of Calgary Press, 2008

ISBN: 9781552382332

300 pages, £23.50 (pbk)

# Reviewed by Fernando De Maio, Simon Fraser University, Vancouver, Canada

Madness in Buenos Aires offers an excellent overview of the history of psychiatry in Argentina – a country well-known for its fascination with mental health, psychiatry, and psychoanalysis. Jonathan Ablard's book weaves together historical data gleaned from patient records, insanity proceedings, official hospital records (when available – there are, as may be expected, many gaps in these documents), medical publications, and popular media accounts with primary interviews with senior psychiatrists in the country and field observations at some of Buenos Aires' psychiatric hospitals. The result is a fascinating account of 'the social, legal, medical, and ideological pathways that persons deemed insane followed in and out of hospitals' (Ablard, 2008: 11; emphasis in the original). Following the work of Allan Horwitz and Jonathan Sadowsky, Ablard's concern is not so much with the validity of diagnoses (an area of debate that he labels 'an intellectual minefield') but with the social processes that lead to patients' (often times involuntary) interaction with psychiatry.

Whilst the bulk of the book is focused on the period 1880-1983 (the year Argentina returned to democratic rule), Ablard's analysis also provides a brief overview of Argentina's history, beginning with the colonial era. A chapter on 'Foundations, Myths, and Institutions' outlines the country's early psychiatric history, focusing on its ambitious attempts to develop a health system and its clear concern with the mental health of immigrants. For Ablard, this centred on fear about who was entering the country: '...by the late nineteenth century, immigration was at the centre of almost all discussions of the country's social ills. The perceived relationship between immigration and insanity, which was confirmed by their numerical over-representation in the asylums, became one of the principal social themes of Argentine psychiatric discourse well into the 1940s' (27).

Closely aligned with Italian criminology, Argentine psychiatry in the early 1900s brought 'dangerous ideas', particularly about anarchism, into the psychiatric gaze. Ablard describes the consensus of the 'reform period' of 1880-1910: '[i]t was the duty of the state... to contain the threat of degeneration not only through progressive policies to foster the health of the population, but also to contain people who, because of inherent biological traits or of dangerous behaviours or ideas, threatened the national well-being' (30-31). Indeed, this fear clearly re-emerged in heightened and powerful forms during the military dictatorship of 1976-1983.

Ablard's book frames the history of Argentine psychiatry within the country's political history. After reviewing efforts to establish and expand community-based care of the mentally ill in the late 1950s and 1960s, he notes that '[t]his fragile period of innovation came to a brutal end with the military coup of March 1976. Military officers took over hospital administration; many progressive doctors were tortured, killed, or exiled. In the vacuum created by their absence, more conservative psychiatrists regained their position of dominance. Since the fall of the military in 1983 and the return from exile of many of Argentina's ablest mental health professionals, some strides have been made in protecting and caring for the mentally ill.' (7) The strongest sections of the book are those where Ablard seeks to analyze the role of psychiatry and psychiatrists during the 1976-1983 dictatorship; he rightly points out that many psychiatrists and their families were the targets of repression, yet other parts of the profession participated in it. Ablard writes: '...certain sectors of the profession updated the definition of social pathology to fit the ideological needs of the military' (164), the result being an ever-expanding range of society under the gaze of professional psychiatry – including members of left-wing organisations, whether guerrillas, intellectuals, or sympathisers, and their relatives.

This important historical period is described in a far-reaching chapter entitled 'From Perón to the *Proceso*: Authoritarianism, Democracy, and Psychiatric Reform, 1943-83'. Many readers will wish that this section of the book had been expanded; those forty years represent some of the most tumultuous in Argentina's complex history, and perhaps the different eras within that period need to be considered as distinct stages. Some readers will also be disappointed not to see analysis of Argentine psychiatry after the return to democratic rule – it is in this very period that the country has attempted to understand its experiences of military dictatorship and abuses of human rights. But to be fair, the book's analysis ends in 1983, and as Ablard notes, it is only in publications after that period that Argentine psychiatrists and social scientists offer reflections on those experiences and their relevance for the treatment of mental illness in the country today.

The book will be of interest to medical sociologists interested in the history of psychiatry and ideas about mental illness as related to issues of immigration, poverty, and economic development. It will undoubtedly also be of interest to students in Latin American Studies programmes, both at the undergraduate and graduate levels.



Sarah Earle and Gayle Letherby (eds)

### The Sociology of Healthcare: A Reader for Health **Professionals**

Palgrave Macmillan, 2008

ISBN: 9781403940803

336 pages, £21.99 (pbk)

#### Reviewed by Carrie Purcell, University of Edinburgh, UK

This edited collection from Earle and Letherby is intended to introduce sociological perspectives to healthcare professionals, and encourage critical thinking in this context, and succeeds as such an introduction by interweaving excerpts from classic texts such as Mills' Sociological Imagination and Freidson's Profession of Medicine with contemporary work from the field. The book is divided into five sections introduced by the editors, and each extract is both preceded by a commentary indicating its relevance or linking it to other readings in the volume, and followed by questions and activities to help the reader engage with the topic.

Part I, Sociological Perspectives on Health and Healthcare, begins with a look at the relevance of the political economy approach to contemporary healthcare, followed by a section on reproduction and women's health. Given its vast significance as an issue, I was pleased to see the medicalisation of women around their reproductive function introduced at such an early stage in the text (most likely a reflection of the editors' common interests). The excerpt from David Armstrong introduces Parsonian functionalism, and the idea of the 'normal' (Canguilhem's *The Normal and the Pathological* is disappointingly absent from the suggested 'further reading'), and the introduction of C. Wright Mills and the sociological imagination as a 'tool' in the final reading of this opening section should be particularly helpful to anyone new to the discipline.

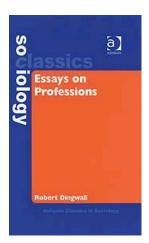
Making Sense of Health and Healthcare is the driest of the five sections, although in turning its attention to epistemology, methodology and research methods - and with a distinction between the latter two made clear from the outset – it will be useful for those in the process of getting health research off the ground. Qualitative and quantitative data collection methods are outlined in an excerpt from Keith Punch's introductory textbook, and secondary analysis in also touched on. Other readings in this part cover the politics and ethics of sociological research in general, including the power issues inherent in the researcherrespondent relationship, and the issue of 'voice' - to which the reading from Helen Roberts provides a useful introduction, alongside the recommended reading.

Of the five excerpts in Part III, which focus on Inequalities and Diversity, reading 12 stands out: Robert Crawford on 'the politics of victim blaming'. Although over thirty years have passed since it was written, Crawford makes several points regarding the culture of victim-blaming and the problem of rising healthcare costs which continue to be pertinent. Other readings in this section touch not only on gender and ethnicity, as we would expect in such a reader, but also on the significance of geography as a factor in health, and on the benefits of listening to children's perceptions of inequalities when studying healthcare in childhood. As with the volume as a whole, this section encourages practitioner reflexivity in terms of awareness of the multiple issues which shape an individual's wellbeing.

It was the final two sections that attracted my attention most prior to reading the book, and I found them to be well selected and thought-provoking in their combinations of excerpts. Part IV, on Bodies, Minds and Emotions, reflects the upsurge in interest in the body in sociology over the last two decades or so. It begins with an extract from Deborah Lupton's exploration of death – which seems appropriate since this is the state in which many healthcare trainees first encounter bodies. The reading on 'dirty work' from Ian Shaw provides another example based on empirical research (in this case on people with psychiatric problems) and highlights the division of labour in healthcare professions that perpetuates an order in which status is inversely proportional to proximity to bodies and their functions. Reading 22 introduces 'emotion work': concisely highlighting its central aspects as conceptualised by Hochschild and others, and again encouraging the reader to consider the theory in relation to their own practice.

The final part, Power, Professions and Practice in Health and Healthcare, begins with the excerpt from Freidson - an essential read for anyone interested in professionalism in healthcare – followed by Kellner et al's take on professionalisation in the CAM sector (an inclusion I was relieved to find given the volume's otherwise exclusively biomedical focus). Body modification and occupational boundaries are also touched upon in this final section, and it ends on a topic which can potentially be seen as both the best and worst thing ever to happen to healthcare: the internet. The argument about whether the latter facilitates the democratisation of healthcare knowledge or endangers lives by spreading inaccurate information is relevant to the work of all healthcare practitioners, conventional and complementary, and in a volume aimed at stimulating debate provides a most appropriate conclusion.

As with any reader of this sort, there is an enormous amount of fascinating material which could have been included, making the editors' job all the more difficult. However, the selections here are well justified and thought provoking in a way which can be expected to promote reflexive practice and debate. The accessibility of the volume makes it relevant not only for practicing professionals, but also as an introductory text for students and trainees in the field, and anyone with an interest in the sociology of health, illness and healthcare.



Robert Dingwall

#### **Essays on Professions**

Ashgate, 2008

ISBN: 9780754646143

186 pages, £55 (hbk)

#### Reviewed by Stephen Timmons, University of Nottingham, UK

Alternatively, Robert Dingwall 's Greatest Hits. This is a compilation of papers by Professor Dingwall, most of which have been published previously. Having said that, it does have a real value as a book, in so far as it shows how the sociology of professions has developed over Dingwall's long career, in which he has been a major contributor to the field.

Like a Greatest Hits album, there is a review of Dingwall's career in the form of the Foreword. Chapter 1 is slightly out of the chronological order that organises the book. It is a reprint of the introduction to a book on the sociology of professions from 1983 which focuses on Parsons and Hughes. Chapters 2, 3, and 4 are based on Dingwall's PhD research in the 1970s on health visiting. They continue to have a relevance both theoretical and practical. My own students (of nursing) are still told the same atrocity stories more than thirty years later. Chapter 5 'A Respectable Profession?' reviews both economic and sociological perspectives on professions. Despite the fact that professions have also been of interest to economists, going back as far as Adam Smith, there seems to have been little work that attempts to draw the two perspectives together, and Dingwall's chapter is a clear, wide-ranging and interesting attempt to do so. It is perhaps surprising that Marxist sociologists and free-market economists reach approximately the same conclusions about the professions, that they are, in the words of George Bernard Shaw, 'a conspiracy against the laity'. Dingwall argues that adherence to a profession's moral code is the price the profession pays for a state-sanctioned monopoly. This adherence is largely achieved through the experience of undergoing the training process, which may explain why the GMC is currently so exercised about the 'character' of doctors, and how to influence its formation, not least because of the shortcomings of medical 'character' displayed in some high-profile cases.

Chapter 6 has not appeared (in English) before. It is a short, but valuable history of the formation of pharmacy as a profession. In chapter 7, Dingwall argues for a revival of interest in the British sociologist Herbert Spencer. He believes that Spencer has been unjustly neglected by sociology, largely because of Spencer's unpalatable political beliefs. In the chapter Dingwall shows how Spencer's evolutionary, organic approach is a valid analysis of the formation of professions, prefiguring, in his view, the much better known work of Andrew Abbott in The System of the Professions. Chapter 8 is more contemporary, considering the attack on the 'market shelters' of the professions by the neo-liberal state. Dingwall speculates that the effect of globalisation may be to bring about the development of new, globalised forms of professions not linked to nation-states.

Chapter 9 is an analysis of the development of mediation as a profession, drawing on the insights of organisational studies as well as sociology, again bringing together disciplines which ought to inform each other perhaps more than they currently do. Dingwall ends this chapter with a rather engaging defence of the virtues of bureaucracy. Chapter 10 is an essay in memory of Eliot Freidson. It's interesting to note that one of the enduring criticisms of medical sociology – that it is obsessed with the doctor-patient encounter at the expense of consideration of wider structures- was made by Freidson as long ago as 1970. One of Freidson's great strengths is that he made concrete proposals for the reform of health care systems, again, something that medical sociology has sometimes been criticised for not doing enough. In this chapter, Dingwall reviews the last 30 years of threats to professional dominance, including increased accountability to both managers and patients, as well as competition. Freidson's later work included an argument for professions being a defence against (neo-liberal) state power. I'm not sure I'm convinced by this, and neither is Dingwall.

One of the problems with works like this is that they are sometimes a bit repetitious. It would also have been nice to have an essay in conclusion. However, these do not detract from an interesting and valuable collection, by someone who has made a substantial contribution to the field in the period of time covered by this book.

# Submitting a book review

Mso welcomes the submission of reviews of books that are of relevance to medical sociology. A list of books available for review is published in each edition, but the editorial team will also be happy to consider reviews of books not listed, provided they are of relevance to the medical sociology community. Please contact the editorial team if you would like a copy of a book for review. There is no prescribed format for reviews, although reviewers should provide the full reference of the book, including the price, number of pages and the ISBN. Reviews should be no longer than 1000 words. Completed reviews should be submitted as a Word document via email to mso@liv.ac.uk. Book reviews will not be subject to peer review, and the decision to publish them will be made by the editorial team. The editorial team also reserve the right to edit articles prior to publication.

#### Books available for review

Bergdolt, Klaus (2008). Wellbeing: A Cultural History of Healthy Living. Cambridge: Polity Press

Berry, Bonnie (2008). The Power of Looks: Social Stratification of Physical Appearance. Aldershot: Ashgate.

Bird, Chloe E. and Rieker, Patricia P. (2008). Gender and Health: The Effects of Constrained Choices and Social Policies. Cambridge: Cambridge University Press

Gabe, Jonathan and Calnan, Michael (Eds.) (2009). The New Sociology of the Health Service. London: Routledge

Green, Judith and Thorogood, Nicki (2009). Qualitative Methods for Health Research (2<sup>nd</sup> edition). London: Sage

Greener, Ian (2008). Healthcare in the UK: Understanding continuity and change. Bristol: Policy Press

Helman, Cecil (2008). *Medical Anthropology*. Aldershot: Ashgate.

Hunter, David J. (2008). The Health Debate: Policy & Politics in the Twenty-First Century. Bristol: The Policy Press

Latimer, Joanna and Schillmeier, Michael (eds.) (2009). Un/knowing Bodies. Oxford: Blackwell/Sociological Review.

Shaw, Ian, Middleton, Hugh and Cohen, Jeffrey (2007). Understanding Treatment Without Consent. An Analysis of the Work of the Mental Health Act. Aldershot: Ashgate.

Vande Berg, Leah and Trujillo, Nick (2008). Cancer and Death: A Love Story in Two Voices. Cresskill, New Jersey: Hampton Press.

Victor, Christina, Scambler, Sasha and Bond, John (2009). The Social World of Older People: Understanding Loneliness and Social Isolation in Later Life. Maidenhead: McGraw Hill/Open University Press.

Williams, Simon J., Gabe, Jonathan and Davis, Peter (Eds.) (2009). Pharmaceuticals and Society: Critical Discourses and Debates. Oxford: Wiley-Blackwell.

#### **CURRENT RESEARCH**

This section allows researchers and postgraduates to share details of new and current research projects and recently awarded research grants of specific interest to medical sociologists. If you would like to include details of your own current research or recent award in the next edition of MSo please go to: http://www.medicalsociologyonline.org.

# The shifting locus of care: Deinstitutionalisation and balance of care in mental health policy and practice in France and England (working title)



PhD researcher: Emilie Courtin

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Emilie Courtin began her PhD in October 2006 on a full-time basis and expects to complete in October 2010. She is funded by the French Ministry of Education and Research.

#### **Supervisors**

Professor Vincent Dubois, Institute of Political Studies, Strasbourg Professor Martin Knapp, London School of Economics and Institute of Psychiatry (during her visiting appointment at the IoP).

#### Abstract

## Aims and Objectives

The aim is to assess the consequences of deinstitutionalisation in France and England. We will try to understand the recent development in the balance of care in mental health practice in the daily life of a community mental health team and an associated in-patient unit in both countries. The objective is to understand the day-to-day reality of the transition from hospitals to entities outside the hospital and how the different actors involved interact. The analysis is conducted at three levels: from the perspective of care staff (doctors, nurses, social workers), of patients, and of the families.

#### Methods

The approach to the task of accounting for the nature and character of this shift combines both sociology and history. First, analysis of the relevant literature and archives will be conducted. During the second phase, in-depth interviews will be made with relevant actors as well as observations of the daily routines of mental health services in both countries. The third phase will pilot in-depth interviews with patients and families. All interviews will be tape recorded, transcribed and analysed.

#### Findings to date

The literature review as well as the analysis of the interviews made in France clearly shows that mental health policy can only be understood as one strand within the wider health and social care context and that it lies at the interface of what is increasingly seen as a continuous spectrum of policy and related services and practices. Mental health policy is very much a 'mixed economy', involving the state, the market, the family and the voluntary sector. The study of the deinstitutionalisation process from an historical and sociological perspective gives valuable insights into the changing balance of mental health services both at micro and macro levels.

#### Related conference and poster presentations

Health care system change: insights from the deinstitutionalisation process in France and England, *Explaining healthcare system change* workshop, University of Bremen, December 4-5, 2008.

Mental health and psychiatric practice in France: a renewed approach or the success of a catch-all category?, Poster presentation, 4th Hera Annual Conference and 1st European Conference for Collaborative Research in Humanities, Strasbourg, 8-9 October 2008.

Mental health and psychiatric practice in France: a renewed approach or the success of a catch-all category? *British Sociological Association Medical Sociology Group Annual Conference*, University of Sussex, Brighton, 6-8 September 2008.

The architecture of change: rethinking the deinstitutionalisation process in France and England, *Writing the history of psychiatry after 1945* workshop, Université Libre de Bruxelles, Belgium, 30-31 May 2008.

# **Teaching and Learning Medical Ethics**



PhD researcher: Nathan Emmerich

Queen's University Belfast

nathan.emmerich@gmail.com

Nathan Emmerich began his PhD in September 2007 on a full-time basis and began data collection in January 2009. The research project is funded by The Changing Ageing Partnership (Atlantic Philanthropies) www.changingageing.com

#### Supervisors

Prof. Lindsay Prior (Queen's University Belfast) Dr Matthew Wood (Queen's University Belfast)

#### Abstract

Aims and Objectives

My research seeks to explore the sociological dimensions of teaching and learning medical ethics on a UK Medical Undergraduate Degree. I conceive of a 'Medical Ethical Habitus' and seek to demonstrate how this structural aspect of medicine arose in its current form; how this produces pedagogical practice; and how it is reproduced or 'encultured' in undergraduate students.

#### Methods

Historical (genealogical) analysis, interviews and participant observation.

This project is theoretically grounded in Bourdieu's reflexive sociology and in his primary concept of habitus. Bauman's postmodern ethics provides the basis for my sociological approach to ethics.

#### **Related papers**

Emmerich, N. (2009). On the Ethics Committee: The Expert Member, the Lay Member and the Absentee Ethicist. Research Ethics Review, 5(1): 9-13.

#### Related conference papers

Emmerich, N. (2008) A philosophical methodology for the social sciences of and in bioethics. 3<sup>rd</sup> Annual Postgraduate Bioethics Conference, University of Manchester, June 2008.

# Exploring experiences of, and attitudes towards, voluntary alcohol intoxication and non-consensual sex amongst a student population



PhD researcher: Clare Gunby

Centre for Public Health, Liverpool John Moores University, UK

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Clare began her departmental funded PhD in January 2008 on a full-time basis. The PhD emerged from a specific interest in sexual offences and the impact of stereotyped beliefs and attitudes about rape case attrition within the Criminal Justice System. The PhD is being carried out in conjunction with the School of Law of Liverpool John Moores University.

#### **Supervisors**

Dr. Caryl Beynon (Liverpool John Moores University)
Dr. Anna Carline (Liverpool John Moores University)
Professor Noel Sheehy (Liverpool John Moores University)

#### **Abstract**

#### Aims and Objectives

The research aims to identify the prevalence of voluntary alcohol use and non-consensual sex amongst a Liverpool based student sample. The research also aims to highlight the frequency with which alcohol related strategies (e.g. intentionally targeting an individual who is too drunk to consent to sex) are used by perpetrators to procure victims. The study will also examine perceptions and misconceptions surrounding sexual consent and the capacity to consent as well as examining a number of beliefs and attitudes regarding alcohol consumption and sexual offences. The PhD aims to develop further understanding of the influence of alcohol on people's perceptions and judgements of responsibility in rape cases as well as highlighting misconceptions surrounding the law of rape. The research aims to propose strategies for addressing these issues as well as promoting awareness and guidance related to 'staying safe'.

#### Methods

The study will adopt a mixed methods approach using quantitative survey data and qualitative semi-structured interview information. The quantitative strand of the research is currently

underway with 800 students to date having completed the relevant on-line questionnaire. Qualitative semi-structured interviews with Merseyside based rape crisis counsellors have just commenced in order to complement and contextualise the quantitative data.

#### Description of argument/results to date

Whilst much American research has addressed students' experiences of non-consensual sex when drunk, this is a largely un-examined area in the UK. The current research therefore attempts to address this gap in knowledge and provide an initial estimate of the extent of the problem. The term Drug Facilitated Sexual Assault has received much recent media coverage despite toxicological evidence demonstrating that voluntary alcohol consumption is most frequently associated with a sexual offence, as opposed to the surreptitious administration of a date-rape drug (e.g. Rohypnol). The current research therefore gives precedence to this highly significant substance and focuses on the importance of voluntary self-administration. Historically, research in the field has been conducted from the perspective of women as the victims of sexual offences and men as the perpetrators of such acts. Whilst this perspective has been well justified, it has neglected those instances of male rape and same-sex assault. The current research consequently takes a gender neutral approach with regard to the reporting of rape experiences and the perpetration of non-consensual sexual acts.

Initial review of the data has found high levels of alcohol related rape, the subscription to a number of stereotyped attitudes regarding the victims of alcohol related rape and the intentional use of alcohol related strategies in order to procure sex. Confusion surrounding the law of rape and the concepts of freedom and capacity has also been identified. Full analysis of survey and interview data is ongoing.

#### Future work

It is anticipated that the next phase of the PhD will involve interviews with barristers prosecuting and defending rape cases. It is anticipated that this will help to gain further insight into the process of rape case attrition, looking specifically at those cases involving voluntary alcohol consumption. This work will also address how a number of the provisions of the 2003 Sexual Offences Act work in practice. It is also anticipated that some of the findings to have emerged from the initial survey will be explored in additional depth in a focus group setting. For example, the widely held attitude that rape is frequently falsely reported to the police.

#### CONGRATULATIONS

On the edge of motherhood in Flanders and the Netherlands: a sociological approach to maternal well-being in two health care systems



Wendy Christiaens,

Ghent University, Belgium

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Congratulations to Wendy Christiaens who began her PhD in March 2002 on a full-time basis and successfully completed it in January 2008. Her thesis is entitled 'On the edge of motherhood in Flanders and the Netherlands: a sociological approach to maternal well-being in two health care systems' and was awarded by Ghent University, Belgium.

#### **Abstract**

#### Background

The care for mothers and (unborn) children during pregnancy and childbirth underwent a transformation during the twentieth century. Medical frames of reference and knowledge have been accepted and legitimated, arguing that the unpredictable process of birth can be managed by means of technology, reducing the risk for adverse outcomes, eliminating pain and discomfort. However, this tendency has been criticised for the steady erosion of maternal choice, control and satisfaction. Moreover, the efficiency and effectiveness of a wide range of obstetric technologies has been questioned. In this thesis I argue that the debate about the beneficial and iatrogenic effects of medicalisation cannot be solved by theoretical arguments, but needs an empirical evaluation. Therefore maternal well-being has been assessed in Belgium and the Netherlands, countries characterised by different organisation of maternity care. The Netherlands are well-known for their high percentage of home births and low intervention rates. In Belgium, however, home deliveries are rare and maternity care is permeated by the biomedical discourse.

#### Methods

Two questionnaires were completed by 611 Belgian and Dutch women, one at 30 weeks of pregnancy and one within the first 2 weeks after childbirth, at home or in hospital. The women were invited to participate in the study by independent midwives and obstetricians during prenatal visits between 2004 and 2005.

#### Results

Results indicate that (1) women giving birth at home report higher satisfaction with childbirth, (2) Belgian women are more satisfied with their birth experience, regardless of place of birth, and (3) being transferred from home to hospital lowers satisfaction scores, especially in the Netherlands. Hence, the medicalisation of childbirth does not unequivocally result in lowered maternal well-being. The thesis concludes by arguing for the contextualisation of medicalisation of childbirth. Childbearing women are reflexive care seekers who use formal care-arrangements in function of their daily life conditions throughout the transition to parenthood.

#### Related publications

Christiaens, W., Verhaeghe, M. and Bracke, P. (2008). Childbirth expectations and experiences in Belgian and Dutch models of maternity care. *Journal of Reproductive and Infant Psychology*, 26(4): 309-322

Christiaens, W. and Bracke, P. (2007). Place of birth and satisfaction with childbirth in Belgium and the Netherlands, *Midwifery*, May 16.

Christiaens, W., Gouwy, A. and Bracke, P. (2007). Does a referral from home to hospital affect satisfaction with childbirth? A cross-national comparison. *BMC Health Services Research*, 7: 109.

Christiaens, W. & Bracke, P. (2007). Assessment of social psychological determinants of satisfaction with childbirth in a cross-national perspective, *BMC Pregnancy and childbirth*, 7: 26.

#### Related conference papers

Christiaens, W., Hresanova, E., and Bracke, P. How do welfare states care for mothers? Medicalisation of maternity care and familiarisation in a cross-national perspective. *The 4th Congress of the European Society on Family Relations: Cultures, generations and family interactions*, Jyväskylä, Finland, September 24-27, 2008.

Christiaens, W., DeVries, R. and Wrede, S. The work-care balance during pregnancy and childbirth: the pattern of maternity care uptake in different gender regimes. *The 12<sup>th</sup> Biennial congress of the European Society for Health and Medical Sociology (ESHMS) 2008 conference*, Oslo University College, Norway, August 28-30, 2008.

Christiaens, W., Verhaeghe, M., and Bracke, P. Childbirth expectations and experiences in Belgian and Dutch models of maternity care. *The International Sociological Association Research Committee on the Sociology of Health & the Canadian Medical Sociology Association Inaugural Meeting*, Montreal, Canada, May 23-25, 2008.

Christiaens, W. A comparison of maternity care in Belgium and the Netherlands. *European Sociological Association 8th Conference*, Glasgow, September 3-6, 2007.

#### **Current and future work**

Wendy is Senior Researcher at the Department of Sociology, Ghent University. Her current and future work concentrates on the transition to parenthood in a cross-national, longitudinal and multi-actor perspective. The interaction between care-arrangements and daily life conditions (e.g. work) during the transition and its consequences for parents' well-being are central to her work.

# The organisational world of emergency clinicians



**Dr Peter Nugus,** *University of New South Wales, Australia* 

#### p.nugus@unsw.edu.au

Congratulations to Dr Peter Nugus who was awarded his PhD in December 2007 for his thesis entitled 'The organisational world of emergency clinicians'. Peter's PhD was conducted on a full-time basis, was funded by a Centre for Clinical Excellence Patient Safety Scholarship and was awarded by the University of New South Wales.

#### **Supervisors**

Professor Jeffrey Braithwaite (University of New South Wales)

#### **Abstract**

#### Aims and objectives

Emergency clinicians are responsible for rapid diagnosis and treatment, and the disposition of patients either to other hospital departments or for discharge from the ED (Emergency Department). The research aimed to reveal the unique and under-explored domain of work involved in their interactions with other emergency clinicians and with clinicians from other departments.

#### Methods

The thesis draws on a year's worth of ethnographic research in the EDs of two tertiary referral hospitals in Sydney, Australia - including unstructured and structured observation, and 56 field interviews.

#### **Findings**

Emergency medicine and ED work are inherently 'clinical-organisational'. Emergency clinicians progress patient care by intertwining time management and negotiation skills with clinical care. This allows them to collectively create a moving 'carousel'. They simultaneously treat individual patients and fulfil the organisation's demands by organising the care for multiple present and future patients. Emergency clinicians are taught to become

part of a clinical-organisational culture. This is especially evident in the complexity of the work of senior emergency clinicians and the way they educate junior clinicians. The pecking order of other medical and surgical specialties has a negative impact on the ability of the ED to deliver collaborative care. In response to the hospitals' structure, emergency clinicians use their knowledge about the way the organisation works, and communication skills, to progress patient pathways.

#### Conclusions/ recommendations

EDs are the link between the community and the hospital. This requires recognition of and support for the unique diagnostic, interventional, organisational and educational work emergency clinicians undertake at the front door of the hospital.

#### **Related Publications**

Nugus, P. (2008). The interactionist self and grounded research: Reflexivity in a study of Emergency Department clinicians. *Qualitative Sociology Review*, 4(1): 189-204.

Nugus, P., Travaglia, J. and Braithwaite, J. (2008). *Report on a Study of the Work of Emergency Department Clinicians in New South Wales*. Sydney: Centre for Clinical Governance Research, UNSW. Report for the Clinical Excellence Commission of New South Wales. ISBN: 978-0-7334-2717-6.

#### **Related Conference presentations**

Nugus, P., and Braithwaite, J. How do clinicians actually deliver care to patients? Local enactments of quality in the Emergency Department, *Conference of the International Society for Quality in Health Care*, Copenhagen, Denmark, 19-22 October, 2008.

Nugus, P., Braithwaite, R., Iedema, R., Holdgate, A., Travaglia, J., McCarthy, S., Fry, M. and Daly, B. El Impacto del Conocimiento Clínico, su Estructura e Interacción en la Experiencia del Paciente: El Recorrido Organizacional del Clínico de Emergencias, Paper presented to the inaugural *Congreso Interamericano de la Medicina de Emergencias*. Buenos Aires, Argentina, 18-21 April, 2007. *Academic Emergency Medicine*, 14(4): e97-e98.

Nugus, P, Braithwaite, J., Iedema, R., Travaglia, J., Holdgate, A., McCarthy, S., Fry, M. and Daly, B. Negotiating the patient pathway: The organisational journey of Australian Emergency clinicians, *Conference on Communication, Medicine and Ethics*, Cardiff, Wales, 29 June-2 July, 2006.

Nugus, P., Braithwaite, J., Iedema, R., Holdgate, A., Travaglia, J., McCarthy, S., Fry, M. and Daly, B. The impact of clinical knowledge, structure and interaction on the patient pathway in Australian Emergency Departments, *Inaugural Inter-American Congress on Emergency Medicine*, Buenos Aires, Argentina, 18-21 April, 2006.

#### **Current and future work**

Currently Research Fellow on Action Research Interprofessional Learning Project between UNSW and ACT Health, pursuing research on EDs, integrated care, and acute care to older patients.