Health, medicine and society

Key theories, future agendas

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ROUTLEDGE

Publisher's Note

In memory of Winsome Gabe who died while this book was
being prepared

Chapter 1

Class, time and biography

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Social class has always been a fundamental concept in medical sociology, demonstrating its empirical value for the understanding of 'health chances' for the individual ever since the early years of this century when Stevenson constructed a classification based on father's occupation for the purpose of analysing infant mortality in England and Wales (Stevenson 1925). In the past, however, medical sociologists have been criticised for an atheoretical use of class. Registrar General's Social Class (RGSC) was undoubtedly useful. In many decades of national statistics, and in countless studies of health outcomes, experiences, behaviour and attitudes, linear trends by RGSC have been the norm. But, increasingly, not only is this time-honoured instrument beginning to falter in certain circumstances, but the processes which lie behind such a classification are coming under scrutiny.

Medical sociology, and especially the 'inequality in health' debate, have thus been criticised as being isolated from developments in wider sociology. The theme of this chapter, however, is to document how this is changing. It is argued that, currently, medical sociology is both taking note of contemporary theory of class and contributing to it.

This is occurring largely through an attempt to incorporate the concept of time. Health is a characteristic where time cannot be ignored: the sociology of health is concerned with birth and death, ageing and the lifecourse, becoming ill and getting better, moving through both personal and historical trajectories. Health is neither simply a characteristic of the individual nor an event, but their meeting as they come together in biography. Thus health is a topic which adds in a special way to both structure and action as they are conceived of in the theory of class.

The questions addressed here (and illustrated in an inevitably selected way by reference to a variety of bodies of research) are:

- in what ways has medical sociology articulated with contemporary debates about the concept of *class*?
- how is *time* being incorporated, both theoretically and empirically?
- in what ways does *biography* represent the synthesis of class and time?

The journey is in part from 'class and health' to 'biography and health'. This is a journey from an area which is stereotypically, though not invariably, quantitative, cross-sectional, static, depending on measures of health and of class which are as precise as possible, to a field of work which is probably, though not necessarily, qualitative, encompassing change and the constructed nature of both health and social structure. This journey is mapped in more detail throughout this volume.

Class

In 'inequality' studies particularly, social class has always been a key concept. For most of this century RG Social Class has played a major role in the monitoring of trends in mortality and morbidity. The principal question of recent decades has been how to explain the observed linear relationship between health and occupational class. This general pattern is seen throughout industrialised societies and across most measures of health, and remains relatively unaffected by social policies and by generally improving health and lengthening expectation of life. Specific diseases may have specific causes, but cutting across these there is a vulnerability which is clearly related to social structure. Thus the importance of 'class' remains, and RG Social Class is still commonly used in analysis on the grounds that it permits comparison with data over a long period of the past, and that it is still a useful predictor of ill health.

In the wider sociological arena, however, the way in which medical sociology has used the system has been criticised for an unclear theoretical basis, and it is argued that contemporary discussion of the meaning of class has been ignored. What Holton and Turner (1994) called the 'debate and pseudo-debate' about the 'future' of class analysis (Goldthorpe and Marshall 1992), or its 'death' (Clark and Lipset 1991), 'attenuation' (Morris and Scott 1996) and 'fragmentation' (Compton 1996), cannot be rehearsed here. In the practical empirical terms which were perhaps first seen as relevant in medical sociology, the basis of the mounting criticism of class analysis was that large and growing numbers of any population are routinely omitted from the standard classification: the retired, welfare recipients, women engaged in household duties, those who have never been employed. In particular, the use of a system designed for male occupations and lifestyles was increasingly found to be inappropriate for women.

The wider debate on class involved more than simply pointing to the problems of detail in a system which might be outmoded, however. Though changes in the social standing of particular occupations and shifts in the occupational structure have led to modifications in the Registrar General system at successive censuses, there are more fundamental criticisms. Among these is that the class structure of modern industrialised societies, and indeed the very meaning of class, have changed: this is not simply

historical change in the relative positions of occupations, but fundamental changes in the significance of occupation. There have been extensive changes in the world of production, with the decline in manufacturing industry. The middle classes have not only increased in size, in both absolute and relative terms, but have also become more differentiated. There has been a shrinkage of the wage labour society, through extended education, earlier retirement, shorter hours, and the development of part-time, shared, and contract work. The boundaries between work and non-work become more fluid, with flexible forms of employment and domestic and wage labour less clearly separated. There is a shortening of the proportion of the lifespan spent in work. Rising living standards, a decline in the influence of traditional institutions, and the erosion of traditional status orders, have all been implicated in the changing meaning of class.

These practical problems of applying RG Social Class, and doubts about the continuing validity of the system, have caused increasing unease about using class as an explanatory variable in health. In the field of inequality of health, for instance, class continues, despite all the problems noted above, to be a useful descriptive variable, but it offers little to *explanation*, to the identification of the factors which cause social variation. There is no clarity about what RG Social Class actually measures, or with what accuracy. The basis is officially described as level of occupational skill, implicitly presumed to be associated with both a material, economic dimension and a status dimension. The conflation has been criticised by Weberians and Marxists alike. In fact, rather little attention has been paid by theoretical sociologists to mapping either changing rewards or shifting prestige in RG classes over time, since in the wider sociological arena it is preferred to dismiss the simple RGSC I–V altogether. It is only medical sociology which has remained to some extent tied to the system because of its use for census and mortality data.

The elaboration of class in medical sociology

Thus it is in medical sociology, particularly, that a large body of work has developed in the elaboration of RG Social Class, seeking associations and explanations for socially patterned health in terms of the possible components of class – education, income, occupation, work conditions, lifestyles. This work was, certainly at its beginning, empirically rather than theoretically driven. It does, however, feed back into the concept of class by trying to 'unpack' its dimensions.

The use of, for instance, house tenure or car ownership can be seen as an early approach to the replacement of occupational categories by consumption patterns (see e.g. Goldblatt 1990; Davey Smith *et al.* 1990). Again, recognising that income and living conditions vary widely within social class groupings, research workers have constructed indicators which

combine social class with living conditions or financial difficulties (Carstairs and Morris 1989; Bartley *et al.* 1994; Power *et al.* 1996). Whilst the UK has continued to emphasise occupationally-based concepts of class, other European countries have tended to use educational qualifications either together with, or in place of, occupation (Rahkonen and Lahelma 1992; Lahelma *et al.* 1994; Kunst and Mackenbach 1994). Dahl (1994) looked at the joint effects of income, occupation, and education in Norway, concluding that in this study, as in others, occupational class remained the most consistent and important predictor of health. Other work sees class as predicting other measures, such as income or education, but something which ought to be kept separate. Townsend, for instance, has argued for the importance of keeping social class out of his area-based deprivation measure, on the grounds that to include it would confuse the measure of deprivation with its causes (Townsend *et al.* 1987).

The particular study of groups to which RG Social Class is less easily applicable has made special contributions. Various elaborated measures have been used to analyse health and class in adolescence (Macintyre and West 1991), for older people (Arber and Ginn 1991, 1993; Martelin 1994), or to test alternative classifications for women (Moser *et al.* 1988; Pugh *et al.* 1991).

The work on women can be instanced as a particular example of this. Just as, in the past, comparison of the health of men in certain occupations with that of their wives was a central tactic of classical epidemiology, so the 'new' social epidemiology is illuminated by considering the meaning of social class for women and for men. Traditionally, the individualistic approach to socio-economic variation in women's health, using married women's own occupations rather than their husband's class, produces narrower class differentials for women than for men, seeming to show that, for married women, 'own' occupation is not so clearly an indicator of the household's material position. For many years alternative ways of classifying have used a combined husband and wife class measure, or have used both the partner's occupation and own occupation separately as indicators for women's health (Britten and Heath 1983; Martikainen 1995) Arber (1997) suggests that the increase in employment rates among married women and the greater fluidity in marital status may mean that in future the individualistic approach may be favoured. In an analysis of a large sample from the British General Household Survey, she demonstrated that the usefulness of different approaches may depend on what outcome measures are being used. Women's 'limiting long-standing illness' was associated with their own labour market characteristics, whereas self-assessed health was better predicted by a range of variables including husband's class and the material conditions of the household. It was concluded that several indicators of social class, each depicting distinct aspects of socio-economic status, should be used.

Class, as a dimension, cross cuts with other social statuses. Arber (1991) pointed out that while women entered into the British debate on class differences in health somewhat belatedly, an American tradition had long been dominated by role analysis, with women's health considered primarily in terms of marital, parental and employment roles. Using, again, the General Household Survey, she demonstrates how both traditions can be reformulated and integrated. The ways in which women's roles are associated with health status is determined by material circumstances, but these cannot be captured by occupational class alone. Much other research has similarly explored the ways in which women's roles and health have to be seen within a structural context, and the interactions between employment status and other variables. Except for those with young children, exclusion from the labour market is clearly associated, for women, with poorer health.

New occupation-based classifications

Another important trend is the work which is beginning to make comparisons of different ways in which occupational class might be defined in explicitly theoretical terms, seeking not just to 'unpack' RG Social Class but to explore other systems. Occupation-based classifications used for other areas in sociology such as mobility studies have, for instance, been associated with the names of Goldthorpe and colleagues (Goldthorpe and Hope 1974). The Erikson-Goldthorpe schema, an eleven-category validated measure based on an explicit theory of occupational groupings (Erikson and Goldthorpe 1992) is currently being used for health studies. 'Classes' are distinguished in terms of such dimensions of the work setting as conditions of employment, occupational security and promotion prospects. This system has been adopted for a large international comparative study (Kunst and Mackenbach 1994) and has been used in Britain by Bartley *et al.* (1996a). Using a 1971 and a 1981 cohort from the OPCS Longitudinal Study, these authors found similar magnitudes of class difference to those represented by RGSC, and they comment

> It is of considerable significance that substantial and persistent differences in mortality between social groups . . . have been identified by a schema designed explicitly to group occupations with similar employment relations and with no reference to health data. ·
>
> (p. 467)

Another example, this time considering morbidity rather than mortality, is the analysis of Wolfarth (1997), who compared classification systems using both conventional measures of socio-economic status (education, occupational prestige) and operationalisations of what was called a neo-Marxist

concept of class in terms of control of production (ownership of the means of production, control over labour and investment and control over own work). The latter classification distinguished eight classes, such as bourgeosie, decision-makers, workers, semi-autonomous employees, etc. It was suggested that socio-economic status describes a gradual, quantitative difference between strata, while these neo-Marxist classes are clear entities qualitatively different from one another. In the empirical test, which was of various measures of psychiatric morbidity in a large Israeli sample, both classifications provided predictors for morbidity, but the overlap between them was small. Each appeared to have a unique relationship to psychiatric outcome variables, with 'class' adding significantly to the prediction provided by 'socio-economic status'. The conclusion is that they are distinguishable both theoretically and empirically, and conceptualising social inequality in different ways can enhance the understanding of – in this case – psychiatric morbidity.

Elaborated and differentiated measures of class position were also used by Pierret (1993), but in this case for the study of health-related concepts and discourses rather than health outcomes. In a sample of 'residents of an old quarter of Paris', 'residents of a new city', and 'farmers from a rural commune', the traditional occupational classification proved inadequate in the search for correlates of discourses about health. A classification based on 'positions in the production system' proved more illuminating. Five groups were formed:

- small farmers
- unskilled or semiskilled workers and persons with unstable jobs
- middle-level employees in the public sector
- middle-level employees in the private sector
- school teachers.

Pierret asked 'Might discourses about health (and illness) be organised ... on the basis of "constants" such as a person's sense of time, relations to the state, or feelings of security?' These groups did indeed provide distinct discourses. For instance, for the groups with manual occupations, bodies were tools, or instruments for work. There were, however, differences between farmers and workers: for farmers, health fitted into a relatively homogenous world view based on a cycle of life, while workers felt socially vulnerable. What distinguished the three non-manual groups was whether they were in the public or private sectors. Public employees referred to concepts of social order; those in the private sector had individualistic models. Pierret concluded: 'In France, persons' relations to the state, and in particular whether they work in the public or private sectors, seem to be as important as social origin' (p. 22).

The risk society

These new types of occupational classification begin to explore class as an explanatory factor in health, rather than simply a descriptive category. Concepts of risk, resources and social control become relevant. Risk, in the form of risk factors for disease, relative risks of mortality, or predictors of ill health, has always been one of the basic concepts of social epidemiology. After a long period when the focus appeared to be on individual risk factors, the concept of the 'risk society' (Beck 1992) is now being found particularly fruitful. In part, this is a consequence of the limitations for epidemiology of the conventional individualised approach: even in one of the best cases, for instance, when all known risk factors for coronary heart disease are considered together, they account for only about 40 per cent of the incidence of the disease (Marmot and Winkelstein 1975).

In the conventional model, risk factors tended to be defined largely in terms of behavioural characteristics, and at one time factors such as smoking were offered as the most important part of social class differentials. Without denying that of course lifestyles and behaviours are socially distributed, it is now seen as less simple: in the longitudinal study of British civil servants of different grades known as the Whitehall study, for instance, the social gradient in coronary heart disease mortality was clearly not explained away by smoking, since gradients were similar among smokers and non-smokers (Marmot 1986). There is also a strong suggestion that such behavioural factors have different significance for different social groups: in the large-scale Health and Lifestyle Surveys in England, Wales and Scotland, for instance, 'healthy' behaviour was found to be more protective against ill health in better environments and more favourably placed social groups (Blaxter 1990). Measured lung function, among those who gave up smoking, was found to improve more over seven years in non-manual men than in manual, and among those who continued to smoke was found to deteriorate to a greater extent in manual men than in non-manual (Cox et al. 1993).

If this conventional individualised risk factor approach is found to be limited, attention has to turn to the characteristics of societies which foster or correct inequalities in health. The work of Wilkinson and others feeds into this, pointing to factors relating to social organisation (Wilkinson 1994, 1996a, 1996b). Improvement or deterioration in national health is, it is suggested, not simply related to economic growth, but also to the distribution of resources within societies.

Thus attention turns back to social class, but in a new form. What are the precise pathways by which social structure affects health? How is health affected by features of the social order? Wilkinson associates the extent of material inequality with social cohesion, and its effect on

psychosocial health. Other forms of explanation turn back to risk. Sooner or later, Beck (1992) suggested, in modernising societies,

> the social positions and conflicts of a 'wealth-distributing society' become joined by those of a 'risk-distributing society'; social risk positions spring up, which are not exactly class positions, but which are associated with them because the ability to deal with risk is unequally distributed in occupational and educational groups.
>
> (p. 20)

Heirarchies are self-created by internal differentiation within classes, by new forms of residential patterns and family structures:

> The reflexive conduct of life, the planning of one's own biography and social relations, gives rise to a new inequality, the inequality of dealing with insecurity and reflexivity.
>
> (p. 98)

What develops is what Beck calls 'a society of employees', defined in terms of socio-political categories, a form of 'class' which neither Marx nor Weber saw. In a current transitional stage, traditional inequalities coincide with an individualised post-class society which is no longer traditional. Inequalities do not disappear but become redefined in terms of an individualisation of social risks. In terms of health, research in medical sociology is relevant which explores the relationship between individual crisis and sickness.

The empirical work which is relevant here is that which has focused on concepts such as stress, 'sense of coherence', insecurity and lack of control. If specific occupational risks are no longer the main cause of ill health related to work, and thus provide only a small part of the explanation for differentials between occupational classes, other explanations must be sought. The possible pathways by which social situations affect health – not only in the context of work, but especially there because of the association of occupational social class with health inequality – have long been thought to be associated with psychological mechanisms to do with stress. A sense of hopelessness, depression, and a lack of sense of control, have all been associated with higher mortality rates (Berkman and Syme 1979; Alfredsson et al. 1982). In the specific context of work, Karasek and Theorell (1990) developed a two-factor model along the dimensions of demand and control. High demands in the presence of high control are not health-harming, but high demands with low control are associated, it is suggested, with increased risk. Siegrist et al. (1990) similarly have a model which takes into account personal coping and adaptation to work demands. High effort and low reward (in the form of money,

esteem or security) produce a sustained distress which is a health risk. Bartley et al. (1996a) note that the clear differentials in health produced by the Erikson-Goldthorpe schema, designed and validated as a measure of employment security and control over the work situation, support the hypothesised mechanism by which the psychosocial characteristics of work affect health.

The question of control has also been particularly addressed in the Whitehall studies, where the distribution of feelings of control and decision-making responsibility have been examined in the context of inequality in health between civil service grades (Marmot et al. 1978). These longitudinal studies, beginning in the 1960s, led Marmot and colleagues to suggest that the use of conventional social class underestimated the association of social factors with mortality. Twenty years later, though a flattening of pay differences between grades suggested that health differentials might reduce, they had in fact widened for a number of measures. It was suggested that this perhaps reflected organisational change and insecurity: the lower the occupational status, the greater the frequency of reported financial problems, stressful life events, and low control and satisfaction at work (Marmot et al. 1991).

One obvious meeting place of this research on stress, control, and the social distribution of risk within the structural approach is in the fields of unemployment or work insecurity. For instance, Bartley et al. (1996b) used the National Child Development Study, the cohort of children born in 1958 and studied longitudinally, to compare men aged 23–33 with more and less secure employment histories. At 23, previous work insecurity rather than economic position was associated with poor self-rated health, independent of the relationship between class background and the risk of unemployment. Work insecurity also had an independent relationship with poor psychological health at 33. Bartley (1994), considering the observed general relationship between ill health and unemployment, suggests that – though of course selection may be operating, in that those with poorer health become unemployed – this may be an indicator of a more general insecurity. In a study of one department in the Whitehall studies, those civil servants who were facing restructuring of their employment into the private sector showed a deterioration in mental and physical health, compared with those whose departments were remaining within the civil service (Ferrie et al. 1995). In a further study, of the whole Whitehall II cohort of over 10,000, adverse changes not only in self-assessed health but also in clinical measures were associated both with anticipation of restructuring and with actual organisational change, with the possibility of selection excluded by controlling for baseline health status (Ferrie et al. 1998).

Consumption, lifestyle and class structuring

A rather different approach to the changing meaning of class is the contemporary emphasis on individualism, lifestyle and consumption: social class not in terms of life chances but as a source of social identity. Much of the work in this area is directed not simply at producing occupational classifications, but at tracing the 'real lines of social division to which life chances, cultural outlooks and household living standards can be related' (Compton 1993: p. 166). Warde (1990) identified two aspects of consumption: economic 'consumption sector cleavages', and an emphasis on social and cultural consumption. If the approaches to the understanding of class which have been described so far relate mainly to the first, there are others within medical sociology which are beginning to take up the second.

In attempts to theorise the structure/agency problem in relation to health-related behaviour, medical sociology has particularly used the work of Bourdieu, concerned with the active process of class structuring, the construction and consolidation of class position or 'habitus': habitus, formed in the context of objective conditions and social positions, generates schemes of perception which in turn produce lifestyle practices (Williams 1995). This implies the mapping of cultural or consumption patterns, rather than orthodox occupational class analysis. Health becomes an expression of the interpretation of the world, and class and health become interacting 'cultural performances'. This may best be captured by qualitative work.

An empirical example of this is the writing of Prout (1996), who demonstrated how families and households are sites for the enactment of these performances, suggesting that 'the dynamic and processual aspects of households' class trajectory may be more important in shaping the views and practices of its members around health than static notions (or measurements) of class position'. Prout demonstrates by case studies of contrasting middle-class and working-class families that though class position might determine a range of social indicators, health attitudes and behaviours were also enmeshed in different 'habituses', and the distribution of these, not straightforwardly related to class position, was explicable if household histories were taken into account:

> Instead of looking at each as statically middle or working class this involved asking: what sort of class origins did the adults have, what were their expectations for the future, what aspirations did they have for their children, what forms of capital were being transmitted to the children, and how were these expressed in the lifestyle constructed for each household?
>
> (p. 16)

Differences between the families were linked to positioning in the private or service sectors in the case of the middle class, and to the families' past, present and future anticipation of their position, their aspirations, social networks, and perceptions of their economic, physical, social and cultural capital.

Time

Though it has not been explicitly discussed, it is obvious that the question of time is already becoming relevant. One of the problems of occupational classifications at a cross-sectional level is that increasingly a current (or a 'last') occupation may not represent a lifecourse or even a life position in any real way. Such things as education, relationship to the labour market, or class 'trajectories', may be better indicators of the accumulation of social capital which can be linked to health. These relationships exist in historical time: generations following one another, social and occupational structures changing, individuals, families and groups perceiving, creating and consolidating class positions. The very meaning of class changes with time, and so also do the variables which are used to represent the phenomenon of 'health'. The mortality of past historic periods is not the same as today's, for the distribution of its causes changes. Illsley and Baker (1997) have noted how all-cause mortality rates conceal historical changes in the prevalence of different diseases, particularly those which are associated with health-related behaviours which are strongly 'mobile' within gender, or age groups, or classes. Even in one lifetime the clinical meanings and social correlates of disease are continuously changing, and these relationships at any one point of time have to be regarded as a 'historical moment', to be viewed in the context of time.

There are, of course, several different sorts of time. There is this social time, with change taking place at irregular rates in society; there is 'real' calendar or clock time, where years go by at a regular pace in the lives of individuals, child following parent and adulthood following childhood; and there is personal time, time as the individual experiences and perceives it.

Calendar time

All these sorts of time, but especially 'real' calendar time, imply longitudinal research. Here, the birth cohorts and other longitudinal data-banks, in Britain and elsewhere, have been of crucial importance. The topics have been health as cumulative within a lifetime, health-related mobility and selection into social classes, 'sleeper' effects and childhood influences on health and on health-related lifestyles, and the patterns over the lifecourse of all those components of class which affect health – material resources,

occupations, risks and security and the cultural and behavioural environment. The concept is of class trajectories rather than static class positions.

One of the major thrusts towards the understanding of class has been the immense research effort devoted to intergenerational and intragenerational health. This can be no more than glanced at, but it can perhaps be argued that it began through the attempt to deal with the problems of class which have been described.

For instance, the old question of whether observed class differences in health are due simply to selective social mobility has, to a large extent, been answered. In particular, the Longitudinal Study of 1 per cent of the population of England and Wales, and the British birth cohort studies following individuals born in 1946 (the National Survey of Health and Development) and 1958 (the National Child Development Study), have been used. These have shown that though, obviously, poor health is likely to have an adverse effect on life chances and movement through the social scale, mobility seems to make only a minor contribution to class differences in mortality and ill health (see e.g. Fox et al. 1985; Wadsworth 1986; Power and Peckham 1990). In the National Child Development Study (Power et al. 1991), for instance, intergenerational mobility either up or down the social class scale when the young people entered the labour market was, at age 23, certainly found to be associated with differences in their health. However, Power et al. noted that mobility was not the only, nor indeed the major, influence on social class variation in health at this stage of life. At each stage of youthful life there appeared to be both direct and indirect effects of factors associated with social class. In a later analysis at the age of 33, for instance, birthweight was still related to achieved social class (Bartley et al. 1994). It was argued that the relationship was not necessarily causal, however, but rather that birthweight acted as a marker for circumstances later in life.

A debate about the importance of the earliest stages of life – events occurring in infancy and in the womb – has re-emerged in Britain. From the 1950s it had been shown that a woman's reproductive performance reflected her social and health history from birth, and that there was a dynamic relationship between health and the environment at birth and later (Illsley 1955). The renewed focus on the first stages of life, associated particularly with the names of Barker and colleagues, emphasises the possibility of biological programming at these early stages which has long-term consequences: contemporary social class (and geographical) variation can be explained by the social conditions experienced by the mothers of the previous generation. Events during gestation (for instance, indicated by birthweight) and in infancy (for instance, indicated by growth in the first year) have been shown to be associated with cardiovascular disease, obstructive lung disease, hypertension, and diabetes, in later life (Barker 1991, 1992, 1994). In the 1946 birth cohort, Wadsworth et al. have

similarly shown, for instance, the association of high blood pressure at 36 with low social class of origin and with birthweight (Wadsworth 1991); through, it is suggested, specific mechanisms in the intrauterine environment. In this lifecourse perspective on health, follow-up, 'catch-up' or 'follow-back' designs of research have made particular contributions. Time has to be accommodated.

As Power et al. (1996) point out, an alternative to the idea of biological programming is that parental social circumstances, and their effect on outcomes such as birthweight, are simply an indicator of life chances: these processes are not mutually exclusive, but are probably additive or interactive. Wadsworth (1996) similarly suggests that though family circumstances in childhood provide the basis for health in later life, throughout life opportunities exist to augment or deplete the capital present at birth, through education, occupation and later family life. Wadsworth offers a summary of how the childhood cohorts have shown in particular detail how social capital and the associated health capital accumulate or are dispersed throughout childhood. A poor start in life, associated with poorer parental circumstances and vulnerability to illness, can be reinforced by lower levels of parental concern about education, poorer achievement, and thus lower socio-economic class and poorer health. On the other hand, the stock of health can be augmented: higher parental socio-economic status and education are associated with greater educational achievement in the child and a higher occupational status for the young adult.

The associations between social class and health are thus shown to depend strongly on time-patterns: some are long-term, some short; some are 'sleeper' effects; some attenuate over the lifecourse; different mechanisms of association are salient at different parts of the lifecourse. Several studies have shown that social class differences are less marked in adolescence than they are in infancy or later adulthood for most health measures (West et al. 1990; Glendenning et al. 1992; Rahkonen and Lahelma 1992). It has been suggested that perhaps social class, as conventionally defined, is becoming less salient for young people (Chisholm et al. 1990).

What is certainly generally agreed, however, is that social class effects on health press most heavily in middle age. It is here that mortality rate differentials are at their widest. The depletion of health capital is most obvious at the ages when chronic or degenerative diseases are beginning to strike. In the Health and Lifestyle Surveys, there were not only clear differences by social class in the proportions of people ·in middle age groups who said, re-interviewed after seven years, that their health had deteriorated during this period, but there were also class differences in deterioration in some measured health characteristics such as lung function (Cox et al. 1993).

The sense of coherence and coping ability already discussed may be part of this accumulated capital, beginning in childhood. Lundberg (1997)

using large samples of both panel and cross-sectional data from the Swedish Level of Living Surveys found that family conflict in childhood had some direct effect on sense of coherence in later life, though family size or the experience of a broken home were not so related. Childhood conditions and adult sense of coherence were, it was suggested, complementary and additive factors affecting adult health.

Questions are now being asked about the meaning of social class in older age. Arber and Ginn (1991), for instance, suggested that the health of the elderly has to be seen in terms of biography: elderly women have fewer resources and experience greater constraints than elderly men, and their health-related capital is profoundly affected by their labour market position in earlier life. Dahl and Birkelund (1997) similarly asked to what extent socio-economic conditions, as measured by social class when people were economically active, have an independent effect in post-retirement age. The social and economic conditions that elderly people experienced fifty or more years before still seem to exert an influence on current health. Work such as this is beginning to discuss the theoretical appropriateness of using occupational class, whether defined as 'last' occupation or that followed for the greater part of the lifecourse, when considering older people. No significant relationship was found between health in old age and *father's* social class, which seems to demonstrate the effect of the changing meaning of specific occupational classes over a relatively long period already discussed: class of origin is too crude a proxy, for an elderly population, for social conditions in childhood.

Socio-historical time

This is at the level of the progression through time of the individual life, or the regular replacement of the generations. Calendar time is not the same, however, as social time. As the work with the elderly suggested, generations are not only distanced differently by numbers of years, but are also cohorts which move continuously through a structure of occupations and social classes which is itself in constant flux. Historical change takes place over generations at varying rates. If a society is relatively static, it may be possible to regard the succession of age-cohorts as simply the repetition of previous generations. If the social environment is changing rapidly, each cohort has a unique history. As Frankenberg (1987) has pointed out, the concept of the lifecycle has its dangers. Life is not in fact cyclical for the individual or for society. Generations have the 'imprint of time' (Wadsworth 1991).

Class-related vulnerability may be associated with economic conditions in particular historical periods, or with changing behavioural patterns (dietary changes, smoking prevalence). Wadsworth (1996) notes that the interpretation of how social factors operate has to be undertaken in

the light of these wider social factors, which condition what is possible for the individual, and so leave their mark on each generation. For instance:

> Those who live their childhood in times of sharply gender differentiated opportunity, as happened to the generation now in their 50s, carry the imprint of that effect in later life ... Similarly, those who were children in times of serious economic depression carry the effects in their thinking and behaviour in later life.
>
> (p. 158)

Changing prevalence of smoking provides one example. Wadsworth (1997) notes that those who were children at the time when smoking was less common among women will have been less exposed to risk than those who were *in utero* or in infancy when smoking was at its peak, and the effects of gender differences in the time of the first popularity of smoking are seen now in gender differences in lung cancer rates. The life of those aged 50 now has seen periods of great change in smoking, as in other factors such as diet; those born into a period of high parental smoking now live in a time of much reduced smoking. One life history study (Mann *et al.* 1992) showed that the risk to health from smoking was greatest among those born into manual classes when parental smoking was very prevalent, who then became smokers. The long-term consequences of other general changes in social conditions and lifestyles, such as those concerned with diet, are equally complex: as early as 1978, for instance, Forsdahl noted the raised risk of arteriosclerotic heart disease mortality in populations born into poor circumstances but shifting as adults into relative affluence.

The opportunity to establish social and health capital is affected by the social environment, both through individual attitudes and behaviour and by social (and medical) policy. There are period effects of living through epidemics. The effects of the American Depression upon parents were associated with their children's behaviour in their own marriages and employment (Elder 1974). As Wadsworth points out, the effects of change are particularly complex since it is early experiences which may affect reactions throughout life, whether behavioural, psychological or biological.

Biography

The movement from calendar time to social time thus leads eventually to personal time, to biography. It is obvious to note both that biography and health are always intertwined, and that subjective time is not the same as either calendar or socio-historical time. A real lifetime is measured subjectively in social periods – infancy, schooldays, family formation, work, retirement – rather than calendar years: periods of life which may

be determined by social roles, but are particular to individuals. These temporal profiles are crucial to our perceptions and expectations: they are part of what Garfinkel called 'background expectancies'. Few people spend much time calculating the probability of the year of their death, but a lot of time is spent considering temporal regularities which are not usually defined very precisely in years. In creating and recounting their biographies, all research demonstrates that people add up periods of time which may not even be juxtaposed in calendar time: the genesis of this problem was this, then something else contributed, then this outcome followed – though the events recounted may be many years apart (Blaxter 1993). These definitions of biotemporal orderliness provide structure to life and health. To suffer physical events outside their proper time is disconcerting: to develop chronic illness in relative youth is, in Bury's (1982) terms, biographical disruption. This 'proper' time is personally and socially constructed, and is not incorporated into the sort of structural regularities represented by Standardised Mortality Ratios analysed according to RG social class. To a considerable extent, it is constructed by family and inter-generational biographies as well as personal ones.

It is a trivial and obvious truth that time goes by at different rates in different circumstances and at different ages. One of the disadvantages of troubled lives is that time accelerates. So, using the example of the women studied by Blaxter and Paterson (1982) in Scotland, for a woman who leaves school at the earliest possible moment, has children in her teens, becomes a grandmother before 40, and is widowed in her 50s, all the stages of life have become compressed. Thus these women spoke of their lives being over, of having, in their 50s, to expect the deterioration of old age. Their daughters, whose lives were following much the same pattern, spoke as if they were middle-aged: as one said, at the age of 23, 'After three children you're past it, it doesn't matter if you lose your figure.' One of the deprivations of disadvantaged lives was to be robbed of time (Blaxter 1985).

People themselves perceive health as biography. Research such as that of Williams (1993), for instance, demonstrates how they recount this, how 'in articulating the experience of illness in relation to their social milieux, individuals elaborate moral discourses based on their own biographical experiences' (p. 92). Individualistic ideology, Williams suggests, may prevent people from seeing the (class) relationships between them and society: nevertheless biographical experience and the accounts of illness which rest on it can be understood only in relation to the wider social and historical settings through which the individual has passed. Health biographies take place in, and are interpreted through, 'the situated pragmatism of everyday life'. So, in the case-history Williams uses, the 'pursuit of virtue' in terms of independence and the issues of control over life, exhibited by a sufferer from arthritis, can be seen as the product of a

social biography. These socially imposed constraints are not, Williams notes, to be viewed in some unidirectional way as determined by class position, but they are certainly related to the structure of society and the individual's perception of her place within it.

Personal time is the way individuals perceive their own lives in the context of historical time, in the light of class situations of the past and class rhetorics of the present. A return to Beck (1992) and the 'risk society' is relevant: Beck suggests that the hierarchical models of social class stratification have increasingly been subverted by the process of individualisation. While patterns of class variation in such characteristics as health have in fact remained relatively stable, their perceived social meaning has changed: 'the experience of historical continuity has been disrupted' (p. 92). Beck suggests that class thus loses its subcultural basis: 'forms of perception become private and ahistorical. Children no longer know their parents' life context, much less that of their grandparents' (p. 235). Instead of being socially prescribed, biography becomes self-produced, with each person's in their own hands. What Beck calls 'the temporal horizons of perception' narrow, until everything revolves around the axis of the individual's own personal life. Thus biographies become reflexive. People choose their own different lifestyles and subcultures, and are no longer so dependent on historical class patterns. What Beck terms 'secondary agencies and institutions' (economic markets, fashion, social policy) take the place of traditional social forms.

This resonates with the idea of class discussed earlier, derived from Bourdieu, as 'performed trajectory', and of class and health as 'interpenetrating performances'. Prout (1996), for instance, showed from his contrasting family case histories, that families who were 'middle class' by occupation could differ fundamentally by a 'habitus' defined in terms of Crawford's (1984) dichotomy of health seen as control/health seen as release, and so could working-class families. Differences in health as a cultural value (and differences in health-related behaviour) could be explained by class trajectories – by family and personal histories over time – rather than simply by class positions.

This and other research shows that it is not necessarily true that family history is now unimportant in people's creation of the story of their lives. Beck's thesis that children no longer know their parents' life context may be an over-statement, or may refer to groups of people with particular biographies: that is, may actually represent part of the process of class stratification. Accounts of people talking of their health can show that intergenerational patterns seemed, at least in the 1970s and 1980s, to be important to them (Herzlich 1973; Blaxter 1983). Those whose family history was within the poorest families were still conscious of the social and health deprivations of their youth or of past generations. They might well have experienced considerable historical change. Wadsworth (1996)

notes that when the members of the 1946 birth cohort were two years old, almost half lived in houses without running hot water. The stories of the childhood living conditions of the sample of middle-aged, social class IV–V Scottish women in the late 1970s were vivid and horrifying (Blaxter and Paterson 1982). Of course, these women were conscious of an improvement in social conditions: the historical perception of which Beck speaks had not disappeared.

However, there is a finding which seems at first sight to be anomalous: that it is people such as this, most exposed to structural inequalities, who are least likely – at least in the interview situation, where they are being asked to talk about the causes of health and illness – to stress social and environmental causes. The idea that there are structured class differences in health (as distinct from the obvious and specific effects of, say, damp houses or dangerous jobs) appears to be an unwelcome suggestion which poorer people may flatly deny. Of course, life chances are unfair in many ways, but health is one area of life where we are all equal. In a study by Calnan (1987) of the health-related beliefs of women in England in different social classes, a working-class woman said: 'No, I couldn't think it makes any difference myself. I mean, it's like people with money, they get the same illnesses as we get. So I shouldn't think it would make any difference whether you are skilled or unskilled' (p. 79). Statements such as this were echoed by the Scottish women, who roundly rejected any idea of class inequalities.

At the level of a large-scale survey, similar evidence emerged from the Health and Lifestyle Surveys (Cox *et al.* 1987; Blaxter 1990) when answers to open-ended questions about the causes of ill health were analysed by social class. Considering not simply answers to single questions, but replies to a large range of questions in different contexts, it was those with higher incomes, better environments, non-manual rather than manual jobs, who were more likely to mention the fact that socio-economic factors might have an influence on health. And work, as a particular element of the social environment, was more likely to be seen as a source of ill health by professional and managerial classes (largely on grounds of stress) and of *good* health by those with the unhealthiest jobs (largely on grounds of physical activity).

There is a variety of possible reasons why 'the victims blame themselves', stressing behavioural factors rather than those outside their control, including features of the research methods themselves (Blaxter 1993, 1997). However, people's perception of the course of historical time seems relevant. The Scottish women were very conscious of improvement in social conditions. They were therefore naturally reluctant to admit inequality in health *now*: everyone was healthier, partly because of what they saw as relative prosperity but even more, in their eyes, because of the advances of medicine. Children no longer died of diphtheria, mothers no longer died in

childbirth. Since it was their families which, they recognised, had suffered disproportionately in the past, then surely they were less 'unequal' now. From this perspective they did not stress the necessity for change in the environment of their social group, or the lives of their children, now.

When elderly people think about – and report – economic hardship during their upbringing, do they have absolute material poverty in mind? Dahl and Birkelund (1997) asked this question, and pointed out that if this is so then future generations, less likely to experience such absolute deprivation, may react in different ways to a present generation. Health effects of childhood conditions may be perceived differently. If, however, there is an element of relative deprivation in the experience and memories of the elderly, the same long-term health effects may apply for those whose childhoods are more recently relatively deprived.

At the individual level the effects on health of the acquisition or deprivation of health capital, of relative deprivation, of lack of social integration, or low levels of perceived control over life, are beginning to be unravelled. As Wadsworth (1996) has pointed out, what is needed now is a greater emphasis on the broader societal level, and the changing effects of historical time. The processes of class-related change in the individual life intersect with broader social change, with health consequences which must always be seen as a process in time.

Conclusion

It would of course be overweening to suggest that medical sociology has offered solutions to any of the problems of contemporary class analysis. What has been described here is no more than a beginning. But what is being added, it is suggested, piece by piece, is the empirical base. Beginning with a practical problem – that those doing health surveys, or analysing health statistics, or investigating risk factors for disease, were increasingly aware of the theoretical problems of the categories they were using, but were still faced with the fact that some concept of 'social class' seemed to remain an indispensable tool – the detailed exploration which has been sketched was begun.

'Class' is elaborated rather than dismissed: in many ways the concept grows in importance, even if the old certainties of Registrar General I–V have to be relinquished. Sociologists have not, of course, been the only discipline involved: much of the work described has been done by social epidemiologists, social psychologists, and others.

The contribution of specific causal factors to health is seen as not necessarily stable over time, and influences are shown to have different relative importance at different historical periods. Successive cohorts experience them differently. All these issues represent new problems for research design and methodology, and for statistics (Dean 1993). It can be suggested

that – in some crude sense – this is a synthesis of quantitative and qualitative approaches: statistical method has to take account of the real complexities of time.

The simultaneous movement through individual lives and through historical time, and the additional complication that perceptions expressed by the people who take part in research represent their personal time, mean that this is never going to be easy. However, this chapter has argued that medical sociology is currently attempting to provide some of the most precise and the most extensive evidence to contribute to theories of class. It may at last be beginning to be more truly theoretically based.

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Chapter 2

Gender, postmodernism and health

Ellen Annandale and Judith Clark

Introduction

'Challenging orthodoxies, and questioning the taken for granted – stirring it', as Gabriele Griffin *et al.* (1994: 1) put it – has long been the 'business of feminists'. Yet feminism's critical acuity is under significant challenge. This comes in the first place from critiques *external* to feminism witnessed in the current backlash literature which blames women's new found 'equality' for all kinds of social ills, such as the so-called breakdown of the family (see Fauldi 1991; Oakley 1997). The second challenge comes from the *internal* fragmentation of feminism, evident in the often bitter disputes that have emerged between competing perspectives. While, of course, internal debates have historically driven feminist thought, the contemporary period is marked by a vituperative stand-off between post-modern and modernist perspectives. The fundamental issue at the heart of this debate is the *nature of feminist politics* in a social world which no longer readily lends itself to being understood through the relatively stable categories of class and gender divisions and their intersection, and the implications that this has for an understanding of the relationships between gender and health. Any contemporary consideration of this topic must therefore grapple with the substantial theoretical task of how to at once appreciate diversity and its radical implications, while also recognising the powerful hegemonic discourses that simultaneously construct similarity and facilitate difference. In this chapter we take up Teresa Ebert's attempt to develop such a position, conceptualised as *resistance post-modern feminism*, as a framework within which to explore the issue of gender and health.

Above all, Ebert is concerned to show that postmodern feminism is not a unitary perspective. Thus her own 'resistance' position is developed in distinction to what she terms 'ludic' (i.e. playful) postmodern feminism (for her, typified by the work of Judith Butler (see 1993) and Drucilla Cornell (see 1991)). Together, both the 'resistance' and the 'ludic' position reject the grounding of 'modernist' feminism[1] in a notion of what Ebert

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Chapter 8

The politics of 'disabled' bodies

Gareth Williams and Helen Busby

Introduction

The language of disability has changed in recent years. The de-regulation of the health and welfare services in capitalist societies, the development of social movements of disabled people, the continuing challenges to medical dominance within and outside the health care system, and the influence of post-structuralism and postmodernism have led to a situation in which many different ways of writing about disability have emerged, each with its own lexicon. Any discussion of the politics of disability and disabled bodies carries the possibility of transgression and controversy. There is no neutral language and analysis of language itself is central to any discussion of how we approach 'disability' (Zola 1993). Impairment and disability; illness and handicap; suffering and oppression; victim and survivor: the only uncontested terms are those which have been erased from the vocabulary; and even they are likely to be excavated by the archaeology of disability studies.

In this chapter we examine the different ways in which medical sociology and 'disability studies' or 'disability theory' have approached an analysis of disability. Disabled people and others who were formerly objects of study and research by medical practitioners, social scientists and other 'experts', are now involved not only in challenging policy and practice, but also in defining what disability is and how it should be conceptualised and researched (Barnes and Mercer 1997). Sociology – so often self-consciously the discipline of the underdog – has itself become the target of a sharp critique from 'disability theorists' and disabled people working within the disability movement (Barton 1996; Barnes and Mercer 1996, 1997).[1]

Although an emphasis on the powerful role of society in the 'oppression' of disabled people is important, it is not possible, we suggest, to encompass all experiences of chronic illness and impairment within a social model that sometimes seems to deny the relevance to disability of bodily damage and decay. Culture and experience remain central to understanding

illness and disability (Shakespeare 1997), and disability theorists cannot altogether pretend that the body has nothing to do with disability. We consider whether new ways of thinking within sociology and cultural studies can help the body find its way back into the picture. Taking the work of Irving Zola as a point of reference, we suggest that a more pluralistic politics of disability, including impaired bodies and oppressive societies, provides the basis for more creative developments in sociological analysis of chronic illness and disability. However, writing on the one hundred and fiftieth anniversary of the publication of *The Communist Manifesto*, we also argue that it is important to recognise the ineluctable power of global economic forces in shaping people's experiences of disability.

We begin by looking briefly at the way in which disability is conventionally understood within medicine. Medicine is important in understanding the politics of disability because it is a hegemonic source of knowledge and set of practices which exerts direct control over many aspects of people's lives and, perhaps more importantly, influences the way in which we define the boundaries between normality and abnormality. Moreover, although people are more sceptical of doctors as they are of other socially sanctioned experts than they were in the past (Gabe *et al.* 1994), there is still a relatively high degree of trust in their motives, their competencies and the legitimacy of their claims to expertise.

The medical model

The medical model which informs traditional approaches to disability takes the biological reality of impairment as its fundamental starting point. This biological reality is taken to be the foundation of all forms of illness and impairment, whether 'mental' or 'physical'. Although ill health may arise from sources outside, it is the body within which illness is situated. In relation to the rehabilitation of disabled people, the focus of the analysis and the intervention is on the functional limitations which an individual 'has', the effect of these on activities of daily living, and attempts '. . . to find ways of preventing, curing, or (failing these) caring for disabled people' (Marks 1997: 86).

Although rehabilitation practitioners may make reference to the way in which disability affects the 'whole person' or 'all aspects of an individual's life', the nature of this wider context is rarely built systematically into analysis or recommendations for intervention (Gloag 1985; College Committee on Disability 1986). From the early 1970s onwards, those professionally engaged in rehabilitation recognised the need to move away from the highly reductive conceptions of functional limitations focusing on deficits in limbs and organs which had traditionally characterised physical medicine and physical therapy. This newly discovered holism was

enshrined in official reports, with the promulgation of broader definitions of rehabilitation as the restoration of patients to their fullest physical, mental and social capability (Mair 1972; Tunbridge 1972).

Increasingly, broader definitions of health status in patients with chronic illness and disability were used for two main reasons (Williams 1987). First, to assess needs for treatment, therapy, services, or benefits; and, second, to provide a baseline from which to perform more realistic evaluations of change in the health and functional status of patients, both informally and as part of research and evaluation. The focus of these evaluations was still very much on the individual, but with a recognition that it was the person who could or could not perform certain kinds of activities rather than the organ, the limb, or the body conceived abstractly as a bundle of capacities and incapacities. The idea of individual deficit continued to have a profound influence on policies, notwithstanding the influence of some other models of disability and associated reforms.

New types of descriptor (developed by sociologists, amongst others) consisted of assessments of performances in daily living stressing those activities which are purportedly carried out habitually and universally (Williams 1987); and this measurement of a range of daily activities extended the conventional clinical measures of 'functional capacity'. However, the fact that they are deemed to be universal rather than context-bound implies that they can be used across multiple settings without any substantial reconsideration of their validity, and without consideration being given to the meaning of the items for the person with the impairment. The Barthel Index, for example, asks only whether a person can walk 50 yards on level ground regardless of whether he or she wants to, needs to, or has anywhere to walk to (Granger *et al.* 1979).

In line with the positivistic underpinnings of medical science the emphasis of traditional assessments is on some universal definition and measure that can be applied by appropriately qualified people without reference to the disabled person's own perspective, the roles they occupy, the relationships in which they are embedded, their circumstances and milieux, or the wider political context of barriers, attitudes and power.

However broad their frames of reference, measures of health, disability, well-being and quality of life continue to be driven by classical positivist concerns with universality and generalisability. In other words, such assessments provide a picture of 'activities of daily living' devoid of a phenomenological grasp of the individual's own experience, on the one hand and any political analysis of the structures and contexts within which the activity takes place on the other.

In the period immediately after the Second World War health and social welfare for disabled people were characterised by a mixture of formal, institutional neglect and charitable, humanitarian concerns for those who had been maimed in war (Bury 1996). In this context, assessments of

function were orientated towards simple arithmetic calculations regarding the effect of damage and deficit in particular limbs. However, medical sociologists became increasingly disillusioned with the positivist assumptions of rehabilitation research, and were concerned to develop specifically sociological ways of thinking about disability and chronic illness. In particular, sociologists began to emphasise the social context of disability, and the meaning of the experience of living with impairments and disabilities (Blaxter 1976; Strauss and Glaser 1975). In the next section, we explore the direction of this critique.

Chronic illness and disability: sociological perspectives

In contrast to class, gender and race, disability has been conspicuous largely by its absence from mainstream sociology (Barton 1996). Within the sociology of health and illness, however, there have been numerous examinations of the experience and social basis of chronic illness and disability. The attempt to understand the meaning of experience by looking at it in its context lies at the heart of work in the sociology of chronic illness and disability (Bury 1991).

The focus on chronic illness and the experience of disability associated with it can be seen as an attempt to move away from the rehabilitation models which were rather static, reductionist, and focused on the mechanics of functional limitations and activity restriction. While the experience of 'adaptation' to a limb amputation or some other trauma-induced impairment clearly has its own dynamics, influenced by personal, situational and treatment factors, chronic illness contributed new dimensions of variation, unpredictability and uncertainty (Bury 1982; Strauss and Glaser 1975).

Sociologists of health and illness have engaged in a wide range of studies of chronic illness and disability. These have been marked by an interest in listening to the point of view of the individual with illness or disability, and using methods that allow this to be done. The outcome is studies which claim in some sense to have explored 'meaning', either by charting the *consequences* of illness, or by examining the *significance* of illness in the wider context of culture and society (Bury 1991).

Some have used these points of view largely as a source of empirical data to comment on problems defined to some extent by the sociologists (Blaxter 1976; Locker 1983; Anderson and Bury 1988). The emphasis is on using what people say to provide better understanding of topics or issues: employment, sexuality, environmental barriers and so forth. Other work using the same kind of data is more methodological or epistemological in its orientation. Rather than looking at what people say, it looks at the way in which they say it, or how their understanding of their illness or disability is constructed. The emphasis in this kind of work is to explore

the nature of the lay knowledge people with chronic illness or disability develop, and what they use it for (Williams 1984). A third variation on this theme is work which uses the accounts of lay people ontologically, to explore the way in which illness is a condition of having a story to tell. Such work attempts to grasp the depth of the meanings of illness and disability as they affect the foundations of a person's being-in-the-world, as a sort of existential sociology (Frank 1995).

These three versions of sociological work are, of course, not mutually exclusive, and the hallmark of each is a focus on the symbolic and material interaction between the individual and society or the social 'environment' and the interpretive processes whereby individuals construct meaning from their experiences. The environment is that which *emerges* in the meaning-giving processes of interaction between the individual, their milieux, and the wider society. Disability, (or 'handicap') in the World Health Organization's (1980) sense, is the product of complex processes of interaction between an individual with an impairment and the discriminating, disadvantaging and stigmatising society. It is neither inside the individual nor 'outside' the individual and 'inside' society:

> The extent to which functional limitations and activity restrictions constitute a problem, or are otherwise handicapping, is not only variable historically and culturally but is also somewhat dependent upon more immediate contexts; their meaning is not the same across different social and environmental settings.
>
> (Locker 1983: 5)

The argument put forward by Locker, and other sociologists developing work on chronic illness and disability in the 1970s and 1980s, was that the development of 'disability' or 'handicap' is not a simple linear process of cause and effect. Disability is caused neither by the external environment, nor any 'facts' of biological trauma or deterioration. It is a relational phenomenon that emerges out of the interaction between a person with impairments and an 'environment' which includes everything from low income and inaccessible transport to a pitying glance from a passing stranger. This kind of analysis is primarily concerned, in Bury's (1991) terms, with the meaning of chronic illness in terms of its consequences – but without implying that the consequences follow in a straightforward way from the illness. It is about the empirical consequences which emerge from the person's relationship with their everyday world when chronic illness develops.

Recent sociological studies of illness have attempted to probe more deeply into the existential interstices between self and world and make their analytical focus the epistemological qualities of the knowledge lay people produced about illness, or the ontological conditions of the stories

they tell. Many of these analyses are either interpretations by sociologists and anthropologists of people's narratives (Williams 1984; Kleinman 1988; Hyden 1997), or 'socio-biographies' (Zola 1982; Murphy 1987), 'pathographies' (Hawkins 1993) or 'autopathographies' (Couser 1997). While much of this work retains an interest in the interaction between an individual and other people or society more generally, it often leads away from the empirical features of the impaired individual's interaction with the material world into the individual's 'self' and 'body'.

There has been some attempt within the sociology of health and illness to incorporate a more satisfactory theorisation of the 'physicality of the body' through making the relationship between body, identity and social experience more explicit (Zola 1991; Kelly and Field 1996; Watson et al. 1996; Seymour 1998). But these developments within the sociology of health and illness have been to some extent limited by sociology's desire to distance itself from the corporeal basis of the body as part of its resistance to biomedicine (Williams, S. 1996).

The danger that lies in wait for social scientists who go in search of the holy grail of embodiment in health and illness is that a view is lost of the structures which shape the experience. History and even biography are dissolved into a quasi-religious or spiritual quest for the truth which illness is supposed to reveal. So profound is the truth of illness that even the person experiencing the illness is merely a vehicle for allowing the body to speak of its suffering. This is the body incarnate:

> The body is not mute, but it is inarticulate; it does not use speech yet begets it. The speech that the body begets includes illness stories; the problem of hearing these stories is to hear the body speaking in them.
>
> (Frank 1995: 27)

These analyses certainly provide rich languages for exploring questions of ultimate concern, but they also reduce the individual to a speaking body, and limit the social reality of illness and disability to a personal quest for meaning and truth. While the testimonies contained within autobiographical accounts can themselves be regarded as political, many of them become so absorbed in the minutiae of experiences on the edge that the politics and history of illness and disability are marginalised and the realities of health and social care are forgotten.

To say that work of this sort neglects power and structure is mistaken, however, because it allows for the development of an understanding of the experience of power and structure. Taking the distinction employed above between three forms of sociological analysis of the experience of disability, the empirical version is political in the sense that it allows for a better understanding of the problems and obstacles people face in their dealings with the outside world. The methodological or epistemological

version is political in the sense that it privileges lay knowledge, and points to its equal worth and equal weight as a way of understanding and challenging the explanation for experiences provided by the medical model and other normative models. The ontological version is political in the sense that it is rooted in people's embodied experiences in the world, their sense of pain and loss described in their own terms, bearing witness to oppression in accounts which 'connect' with the experiences of others in similar situations, and seeks to 'recover' the body from the dominance of biomedicine (Couser 1997).

Nonetheless, although politics is immanent in these accounts it remains implicit: stories of self and body standing as testimony to the objectifying, reifying, commodifying forces of science and capitalism. It is an ethical or a religious politics, a politics of redemption which resists alienation but leaves the structures of hegemony intact, and does not in itself form a political programme or strategy for change. In focusing on telling it like it is for individuals, such accounts – however contextualised and politicised – do not directly take on the structures of power and knowledge which the medical model of disability represents. These stories provide solidarity of meaning but do not in themselves lead to solidarity in action.

The politics of disability and disability theory

With the alienating power of the medical model, and the focus on 'experience' of much phenomenological sociology, it is perhaps not surprising that those who regard disability studies as a political as much as an intellectual project (Davis 1997), should want to distance themselves from sociological or any other 'scientific' contributions to the study of chronic illness and disability. As Davis has argued:

> People with disabilities have been isolated, incarcerated, observed, written about, operated on, instructed, implanted, regulated, treated, institutionalized, and controlled to a degree probably unequal to that experienced by any other minority group.
>
> (Davis 1997: 1)

For many disability theorists in Britain and elsewhere the cause of disability is neither the illness, nor the individual in a state of tragic adaptive 'failure', but the oppressive society in which disabled people live. If disability is seen as a personal tragedy, disabled people are treated as individual victims of unfortunate circumstances. If disability is defined as a form of social oppression, disabled people can be seen collectively as the victims of an uncaring, discriminatory society, whose most effective remedy for their conditions is protest and resistance. This fundamental position is that which has underpinned most of the writing by disability theorists in Britain.

Dependency is created amongst disabled people, not because of the effects of functional limitations on their capacities for self-care, but because their lives are shaped by a variety of economic, political and social forces which produce it.

(Oliver 1990: 94)

The problem to be overcome is not anything within the individual's body, mind or soul. There is no personal road to redemption and salvation. The problems are unequivocally located in the structures, attitudes and beliefs which exist in a society run by able-bodied people. However, in this case, the relationship between the individual and society is much more clearly stated: disability and dependency are caused by society, and 'hostile environments and disabling barriers – institutional discrimination' – are seen as the 'primary cause of the problem' (Barnes 1992: 20). Proponents of this 'social model' of disability argue that disability is caused by society, and if you change society you can eliminate disability.

The causal relation is reversed and, as a consequence, the traditional models and practices of those engaged in rehabilitation come to be seen as part of the problem. If the dominant ideology of the medical model informing rehabilitation defines the focus as what has happened to an individual and what can be done 'for the patient', attention is distracted from the primary structural causes; and the medical profession and those working along side them become key figures in the perpetuation of oppression. For example, the World Health Organization's (1980) classification that was developed to clarify the terms used to describe disablement through the differentiation of 'impairment', 'disability' and 'handicap', and to enhance understanding of the needs arising out of the interaction between chronic illness or impairment and the wider environment (Bury 1996), is seen as an extension of the medical model focused on individuals (Oliver 1990; Marks 1997). Sociological analysis of what disability is like, from the point of view of someone with an impairment or disability – the phenomenological or interactionist exploration of the construction of reality – becomes another ideological justification for the oppression of disabled people.

In recent years the original formulation of what has come to be known in Britain as 'the social model' (UPIAS 1976; Finkelstein 1980; Oliver 1983) has been developed and elaborated through seminars and workshops, books, and journals like *Disability and Society* (Oliver 1990; Barnes and Mercer 1996; Barton 1996; Barton and Oliver 1997) and increasingly through lively and combative debate on the internet (disability-research @mailbase.ac.uk). These publications show increasing internal differentiation in discussions about the social model (Swain *et al.* 1993; Barnes and Mercer 1997; Barton 1996). Through various media many different voices, definitions of disability, and subjects for research and strategic development can be found amongst people who have come to disability

theory at different times and from a variety of places. While there is common agreement on the need for resistance to 'disability oppression', criticism of the biomedical model and rejection of the primacy of impairment in thinking about disability, Marxism, feminism and post-structuralism provide variations on the theme.

Although the principles of the 'social model' have been used to inform the work of transnational organisations such as Disabled People's International, there is still a rather parochial quality to it. Those whose perspectives have been forged within an American civil rights context (Charlton 1998), have a different way of thinking about the relationships between impaired bodies and disabling societies from those developed in the British context, and recent feminist developments of the social model point to the patriarchy embedded in its original assumptions (Morris 1991). In addition there are those who feel that the materialist analysis of the original model is over-simplistic, and are now drawing on a wider range of philosophical and other sources in cultural studies in order to elaborate new versions of the origin and nature of oppression for disabled people (Shakespeare 1996a, 1996b, 1997).

Although its base rests on resistance to the medical model, and the giving of epistemological and political primacy to society over the body, there is a growing recognition that a strict social model excludes 'personal tragedy' and discussion of 'impairment' to a point where bodies and identities – the experience of being ill and disabled in society – are discounted as subjects for discussion. It is the development of thinking at the interfaces of body, identity and society – situated knowledge – that provide for the kind of exploration of the divide between sociologists and disability theorists that are needed to move this subject forward (Crow 1996; Peters 1996; Shakespeare 1996a, 1996b).

Situated knowledge

Sociological perspectives on disability have been criticised by disability theorists on a number of different (and sometimes seemingly contradictory) grounds: for not paying attention to disability, for enhancing rather than rejecting the medical model, and for becoming obsessed with the details of illnesses and impairments. All these concerns contain some truth: disability has not excited the same interest in mainstream sociology as class, gender, or race. Early work on disability by social scientists was undertaken in collaboration with rehabilitation specialists and epidemiologists which took the reality of individual impairments as its starting point (Bury 1996). And some of the more phenomenologically orientated work on chronic illness has attempted to reach the deepest interiors of people's subjective experiences to a point where the connection between those experiences and the outside world is not easy to see. But these criticisms

contain a truth that depends to a large extent on the setting up and knocking down of straw men and women.

Mainstream sociology may have neglected disability, but the large and growing constituency of the sociology of health and illness has not (even if the conceptualisation of its interest has not been to everyone's taste). Social scientists' early work on the conceptualisation and measurement of need amongst disabled people was to some extent individualistic, medically orientated and 'paternalistic', but much of this work was important politically in drawing attention to large numbers of people whose needs were not being met by the health service or the welfare state more generally. Moreover, the work of sociologists like Blaxter (1976) in the UK and Strauss and Glaser (1975) in the USA, did start an important process of using lay people's own accounts of life with symptoms and difficulties with professionals. This work was used as the basis for developing an understanding of chronic illness and disability and making recommendations for how doctors, health services and society should be educated, organised or constituted differently. While such studies may be criticised from the viewpoint of the social model for having looked at social aspects by starting with the individual (Oliver 1996), this is only to say that if you allow individuals with chronic illness or disability to speak, they will start with themselves, autobiographically, and the virtue of this kind of work is that it allows that to be possible.

Increasingly, knowledge and frameworks developed by sociologists are interrogated, interpreted and made use of by groups who were formerly its objects. More recent critiques of sociology by disability theorists, point to the assumptions which have framed much of the research agenda, with the methods which are used producing answers which reinforce predominant models of disability (Barnes and Mercer 1997).

Taking as his example some of the questions used in the OPCS survey to ascertain 'levels' of disability, Oliver (1990) suggests how questions which ask about an individual's 'difficulty in holding, gripping or turning things' could be reframed as a questions about defects in the design of everyday equipment which limit a person's activities; or how a question about an individual's 'scar or blemish' could be reframed to ask about difficulties caused by other peoples' reactions to any such blemish.

While the extent to which these questions offer any practical alternative to current survey items is debatable (Bury 1996), and is being tested empirically (Zarb 1997), they do turn the world upside down in a manner which requires us to question our framing of the relationship between individual experiences and social circumstances. Oliver's satire also raises questions about the relationship between lay and professional expertise within the processes whereby knowledge about 'disability' is produced. However, we need to be sensitive to the way in which methods and research questions are embedded in the political economy and culture of a certain time and

place, whether postwar collectivism, 1970s corporatism, or Thatcherite monetarism, while also being the product of decisions by particular politicians, civil servants and researchers, to ask questions in one way rather than another (Abberley 1996a).

The critique of the dominant methods used in the social sciences for understanding disability goes beyond a replacement of one set of survey questions by another. It seeks to contextualise the concept of disability within '. . . knowledge which arises from the position of the oppressed and seeks to understand that oppression. Such sociology requires an intimate involvement with the real historical movement of disabled people if it is to be of use' (Abberley 1996b: 77). However, to imply that the position of disabled people is uniquely oppressive replaces one kind of exclusivity with another, and defines disabled people as an undifferentiated class in itself, without the differences of body and identity which clearly have cultural significance for disabled and able-bodied people alike (Hughes and Paterson 1997).

Recent post-structuralist, neo-Foucauldian analysis attempts to bring the body back in by conceptualising it as the object of knowledge and the target of power. In Hughes and Paterson's terms: 'Post-structuralism can be useful in theorising impairment outwith a medical frame of reference' (1997: 333). Proponents of a social model who ignore impairment because of its clinical connotations miss the opportunity to develop a social model that applies to a wider range of disabling experiences and can inform a more inclusive disability politics. If the embodied person were conceptualised as the site of oppression, impairment could be brought back into the analysis without compromising the social model. Such developments would mean that some of the current difficulties involved in including people with learning disabilities, mental health problems, and other less visible forms of impairment into the disability movement might be reduced, allowing an understanding of politics that is as much about aesthetics as economics (Hughes and Paterson 1997). It would also allow for 'the near universality of disability' and the diverse 'chorus of voices' which disability represents to be part of the movement in the manner championed by Zola (1989, 1994).

However, there are other ways of situating knowledge and praxis in relation to disability which cut across this post-structuralist conceptualisation. For example, it has recently been argued that a more productive way to think of the oppression of disabled people is within a materialist conception of history which places disability in a broader context:

Political economy is crucial in constructing a theory of disability oppression because poverty and powerlessness are cornerstones of the dependency people with disabilities experience.

(Charlton 1998: 23)

Charlton goes on to argue that we need to see the oppression experienced by disabled people as a worldwide reality – 80 per cent of the world's 500 million disabled people live in 'developing countries'. This oppression, Charlton argues, results from structures of domination and subordination and ideologies of superiority and inferiority. The oppression of disabled people – defined as exploitation, marginalisation and powerlessness – cannot be understood within a post-structuralist framework. While there are cross-cutting identities and relationships of disability, gender, race, age, and class, these cannot be understood in a non-structural way. As Charlton puts it:

> Foucault's paradigm, which situates the body as the only verifiable 'truth' or site of oppression, contradicts the political thrust of the disability rights movement, which posits that disability is an oppressed social condition … The oppression of individual disabled bodies is not the basis for the oppression of people with disabilities, it is the oppression of people collectively that is the basis for the oppression of their bodies.
>
> (Charlton 1998: 57)

Towards an understanding of living in bodies in places

Placing too great an emphasis on the politics of exclusion obscures the real effects of different impairments and the complex, 'negotiated' aspects of everyday life, and creates a spurious impression of homogeneity. Crow has written about the discounting of the experience of impairment resulting from 'keeping our experiences of impairment private, and failing to incorporate them into our public analysis' (Crow 1996: 66). Others have emphasised the need to explore the nature and status of impairments, without being restricted by seeing them as either purely biological, or simply social (Kelly and Field 1996; Williams, S. 1996).

Closure of debate about the body has been characteristic of the disability movement, and perhaps for good reasons. As Benoist and Cathebras (1993) point out, closure of 'the body' is characteristic of most systems of thinking underpinning utopian projects and visions. Pinder's (1995) work about how fixed definitions of disability may have obscured the experiences of some disabled people at work draws attention to some of the consequences of excluding the dimension of lived experience. Pinder argues that many fall into 'no-man's land' between definitions of able/disabled, and that these have done some disservice to the task of promoting the interests of disabled/differently abled people at work. Similarly, Zola has argued that the exclusivist leaning of some of the writing about disability has led to the marginalisation of the growing numbers of older people whose bodies will slowly, but surely, let them down (Zola 1991).

Increasingly post-structuralist, postmodernist and feminist analyses have argued that all-encompassing theories of disability and oppression can never account for the diversity of lived experiences (Hughes and Paterson 1997; Crow 1996). As Radley (1995: 19) argues, being disabled involves distinctive bodily experiences, but such experiences cannot be seen as unique inasmuch as they 'symbolize and are symptomatic of social contradictions and struggles sited on the body'. Peters (1996) draws on the postmodern perspective for the development of what she calls a critical pedagogy which involves working towards an understanding of the world and one's relation to the world with disabled people and others. In Peters' interpretation of postmodernity one implication is that different, insider voices can be articulated and heard and can challenge those of the academy (in this case professional sociologists). For her, as for other feminists, making private experience speak to public policies is a radical act.

Within sociology the work of Irving Zola, a sociologist and disability activist, represents an important attempt to link the material, social and cultural dimensions of disability (Williams, G. 1996). During the early 1980s, Zola recognised that while his politics had to be unwavering in the articulation of demands for independence and an end to discrimination, there was more to a sociological analysis of disabled people's oppression than an empirical identification of environmental barriers conjoined with a conspiracy theory regarding the interests of professionals engaged in rehabilitation. In line with many other activists in both Britain and the USA, Zola recognised the undermining power of the dominant ideology of disability which regarded 'it' – that is the thing from which the individual 'suffers' – as a personal tragedy.

Zola resisted the temptation to sociological solipsism, and recognised the implications of ageing societies peppered with chronic illnesses for the development of the disability movement (Zola 1991), pointing out that the processes of ageing were something that linked the interests of 'the able-bodied' to those of 'the disabled'. However imperative it may be politically to define people with disabilities as a minority group, it is a curious minority which will include us all if not today, then tomorrow, or the day after, and that:

> only when we acknowledge the near universality of disability and that all its dimensions (including the biomedical) are part of the social process by which the meanings of disability are negotiated, will it be possible fully to appreciate how general public policy can affect this issue.
>
> (Zola 1989: 420)

In place of the reification of the 'medical model' on the one hand and the 'social model' on the other, we find in Zola a willingness to examine

disability from many points of view, and a desire to understand the contribution the different voices have to make to our discussions about disability. Zola's work was a bold attempt to hold firm to the politics of disability while remaining free to explore its darker phenomenological waters. He wanted to place at the forefront of any discussion of disability the bleak realities of economic deprivation, disenfranchisement, and marginalisation, while insisting on the continuing need to find a place for research in clinical rehabilitation and an interpretive phenomenology of the personal worlds of people with disability and chronic illness. Within this context the ontological reality of the impaired body is central to the development of any social theory of disability.

In conclusion, we suggest that while the attempt to bring the body back into the sociology of disability can overemphasise the self-authorship of possibilities, thinking about the lived body forces a recognition of the constraints as well as the possibilities of interpretation. As the philosopher Martha Nussbaum argues: 'We all live our lives in bodies of a certain sort, whose possibilities and vulnerabilities do not as such belong to one human society rather than another' (Nussbaum 1995: 76).

Any theory, whether expounded by sociologists or by disability theorists and activists, which overdetermines social control risks paralysing the possibilities for change. Within sociology, the turn towards 'the body' can be seen as representing a longing for community, for connection, and for meaningful participation (Kirkmayer 1992) – a turn away from some of the more sterile territories of critical theory. But if theory is not to incapacitate meaningful politics altogether (Hallsworth 1996), then it must use the insight of lived experience as grit for its development, and closure of the subject of the body is no longer possible. The dangers of incapacitating meaningful politics are recognised by Charlton when he argues that it is important to work for unity in the theory and practice of disability politics while recognising individual difference and self-identity:

[The] postmodern or poststructuralist position revels in diversity . . . When universality is abandoned, when difference becomes everything at the expense of collectivity, only the lonely, isolated individual remains.

(1998: 157–8)

Post-structuralist theorising about the body will not reproduce the methodological and political individualism of the medical model unless it remains connected to the material basis of embodiment. We hope we have indicated how work in both sociology and disability studies attempts in different ways to retain that connection.

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