

Medical Encounters

The Experience of Illness and Treatment

Edited by

Alan Davis and Gordon Horobin



Medical Encounters

Original review of *Medical Encounters*:

'This is an interesting and worthwhile publication, which should be read and enjoyed by a wide circle of people including students, general practitioners, and vocational trainees. It should be on most library shelves.' J. S. McCormick, *Journal of the Royal College of General Practitioners*, (1978)

Originally published in 1977, this book looks at medical sociology from the inside. Each chapter has been written by sociologists who themselves were patients – participant observers. Each experienced problems and sought solutions in the health services, at the same time bringing their training in social science to the analysis of experience. This is a unique contribution to medical sociology, bringing a directness to the recorded experiences.



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The Experience of Illness and Treatment

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THE EXPERIENCE OF ILLNESS AND TREATMENT

Edited by
ALAN DAVIS and GORDON HOROBIN



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PREFACE

Alan Davis and Gordon Horobin

The origin of this collection of essays lay in a seminar at the Institute of Medical Sociology some two years ago. Our colleagues invited us to prepare a discussion paper based on our then recent experiences of hospitalisation. One of the first problems we faced was that of relating our experiences to an existing body of sociological literature; the texts we had routinely used in teaching medical sociology only seemed to cover our experiences elliptically, if at all. The formal analyses of 'illness behaviour' in no way captured our perceptions of the processes, both 'pre-patient' and 'patient', through which we had passed. Similarly we could find few naturalistic studies of hospital wards which dealt with the kinds of problems we had encountered while 'doing patienthood' or 'adopting the sick role'. There were surveys of patients, their attitudes to care, their sources of satisfaction and dissatisfaction, and so on, but these seemed to us somehow 'frozen', temporally fixed, devoid of any sense of cognitive emergence. The larger-scale studies of structures or systems of health care, whether intra- or cross-national, seemed even more remote from our mundane concerns of 'getting by' as a patient. We found few accounts of the *processes* by which people became 'patients', got a 'diagnosis', experienced 'treatment' or coped with 'illness'. Instead we found elements of these 'problems' studied in such a fashion as to detach them from their context, from the multiplicity of processes in which we engaged, and hence from the essentially problematic nature of 'illness careers'. Our colleagues shared our view of the available literature and suggested that we consider 'writing it up for publication'.

Some time later we discovered a book which came nearer than almost any of the sociological works to the kind of project we had in mind. *Sick Doctors*¹ is a collection of accounts of their own illnesses, written by doctors for other doctors. We found their stories interesting, often informative and not infrequently very funny. An idea grew that we might produce a parallel collection by 'sick sociologists' (a working title that we abandoned only with reluctance) and accordingly we solicited by means of an advertisement in *Medical Sociology Newsletter*² accounts of illness and patienthood from our colleagues. This volume of essays is the result.

We asked our contributors to treat their own experiences as 'strange', and to prepare an account of how they attempted to produce order out of these experiences, availing themselves of whatever literature they found helpful. An interesting feature of this has been the way in which most of our contributors had felt obliged *at the time* to produce such accounts. We wonder how many more diaries, essays or other unfinished papers, written as a response to experiencing illness and treatment, lie buried in filing cabinets, unused and relegated to the background knowledge that we all have about health and illness.

Everyone becomes ill at some time, everyone has some experience of seeking help and many have been treated in hospital. Medical sociologists (like doctors) are not immune through their professional concerns to such experiences. Yet, as we have suggested above, sociologists' analyses of illness, with a few notable exceptions,³ have been formal, objectified, detached and 'scientifically rigorous'. Their background knowledge, derived from experience, is ruthlessly eliminated (at least overtly) from their research designs, their data, analyses and discussions. As we argue below, we believe that such scientific 'purity' is mistaken.

For the individual the experience of illness forces to his attention the problematic state of body and mind, and their relationships to the services set up to handle such problems. Each illness experience and encounter with organised care is unique, or at least uniquely related to his own past experiences and, except for frequently occurring minor complaints or problems of long-term impairment, recipes for action are not obviously available.⁴ On the other hand for doctors, nurses and others engaged in the provision of service, illness is work, an everyday occurrence. Thus, while patients may be treated as individuals, they are treated in such a way as to assimilate them to classes of individuals characterised by combinations of age, sex, condition, diagnosis, or simply 'patienthood'. They are, in short, dealt with routinely, as 'normal cases'. Implicit in such treatment are notions of appropriate illness behaviour and the proper role of the patient. Models of ideal patient behaviour in turn create the potentiality for deviance, with non-conforming patients labelled 'non-compliant', 'awkward', 'troublesome', or even 'neurotic'.⁵ Such models and typifications are however rarely explicit and one of the (for us) interesting trends in sociology is the attempts by some practitioners to uncover how typifications emerge in practice.⁶

Things look very different from the patient's perspective. Intake procedures, ward organisation, 'tests', constraints on staff time etc. may be well understood and taken for granted by staff, but few patients

have received training in the management of medical worlds or have encountered them sufficiently often as to become expert. Instead the patient is confronted by problems of interpretation – of his symptoms, the effects of drugs, doctors' orders, ward procedures, and so on. He encounters too problems of comportment – how to 'do' illness and patienthood, how to interact with medical staff and other patients. Related to these are problems of legitimacy (– is he 'really' ill, is his claim to treatment a legitimate one?) and by problems of identity and domestic organisation – how far does illness become incorporated into normal life, how is chronic illness managed in interactions with others, and so on. It is the nature of these problems and the solutions which patients construct for themselves which form the main topics of this collection of essays. The ambiguity of illness experience is of interest precisely because we have constantly to engage in work to construct a version of illness and its social contexts. Medical sociologists have a professional interest in such constructions but, by isolating segments of them for study, they often miss out on the essentially problematic nature of the *process* of construction, arising from its emergent and contingent nature. The 'episode'⁷ has to be grasped as a whole if we are to make the experience of illness intelligible.

Some of the accounts in the collection have unpleasant aspects; pain, fear and the sudden disruption of normal timetables *are* unpleasant. We should stress, however, that they are not intended as 'atrocious stories' about the health services. Indeed we believe that a naturalistic account of the work which a patient has to do as he proceeds through the labyrinth of social interactions that make up illness behaviour and 'the health service', cannot but have elements which appear variously as bizarre, funny, and even frightening.

The essays all have one overriding characteristic – their methodology. Each writer has been in the purest sense a participant observer. Each has been a patient, experienced the problems outlined above and sought solutions to them. At the same time they have brought their training in social science to the analysis of their experiences. Clearly this demands a greater degree of reflexivity than is normally required of an actor in a social situation and it must be acknowledged that there are occasions when the experience overrides the observation. Of course the accounts differ from other participant observation studies in that the situations were not deliberately chosen for their research potential. Their strengths are at the same time their weaknesses; they gain 'feel' at the expense perhaps of systematic recording, analysis and representativeness. We do not apologise for this for we feel that, for a number of

reasons, the strengths outweigh the weaknesses.

In the first place conventional sociological analyses of medical worlds rarely lay out for inspection the ways in which the sociologist's own experiences and knowledge of health and illness are incorporated into what is deemed researchable and their interpretation of data.⁸ As members of society who are periodically ill we continually trade on our background knowledge about illness to warrant our data as phenomenologically adequate and to interpret those data or the work of others. We do not approach our own bodily states as strangers. Rather we assume a basic level of shared assumptions about health and illness which makes research, teaching and conference discussion possible and sensible. Our contributors have tried to engage their own experiences and match them against available knowledge, and to lay out some of the ambiguities from which we begin analysis. They have tried, in other words, to take seriously the relationship between personal experience and insight into problems⁹ and to incorporate their professional and their 'ordinary member' knowledge into their analyses of the social processes in which they were involved. This is rarely done in sociology and anthropology unless it is through work embodying what Lofland¹⁰ called 'my adventures and nausea among the natives', or those breast-baring collections in which sociologists relate how they grappled with intractable research problems and situations.¹¹ While interesting as a special brand of confessional literature, whereby the professional self is purified, such publications tell us little other than that research is hazardous, and are rarely as constructive as the accounts in *Urban Life and Culture*¹² which give insight into how sociologists brought order into qualitative data on such diverse research topics as cab drivers and hippie caravan parks. Most such discussions are, however, concerned more with what constitutes intellectual craftsmanship than with substantive analyses of the phenomena under investigation. Research 'cook-book' compilers are still more guilty of divorcing technique from topic, creating the impression that data can be generated independently of the thought processes of the researcher.

The one technique that perhaps raises these issues most acutely is participant observation. There seems to be an uneasy feeling about its use, stemming perhaps from a fear that its user will become too immersed in the field of study, preventing that objective or 'value-free' stance that is still seen by many as the hallmark of a truly scientific sociology. Ethnography lacks respectability as the sociological community worries about the ethics of 'deception', the scientific status of an observer mediating directly between the data and the reader, the

generalisability of data, and so on. Observers, it is claimed, contaminate the situations they study and, if on unfamiliar territory, run the risk of being led astray by contact with the 'wrong people'.¹³ The observer, seemingly free from overt scientific control, is open to the charge that he has either sold out to one side or another, or uses his own hidden values to inform his analysis.

What kinds of remedy are suggested for this contamination? Sociological methodology, with its so self-conscious preoccupation with 'contamination', might best be analysed along the lines suggested by Douglas¹⁴ as rituals for demonstrating purity and for removing the anomalies and danger which reside in too close an association with one's subject matter. Neutrality is conventionally assured by observing the rituals of survey technique, with its standardisation of questions in formal questionnaires and interview schedules, its pre-selected samples and its tests of validity and reliability. All serve the purpose of hiding the researcher, and his assumptions, from view. Counter-arguments against this kind of work are now legion and include such criticisms as the imposition on the object of study of *a priori* assumptions; the refusal to lay out the auspices under which the study is formulated and proceeds; the absence of any discussion of the social relationships that produce the statistics; and its unacknowledged reliance on background knowledge of 'what is reasonable'.¹⁵ The critical reviewer of such work is forced to employ an interpretive sociology in order to make sense of what is offered. Further, as Scott and Lyman¹⁶ point out, where such an approach is linked with 'social meliorism' it often attempts to convince policy-makers that sociologists have the appropriate scientific techniques to answer their questions and is better treated as a 'rhetorical stratagem' for a policy-oriented audience.

Conventional 'scientific' sociology then fails to confront the problem of reflexivity. Indeed its procedures rule out the possibilities of a reflexive sociology. Whilst we can claim that the essays in this volume have made only a modest contribution to such an enterprise, the important issue of the relationship between the professional sociologist's interpretive work and that done by ordinary members of our society has at least been confronted. That people, particularly in puzzling and problematic situations, attempt to bring order into their experiences by use of diverse interpretive methods, has been a central concern of some writers.¹⁷ The new schools in sociology, however, should make us all think carefully about the nature of the enterprise in which we are engaged when we 'do' sociology. There has always been a tension between scientific sociology and humanistic, interpretive sociology, a tension so

far unresolved. The relationship between the sociologist as a member of society and the sociologist as professional scientist lies at the heart of this tension for, whenever formal techniques are eschewed, the dilemmas inherent in the relationship are raised in their most dramatic form. We hope to see these essays used as a contribution to that methodological debate as well as providing practical demonstration of the ways in which the sociologist moves back and forth between members' knowledge in interpreting the ambiguities of illness and health.

In line with our concern with the tacit assumptions which we have to make so as to proceed with sociological analysis, we asked Julius Roth to add a commentary on the other papers. Our intention was that, as an outsider to the British health care system, he would be able to treat our substantive topic as 'strange'. From this standpoint and from his knowledge of a different system of care, he identifies a number of points where we take for granted certain aspects of service delivery, control, lack of consumer choice, etc. We, in common with our contributors, take for granted our right to treatment without payment, for example; we do not raise it as an issue but use it as part of 'what everyone knows'. His comments, then, as well as his discussion of 'consumerism' are a useful corrective to our own culture-bound perspective. There is a hidden ethnocentrism in much research and there are, to our knowledge, no published studies of people who have experienced other kinds of medical care, especially pre-1948 British medicine, and of what the differences mean in terms of the interpretation of illness and health.¹⁸ The sense of strangeness is enhanced by Roth's own story of his encounters with the NHS and challenges us further to reflect on what we take for granted. The extent to which British readers can say 'he didn't know how to work the system' is a measure of the extent to which we routinely use our background knowledge, both in everyday behaviour and in our professional analyses.

With the foregoing considerations in mind, then, we invite the reader to approach and judge these essays.

Notes

1. R. Greene (ed.), *Sick Doctors*, Heinemann Medical Books, London, 1971.
2. *Medical Sociology Newsletter* is distributed to members of the medical sociology study group of the British Sociological Association.
3. See, for example, J. Roth, *Timetables*, Bobbs-Merrill, Indianapolis, 1963; F. Davis, *Passage Through Crisis*, Bobbs-Merrill, Indianapolis, 1963.
4. See M. Bloor and G. Horobin, 'Conflict and Conflict Resolution in Doctor-

- Patient Interactions', in A. Cox and A. Mead (eds.), *A Sociology of Medical Practice*, Collier-Macmillan, London, 1975.
5. See, for example, J. Lorber, 'Good Patients and Problem Patients', *Journal of Health and Social Behaviour*, 16, 1975, pp. 213-24.
 6. See, for example, D. Zimmerman, 'The Practicalities of Rule Use', in J. Douglas (ed.), *Understanding Everyday Life*, Routledge and Kegan Paul, London, 1971; R. Scott, 'The Construction of Conceptions of Stigma by Professional Experts', in J. Douglas (ed.), *Deviance and Respectability*, Basic Books, New York, 1970; T. Scheff, *Being Mentally Ill*, Aldine, Chicago, 1966.
 7. S. Lyman and M. Scott, *A Sociology of the Absurd*, Appleton-Century-Crofts, New York, 1970.
 8. This is of course equally true of the work of sociologists of the family, work, organisations and so on.
 9. C.W. Mills, *The Sociological Imagination*, Oxford University Press, New York, 1959.
 10. J. Lofland, 'Analysing Qualitative Data', *Urban Life and Culture*, vol. 3, 1974, p. 307.
 11. P. Hammond (ed.), *Sociologists at Work*, Basic Books, New York, 1964; A. Vidich, J. Bensman and M. Stein (eds.), *Reflections on Community Studies*, Wiley, New York, 1964.
 12. *Urban Life and Culture*, Vol. 3, No. 3, 1974.
 13. R. Wax, *Doing Fieldwork*, University of Chicago Press, London, 1971.
 14. M. Douglas, *Purity and Danger*, Routledge and Kegan Paul, London, 1966.
 15. See, for example, H. Blumer, 'Sociological Analysis and the "Variable"', *American Sociological Review*, 21, 1956, pp. 683-90; A. Cicourel, *Method and Measurement in Sociology*, Free Press, New York, 1964.
 16. S. Lyman and M. Scott, op. cit.
 17. A. Schutz (ed.), *Collected Papers 1*, Martinus Nijhoff, The Hague, 1971; P. McHugh, *Defining the Situation*, Bobbs-Merrill, Indianapolis, 1968; H. Garfinkel, *Studies in Ethnomethodology*, Prentice-Hall, New Jersey, 1967.
 18. H. McCarthy, *State Medicine, Golden Age in the Silver City*, unpublished manuscript, Aberdeen, 1974.



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1 BECOMING A HYPOCHONDRIAC

Paul Atkinson

When it comes to deciding whether or not to consult a doctor we all find ourselves confronted by moral and practical dilemmas. It is a perfectly normal part of everyday life that we should experience a degree of discomfort, pain and disease periodically.^{1, 2} Yet it is highly unusual and inappropriate behaviour to treat all these passing episodes as occasions for being 'ill' or for consulting a doctor. The model patient, or would-be patient, should be able to interpret his changing physical state — only resorting to the doctor's surgery when symptoms really merit the intervention of a professional. Studies of doctors and their patients, however, show that there is often a considerable degree of mismatch between lay and professional opinion on appropriate presentation. On the one hand, investigators find that many serious illnesses go unreported and untreated.^{3, 4} At the same time, doctors frequently complain that they are too often consulted for 'trivial' complaints.^{5, 6} For the layman there is potential conflict between alternative courses of action — between over-hasty presentation at the doctor's surgery with what may turn out to be a common-or-garden, self-limiting complaint, or 'delaying' and running the risk of serious illness going undetected. There are grounds for conflict between patients and their doctors as well. If the patient's adjudication of his illness does not tally with the doctor's, then he may find himself classed as a 'troublesome' patient.

Bloor and Horobin have suggested that for these reasons, patients face a 'double-bind' situation.⁷ To begin with, the model layman is required to act as what Schutz called a 'well-informed citizen',⁸ he should display the knowledge and judgement to present himself to the doctor at the right time and for appropriate reasons. However, once he has become a patient, he is normally expected to surrender any further responsibility and judgement to the doctor in his role of professional 'expert'. He relinquishes the position of well-informed citizen for that of the 'man on the street'.⁹ Bloor and Horobin summarise the position in this way:

. . . the sick person is expected to analyse his condition in terms . . . which imply diagnostic and prognostic evaluation, but on presentation to the doctor the sick person is expected to 'forget' his own prior assessment of the condition and defer to the doctor's; the sick person is first encouraged to participate in and then excluded from the therapeutic process¹⁰

On this basis, it would appear that 'experts' do not make good patients, as they will be unwilling or unable to surrender their expertise to the doctor. (Doctors themselves are notoriously bad patients from this point of view.) At the same time, 'experts' may not be ideal candidates for patienthood either; their knowledge may exacerbate, rather than resolve, the dilemma of 'to consult or not to consult?' In this paper I want to examine some of the consequences of acquiring medical knowledge and illness behaviour. I shall suggest that becoming a 'hypochondriac' may be an occupational hazard for those who are in process of becoming medical experts.

Medical Students' Disease

My comments in this paper derive from my research on medical education. I spent two years working on the teaching of clinical medicine and surgery in the Edinburgh teaching hospitals. My chosen method of working was by participant observation. Each morning I went into one of the hospitals, put on my white coat and joined the students. I mingled with them as they were taught at the patients' bedsides, in the operating theatres and out-patient clinics. For the time that I was on the wards I was virtually indistinguishable from the students, and in many ways I came to identify closely with them. The students I was working with were in their first year of clinical studies; they were encountering the work of the hospitals for the first time. In many ways the medical students and I were novices alike, and in the course of time we all came to acquire (in varying degrees) privileged and expert knowledge of clinical medicine and surgery. In the course of this learning, the students and I had elements of shared biography and experience.

Something which struck the students and me was the sheer extent of illness that we encountered. The incidence of illness, the number and turnover of patients appeared to be high – higher, probably, than many of us had thought. (This impression may be supplemented by the information that the Royal Infirmary in Edinburgh has close on a thousand beds and an annual turnover of over 27,000 patients).

This sense of the pervasiveness of illness was supplemented by the

range of pathology that we encountered. All the clinical units we found ourselves in practised general medicine and surgery, and in addition, numbers of the staff had specialist interests and expertise. Such specialisation was reflected in the patients' disorders on the wards. Among the medical units, for instance, there were those which specialised in gastro-intestinal diseases, neurology, endocrine and haematological disorders and so on. Similarly, among the surgeons I found myself on units with special concern for operations on the thyroid and parathyroid, cancer of the breast, for gastro-intestinal surgery and so on. In this way the students and I were vividly impressed with the number of things that can go wrong with all the different systems of the body.

Given the acute nature of much illness seen in the teaching hospital, many of the patients we saw were seriously ill. In the context of our immersion in the clinical milieu, the students (or some of them at least) and I became 'hypochondriacs'. We shared a sense of personal vulnerability and insecurity in the face of the prevalence and apparent capriciousness of ill-health. As we heard more and more case histories, and as patients recounted the insidious onset and development of grave illness, so we came to take our own continuing good health less and less for granted.

Medical students' hypochondriasis has been noted before — for example by Richard Gordon, in what remains one of the best available accounts of medical education in Britain:

I slunk into the library and looked up the psychology books: horror overcame me as I turned the pages. In my first few weeks on the wards I had been convinced that I was suffering from such complaints as tuberculosis, rheumatic heart, cancer of the throat, and pernicious anaemia, all of which successfully cleared up in a few days, but now I faced the terrible possibility of harbouring a mother-fixation, oral eroticism, and a subnormal libido.¹¹

The phenomenon has even been described as 'medical students' disease'.¹² It has been estimated by some researchers that a high proportion of students — possibly up to 70 per cent — experience something of this sort.

The following constellation of factors occur regularly . . . [The student] notices in himself some innocuous physiological or psychological dysfunction, e.g. extra-systoles, forgetfulness. He attaches to this an undeserved importance of a fearful kind usually modelled

after some patient he has seen, clinical anecdote he has heard, or a member of his family who has been ill.¹³

Leukaemia is often reported as a favoured candidate disease for students to opt for in their hypochondriacal phases. Although it is usually spoken of as occurring during the early days of clinical work, Woods and his colleagues found that 'medical students' disease' could be a chronic condition, lasting throughout a student's training.

From time to time in the course of my field-work I noticed students applying various diagnoses to themselves – and to each other:

As we walked along the hospital corridor, Diane Michael stopped and said, 'What do you do when you've got an itching ankle and boots on? . . . God – primary psoriasis of the ankle!'

Not surprisingly, perhaps, none of the other students seemed to take this 'diagnosis' very seriously, and my impression is that the student 'hypochondriac' can expect little sympathy from his peers. On the contrary, they are likely to prove Job's comforters, as they find diagnoses for each other as well as for themselves. For instance, on one medical round one of the girls had to leave the ward as she was feeling faint. This was not uncommon – the reason usually seemed to be the effect of standing in overheated wards rather than squeamishness on the students' part. Later two of the boys speculated on the reasons for her fainting – it had, apparently, happened to her on previous occasions. They debated between them whether she might be suffering from ischaemic heart disease. (I suggested to them that a lack of breakfast might be more plausible . . .)

In a similar way, students sometimes used 'diagnoses' to characterise their clinical teachers:

Returning to a discussion of their present clinique, the two boys [I was interviewing] described another consultant to me, who, they said, never waited for anyone to answer his questions. They described him as living in a world of his own. They added he was interesting because he had *nystagmus* and had to keep moving his head to compensate for it. Collins suggested *spasmodic torticollis* as an alternative cause for his head movements, whilst Priestley suggested that he might also be *thyrotoxic*.

As we ambled round the hospital corridors and the canteens, the