Gareth Williams

The genesis of chronic illness: narrative re-construction

Abstract  In this paper I demonstrate the way in which people's beliefs about the aetiology of their particular affliction (arthritis) need to be understood as part of a more comprehensive imaginative enterprise which I refer to as narrative reconstruction. The intrinsically teleological form of this enterprise means that identified 'causes' represent only putative efficient connexions between the disease and antecedent factors but also narrative reference points between the individual and society in an unfolding process which has become profoundly disrupted. Through the presentation of case material taken from lengthy interviews I illustrate the way in which my question to the subjects about the cause of their disease: 'Why do you think you got arthritis?' was translated by them into a narrative reconstruction of their changing relationship to the world in which they live and the genesis of illness within it.

Introduction

We are seated in the living-room of a modern, urban council house somewhere in the north-west of England. Bill, the fifty-eight year-old man with whom I have been talking for almost an hour, leans forward. Then, in a strained voice and with a look of exasperated incomprehension on his face, he says: 'and your mind's going all the time, you're reflecting ... how the hell have I come to be like this?' ... because it isn't me' (B13.6).

Bill has rheumatoid arthritis (RA), which was first diagnosed eight years ago following two years of intermittent pain and swelling in his joints; a serious heart attack has added to his difficulties. We have never met before. His words indicate the way in which a chronic illness such as RA may assault an individual's sense of identity, and they testify to the limitations of medical science in delivering a satisfactory explanation for the physical and social breakdown to which such an illness can lead.

In the Collected Reports on the rheumatic diseases published by the
Arthritis and Rheumatism Council, and with a beguiling acknowledge-
ment of the popular image of the scientist as Great Detective, the
experts admit their limitations and pronounce RA to be 'one of the
major medical mysteries of our time'. What is striking about Bill's
interrogative, however, is that it points to a concern with something
more than the cause of his arthritis, and what I would like to do in this
paper is to examine the nature of his question, and those of two others,
and to consider the significance of the answers they provide. That is to
say, I want to elucidate the styles of thought and modes of 'cognitive
organization' employed by three people suffering from RA in making
sense of the arrival of chronic illness in their lives. I will not be claiming
that these three cases are 'representative' in any statistical sense, but I
do suggest that they symbolise, portray, and represent something
important about the experience of illness. They are powerful, if idio-
syncratic, illustrations of typical processes found in more or less
elaborate form throughout my study group.

The fieldwork on which this study is based consisted of semi-
structured, tape-recorded interviews with thirty people who had been
first diagnosed as suffering from RA at least five years ago prior to my
contact with them. The rationale guiding selection of people at this
point in their illness was that in pursuing a general interest in what
might be called the structured self-image of the chronically sick person
it seemed sensible to talk to those who were 'seasoned professionals'
rather than novices in the difficult business of living with a chronic
illness. Four members of my study-group were in-patients on rheuma-
tology wards and the rest were out-patient attenders at rheumatology
clinics at two hospitals in north-west England. The in-patients were
interviewed in a relatively tranquil side-room off the busy ward while
the out-patients were first approached in the clinic and subsequently
interviewed in their own homes. Of the 30 respondents, 19 were
women and 11 were men, so my group had proportionately more men
than one would expect to find in the general population. Their ages
ranged from 26 to 68 years at time of interview; thirteen being between
26 and 49, eleven between 50 and 64, and six were 65 years of age or
over. Twenty-two were married, the rest being a mixture of single,
widowed, and divorced or separated.

The interview covered a variety of themes relating to the experience
of living with arthritis, and the data were elicited according to a simple
checklist of topics. The duration of the interview as a whole and the
sequencing of particular topics were influenced more by contingent
features of the interview process than by any well-considered plans of
my own. Where I had to compete with an obstreperous budgerigar or a
boisterous young child, the interviews would likely be short and
The genesis of chronic illness: narrative reconstruction 177

fragmented. On better days, with a minimum of interruption and an
eager and lucid respondent, the interview could last for three or even
four hours.

Although my central concepts - narrative reconstruction and genesis
- are, I believe, novel, the issues they are designed to address - how
and why people come to see their illness as originating in a certain way,
and how people account for the disruption disablement has wrought
in their lives - have been the subject of innumerable investigations.
Sociological and anthropological research into illness behaviour and
health beliefs and psychological research into processes of attribution
have all, in one way or another, attended to related issues; but there is
so much of it! I cannot possibly indicate all my debts, but perhaps the
body of work which has had most influence on this paper is that which
examines lay beliefs or folk theories about the causes of specific diseases
or illness in general. Although much interesting material has been
collected in this line, it has tended to rest content with treating people's
casual beliefs as simply that: beliefs about the aetiology of illness. How-
ever, it seems to me that if, in some fundamental way, an individual is
a social and historical agent with a biographical identity (in the fullest
sense) and if the prime sociological importance of chronic illness is the
'biographical disruption' to which it gives rise, then an individual's
account of the origin of that illness in terms of putative causes can
perhaps most profitably be read as an attempt to establish points of
reference between body, self, and society and to reconstruct a sense
of order from the fragmentation produced by chronic illness.

In this paper, therefore, I use my three cases to illustrate the way in
which people's beliefs about the cause of their illness needs to be under-
stood as part of the larger interpretive process which I have chosen to
call narrative reconstruction. Before looking at the specifics of my
analysis, however, I would like to clarify the theoretical concepts
which inform it.

Theoretical prologue

The concept of 'narrative' does not hold an established theoretical place
in any sociological school or tradition. In general speech it is often
used, in noun form, as a synonym for 'story', 'account', or 'chronicle'.
When used as an adjective, as in 'narrative history', it typically refers
to the process of relating a continuous account of some set of events
or processes. When A.J.P. Taylor, for example, refers to himself as a
'narrative historian', as he often does, he implies both a concern with
telling a good story and also a preference for a common-sense, empirical
reading of historical events, unencumbered by any theoretical baggage be it marxist, structuralist, or psychoanalytic.

As I see it the term has two aspects: the routine and the reconstructed. In its routine form, it refers to the observations, comments, and asides, the practical consciousness which provides essential accompaniment to the happenings of our daily lives and helps to render them intelligible. In this sense narrative is a process of continuous accounting whereby the mundane incidents and events of daily life are given some kind of plausible order. If 'biography' connotes the indeterminate, reciprocal relationships between individuals and their settings or milieux and between those milieux and the history and society of which they are a part then narrative may be seen as the cognitive correlate of this, commenting upon and affirming the multiform reality of biographical experience as it relates to both self and society.

In his fictional, philosophical chronicle, The Man Without Qualities, Robert Musil, speaking through his central character Ulrich, suggests that narrative order is: '... the simple order that consists in one's being able to say: "When that had happened, then this happened"'.

Musil/Ulrich goes on to argue:

In their basic relation to themselves most people are narrators. They do not like the lyrical, or at best they like it only for moments at a time. And even if a little 'because' and 'in order that' may get knotted into the thread of life, still they abhor all cogitation that reaches out beyond that. What they like is the orderly sequence of facts because it has the look of a necessity, and by means of the impression that their life has a 'course' they manage to feel somehow sheltered in the midst of chaos.

The trouble is that sometimes the 'orderly sequence of facts' gets broken up. It cannot be sustained against the chaos and, for a time at least, the life-course is lost. The routine narrative expressing the concerns of the practical consciousness as it attends to the mundane details of daily life is pitched into disarray: a death in the family, serious illness, an unexpected redundancy and so forth. From such a situation narrative may have to be given some radical surgery and reconstructed so as to account for present disruptions. Narrative reconstruction, therefore, represents the workings of the discursive consciousness.

In my interviews, the reason for the conversation and the excuse for the occasion was the fact of the person being ill. In this context, the aetiology of the affliction and the narrative history of the illness held a key place in the dialogue. I remarked earlier on the many studies examining lay theories about illness. In one such study comparing the beliefs of cancer and non-cancer patients with regard to the aetiology of that disease, the authors suggest:
The person without cancer can afford to be more dogmatic about cancers and likely to think in stereotypes. The closer he comes to dealing with the disease, the less clear-cut and more complex the explanations may become.¹⁰

The reason for such complexity, it seems to me, is that the explanations advanced by afflicted individuals have both causal and purposive or functional components. They represent not only explanations for the onset of a given disease, but also acts of interpretation, narrative reconstructions of profound discontinuities in the social processes of their daily lives. The illness is part of their story and as with any story, to borrow from George Orwell, the closer one gets to the scene of events the vaguer it becomes.¹¹ In some ways narrative reconstruction may be seen to involve a process of remembrance akin to R.G. Collingwood’s notion of historical thinking where:

Every present has a past of its own, and any imaginative reconstruction of the past aims at reconstructing the past of this present, the present in which the act of imagination is going on, as here and now perceived.¹²

In confronting the experience of chronic illness, then, like any unusual or disturbing experience, Musil’s narrative thread—‘when that had happened, then this happened’—becomes questionable. The individual’s narrative has to be reconstructed both in order to understand the illness in terms of past social experience and to reaffirm the impression that life has a course and the self has a purpose or telos. It is from this viewpoint that I have read the ‘causes’ to which my respondents refer both as delineations of putative, efficient connexions between the ‘dependent variable’ (arthritis) and various ‘independent variables’, and also as narratively reconstructed reference points in an unfolding historical relationship between body, self, and society. These reference points may be seen as constituents in the genesis of a misfortune within a narrative which imaginatively reconstructs the past so that it has meaning or purpose for the present.¹³ In this way narrative reconstruction becomes a framework for teleological explanation.

Given the teleological form of narrative reconstruction, I employ the concept of ‘genesis’ not for stylistic or rhetorical purposes, but in order to liberate myself from the semantic straitjacket imposed by the term ‘cause’ as it has been generally understood since Hume,¹⁴ and so as to establish a connexion with the Greek tradition of reflection on the origins of things which attained its apogee in Aristotle’s doctrine of the four causes.¹⁵ Robert Nisbet has remarked that the modern consciousness has been, inevitably, so influenced by Roman, Christian and sceptical thought about causality that it is difficult for us nowadays to tune-in to the Aristotelian schema. Nisbet argues:
To Aristotle — and to the Greeks generally, I believe, — something different is involved, something that is somewhat less 'cause' in our inherited sense of the word than it is a point of reference in a self-contained, developmental process. In Aristotelian philosophy different levels of causality are conceived within an overall process of becoming which includes an account of ends as well as beginnings and purposes alongside 'causes' (in the modern sense). In this regard the 'causes' to which my respondents refer are seen, in part, as points of reference within the process of becoming ill, and the genesis, or mode of formation, of the illness constitutes, in a sense, the dominant theme of the account. It is an analytic construct through which the respondent can be seen to situate a variety of causal connexions as reference points within a narrative reconstruction of the changing relationships between the self and the world; a world within which the biographical telos has been disrupted. In this way Humean 'constant conjunctions' are absorbed into an Aristotelian teleology.

The three case studies in this paper illustrate the way in which distinctive narrative forms are reconstructed to answer the question of genesis as it arises in different lives. The first two reformulate my abstract question: 'Why do you think you got arthritis?' into substantive questions more suitable for interrogating the genesis-of-illness experience. Bill, as we saw at the start, wants to know 'how the hell have I come to be like this? . . . because it isn't me'. In the same vein, Gill wonders: 'Where have I got to? There's nothing left of me.' The third case is rather different. Betty exemplifies a situation in which both 'causal' analysis and narrative reconstruction may be transcended when the telos of life is gently enshrouded within a powerful theodicy. She does not need to reformulate my question because: 'people say: "Why you?" Well, why not me? Better me who knows the Lord'.

**Bill: narrative reconstruction as political criticism**

A significant portion of Bill's working life had been disrupted. In fact, he had had a tough time. He had worked as a skilled machine operator in a paperworks and, shortly before the first appearance of symptoms, was promoted to the position of 'charge hand' which entailed his supervising three floors in the factory. It was shortly after assuming his expanded responsibilities as a 'working gaffer' that things began to go wrong:

'I was a working gaffer . . . but, you know, they were mostly long hours and the end result, in 1972, was every time I had a session like, my feet began to swell...
and my hands began to swell. I couldn’t hold a pen, I had difficulty getting between machines and difficulty getting hold of small things.’

At this time he also had a massive heart attack and was off work for five months. A series of blood tests were done by his heart specialist who then referred him to a rheumatologist, and within the space of a couple of weeks he was hospitalized. At the time this unpleasant sequence of events was ambiguous and confusing, but over ten years Bill had become clearer about it:

‘I didn’t associate it with anything to do with the works at the time, but I think it was chemically induced. I worked with a lot of chemicals, acetone and what have you. We washed our hands in it, we had cuts, and we absorbed it. Now, I’ll tell you this because it seems to be related. The men that I worked with who are all much older than me — there was a crew of sixteen and two survived, myself and the gaffer that was then — and they all complained of the same thing, you know, their hands started to puff up. It seems very odd.’

Yes, very odd indeed. If I were simply interested in identifying his central aetiological motif no more need be said because the rest of the discussion was essentially a reiteration of this connexion. However, in order to understand the strength of his attachment to this belief, in the face of highly plausible alternatives, it is necessary to examine how his view of life has called forth this essential connexion between work and illness.

An important point about narratives, whether they be routine or reconstructed, is that they are necessarily co-authored. The interview, of course, is itself a particularly clear case of co-authorship, but, more generally, narratives are bounded by and constructed in relationship with various individual people and organizations. With regard to illness, any narrative built around it needs to take account of the medical world within which the official definition of that illness has been specified. Bill described how, following the diagnosis of ‘rheumatoid arthritis’ resulting from clinical and laboratory investigations, the doctors disclaimed any interest in his hypothesis about workplace toxicity and pursued alternative hunches:

‘I was assured by them (the doctors) that this is what it was, it was arthritis. Now, it just got worse, a steady deterioration, and I put it down that it was from the works. But with different people questioning me at the hospital, delving into the background, my mother had arthritis, and my little sister, Ruth, she died long before the war, 1936/7, and she had not arthritis, just rheumatism and that naturally did for her.’

From a clinical perspective and, indeed, from a common-sense appreciation of ‘inheritance’, there appeared to be a strong case for accepting
an explanation in terms of genetic transmission. Certainly, in rheumatological circles, genetic and viral hypotheses are those receiving most serious and sustained attention. Why was he not content with this?

Bill had spent many years in the military services, and had served eighteen years with the paratroopers completing 211 successful jumps. Had he suffered any joint trouble during this time?

‘No, none whatever. This is why I couldn’t associate it. All that time during the war we had a minimum of clothing on, we never went under shelter, we kipped in holes, slept on the deck — great stuff! You know, no problems’.

What he appeared to be suggesting by reference to his life in the services was two separate but related things. Firstly, given that he had ‘no trouble’ during a hard life in the services, he could not realistically entertain any idea of inherited weakness. On more than one occasion he said that because of his harsh experiences he ‘couldn’t associate anything with it’ (his arthritis). If there had been some inner predisposition surely it would have become manifest sooner? The second theme was that the absence of symptoms while he was in the services made it unlikely that those activities themselves were responsible for creating physical vulnerability. It all happened so much later and with such suddenness.

Bill was never entirely clear about his state of health while in the services. At a later point in the interview he mentioned that he had some symptoms at that time, and that parachuting with 60lb packs was a ‘probable factor’ but, in clarification, he remarked that many of his mates in the services had symptoms of a similar kind and that it was put down to ‘fatigue’. Whilst conceding that the tough life with the paratroopers must have had some effect on his body, he could not square those experiences with the debilitating development of RA: ‘To see myself as that, and now, from 1956, I can’t accept it, it’s not on’.

The references to the services, like the account of the workplace, make it clear that, for Bill, the body is defined by its relationship to the world of social action not in isolation from it. The medical model, employing a reduced range of clinically ascertainable factors, has no sensible meaning in the light of his pragmatic perspective. He was never dogmatic in his beliefs, but his pragmatism would not allow him to accept the validity of the medical model which appeared to rest upon an image of biological arbitrariness and caprice:

‘I was trying more or less self-analysis — where have I got it from? How has it come? And you talk to different people over all ages and you find that they are at a loss. They don’t know, they don’t know, nobody knows. And who do we ask? We ask the doctor (who says): “It’s just one of them things (...) and there’s nothing to be done about it.” ’
At this point there is no indication of the basis for Bill's refusal of medical rationality. All we have is a statement of preference for one explanation, workplace toxics, over others. A little later we returned to the workplace and to the experiences of his fellow workers as he remembered them:

'But thinking back to the way the other blokes were who are now gone, so we can't ask them, and what I remember of them, they more or less came to it in the same manner . . . I wasn't in there with them all the time, I was travelling between floors so I was coming out of it and getting fresh air and washing more frequently than they did. So this is something to do with it.'

Bill had mentioned the 'odd' coincidence of similar symptoms at the start of the interview, but his thinking had clearly gone beyond a simple observed correlation. Not only, it seems, was there evidence of definite patterns of symptomatology amongst the workers, but also a differential severity which he explained by reference to the amount of time spent in contact with toxic substances. In the language of classical epidemiology Bill is invoking, unwittingly, the 'dose-response criterion', according to which the investigator considers: 'whether the risk of disease increases commensurately with degree of exposure' and then examines this in relation to characteristics of both host and environment.

It seemed then, that, notwithstanding the doctors' declared disinterest in Bill's hypothesis, there was something happening at the factory:

'They just complained, and I noticed their hands were getting puffy, and that was one of the things, this seemed to be a common factor for everybody. Their hands started to puff and their shoes busted. And there was one guy, Joe (...), he was a very tall man, walked fairly rapidly, and he became slower and slower. And he said: "That's it, I'm out, it's this . . .". He said straight: "It's killing me, I'm getting out", and it fetched him straight down. And that's where it's stuck, in the back of my mind. If Joe . . . remembering the way Joe was, a good walker, he could nip up and down steps, seeing him just shuffling till he couldn't even get from the lodge to the workshop without coming through the lift, he just couldn't make the steps. Well I got that way till I couldn't make the steps, just couldn't make the steps.'

This graphic description of the destruction of men by their work adds little to the facts of the matter. What it does is to shift the quality of the discussion away from a simple description of illness associations to an intimation of the sense of revolt which existed amongst the workers in their consciousness of the situation.

Bill recognized the pressure to accept the doctors' analysis as legitimate, but in the light of his practical knowledge he felt that their analysis was inadequate:
'But putting it out of my mind, and having spoken to the specialists, they say: "No way". So you take their word for it. But it seems a bit ... thinking in my mind when I go to bed ... I can't go to sleep straight away, I have to wait until I get settled and your mind's going all the time, you're reflecting "How the hell have I come to be like this?", you know, because it isn't me.'

Bill has gone some way towards answering the question. He has identified a causal agent which seemed to explain his arthritis as well as symptoms in others, and he has described the milieu in which the causal nexus was situated. He has also portrayed a critical consciousness and a feeling of revolt amongst the workers which helps to explain his own unswerving attachment to his explanation when faced with a plausible clinical alternative. But is this observation of work experiences also part of a far more pervasive image of the world?

At another point in the interview, echoing his observation of the workers whose shoes 'busted', Bill told me of the experience of his wife who 'busted her back' while working with the local authority school meals service. How did this happen?

'Well, it was ridiculous because there were no men working there, and they had to go into a stock-room and the "veg man" had stacked spud bags which are 56lb five high. And it came to a particular day where they had to get one off the top, and she (his wife) was on her own, and she stood on a chair to get one off, and as it came down - up to that point she was a very strong woman - it just pushed her over and she went right down on the table. But she didn't realise at the time just how badly hurt she was. It was a couple of days after, she just couldn't move, she was almost paralysed.'

This episode, as well as providing an analogue with his own experience, has also led to shared involvement in a long struggle with medical and governmental bureaucracy:

'She has a pension from [her employers], but the [invalidity] allowance which was taken from me has been stopped for her, and they didn't even have to give it back. It's the usual "cock-up" at the DHSS.'

Whilst Bill did not cite his wife's experience as an explicit parallel, these details of his biography, it seems to me, provide the basis for analogical reasoning and are central to an understanding of the explanation he elaborates for his own affliction. Taking these details into account, the narrative reconstruction of his personal experience has expanded into a more general political criticism exposing the illusions and false consciousness purveyed by various representatives of officialdom. Within this act of interpretation, the model of causation which informs his perception of his own illness and his wife's accident is one where the origins of misfortune are seen as direct, immediate, and
within the bounds of human agency, but where the sick/injured person is not culpable in the slightest degree. In both episodes the workplace is defined not in terms of neutral tasks and accidental events, but as the locus of exploitative social relations in which workers are the victims of injustice and neglect.

The increasingly political tenor of his discussion of work and illness became even clearer in a section of the interview where Bill discussed issues surrounding his wife’s claim for compensation. She was refused compensation, he told me, firstly because there was no witness to her accident, and secondly because the DHSS medical advisor had diagnosed ‘osteoporosis’ (a chronic deterioration in bone strength) ante-dating her accident. Bill’s response to this was unequivocal:

‘I think that “osteoporosis” is a cop-out. Nobody examined her or tested her, nobody took any samples from inside her bones. And this would be the only way, decalcification of the bones, because she’s on calcium tablets now. But this only came up to my way of thinking because it was a cop-out, so they wouldn’t have to pay a great deal of compensation. You know, so what the people at the DHSS said was that everybody has this, you have it, I’m a liar but you’ve got it. They will say so without even examining you.’

When issues of diagnosis are removed from the quiet location of the doctor’s clinic and situated within the context of a struggle for compensation, the neutrality of the medical task and the objective validity of its procedures are thrown into doubtful relief. Bill recognised that technology and science are ideological, and that medicine can support political bureaucracy in preventing the establishment of social justice.

The tenacity of Bill’s attachment to a workplace toxics explanation for the aetiology of his own arthritis takes on clearer significance in the light of these other experiences which, together, form a narrative reconstruction of the genesis of illness which carries a highly political image of the social world. Both illness, and the response of professionals to it, suggest a world of power inequality. There was much more in Bill’s account that drew upon images of injustice in society. His experience of getting beaten-up by the police was introduced into the interview and recounted at some length and, as a whole, the world was presented as a place where ordinary people are exploited, conned, and manipulated by a range of social ‘powers’ be they doctors, bureaucrats, or the police. However, it is important not to jump the gun. So far, all I have shown is that Bill locates the onset of his arthritis within the workplace, and that other features of his account suggest mistrust and scepticism with regard to the interests and intentions of people in positions of power. What we have to do now is to look further to see if this radical populist image of society directly influences his ideas with regard to the genesis of his own illness.
Following the excursions into the subjects of his wife's accident and the incident with the police, we returned to his own illness and disablement, and Bill related more scenes from his working life:

'cause there you had extremes of heat, in the tapes section, we were doing computer tapes. There was a special section, and that was quite hot up there. Your entry and exit was through the fire door, and there was no air intake, no fresh air from the outside because it had to be at a particular temperature. And even the chemist down there realised that they're like ovens. It's totally enclosed, it's double thick glass, and they always had the damn things shut till we opened them. We said: "Get us a vent in here or we're not running". And he got one in — that's the chairman who is now dead — he got us an intake. But it was too late for them lads. They had been in it all the time and they were much older than me, and I think their age was against them. They had minimum resistance.'

Not only, then, was there a sense of revolt amongst individual workers such as Joe, but a collective refusal by a number of workers to continue what they were doing until certain health and safety measures were instigated. It was not clear how long it was from the workers' recognition of detrimental effects to management compliance, but it was certainly too long for some of them. In this way, Bill's particular arthritic symptoms and their origin became absorbed into a public issue, the issue of health and safety at work, and the original question about the causes of his arthritis was transformed into an examination of the power struggle between workers and management.

By situating the cause of his own misfortune in this context and juxtaposing it with the experience of his wife and friends, Bill's narrative reconstruction articulated a nascent political criticism of the way of life in modern society in which the genesis of his own misfortunes and those of others could be understood as the product of malevolent social forces. Bill himself, of course, did not make such extravagant claims on behalf of his own thinking and, with an almost apologetic appreciation of the limitations of biographical evidence, he said:

'I'm just going off the way the other fellows were, that it became too much for them, and they probably had arthritis at one time, of one type or another. Because none of them walked with a proper gait apart from myself at that time.'

Nonetheless, if his narrative reconstruction is read as a sort of historically rooted political criticism his original identification of workplace toxics as the cause of his arthritis can be seen as part of a more complex attempt to define the dynamics of the relationship between illness, the individual and society. This society is seen as the locus of exploitation,
bureaucratic silence and multiple frauds upon the laity, where personal troubles are also public issues requiring political intervention.

Bill's analysis did not stop at the workplace. In a final statement he located the issue of illness in the workplace in the context of societal power:

'All those other lads, all their dependants got was two and a half years pay. Probably any investigation that the company made into it had been hushed up a bit 'cause the man I worked for at that time, Sir John Smith, and he became a Lord and is now deceased, and Lord Green and Lord Black were into the company and therefore had very powerful knowledge, and they shut owt up if they were giving toxics out and killing men you see. 'Cause nothing's happened since . . . nothing's happened since.'

The precise extent of the damage incurred by the workers was never made entirely clear (although it is clear enough). Apparently, the company accepted liability and paid compensation, but Bill argued that the full scale of damage and responsibility was hidden within a strategy of non-decision and silence, ultimately controlled by powerful members of the ruling class who wanted to protect their economic and political interests.

The fact that Bill should have talked of all these things is not necessarily surprising. What is important is that these observations constitute essential reference points in a narrative reconstruction within which the genesis of illness and other misfortunes can be defined and rendered sensible. Within this reconstruction Bill encompassed what had happened to his body, the nature of his social roles, the quality of his immediate milieu, and the structure of power in society. In doing so, he linked his own demise with that of others, transcended the particulars of his own illness, and redefined his personal trouble as a public issue.

Gill: narrative reconstruction as social psychology

In Bill's long and detailed reconstruction, both discrete causes and biographical genesis were located essentially outside himself. Although his account encompassed social relations, it left out any reference to his identity or self; there was no sense of personal responsibility or even of any socio-psychological involvement in the development of his affliction. Social relations, however, are also the place in which a sense of identity is developed and constrained, nurtured and broken. In this regard the genesis of an illness may be seen in terms of the body's relationship to the self and the self's relationship to the world.

Gill was a middle-aged school teacher living in a wealthy and
conservative suburb. She had had RA for approximately five years, and the onset of the disease took place in a twelve-month period which included a number of tragic events. In my interview with her we spent less time discussing the cause of her affliction than had been the case with Bill. Nevertheless, her ideas were interesting and they represent an illuminating form of narrative reconstruction. As with Bill, I simply asked her why she thought she had got arthritis:

'Well, if you live in your own body for a long time, you're a fool if you don't take note of what is happening to it. I think that you can make naive diagnoses which are quite wrong. But I think that at the back of your head, certainly at the back of my head, I have feelings that this is so and that is so, and I'm quite certain that it was stress that precipitated this.'

Now, there is nothing unusual about the identification of 'stress' as an important aetiological factor. Indeed, in my study group stress was one of the most popular factors, particularly amongst women and, as Allan Young has indicated, the 'discourse on stress' is firmly entrenched in modern thinking on illness and disease. However, more often than not the content of 'stress' is left unspecified and, indeed, part of its attractiveness is that it can be used to designate anything from excessive noise to bereavement. Gill, however, felt it necessary to specify exactly what she meant by stress, and having suggested that it precipitated her arthritis she went on:

'Not simply the stress of events that happened but the stress perhaps of suppressing myself while I was a mother and wife; not "women's libby" but there comes a time in your life when you think, you know, "where have I got to? There's nothing left of me".'

Gill did not conceptualize stress in terms of external stressors, exogenous agents which impinge upon the body in some arbitrary fashion, rather she saw her illness as the bodily expression of a suppression of herself. However, while it was not simply a question of external stressors, neither was it a question of internal psychological pathology because she saw the stress of events and the suppression of herself as merely components in the social process of being a wife and a mother. It is within this process that the genesis of bodily breakdown finds its meaning. The causal efficacy of certain events could only be understood within a purposive account of the social process of womanhood in which her personal telos and sense of identity had become lost.

However, as Gill has implied, within this overall social process there were specific events that were deemed to have a causal import and which are needed to explain why arthritis supervened at this precise moment in her life-course:
And then on top of that feeling of... not really discontent, but rather confusion about identity... to have various physical things happen like, you know, my daughter... I'm quite certain that the last straw was my husband's illness. So, I'm sure it was stress induced. I think that while my head kept going my body stopped.'

The various 'physical things' that happened to Gill were a number of life-events that followed in sequence in a twelve-month period. Her daughter went away from home in distressing circumstances (which she asked me not to reproduce), her husband became seriously ill, she suffered a rapid onset of RA (from ambulant to bedridden within 36 hours), her sick husband died, her youngest son was killed in a motorcycle accident, and finally, as a consequence, she lost her longstanding belief in God. Thus, within the social process of womanhood, which was itself stressful, aspects of that womanhood which gave meaning and definition to it — her relationships with her husband and daughter — were damaged. Her arthritis developed in the wake of these events only to be followed by the tragic losses of her husband and her youngest son and the obliteration of the cosmological framework that might have helped her come to terms with these losses: 'I feel very lost now that I've lost God. I do. I feel that terribly.' It was after the death of her son that she lost God, and she was left with: 'A big black hole. Nothing.' The symbolically reconstituted past revealed in her narrative reconstruction is one of almost total loss: the disappearance of her daughter, the loss of her physical competence, the death of her husband, the destruction of her youngest son, and, not surprisingly perhaps, the death of God. Now, one of the crucial criteria required for the ascertainment of a causal relationship is a clear time-order separating independent and dependent factors. In this regard, the loss of her husband, her son, and God can have no effective relationship to the onset of her arthritis, but they nevertheless lie within the same crucial matrix of social relationships within which her arthritis has arisen, and they thus form an essential component of her narrative reconstruction. They represent critical ruptures which have formed her present ideas about the causal role of other factors antedating the onset of her arthritis.

At this point, Gill has located the cause of her arthritis within a web of stressful events and processes: a genesis arising out of particular features of a woman's relationships in the modern world. It is a recognition of the distorting and constraining tendencies in these relationships that leads her to the question: 'Where have I got to? There's nothing left of me,' and to develop her narrative reconstruction around this theme of loss of self and confusion about personal identity. Gill is a good example of what Alasdair MacIntyre has in mind when he suggests:
‘When someone complains — as do some of those who attempt to commit suicide — that his or her life is meaningless, he or she is often and perhaps characteristically complaining that the narrative of their life has become unintelligible to them, that it lacks any point, any movement towards a climax or telos.’

Gill did not commit suicide; her mind did not admit the problems and kept going, but her body indicated the necessity of rebellion by breaking down. Because her sense of ontological security was so firmly located within the context of conventional social relationships, the disturbance in those relationships led to an intimation of pointlessness, the development of illness, and the obliteration of all metaphysical referent.

What we have so far then is Gill’s essentially sociological explanation of why she developed arthritis. But, in the years between onset of the illness and our meeting, Gill had regular contact with the medical profession and its mode of rationality. To forget this is to create an artificial abstraction. The medical model has often been disparaged by sociologists for, on the one hand, reducing the problems of the sick individual to a set of biophysical parameters and, on the other, reifying the concept of disease to a thing-in-itself. In opposition to this, Mike Bury has argued that the medical model is often a useful symbolic resource which can be employed by individuals to mitigate the feelings of guilt and responsibility which often inform their response to illness, and to help them maintain some sense of integrity and autonomy in the context of meaninglessness. Whilst Gill developed a sophisticated sociopsychological model to explain her illness, she also understood that, in terms of the way illness became manifest, a general and popularized version of the medical model had a pleasing common-sense plausibility:

‘I had quite forgotten until you mentioned the word virus . . . I said myself that I thought stress had precipitated this, but I would not preclude the fact that it might have been a kind of virus, because in the early stages I did feel as if I had had “flu” . . . Do you remember when you get like that?’

And, of course, I did remember. In this instance, the medical model provided us with a shared concept and a common understanding. The sociological model of ‘womanhood’, on the other hand, was not something which I could possibly have encompassed within my social experience. But the problem with the influenza analogy is that it merely describes a sensation from which a viral aetiology may be inferred. It does not provide an adequate account of the genesis of her illness because it fails to locate it within a context of the changing relationship between herself and the social world.

Although Gill was not racked by feelings of guilt about her illness
and did not feel personally responsible, she did have a sense of involvement in what had happened:

'It's the old Adam, we've all got to be ill. No... well, I don't know, certainly things like osteoarthrosis, you're bound to get worn out parts, like cars.... Mind you, I sometimes wonder whether arthritis is self-inflicted... not consciously. You know, your own body says, "right, shut-up, sit down, and do nothing". I feel very strongly about myself that this happened to me, that one part of my head said, "if you won't put the brakes on, I will". Because I had had many years of very hard physical work, you know — washing and ironing and cooking and shopping and carting kids around and carrying babies and feeding babies and putting babies to bed and cleaning up their sick. It all sounds again so very self-pitying, but its fact. Bringing up five children is hard work. That, and with the stress on top, I'm sure that I just cut out, I just blew a fuse.'

In this passage from my interview with Gill, the final one relevant to the subject under consideration, the relationship of womanhood, and specifically motherhood, to illness was reaffirmed and described in the bold style of someone confident of their position. But some new elements have been introduced which elaborate that original relationship. Gill brought into play two metaphors, one religious and one mechanical, to suggest the inevitability of illness in society. The image of the Fall from Grace was introduced to account for the ubiquity of illness in human life and then, hesitatingly, wary perhaps of the fatalism in a religiosity she has lost, she rejected this in favour of the idea of an obsolescence built into the body-machine where certain kinds of mechanical degeneration are a necessary consequence of the structure and functioning of the component parts. Whilst both these images fit nicely into the teleological framework of an Aristotelian world-view, they do not explain the particular manifestation of illness in her life at this moment in time. Thus, following this metaphorical addendum, Gill returned to the central motif of her narrative reconstruction. Given the necessity, mechanical or metaphysical, of some kind of illness, the genesis of her arthritis was seen to reside in the social processes of stress and hardship which are the result of the role of women in the modern social structure. The notion of arthritis being self-inflicted implies not simply an individual flaw in a psyche brutalized by contingent events, but more the constraints placed upon the self within a social flow of essential activity.

Much of the work that has considered 'lay beliefs' about the causes of particular diseases or illness in general have drawn a line between those beliefs which refer to the source of illness as outside the individual and those which see it as coming from within the individual. Gill's account indicates the inadequacy of such an analytic bifurcation.
In a crude sense, she located the source of her arthritis outside herself in a variety of events and processes, but the events she cites are precisely those which speak of the complex relationship between her personal telos and her social roles in modern society. What she was attempting to express, it seems to me, was that illness arises out of our relationship to the social world when personal identity and the social processes within which that identity is defined come into conflict. When the social self is forced to continue its everyday work and where personal revolt is impossible, the body may instigate its own rebellion. This is what Gill means when she refers to her arthritis being self-inflicted but not consciously.

In her illuminating account Gill managed to describe the relative autonomy of the body, the self, and the social world while indicating the way in which they interrelate. If her narrative is read as a simple description of cause and effect processes, it could be easily categorized as a belief model invoking social stress/life events plus (possible) virus, but this would be to violate it. As a narrative reconstruction, Gill's account can be read as an attempt to portray the genesis of illness within a socio-psychological interpretation of the relationships between personal identity and social roles in modern society, given the inevitability of some kind of illness and the ever-present possibility of viral attack. The complexity of her account results less from her concern to identify the causes of her arthritis and more from her need to reaffirm telos and to reconstruct a narrative order in the presence of profound disruptions in the biographical processes of daily life.

Betty: the transcendence of causality and narrative reconstruction

I have indicated that the degree of narrative embellishment or complexity in the process of reconstruction is related to the amount of biographical disruption to which the individual's life has been exposed. It could be argued, however, that since the amount of biographical disruption cannot be assessed apart from the actors' accounts of their perceptions the whole argument becomes circular. There is a horrible logic to this, and it is something which I cannot properly refute within the constraints of my present methods. Nonetheless, in partial mitigation of this objection, I would suggest that it is reasonable, if not entirely valid, to infer the amount of disruption from certain brute 'facts'. Bill's own premature retirement followed by his wife's accident would certainly spell disruption for the home economy of most working-class families and, in the same vein, it would be difficult to imagine the tragic chapter of accidents experienced by Gill being
accepted by anyone with equanimity. Their narrative reconstructions were attempts to account for and repair breaks in the social order. I realise that there are all sorts of methodological and epistemological objections to this but, as I write, there is little else I can say in my own defence. Instead, I rest content with presenting the experiences of Betty who, in spite of inability to hold a much-needed job, to wash and dress herself, and, because of chronic pain, to sleep in the same bed as her husband, appeared remarkably composed.

There are some situations in which the central meaning of a life is defined by some transcendent principle — whether or not we accept the validity of the principle or the authenticity of the proclaimed belief in it. Where God is a powerful feature of an individual’s cosmology His existence may be adduced not as a cause of the illness, as some other studies imply, but as good reason why, in matters of illness and other misfortunes, the believer is not granted automatic exemption. Where God is the Cause or the Unmoved Mover, the individual may be liberated from the burdens of narrative reconstruction and causal analysis and left free to indulge their lyrical sensibility.

Betty was in her early sixties, married, and had worked full-time and then part-time in a shop until developing disablement made continuation impossible. She had had arthritis for about seven years. Her life was not a comfortable one, and she had worked, as she put it, ‘out of necessity’, in order to supplement her husband’s low wage, to pay off the mortgage, and to maintain a base equilibrium in the home economy. The loss of her wage rendered the future profoundly insecure. I asked her why she thought she got arthritis:

"The Lord's so near, and, you know, people say "why you?". I mean this man next door, he's German, and of course he doesn't believe in God or anything (sic) and he says to me, "you, my dear, why he chose you?" And I said, "Look, I don't question the Lord, I don't ask (...), He knows why and that's good enough for me." So he says, "He's supposed to look after ..." [and] I said, "He is looking after his own (...) and he does look after me", I said, I could be somewhere where I could be sadly neglected (...), well, I'm not. I'm getting all the best treatment that can be got, and I do thank the Lord that I'm born in this country, I'll tell you that.'

Instead of simply affirming that her arthritis originated in the mysterious workings of God's will, Betty tells a story that locates her attitude to her illness within a framework of justification that has been called forth on other occasions by non-believers. She suggests that her personal misfortune can only be approached within an understanding of the good fortune in other aspects of her life. The goddess Fortuna faces both ways. The secular search for cause and meaning or
what Alasdair MacIntyre calls the ‘narrative quest’ is redundant because the cause, meaning, and purpose of all things is pre-ordained by God:

‘I’ve got the wonderful thing of having the Lord in my life. I’ve got such richness, shall I say, such meaning. I’ve found the meaning of life, that’s the way I look at it. My meaning is that I’ve found the joy in this life, and therefore for me to go through anything, it doesn’t matter really, in one way, because I reckon that they are testing times... You see, He never says that you won’t have these things, He doesn’t promise us that we won’t have them, He doesn’t say that. But He comes with us through these things and helps us to bear them and that’s the most marvellous thing of all.’

So, for Betty, biographical robustness, narrative order, and the personal telos were not actually contingent upon what happened to her in the profane world. In fact the idea of a separate and vulnerable ‘personal’ telos would make little sense in the context of her essential relationship with God’s purpose. MacIntyre argues that teleology and unpredictability coexist in human lives and that the intelligibility of an individual life depends upon the relationship between plans and purposes on the one hand, and constraints and frustrations on the other. The anxiety to which this might give rise did not exist for Betty because the unpredictability of say, pain and illness, are part of an ulterior teleology.

This kind of interpretation of life and its difficulties is hard to appreciate in the context of a secular society with its mechanical notions of cause and effect. In talking of ‘God’s purpose’ as a component in people’s understanding of the genesis of illness, it is important to think carefully about what exactly is entailed in the use of such expressions. When Betty talked about God and personal suffering, she did not imply that God’s will was an efficient or proximate cause in the development of her arthritis, rather He is the cause of everything and, as such, makes narrative quests unnecessary. Nonetheless, from a sociological viewpoint, Betty’s concept of ‘God’ had similarities to Gill’s image of ‘womanhood’ and Bill’s notion of ‘work’ in that it transcended linear frameworks of cause and effect so as to define a symbolic and practical relationship between the individual, personal misfortune, social milieu, and the life-world. However, although both Gill and Bill went beyond a linear explanation of disease by placing their experiences of illness within, respectively, a socio-psychological and political narrative reconstruction of their relationships to the social world, Betty’s ‘God’ implied a principle of meaning that transcends the social world as such. Betty did not have to reconstruct order through narrative because God, existing ‘outside’ both the individual and society,
The genesis of chronic illness: narrative reconstruction

encompasses within his plans what appear to us as biological caprice and senseless biographical disruption. Physical suffering was only important insofar as it signified a feature of her essential relationship to God and so her sense of identity was not unduly threatened by the body's afflictions. The body itself is nothing as was made clear when, elsewhere in the interview, Betty aired her thoughts on donating her body to medical science:

'Your body is dust and that is what it goes to. I mean the spirit goes to the Lord, the part of me that's telling you all that I am and what goes to the Lord.'

Although much that Betty said of her material life would suggest profound disruptions in socio-economic circumstances, there was no sense of disruption because her life was part of God's unfolding purpose. Moreover, 'God's will' does not imply self-blame where the individual is bad and illness is retribution; at least, there is no direct relationship:

'You see, it's got nothing to do with Man's goodness. It's all to do with Christ, all to do with Him being born to save me, to suffer my sins and everything I've ever done. I'm made righteous and sanctified by the wonder of that cross and that to me is marvellous, that to me is the jewel of life (...). You see, there's a beauty about everything and you can sort of go through it in this way, you know, talking to the Lord and entering into it. He knows all about it. So people say, "why you?" Well, why not me? Better me who knows the Lord.'

Because she did not see herself as the author of her own narrative there was nothing for her to reconstruct or explain. For Betty the course and end of her life were defined outside herself and history:

'And I think that, yes, it's helped me to understand, and even to the [point where] it can have a mental depressive [effect] on some people, because if they haven't got the Lord in their lives, of course, it must do. You know, "why am I here? why this, that and the other?" To me there's an end to it, something the Lord has for it, and He knows best what to do. I reckon, you know, that with faith I'll go through with this to an extent and that'll be it, and God will say, "well, that's it".'

The interview with Betty was a particularly difficult one to conduct because my sociological questions appeared insignificant and redundant in the face of the teleological certainty of her beliefs. When interviewing someone with such a profound sense of meaning, it seemed almost meaningless to ask whether the illness had damaged her sense of self-worth or whatever. For Betty, most people live their lives in the immediacy of personal and material interests. Their lives follow a narrative thread defined by everyday events and happenings and routines, and when major problems occur in their social world their identity is
bound to be threatened and it is not surprising that they should become lost and depressed. But for her 'there is an end in it' and all analytic puzzlement and personal doubt evaporate in the glare of God's purpose.

Conclusion

In his study of the Gnau tribe of New Guinea, Gilbert Lewis describes how these people say of some illnesses that they 'just come' and how they say of the sick person that he or she is 'sick nothingly'. In this way, sickness may be defined as having no cause or function, and no intent. He goes on to contrast this situation with that of western societies where illness is seen as the result of natural processes which we can study by the scientific method. However, recognizing perhaps the bluntness of this viewpoint, Lewis adds a crucial caveat:

Individual people in our society may not accept it (the scientific view) as fully adequate to account for illness and seek religious and moral reasons for the illnesses of particular people, or even for illness in general; or individuals may feel an obscure and yet deep emotional dissatisfaction with explanation purely in natural terms, but the general view remains.\(^\text{25}\)

The cases I have presented show a far more eclectic search than this. It is true that Bill's account, and those of some other respondents, have the same quality of systematic observation and inference that characterizes representations of scientific procedure. Many of their belief models, at least in formal terms, bear a striking resemblance to the multifactorial models of susceptibility/vulnerability/trigger employed in sophisticated medical discourse, and a large number of respondents resembled those women in Mildred Blaxter's study of lay beliefs in whom:

Their general models of causal processes, painstakingly derived from their experience as they saw it, were often scientifically wrong in detail, but were not in principle unscientific.\(^\text{26}\)

I have tried to show that there may be more to such 'causal' models than at first meets the eye. Although in my interviews I framed the question in terms of 'what causes arthritis?' I have shown in the cases presented that this question was explicitly translated into more substantive biographical questions. It was not just that they were 'personalizing' the question they were transforming the meaning of it.

In this light, Lewis appears to be conflating two different levels of analysis—disease and illness, fact and value, science and morality.
People may well draw upon some common-sense version of science and the medical model, but when Gill asks: 'Where have I got to? There's nothing left of me', she is asking a question that breaks the bounds of traditional scientific discourse and shifts into a complex social psychology and practical morality. Furthermore, developments in science itself have rendered it increasingly distant from the language and perceptions of everyday life while, at the same time, forming part of the secularization of the western mind which has made overarching cosmologies less available and less plausible. As Comaroff and Maguire put it:

In our society biomedical science and practice may provide satisfactory explanation and resolution for a wide range of afflictions often (but not always) seeming to render more thorough-going metaphysical speculation redundant. But precisely because of its apparent wide applicability in everyday life, particularly in the wake of the decline of overarching cosmological systems, we are especially bereft when we have to face events for which no rational explanation or remedy is forthcoming.²⁷

This was written in relation to childhood leukaemia where the limits of rational explanation are particularly obvious, and, to paraphrase Turgenev, death may be an old jest but it comes new to everyone.

RA is not a terminal illness, and therefore lacks the existential gravity of leukaemia or typhus. Nevertheless, it assaults the taken-for-granted world and requires explanation. Bill and Gill, finding no meaning in the medical view and having no overarching theodicy or cosmology, elaborated reconstructions of their experience in such a way that illness could be given a sensible place within it. These reconstructions bridge the large gap between the clinical reductions and the lost metaphysics. Once you begin to look at causal models as narrative reconstructions of the genesis of illness experience in the historical agent, moral or religious and, indeed, political and sociological factors become central to elucidating illness experience and rendering intelligible the biographical disruption to which it has given rise.

The body is not only an object amongst other objects in the world, it is also that through which our consciousness reaches out towards and acts upon the world. This is the dual nature of the body referred to by Sartre,²⁸ and within this duality chronic illness is a rupture in our relationship with that world. However, consciousness is itself biographically framed, so that consciousness of the body and the interpretations of its states and responses will lead us to call upon images of the private and public lives we lead. Narrative reconstruction is an attempt to reconstitute and repair ruptures between body, self, and world by linking-up and interpreting different aspects of biography in order to realign present and past and self with society. In this context,
the identification of 'causes' creates important reference points in the interface between self and society. My respondents were, perhaps, not so different from the baladi women in Evelyn Early's study for whom 'The dialectic between the diagnosis and the life situation is crystallized in the illness narrative, where somatic progression and social developments are both documented.'

For Bill, illness developed out of a working life but where the significance of work could only be understood by elaborating an image of the kind of society in which that work was situated. His attachment to workplace toxicity as a causal factor could be understood only in terms of his image of society as a place of exploitative relationships and power inequality. In Gill's case, illness was seen to arise out of a way of life in which personal identity had been defined and constrained by essential features of womanhood. The genesis of her illness was located not solely in the person nor outside in the external world, but within the relationships constitutive of social being. For Betty, the genesis of illness was seen to reside in the transcendental realm of God's purpose. This is not to say that God was seen as an efficient cause of her illness, but rather that her illness was necessitated and justified by reference to her intrinsic relationship to a suffering God.

These accounts all speak of illness experience at one moment in time. Their pasts were the pasts of those presents in which they were interviewed, and I have no evidence for or against the proposition that their image of the past would have been substantially different in other presents. To test that would require an altogether more sophisticated piece of research. Within the constraints, what I have attempted to demonstrate is that causality needs to be understood in terms of narrative reconstruction and that both causal analysis and narrative reconstruction may be rendered redundant in the presence of an embracing theodicy. For medical sociologists such an approach suggests caution in attributing particular belief models to individuals out of relation to other aspects of their narrative, and for doctors it could alert them to reasons for the apparent resistance of some patients to clinical explanations.

**Acknowledgment**

A shorter version of this paper was presented at the BSA Medical Sociology Conference, University of Durham, September 1982. This
elaboration owes a lot to the advice and criticism of Peter Halfpenny, and to the valuable comments of Philip Wood and the anonymous referees of this journal.

Notes

4. The term 'genesis' is used by Claudine Herzlich in her monograph: Health and Illness: A Socio-Psychological Approach, London: Academic Press, 1979. Although I employ a somewhat different definition, I have been much influenced by both the style and substance of that excellent book.
14. Probably the best version of Hume’s ideas on causality and related issues may be found in: David Hume, A Treatise of Human Nature, Oxford University Press, 1978. This includes a helpful analytic index by L. A. Selby-Bigge.


22. For example, R. Elder, op. cit.; R. Pill and N. Stott; op. cit.


24. A. MacIntyre, op. cit.


This document is a scanned copy of a printed document. No warranty is given about the accuracy of the copy. Users should refer to the original published version of the material.