

## **Illness narratives: fact or fiction?**

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**Abstract** There is currently considerable renewed interest in narrative analysis in the humanities, social sciences and medicine. Illness narratives, particularly those of patients or lay people, are a particular focus in health related settings. This paper discusses the background to this interest, especially its roots in critiques of medical dominance and distinctions between disease and illness, drawn by sociologists and anthropologists in the 1970s. The current emphasis on patient or personal narratives can also be seen to stem from changes in morbidity patterns, the expansion of information about disease and illness, and in public debates about the effectiveness of medicine. The paper then goes on to outline a framework for analysing illness narratives. This involves exploring three types of narrative form: 'contingent narratives' which address beliefs about the origins of disease, the proximate causes of an illness episode, and the immediate effects of illness on everyday life; 'moral narratives' that provide accounts of (and help to constitute) changes between the person, the illness and social identity, and which help to (re) establish the moral status of the individual or help maintain social distance; and 'core narratives' that reveal connections between the lay person's experiences and deeper cultural levels of meaning attached to suffering and illness. Here, distinctions are drawn between such sub forms as heroic, tragic, ironic and comic, and regressive/progressive narratives. Finally, the paper discusses some of the methodological issues raised by narrative analysis. Given the complex character of illness narratives, their social and psychological functions, together with the motivational issues to which they relate, it is suggested that they constitute a major challenge for sociological analysis. From this viewpoint current claims about narrative analysis in medicine need to be treated with caution.

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## Introduction

The telling of stories, whether about oneself or others, is universal. The development of language in human life, in both evolutionary and individual terms, leads to the elaborate use of metaphors and other figures of speech, and thus narrative form. All human cultures (or cultural segments) rely on such symbolic repertoires in order to achieve a minimum of social integration. In such contexts narratives convey and constitute an 'infinite reservoir of meanings and comprehension', though these are necessarily constrained by linguistic rules and social conventions (Gellner 1992: 124). Not only do language and narrative help sustain and create the fabric of everyday life, they feature prominently in the repair and restoring of meanings when they are threatened. Under conditions of adversity, individuals often feel a pressing need to re-examine and re-fashion their personal narratives in an attempt to maintain a sense of identity.

Thus, universal, cultural and individual levels of human existence are tied together with narrative threads. As Johnson has argued, 'Not only are we born into complex communal narratives, we also experience, understand and order our lives as stories that we are living out. Whatever human rationality consists in, it is certainly tied up with narrative structure and the quest for narrative unity' (Johnson 1987: 171–172). As Charles Taylor puts it, 'we understand ourselves inescapably in narrative' (1989: 51).

In recent times, the study of narratives has received considerable attention, in both the social and human sciences (especially in sociology and anthropology connected with medical matters) and in the field of literary criticism. Books such as Ricoeur's *Time and Narrative* (1984) have acted as wide-ranging philosophical sources for both. Though Ricoeur is essentially concerned with textual narratives his watchwords may be applied to 'story telling' in other contexts: 'The world unfolded by every narrative work is always a temporal world' (Ricoeur 1984: 3). This paper explores the importance (and, to some extent, the limitations) of studying narratives in circumstances where the 'unfolding' of illness, particularly chronic illness comes to dominate people's experience of everyday life. Here, time is important in a mundane as well as an existential sense, for, as the paper will argue, such illness constitutes a major instance of 'biographical disruption' (Bury 1982, 1991) in which the relations between body, mind and everyday life are threatened.

The study of 'illness narratives' constitutes a dual process, in examining these dynamics. On the one hand the exploration of chronic illness narratives may throw light on the nature of disrupted experience, its meanings and actions taken to deal with it. On the other hand, the study of such narratives has the potential to reveal a wider set of important issues to do with the links between identity, experience and 'late modern' cultures. Whilst this paper largely concentrates on chronic illness narratives from the

viewpoint of lay thought and 'patienthood', connections between personal and bio-medical narratives of chronic illness under conditions of modernity will also be made at various points.

The paper explores these themes in three stages. First, the rise in importance of illness narratives in modern societies is sketched in as a necessary historical background and context for the discussion that follows. Here the limits (as well as socially meaningful character) of bio-medical narratives of illness will become readily apparent. The current emphasis on 'personal narratives' and 'lay beliefs' or 'lay knowledge' in social research is thus immediately seen as part of a general feature of late modern cultures, involving the loosening of the authority of the 'grand narratives' of science and medicine in the ordering of everyday experience, and especially in responses to illness (Hyden 1997: 49). As will be seen, this is especially relevant in an era dominated by chronic illness.

Second, the paper offers a framework for studying chronic illness narratives. This involves the exploration of three types or levels of narrative formation in the face of illness: 'contingent narratives' which involve explanations of illness onset that deal with its 'proximate' causes and the practical and disabling effects of symptoms; 'moral narratives' that provide accounts of the changing relationship between the person, the illness and social identity; and 'core narratives' that reveal the connections between the lay person's experience and deeper cultural levels of meaning attached to illness and suffering. In the third and final part of the paper some tentative reflections on the methodological issues and limitations of narrative analysis in chronic illness are proffered.

### **The rise of chronic illness and the crisis of bio-medical narratives**

Writings in the history of medicine make clear the importance of illness narratives, particularly with the rise of the doctor-patient relationship in early modern times. Before the advent of the 'bio-medical model' of illness in the understanding of disease, during the mid and late 19th century, the ability of the doctor fully to take a history from the patient was paramount. This involved information about the patient's lifestyle, his (or her) moral stance and the wider environment in which the patient lived. Eschewing all but the most rudimentary physical examination of the patient, the aristocratic doctor (or, rather, the 'elite' doctor treating patients from the upper classes) in the 17th and 18th century was expected to attend to patients' narratives and develop treatment regimens accordingly, usually through procedures that restored the body's equilibrium (Lawrence 1994: 12). The fact that such procedures, included bleeding, purging and cupping, were unlikely to bring about any efficacious result (at least from a modern perspective, though they may have 'worked' in other ways) only reinforced the need for the doctor to concentrate on attending to the patient's story. As Porter has recently put it:

In the absence of decisive anatomical or physiological expertise, and without a powerful arsenal of cures and surgical skills, the ability to diagnose and make prognoses was highly valued, and an intimate physician-patient relationship was fostered (1997: 9–10).

With the rise of scientific bio-medicine, linked with the development of the modern hospital and the laboratory, the importance of the patient's experience, and thus his or her narrative can be seen to have diminished (Jewson 1976). As the study and treatment of disease became separated from the individual, and located within body systems only understood by experts, the need to attend to the patient was reduced to eliciting information about the objective signs and symptoms of the disease. The task of the doctor, increasingly in the 19th century and into the 20th, was to translate these pieces of information into a definitive diagnosis that linked the disease to specific biological causes and outcomes, rather than to the patient's circumstances or lifestyle, let alone to their beliefs or values. Whereas 18th century medicine had been concerned with the 'natural', and with disease as a deviation from the individual patient's 'natural state', the 19th century became preoccupied with the 'normal', and with disease as a deviation from statistical norms, independent of particular experiences or circumstances (Lawrence 1994: 45). These new scientific approaches to disease and illness were also associated with social and sometimes political reform, and an attack on what was regarded as 'professional elitism' as well as 'conservative science' (Lawrence 1994: 36).

Many of the sociological accounts of the progressive separation of the medical model of disease from the lay experience of illness, and the growing power of the medical profession in the 20th century to define what is and what is not illness, have emphasised, however, the negative effects of the putative gulf between lay and professional worlds (*e.g.* Eisenberg 1977, Freidson 1970). Indeed Lawrence himself notes that in Europe and North America by 1920, the idea of disease as individual pathology had become the dominant paradigm, and was inextricably linked to the development of a 'bounded' medical profession, that exerted almost complete jurisdiction over illness and its treatment (1994: 77). The acceleration of this process with the enormous expansion of medical and surgical treatments and procedures from the 1940s onwards only seemed to reinforce the tendency to render the patient passive; subjective accounts of the patient were virtually irrelevant. As illness was increasingly sequestered from everyday life by professional medicine, so the patient's suffering was effectively silenced, especially under the impact of 'the technology-assisted physical and chemical probes of our century' (Risse 1999: 9). This process may also have been seen as part of a more general separation and 'lifting out' of key aspects of everyday life into the professional sphere under conditions of modernity (Featherstone 1992, Giddens 1991).

However, though many analyses have emphasised the overshadowing of the patient's view by bio-medicine, various factors have acted to bring lay

narratives back into focus in recent years. Two processes are of particular note. First, and most obvious, is the relative decline in the importance of the infections on which the bio-medical model was founded, and the growing impact of degenerative and chronic illnesses (Strauss 1975; Bury 1991, 1997). As everyday experience and medical practice has increasingly had to grapple with the effects of an ageing population, and the related predominance of chronic physical and psychosomatic illness, so management and care have superseded treatment and cure (Gerhardt 1989: 139).

Here, in chronic illness, the contingencies of everyday life reassert themselves, and the subjective patient view becomes audible once more (Bury 1998: 13). In order for the everyday management of chronic illnesses to proceed, their heterogeneous character (in terms of the multifarious ways disabling symptoms interact with the 'life worlds' of the home and the work place) become the focus of both lay and professional concerns. Assessment of quality of life, the impact of illness on carers and a renegotiation of the role of professional care all appear on the professional agenda. The consequent loosening of the bio-medical grip (with its 'grand narrative' connotations), provides the space for lay narratives to flourish.

Second, as high tech bio-medical care becomes ever more expensive to provide, and open to increasing questioning and evaluation, the hospital sector in health care systems gives way to a renewed emphasis on primary care. Debates within primary care and general practice about the value of 'holistic medicine' and of listening to the patient, which began in Britain in the 1950s by individuals such as Balint (1955) and pursued in recent years by others such as Pietroni (1988) (see Watts 1992 for a review) also provide an opportunity for patient narratives to be given space and attention. Most recently, illness narratives, and the links with 'history taking' in medicine, have themselves been associated with moves to improve care (and further develop an ideological underpinning for general practice) that do not rely entirely on what may be regarded as a narrow view of scientific medicine or its 'evidence based' practice and evaluation (Jones Elwyn 1997, Greenhalgh and Hurwitz 1999).

As Kleinman (1988) has pointed out, in the face of chronic illness especially, the physician may best act as a witness to suffering and as a sources of practical advice and guidance, based on the 'sensitive solicitation of the patient's and the family's stories of the illness' (1988: 10). Though renewed attention to patients' narratives implied in this view holds out the possibility of physicians (and other practitioners) redefining their roles away from a preoccupation with a reductionist bio-medical model of illness, the ambiguities of a professional expansion into 'patient based' and 'holistic' health care has not been lost on some sociological writers (Armstrong 1986). The contradictions of current medical attention to patient narratives will be returned to later in this paper.

Two other sources of change in medical practice and the experience of illness need to be noted, before the discussion proceeds. The first of these is

a recent and powerful 'democratic' impulse, leading to a reduction in hierarchical relationships in late modern cultures, including those in the medical sphere. As Porter, again, has pointed out, recent developments in health care, including debates about the effectiveness of the medical response to diseases such as AIDS (and we might add, in the British context, at least, a series of crises in the fields of mental health and surgery) have 'opened a chink into which users and lay people could insert themselves as new carriers of credit' (Porter 1997: 708). Health care, as a result has become 'more democratic, accessible and user friendly. Thus the 20th century closes with the ownership of the body and the right to speak on sickness profoundly contested' (1997: 708). Patients' illness narratives, once almost silenced by a paternalistic if not overtly authoritarian medicine, suddenly find a new voice.

In addition, the enormous expansion of information about illness, especially chronic illness, available to patients, via media coverage, the internet and alternative forms of health care is transforming the medical landscape. Where once the bio-medical paradigm held sway (and where doctors jealously guarded its secrets), now lay people have access to an increasing range of information and ideas about the origins, course and outcomes of illness and its treatment. This, too, fuels the reduction of medical authority as the fountain of all official knowledge about illness, and expands the range of culturally available narratives that can be articulated. Though these, admittedly, are often drawn from alternative professionally-crafted knowledge, for example, via self-help groups focusing on specific chronic disorders, or 'mediated ideas' taken from multifarious public discourses, their scope provides lay people with a much greater opportunity to fashion personal narratives that connect the private sphere with public forms of knowledge. As Giddens has noted, the weakening of sources of an 'over-arching authority' such as that of medicine means that lay people may 're-skill', developing responses that offset earlier 'sequestering' tendencies (Giddens 1991: 140). Under all of these conditions it is not surprising to see illness narratives gaining greater attention once again.

### **Form and content in chronic illness narratives**

As stated in the introduction to this paper, a framework for analysing illness narratives suggests three broad forms that need to be considered: contingent narratives; moral narratives; and core narratives.

#### *Contingent narratives*

Under this heading, the analysis of illness narratives is concerned with those aspects of the patient's 'story' or 'account' that deal with beliefs and knowledge about factors that influence the onset of disorder, its emerging symptoms, and its immediate or 'proximate' effects on the body, self and others. Although writers such as Good warn against the 'transformation' of

narratives and stories into 'beliefs' and 'explanations' of illness (with their 'analytic assumptions associated with progressive science' Good 1994: 163) lay people's responses to illness frequently draw upon and, in turn, constitute culturally available concepts of disease and illness that powerfully influence the fashioning of narratives.

Bearing in mind the introductory remarks in the previous section, concepts of disease and illness in modern society may be divided, at the risk of gross over-simplification, into two broad types which can deal with their 'contingent' character. On the one hand there is a *categorical* view of illness based on the separation of the normal and the pathological, where objective signs and symptoms are differentiated from known or putative normal states, and where the onset and course of the disease is relatively clear cut. On the other hand, there is a *spectral* view in which the difference between disease and illness is a matter of degree and a function of social process; the occurrence of illness, especially chronic illness, is here essentially emergent in character, depending strongly on social circumstance and societal reaction. Though the first, (categorical) view may be characteristic of a bio-medical approach, and the second (spectral) of a more social or personal perspective, a great deal of overlap can be observed in their usage, especially in personal narratives. Moreover, chronicity tends, almost inevitably, to bring with it a range of 'relational' issues, as the illness interacts with everyday contingencies.

For example, in work on chronic arthritis (Bury 1982, 1988) it was found that respondents' stories moved back and forth between lay concerns and perceptions, and a growing familiarity with medically-based ideas. Indeed, at times it was difficult to identify where 'lay' and 'expert' modes of thought began and ended. This was particularly evident when the question of causation was discussed. Patients would frequently discuss the onset of the condition with respect to the possible effects of events occurring at the time of the onset, yet leave themselves open to more strictly medical explanations as well. One respondent recalled a series of difficulties with her seven-year-old son prior to the onset of the illness, culminating in the son collapsing at the school, where, coincidentally, she worked as a dinner lady. She recalled:

I went to the cloakroom and found him in a terrible state. Nobody seemed to be doing anything so I carried him home myself. I'm not very big and it nearly killed me. In the end the ambulance came and rushed him off to hospital. Appendicitis. He had an emergency operation and was on a drip for two days. He recovered but it was a shock. I often put my trouble down to that time. I'm not saying it caused it only that's when things started happening (Bury 1982: 174).

The story of this woman's illness contained a number of elements which touched not only on the question of onset and possible causation – an approach which, as indicated in the above quotation, has the hint of a 'life

event' approach to illness occurrence – but also on her social situation into which her illness brought yet another element of hardship. Throughout the account of her own illness, and that of others such as her son's, she drew on ideas and forms of 'lay knowledge' that were often difficult to disentangle in terms of separate spheres of 'lay beliefs' and 'medical expertise'. Both were called upon to construct a meaningful account of the unfolding events, what Hyden refers to as 'illness as narrative', integrating 'the symptoms and consequences of the illness into a new whole' (Hyden 1997: 54).

A more detailed analysis of the onset of arthritis, from a long interview with another respondent from the same study, illustrated how contact with medical personnel, and members of a social network, including work mates, could provide complex settings in which the contingencies of illness onset might occur. The development of symptoms, in this case, could not be pinpointed to a particular event, but emerged over several months. Visits to the general practitioner began to suggest that her 'aches and pains' were more than normal wear and tear, and on one occasion the doctor mentioned that the condition might be 'rheumatoid' arthritis, prescribing aspirin for her symptoms. She stated:

By that time I was beginning to think it was a bit more than just a bit of weakness, because I have a friend in London, she's had arthritis since she was about 30. She's had operations on her feet and it did set me thinking a bit, when I started to feel a bit better with the aspirin I thought Oh well its going (Bury 1988: 97).

Throughout this period however, the doctor's reference to 'rheumatoid' played on her mind, contrasting as it did with more general references to a less threatening 'rheumatism'. Then, one day, she became ill at work. To quote her once more:

It seemed to come and go a little bit until March, and one day I went out at my lunch hour and I did some shopping and I felt really quite ill. One of the girls said, when I got back, was I alright, and I said, well I don't feel too good, because every bone hurt, I don't think there was a bone that didn't hurt. But I just thought it was, maybe, flu coming on or something, but with every bone hurting (1988: 97).

This patient's story continued to unfold. Her earlier optimism now had to be revisited, and her fears of a more serious disorder took on renewed significance. Within weeks of her 'flu like' illness, her GP had sent her for blood tests which confirmed that she probably did have rheumatoid arthritis. Particular difficulties arose at home, due partly to the fact that her husband was already suffering from heart disease and this made it difficult for her to disclose her own difficulties (Bury 1988: 98–100). In fact, during the interviews with this particular woman, family members gave various

accounts of how they had perceived the changes taking place, sometimes in accord and sometimes at variance with the woman's own account.

Throughout these chronic illness narratives it was found that the 'biographical disruption' occasioned by the occurrence of illness, led to a re-examination of personal, familial and work-related issues that were associated with the onset and unfolding of the condition. But it also led to a growing familiarity with current medical thought, for example on whether the arthritis might be confirmed by blood tests, treated with aspirin and other drugs, or be related to stress or inheritance. Thus, both categorical and relational aspects of disease and illness could be found interwoven into these patients' narratives. Here 'narratives about illness', drawing on different types of expert knowledge, came into play (Hyden 1997: 54) feeding into the 'illness narratives' being constructed by the patient.

It should be noted in passing that work outside the patient context, on the narrative form of lay beliefs about the contingencies surrounding the occurrence of illness, also reveals its dual character. Respondents in Davison's South Wales study of heart disease, as both a life-threatening and chronic disorder (Davison *et al.* 1991, 1992) has shown how lay accounts draw on ideas from bio-medicine and health promotion about the connections between risk behaviours and disease onset (smoking, diet and alcohol, for example) while at the same time fashioning this knowledge in the context of observations made concerning the environment in everyday settings. Whilst heart disease is accepted as a product of unhealthy lifestyle in some people, it is recognised that this is not always the case.

Stories of individuals within the family or community who live high-risk lives and are clearly 'candidates' for the disease, but who do not succumb, abound, and provide lay correctives to mechanistic views of risk. Indeed, somewhat ironically, this study suggests that the 'contingent narratives' in lay accounts of disease causation may expose serious flaws in professional modes of health-promoting communication on the topic, producing, instead, 'lay' observations of disease occurrence that parallel epidemiological accounts. Davison *et al.* comment that: 'In our observation, popular belief and knowledge concerning the relationship of health to heredity, social conditions and the environment may be more in step with scientific epidemiology than the lifestyle-centred orientation of the health promotion world' (1992: 683).

Lay accounts of the onset of illness and the nature of disease causation and occurrence, quickly spill over, at least among sufferers, into accounts of what is done in the face of illness. Here, chronic illness narratives, in particular, are concerned with the immediate reactions of family and friends to growing difficulties and the steps that are taken to mitigate the effects of symptoms, including the nature of treatments that may be offered by doctors. Here the meaning of illness concerns the practical as well as emotional consequences of managing symptoms in everyday life.

Various reports in the research literature testify to the importance of the practical management of illness in patients' accounts. In eliciting patients'

stories it is important to note the centrality of these everyday and mundane dimensions of experience, before engaging in more detailed analysis of the 'deeper' narrative forms that may be employed. Aspects of normalisation, coping, and strategic management of chronic illness figure prominently in patients' 'contingent narratives' (what Riessman calls 'habitual narratives', about 'what happened in general' (Riessman 1990: 1196)).

Normalisation as a concept means two kinds of process in patients' experience of chronicity. On the one hand patients may well try to 'normalise' in the sense of keeping their pre-illness lifestyle and identity intact. This may involve the maintenance of as many activities as possible, and the disguising or minimisation of symptoms in behaviour and in accounting processes. Research on diabetes (Kelleher 1988) and colitis (Kelly 1992) for example, has shown varieties of normalisation along these lines. Kelleher argues that minimising symptoms 'allows feelings of being different from others to be pushed backstage' (1988: 41). But normalisation may also mean the incorporation of illness into the patient's changed lifestyle. 'Normal life' is redesignated as containing the illness, and being open about it. Under these circumstances, the stories people tell of themselves are likely to disclose illness, rather than disguise it, signalling changes in identity rather than preserving earlier appearances.

'Coping' as a term is used widely in the research literature on chronic illness. Elsewhere I have discussed the strengths and weaknesses of the concept for a sociology of chronic illness (Bury 1991). But the importance of coping in the context of illness narratives lies in the link it makes between the mundane and the moral components of story telling. As Kelly has noted, 'people develop a sense of self, and attempt to construct a public identity for themselves on the basis of the way they *talk* about coping' (Kelly 1994: 6 emphasis in the original). Such talk may deal with the practical management of the illness, how symptoms are 'put up' with at the cognitive level, or with interpersonal matters such as disclosure and revelation (Kelly 1994: 5) and the responses of family and friends. For example in an extended passage from an interview with a young patient suffering the onset of the distressing symptoms of colitis, many of these elements were clearly in evidence, and the following extract throws them into relief:

I went home from University. This was still April. Went home, went to bed. My Mother called the doctor... He wouldn't say what it was. My Mother of course by this time was very worried, and also I wasn't eating. I was dashing to the loo. Y'know folk would come and see me to try to cheer me up, y'know what students are like. 'We'll go and cheer Donna up.' That was the last thing I wanted. I just wanted to sleep... [Eventually] the surgeon came to the house and said 'I think we should have you in'... We'll *even* get the blue flashing light for you when we take you in'... that was meant to be the highlight of my day, getting me this blue flashing light (Kelly 1994: 5).

But Kelly makes it clear in his analysis that talk of this kind is itself a means of coping in dealing with such contingencies; not so much in *what* is talked about, but in *how* the different components of living with illness are confided or presented to others: 'Speech practices are therefore not just a representation of reality. They integrate the human actors into their social world. The speech allows for a means for interpreting, and acting in, the world; it is one of the principal ways in which the self is presented to the outside world' (Kelly 1994: 13). Put in other terms, narrative is often *performative* in character, as 'narrative makes actions intelligible to the self and others, by showing the part they play within an intentional project' (Skultans 2000: 9, see also Williams 2000: 137).

If 'coping' refers to aspects of how people maintain some sense of worth in the face of intrusive symptoms (Bury 1991), the term 'strategy' has been employed in studies of illness in order to distinguish the mobilisation of resources in the wider social environment (including those from health and welfare agencies) from the more psychosocial issues of normalisation and coping (Bury 1997: 131–2). Here, patients' accounts touch on such matters as the strategic management of time and the pacing of activities in the home, the range of support that might or might not be available from the wider social network, the impact of illness on work and income, and efforts to overcome social isolation.

For example, in a study of disabling illness in the workplace, Pinder (1995) has outlined the many contingencies that affect the impact of chronic illness on paid employment. In a detailed examination of narratives provided by women suffering, again, from arthritis, Pinder shows how pain and disability interact with a variety of factors in the workplace. In the case of 'Sally', the importance of being well educated, and having secured a good job *prior* to the onset of her condition, meant that she was managing its impact at work in a relatively favourable context, unlike others in Pinder's study. This case also showed that factors such as the attitude of a supervisor to illness, the 'pacing' of everyday tasks, and the careful protection of weekend rest in order to 'recharge your batteries... to sort of get you ready for Monday' allowed Sally to maintain her job through the illness's exacerbations and remissions (Pinder 1995: 619). Sally stated:

I really try to make sure that I go to bed at a good time. If I get to bed late it's fatal. I'm tired, and I can't work when I'm tired... It's not the sort of job you can do when you feel tired, because you do have to think and concentrate. If it was something mindless, it wouldn't matter so much, if it was just copy typing or something (Pinder 1995: 619).

Pinder also makes clear, however, that her respondents were not only concerned with strategies to deal with the constraints of symptoms in the context of working life, but also with the need to present themselves as 'morally competent actors' (1995: 624). The link between chronic illness and

identity was especially important in light of changes in the body that might clash with culturally approved appearances, and in some cases be difficult to handle because of a *lack* of visible signs. Here it is the person's self image, and identity as a 'culturally competent' person, that comes to the fore, and this more moral dimension of experience and narration now needs to be considered more fully.

### *Moral narratives*

If contingent narratives describe events, their proximate causes and their unfolding effects in relation to the performative in everyday life, moral narratives introduce an evaluative dimension into the links between the personal and the social. Here, valuations enter the picture, as sufferers seek to account for and perhaps justify themselves in the altered relations of body, self and society brought about by illness. If narratives represent an 'ordering of experience' in the face of disruptive experiences they also give expression to (sometimes) concealed 'dynamic relations' between people and their social contexts (Good 1994: 161).

In Williams' paper on *Narrative Reconstruction*, for example, the re-ordering of experience as the result of illness (in this case, once more, of rheumatoid arthritis) involves the consideration of patients' beliefs about the aetiology of the condition, and its place in their lives. But the lay narratives Williams describes bring together moral considerations which connect family background, coincidences of symptoms and biographical events, and the particular social contexts in which some of them occurred. One man's account focused particularly on events surrounding exposure to toxic substances in the workplace and the onset of his illness (Williams 1984: 183). Through his narrative this respondent could present himself as an active and politically aware individual, as well as a victim of circumstance. 'Bill' stated:

I didn't associate it with anything to do with the work 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... they all complained of the same thing, you know, their hands started to puff up. It seems very odd (Williams 1984: 181)

More importantly, perhaps, in the current context, is the example of 'Gill' in Williams' account. For Gill, the onset and development of illness interacted powerfully with other events in her life, including her daughter leaving home, the death of her husband, and then the death of her son in a motorcycle accident. As time went on, the meaning of illness in this woman's life went beyond the impact of events to notions of guilt and fatalism. Williams describes how Gill's story involved a loss of religious faith and by the same

token a sense that illness might represent a 'loss of grace'. When the moral opprobrium implied by this was too much to bear Gill moved back and forth between various views of the body, including stress and parts 'wearing out' (Williams 1984: 191). She stated:

It's the old Adam, we've all got to be ill. No... well, I don't know, certainly things like osteoarthritis, 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 many years of 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... That with the stress on top, I'm sure that I just cut out, I just blew a fuse (1984: 191).

As can clearly be seen here narrative forms suggesting culpability can be combined with those that exonerate the individual from blame, and help to maintain self worth. As Alan Young (1981) has pointed out, consistency in accounting for illness may not always be an overriding concern in lay views or in social interaction. Riessman (1990) has also underlined the tensions that can be set up in personal narratives, as a moral stance is developed in relation to the many conflicting events occurring in people's lives.

In a later paper by Williams (1993), the theme of morality in chronic illness is developed by locating patients' stories within a cultural framework that increasingly portrays health as a virtuous state. Although 'illness may not itself be regarded as a sin' (1993: 92), current health promotion activities reinforce the view that much illness results from 'inappropriate' individual behaviours. In examining the particular narrative of one patient's illness, that of 'Mrs Fields', Williams describes how 'coping strategies' designed to maximise normal activities in the home, 'revealed a vulnerability and a sense of urgency' which amounted to the 'pursuit of virtue' (1993: 96).

Briefly, three dimensions of 'virtue' in this narrative articulated the connections between self and society. In the first place, Mrs Field, a widow, was concerned to avoid being regarded as a burden, especially to her two sons, who acted as a potential resource for her. The idea and fear of being seen as a burden will be familiar to all those who have studied chronic illness, especially as it interacts with old age, especially very old age (*e.g.* Bury and Holme 1991: 122). Part of the moral dimension of dependency is that it threatens a sense of reciprocity, raising anxieties that the limits of tolerance of valued others may all too soon be reached.

Second, Mrs Field's account of her illness linked her need to be seen as independent with a sense of orderliness and cleanliness in the home. The disabling consequences of her illness threatened to undermine her ability to

present herself and her home as respectable. Fears of being seen as having 'let herself go' or not 'being clean', for example by a visiting district nurse, could be reconciled by insisting that people must 'take me as I am' (1993: 99). Two extracts in Mrs Field's own words illustrate the point:

The other week, the district nurse came running in saying, 'Do you mind if I use your toilet?' Now the first thought in my mind was 'She's a nurse, they're particular, she wouldn't ask to go to my toilet if I was dirty'. You know, you think you've achieved something. I know it may sound simple to you, but it's not. That was something important. She can't think I'm careless, and she's not frightened of touching anything in the house.

I'm not so posh... but I'm comfortable. If anyone comes along and they don't like it... what can I do about it? I'm fortunate to keep it as straight as it is. If somebody's coming they take me as I am because doing too much I could cause myself a flare-up? Why should I do it to cover something up? They must come in and find me as I am day to day, which is right (Williams 1993: 98–99).

Finally, Mrs Field's moral universe extended to the world outside the home, expressed in her concerns and worry about falling into debt. Williams states that 'In the context of Mrs Field's account, being in debt, like being dirty or untidy, could be taken to mean that she was careless, or that she was letting herself go' (1993: 101). Effective control over money and the prompt payment of bills helped to reinforce a sense of virtuous living that reduced a sense of loss brought about by illness.

It should be noted, perhaps, that fears of the 'dirty' side of illness are, of course, a feature of many forms of chronic illness, especially those with symptoms that breach the boundaries of the body. In Pinder's study of arthritis already cited, she notes the impact of bodies that are 'flawed or conspicuously ill' on a sense of social order (Pinder 1995: 624, see also Good 1994: 98–99 on the links between the body and the rituals of restorative healing).

The moral qualities of illness narratives, however, are not confined to the maintenance of 'normal appearances' and the virtuous 'presentation of self', important though these are to many people with chronic disorders (Nijhof 1995 for example, discusses narratives concerned with 'shame' brought about by changes in appearance and behaviour due to Parkinson's disease). In the 1990s a more 'self development' dimension to illness narratives could also be detected, especially in the American literature. Here, patients' stories speak to illness as a form of disruption that can be turned into self discovery and renewal. The idea of people's *active* engagement with their illness, of effecting a 'come back' approach to the disruption involved, to use Corbin and Strauss' (1991) phrase, is developed to counteract a static and wholly negative view of illness and its effects, as well as to suggest a more evaluative view of medical care by patients.

The work of Frank, in using both his own biographical experience (Frank 1991, 1995) and the autobiographical narratives of others (Frank 1997) provides an eloquent espousal of these more positive moral dimensions of illness narratives in what he dubs the 'remission society' (Frank 1995) where large numbers of people live with chronic disorders, or in states of recovery short of cure. In such contexts, Frank argues, people strive to be 'successfully ill' (Frank 1997: 117) and illness and suffering present people with a 'moral opening for witness and change' (1997: 141). Through illness, and in sometimes difficult encounters with health care professionals (many of whom are reported by Frank as marginalising the personal and existential dimensions of illness), people are able to identify more clearly their own personal values and sense of self hood. Under conditions of adversity people may understand illness 'as an active responsibility first to understand the self, and then to place the self within an extensive ecology of relationships' (Frank 1997: 142). The latter may refer to family relationships, or to those in the wider society. Out of the badness of illness comes some good, as people attempt to rescue valued life, against the onslaught of symptoms and their effects on self and others. As Charmaz has put it: 'chronic illness often crystallizes vital lessons about living' (Charmaz 1991: vii).

Whilst this form of 'postmodern morality' of renewal and change presented by illness resonates with much that is said and written about self identity in contemporary societies, such narratives are, perhaps, more contradictory than Frank and others allow. The emphasis on 'suffering' and 'witness' in such accounts (or in the 'accounts of the accounts') carry a strong echo of religious thought as well as secular morality. Religious (not to say Christian) connotations of redemption through suffering in such writings have not gone unnoticed (Williams 1998: 241). The individual in pain and distress is portrayed at times in romantic if not sentimental terms, and the actual relationships in which the individual is embedded may be lost in an overemphasis on positive 'personal narratives' that are uncritically reproduced by the sociological author.

In this form of narrative analysis another important issue may also be ignored, namely the function that moral narratives have in establishing *social distance* as well as personal worth. By developing a narrative of 'successful living' in the face of illness, or by suggesting that reflexive and 'meaningful' deliberations on experience have been achieved, the individual may, of course, be self praising or implying criticism of those that fail. Indeed, failure has come to be the 'great modern taboo' (Sennett 1999: 118) unwittingly reinforced, perhaps, by those stressing the value of success in all areas of life, including those of illness and disability. The question of what is explicit and what is hidden in narratives brings us to their 'core' forms, which may not always be comprehended by those constructing them.

### *Core narratives*

So far this analysis has presented a view of chronic illness narratives as

revealed in the accounts patients give to researchers, and, to a lesser degree, those provided in first-hand accounts published for a wider audience. Such narratives seek to order experience in a temporal sequence, as the events of the illness unfold (its onset, diagnosis and treatment) and give expression to the changed relationship between body, self and society which such experience invariably entails. Although it may be argued that 'coping with the physical body has to precede coping with relationships' (Kelly and Field 1996: 192) it is clear that the need to deal with changes in identity and 'self presentation' are part and parcel of the unfolding of events.

However, the 'contingent' and 'moral' components of experience and of 'narrative reconstruction' involved in these processes does not exhaust the levels, one might even say 'functions', of narrative form. When lay people construct and present narratives of their experience they do so within cultural settings which provide specific forms of language, clichés, motifs, references and other elements of linguistic and symbolic repertoires which allow and constrain what is said and how it is expressed. The creative and active elements in personal narratives do not, though, mean that the speaker can always know or control what is being revealed or conveyed to others.

It has been argued in a number of different intellectual contexts, but perhaps most notably in psychology, that particular stories or accounts draw upon and constitute 'core narratives', whether consciously or otherwise. There are two main ways in which, at least in the present analysis, these can be summarised.

Following the early work of Burke (1937) and the more recent work of writers such as Gergen and Gergen (1983), Kelly (1994) has identified a series of 'genres' that can be seen to underpin all forms of narrative. These include: epic or heroic; tragic; comic or ironic; disembodied or romantic; and didactic. Although individuals may, of course, draw on more than one of these genres, it may equally be the case that the reconstruction of identity and interaction with others is expressed more or less within a particular narrative form. There is not space to deal with all of these genres here, but Kelly and Dickinson (1997) provide a useful discussion (based on a study of ulcerative colitis) which illustrates some of the elements involved.

Kelly and Dickinson present two cases which contain identifiable elements of comic/ironic and epic/heroic narratives. With respect to the former, the example of 'Josephine' suggests that, although pain and extreme discomfort may be present, one way of expressing a 'turning of the tide', towards a more positive view of the experience, is to distance the self through humour. At one point in her account she states:

I have a completely different attitude to life through it all. I have now accepted that I am OK, y'know, I mean I've got bad points, I've got good points too, and I feel that because I can accept myself as a person people can accept me as a I am... I am not a freak, don't be ridiculous, how would I possibly think... Cos I never think of myself as an

ileostomist. Because I would never say because I wear glasses I am a spectacalist . . . It just amuses me eh when somebody has to say 'I am an ileostomist'. Cos I always want to say 'I'm Josephine, I am a spectacalist, I am a false teethist' (Kelly and Dickinson 1997: 261).

In contrast, the story presented by 'Martin' gives expression to elements of tragedy and heroism in illness. Martin's illness takes a heavy toll on his body, and pulls him down to a very low level, in which his life seems to be threatened. The tests and treatment he receives for his illness only seem to make matters worse, and every attempt he makes to 'assert his own control over what is happening' is thwarted (Kelly and Dickinson 1997: 262). Yet his determination to fight his illness leads him to read up on the subject. Martin states:

I tried, y'know to make it a challenge, y'know, eh. I know it's an illness, a disease that er, but er, to my mind it was a challenge . . . Well anyway, try to make it something that I would overcome, er, if possible, er, y'know, er, fight it, if you like, y'know'. So I started to go to the library and read up all these texts books. And eh, y'know, read about all become malignant and all that sort of things. And I thought 'Och well'. I didna really bother me too much, cos although it said after 10 years or so. But even at that I thought, well, I know I'm getting now barium enemas and all this, em, every couple of years . . . So I thought 'Well, the disease itself can lead to an operation, but cancer itself would lead to an operation, but no worse than the disease itself'. So that didn't worry me . . . (Kelly and Dickinson 1997: 263).

Kelly and Dickinson go on to add that in this account 'Martin is using a trope very much invoked in late 20th everyday thinking about bodily illness. Media accounts of anyone suffering from a life threatening illness are almost invariably couched in term of a courageous "fight" by the sufferer' (1997: 268).

Through the employment of core narratives, people can both account for events and give shape to them in terms of the way in which they feel they relate to self and others. Whether self presentation in 'comic' or 'heroic' form is a conscious or unconscious process is less important, perhaps, than the fact that such 'core' narrative forms are available to people as cultural resources with which to fashion experience. By the same token, narrative 'genres' may 'catch people up' in presenting themselves in unfavourable as well as favourable lights. We cannot know, for example, from the narratives provided by Kelly and Dickinson how other people in Josephine and Martin's lives hear their stories and whether others accept or reject the self presentations that are being offered. As has been noted elsewhere, meanings are always 'at risk' in the context of demands and constraints people face in everyday settings, most notably within the family (Bury 1988).

However, although narrative forms of these kinds are frequently shot through with ambiguity and complexity, it is still possible to detect the ways in which narrative 'genres' coalesce into more obviously identifiable types, and this brings us to the second way in which core narratives may be approached.

In a long essay on patient narratives, in the context of multiple sclerosis, Robinson (1990) presents three major types of core narratives, on this occasion drawing on a later paper by Gergen and Gergen (1986). This approach suggests that narratives may convey 'stable', 'progressive' or 'regressive' qualities. In each of these narratives, 'causal linkages between one event and another are orchestrated and stressed' (Robinson 1990: 1176). Robinson goes on to add that, 'A progressive narrative moves towards the personally valued goal(s), a regressive narrative moves away from such valued goal(s), and a stable narrative evaluatively sustains the same position in relation to the valued goals throughout the narrative sequence' (1990: 1176).

Robinson suggests that 'stable narratives' are 'less engaging' than others, in that they tend to relate a sequence of events without great drama, a form of story telling which has been alluded to above under the heading of 'contingent narratives'. Often the events are encoded in a way which draws heavily on the 'culture of biomedicine' and where 'valued personal goals' are not at the forefront of the account (Robinson 1990: 1178). 'Progressive narratives' on the other hand, present the individual in a more positive light, where the 'essence is that of a positive construction of (putatively negative) events and experiences' (1990: 1178). This connects with the more recent kind of 'moral analysis' offered by writers such as Frank and Charmaz. The ironic/humorous account of 'Josephine', given above, can also be seen in this light (Kelly and Dickinson 1997: 261). 'Regressive narratives' are those in which there is 'a continual and increasing discrepancy between "valued personal goals" and the possibility of their attainment' (Robinson 1990: 1178). Robinson notes that regressive narratives in their extreme form turn on 'tragic' accounts (of the sort presented by 'Martin', above) though in Robinson's own work on MS these were in a minority.

So, while core narratives may reveal deep-seated cultural forms, they can also be analysed within a somewhat more mundane or descriptive framework. The use of a 'stable', 'progressive' and 'regressive' framework allows for a form of analysis that safeguards against over interpreting the range of meanings conveyed by patients' accounts. It is important to underline, however, that whatever narrative form may be identified in analysis, many accounts move from one to another, from tragic to ironic, for example, or from regressive to stable. To repeat an earlier point: consistency in narrative accounts may well be sought or achieved by lay people or patients, but it may not. Much will depend on the context in which the narrative is being constructed and presented, and on the intentional acts which they help to constitute.

### Concluding remarks

As has been intimated above, personal narratives are means by which the links between body, self and society are articulated. As such they are an attractive subject for sociological analysis, especially in the context of chronic illness, where 'biographical reflection' or 'biographical reconstruction' (Carricaburu and Pierret 1995) may occur, against the backdrop of disruptive events and experiences. 'Talk', in this sense, is part of the attempt to normalise in the face of serious and threatening symptoms, not simply a commentary upon it (Kelly 1994: 6). At the same time, this paper has suggested that caution needs to be exercised in dealing with chronic illness narratives. Not only may the mundane aspects of experience (and of narrative accounts) be underestimated in a concern with elaborating moral virtues or 'deep structures', but the shaping of narratives by motive and context may be downplayed if personal accounts are taken only at face value. It has been noted that some recent analysts have tended to treat patient narratives (especially published autobiographical accounts of illness) as if they represented a form of unalloyed subjective truth, the authentic voice of the patient 'underdog' as opposed to the voice of dominant medicine or that produced by more quantitative survey data (*c.f.* Gerhardt 1990: 1152). Rather, narratives take many forms, have many uses and serve many purposes, for individuals and for social groups. In these circumstances links between chronic illness and self-identity are neither self evident or unproblematic. If they were, the need for an interpretative act on the part of the investigator would be redundant. The desire to represent the 'patients' viewpoint' does not mean that an evaluative and contextual approach to patient narratives is not required. Quite the reverse.

As Riessman (1990, 1993) has pointed out, narrative analysis takes us to the heart of interpretive sociology. The interpretive act involves a series of steps in trying to understand the 'inevitable gap between the experience... and any communication about it' (Riessman 1993: 10). Most importantly, narrative analysis leads the researcher to ask 'why was the story told that way?' (1993: 2).

The distinction between narrative analysis and other forms of qualitative analysis lies in the way lay people's accounts or stories are dealt with. In much content analysis of interview data, various themes are identified and then illustrated with quotes from across the interview data set; hopefully, across the whole range of interviews. This can be done with the use of such devices as 'topic cards', or, now, with their computerised equivalents, which provide a summary of 'all comments' about a given issue (Scambler and Hopkins 1990: 1188). In narrative analysis the interview or story is taken as a whole, and set in the context in which it has been generated and told. 'Unlike traditional qualitative methods, this approach does not fragment the text into discrete categories for coding purposes, but, instead, identifies

longer stretches of talk that take the form of narrative – a discourse organised around time and consequential events in a “world” created by the narrator’ (Riessman 1990: 1195, see also Becker 1999: 207–211).

Comparisons between whole accounts across an interview sample can then provide the means of identifying the range of narrative forms that have been discussed above. In other words, the balance between contingent, moral and core narratives among respondents’ accounts can then be assessed. Indeed, it may be possible to use other forms of data (*e.g.* observational data), or comparisons with other published data sets in similar areas, to increase a sense of validity in the interpretation being offered.

In any event, the interpretation and categorisation of narratives generates second-order constructs that are of theoretical interest. Although the sociologist may be concerned to produce an authentic account of the person’s (or group’s) experience, this is, of course, of a different kind from the account itself. If it were not, then ‘words could speak for themselves’ and, again, the need for interpretation would fall. But with interpretation the question of who should determine what a narrative means is raised. Riessman suggests that the reader has to judge the fit between what the teller says and what the analyst offers by way of interpretation, and although the teller may not have the final word in such a process, the teller ‘has the first word on which the interpretation depends’ (Riessman 1993: 52). At the same time, it is important to recognise that ‘narratives are always edited versions of reality, not objective and impartial descriptions of it... and interviewees always make choices about what to divulge’ (Riessman 1990: 1197). In this sense chronic illness narratives might be called ‘factions’ rather than either fact or fiction<sup>1</sup>. The creation of meaning also has to be seen in relation to the structure of narratives, which may exist ‘prior to their content’ (Young 1995: 169, see also Mattingly 1998: 13).

As has been noted, the starting point for much of the current interest in illness narratives has been the perceived need, expressed most clearly, perhaps, by Kleinman (1988) to ‘witness’ the suffering of those with serious, and especially disabling chronic disorders. Despite the religious overtones of such sentiments they also stem from a secular desire to limit the sometimes dehumanising effects of a medicalised society, and the effects of forms of medical practice that deliver increasing technical sophistication but fail to offer ‘comfort and care’ for patients as whole human beings.

Though this impetus remains important, however, the present discussion suggests that sociological and medical attention to narratives needs to distinguish different levels of experience and the verbal accounting processes relating to them. This leads the analysis to a wider understanding of the contexts and the ‘vocabulary of motives’ in which narrative forms and thus self-identity are constructed and employed. It has been argued here that attention to narratives has the ability to provide clues to the ways in which body, self and society are linked in late modern cultures. It should always be remembered that ‘A particular self is constituted through these narratives,

occasioned by the presence of a listener, her questions and comments. Typically, the moral character of the protagonist is maintained' (Riessman 1990: 1195). In this sense, chronic illness narratives are important for a better understanding of the social fabric, and the contradictions of social interaction and self-presentation, not simply a 'truer' picture of illness or the basis for improving medical practice, important though the latter may be.

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## Note

1 I am grateful to Ian Robinson for this suggestion.

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