IDENTITY AND HEALTH

Edited by David Kelleher
and Gerard Leavey

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Experiences of health and illness are fundamental to how we understand ourselves, and the postmodern obsession with body image has made health even more significant in identity formation. The study of objective experiences of health and illness can also provide a challenge to traditional objective medical knowledge and, particularly with current healthcare interest in user involvement, can highlight the need for change in health service provision.

This book explores the interplay between identity and health, private and public, mind and body. Drawing on new material, and using and exploring innovative biographical and narrative methods, it covers a broad range of identities in relation to health and illness, including race, religion, ethnicity, disability, age, body image, sexuality and gender.

Identity and Health will be of great interest to academics, researchers and students of sociology, medical anthropology, health and psychology.

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We would like to dedicate this book to our parents
May and Jerry
Maureen and Ben

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Introduction

Gerard Leavey and David Kelleher

> 'And who are you?', said he. 'Don't puzzle me', said I.
>> L. Sterne. Tristram Shandy

Within medical sociology, identity has become a significant area of interest, which has brought through the use of phenomenological methodologies the authentic experience of the much-neglected patient into the frame. Kelly and Millward skilfully differentiate between two essential types of identity; an identity that relates to self (private) and an identity that relates to others (public or social). There is of course considerable interplay between the two and it is important to stress that identity is always located in the social. Sociological accounts of identity differ from those found within social psychology in that they tend to focus, respectively, on social experience in the production of identity rather than on internal processes such as personality or cognition. These are not oppositions, as the authors point out, but more the outcome of distinctive disciplinary preoccupations. In order to examine the concept of identity within chronic illness sociological and anthropological perspectives distinguish between disease, essentially a bio-medical concept related to organic pathology and is disconnected to the personal and social dimensions of the individual as they experience illness which is shaped and understood by culture. Given that illness is amenable to cultural influence, it is increasingly understood, if little practised clinically, that the needs and outcomes for patients would be better appreciated and achieved, if attention is paid to the patients' conceptualisation of the problem (Hillier and Kelleher 1996).

For Kelly and Millward (Chapter 1), the importance of medical sociology's examination of identity and illness through the patient experience was not simply that it provided an important conduit for the articulation of suffering, strikingly absent from medical discourse and valuable in its own right, but that it opened up a legitimate and powerful means of challenge to medicine and intensified the need for change within healthcare. Drawing on work within symbolic interactionism such as that of Erving Goffman (1961)

the authors view human suffering as not just a 'product of illness' but that it says something more profoundly emanating from the 'the sheer awfulness of the human condition' whereby the essential truth of being human is only grasped through suffering and indeed, redemption through suffering is a motif that runs through much of religious thinking and especially prominent in Judeo-Christian thought on the individual's life journey. In similar vein, at the wider social level it has been suggested that ethnic or group identity is only made transparent when it is in crisis (Mercer 1990). Kelly and Millward, while reinstating the theoretical importance of Parsons' work on the sick role suggest that the concept of identity is an antidote to the flaws in the Parsonian structure in that human experience is brought back into the otherwise rigid prescriptiveness of role (Parsons, 1951). In other words, the patient is not simply a conforming and passive sick object but rather an active participant and manager in the doctor-patient relationship, a relationship that is embedded within a wider social and cultural world – a healthcare system as Kleinman conceptualises it (Kleinman 1980; Kleinman 1978). To some degree, biomedicine has attempted to divorce the body from the person as rational agent, ignoring profound alterations to the self that medical intervention brings. Moreover, the body belongs to the wider community body, acting as both communicative agent and medium. As Lock suggests, the body carries the imprint of the community in terms of habitus, posture, gesture and action (Lock, 1993).

Neither experience nor identity is frozen, fixed in discrete stages but instead they have a malleability that is influenced, but not wholly determined, by social structures. However, while the illness narrative of the patient may provide an articulation of suffering and meaning, the emphasis and reliance on a methodology that is essentially language-based may not have relevance to acute illness. In addition, the construction of meaning through narrative tends to obscure identity change that is embodied and visible. Self and identity gain salience within chronic illness. Thus the body-mind relationship is one of complex mutual influence and one that interacts with the social world. For the individual whose body or bodily function is altered through chronic illness there are correlational changes in the self but contingent upon the extent to which these bodily changes are on view to others (Kelly and Millward 2003a). In the case of young, predominantly female, patients with anorexia nervosa it is argued that bodily change, that is, a natural progression to an identity of sexual maturity is arrested by a determined effort of mind, either conscious or unconscious. Quite literally, the person refuses to grow up and is likely to die in the effort. As with the bodybuilders described by Scambler *et al.* these young people view the body as a project with distorted and ultimately pathologising views of weight, shape and beauty. Likewise, it can be argued that the iconised images of starved beauty generated by a post-modernist obsession with aesthetics and individuality creates a culture where such distortions to perception are inevitable.

Kelly and Millward (Chapter 1) identify four ways in which illness and bodily change in the chronically ill can impact on identity and self. Briefly, these are: the impact on self image rooted in physicality; a conscious regime of maintenance (which in itself reflects the sick identity); a self-consciousness emanating from a 'loss of spontaneity' (Kelleher 1988); and the rupture to previous held conception of self. I can no longer do what I used to, in the same way that I used to do it – am I still the same person? These existentialist questions are developed by Jane Garner.

Kelly and Millward also discuss the link between the personal and social and the way in which the social world assesses, judges and manages deviance by the use of stigma and labelling of individuals and groups who fail to uphold conventions and norms of social etiquette. The difficulty of this labelling for the self is that these responses may become internalised by the individual. By and large, the language commonly employed with respect to people with illness or disability reinforces a conception of the person thus labelled as the illness incarnate – people with severe mental illness become 'schizophrenics'. Goffman's classic work on institutions revealed the 'machinery' of the asylum as it stripped the individual of recognisable (communicated to others and self) instruments of identity and self-hood. Kelly and Millward discuss labelling theory with regard to secondary deviance 'a process of shifting and negotiations that gradually build a deviant self' (Plummer 1979). The authors describe a persistent narrowing of choices faced by the psychiatric patient – setting limits on conduct and reinforcing the identity being conferred. This suppression of self resonates with the views expressed in Leavey's chapter in this book concerning the self-censorship of religious beliefs by young black Pentecostalists with mental health problems who, over time and contact with psychiatric services, come to understand that religious beliefs are often considered as part of the pathology.

Scambler *et al.* (Chapter 6) consider and challenge universally held assumptions about the salutogenic assumptions that sport is good for you. The challenge is made within the context of globalisation and particularly the transition to disorganised capitalism. They argue that in our post-modernist culture, exercise and sport have become extensions of life-style and consumerist choices. Thus, as illustrated by bodybuilding, the body has become 'the project', 'a site of pleasure and a representation of happiness and success' and where gym culture can be better understood within Foucauldian 'technologies of the self'. The problem however lies in the fact that the pursuit of identity through the glorification of the body, the achievement of 'the look' – the pursuit of an idealised image of youth, fitness and beauty – is unlikely to bring health benefits. In fact bodybuilding is more likely to do harm than good through the use of illicit steroids and excessive bodily strain. Bodybuilding is thus preoccupied by an identity that is visible and external. Sense of self and self-worth is maintained and must be maintained via the body. The authors argue that while post-modernism

promises a liberation of sorts for the individual to pursue personal self-constructed identities, the reality is situated more within the highly profitable health and fitness industry and the hypercommodification of global capitalism. The authors examine as the second focus of their challenge, the transition of rugby from a mainly amateur competitive sport to its professional status fired by capitalist need for return on investment ('getting their monies worth'), which in reality means extracting it from the performance of players regardless of risk to health. In addition, the traditional emphasis and veneration of manliness within rugby has, they argue, taken on a harder edge. The nonsense that 'real men' are tough and don't feel pain has cascaded down through male social discourse with huge personal and social costs.

In western societies people are living longer. It should be a cause for celebration but it isn't. Our increasing longevity is presented as a damoclean sword waiting to slice chunks from the public and private purse. The old are not givers, only takers at the social table. To be sure, old age in western societies has rarely achieved the venerated status found within more collectivist cultures but as the preoccupations of post-modernity (beauty, speed, self) bite, the position of older people indeed appears parlous. Old age happens to other people – the young cannot identify with the old. We appear unable to incorporate an image of being elderly into our imagined selves of the future. The importance of continuity as a philosophical concept is one that appears in most discourses on identity, in part because this touches on the existence of a personal, individual human core (in religion sometimes considered as soul) and which has relevance to concerns of ontological security, validity or reliability. Post-modern society characterised by the non-essentialism of rapid change, hybridity, flexibility, identity as consumerist life-style choice and ambiguity undermines the requirement of continuity for identity. With continuity gone, can identity remain? The problem is considered in Garner's chapter on Alzheimers' disease as she discusses the impact of memory loss on dementia sufferers and carers. Can a person exist without consciousness? (Locke 1690). Is memory a complex fiction from which no true identity can emerge (Hume, 1739) or rather, is identity a collection of past selves (Parfit 1971). Philosophically at least, it would appear that identity is understood as unity and continuity ruptured is for the person with dementia. Garner addresses the problem of unity within a humane and pragmatic framework of the person's social context and details of biography and personal values. The implication of continuity within the care of dementia sufferers has a significance that must be considered. If the patient has no memory of being Jewish, religious and married – should we allow these aspects of her 'self' to be also 'buried' by the caregivers? Is identity a sacralised element of humanity and do we violate it through neglect? As Garner points out that, in dementia, although the person has little control over personal identity, the self is not lost.

Western secular notions of identity continue to accept and encompass fragmentation and compartmentalisation of 'self' in a rational and increasingly bureaucratised world, a vision close to that of Weber's disenchanted universe (Weber 1946). Psychiatry as a post-enlightenment discipline has hitched its identity to that of science and, self-consciously perhaps, makes strenuous effort to detach itself from its religious origins. How then should psychiatry address the religious identity and beliefs of people with mental health problems? With a focus on black Pentecostalism in the UK, the fastest growing sector of the religious market, Leavey (Chapter 3) examines aspects of religious identity that are protective to the self-esteem of marginalised or oppressed groups as they encounter the turbulence and anomie associated with modernity and change. Sociological considerations of religion have tended to stress functionalist aspects such as community cohesion and continuity (with perhaps less thought to change and conflict). However, the cognitive, experiential and affective components of religious belief and worship need also to be considered. Pentecostal belief brings unity of identity to the believer or at least attempts to reconcile aspects of the self and its connectedness with the universe. A Pentecostal identity, which is more bound by the spiritual than the material and a belief that healing is always a matter for God, with or without medical intervention is a challenge to a secular psychiatry?

Since the early twentieth century, beginning with studies such as Odergaard's (1932), there is general agreement that contingent upon a number of factors, immigration is linked to higher rates of mental illness (Murphy 1977). Earlier commentators assumed that the explanation lay in the export of psychologically vulnerable individuals. Though the discussion continues, the accepted wisdom suggests that environmental factors related to reception and settlement play a major role. The Irish are often considered the closest migrant group in terms of geography, skin colour, language and a shared troubled history, factors that intuitively might suggest protection. Instead, this largest and oldest migrant group in the UK continues to have the highest rates of severe mental illness (with the exception of schizophrenia), suicide and self-harm for all ethnic and migrant groups. Irish-born migrants in the UK fare no better on physical health. Kelleher and Cahill (Chapter 5) explore the possibility that some of the explanation might lie in the difficulties faced by Irish people as they attempt to maintain an authentic identity (though not always consciously an Irish one), which for a number of reasons fail to achieve value and acceptance. They explore the impact of stereotyping and the destruction of the individual through the imposition of an unwanted collective identity, which is intended to sabotage attempts by the individual to construct or reconstruct a fresh identity. Drawing on recently gathered information through in-depth interviews, Kelleher and Cahill illustrate the diverse range of reasons for migration and the experiences of Irish people in England as their differences collide and the problems

this makes in continuing the narrative of identity. The chapter by Moore also uses interview data as a basis for discussing the links between religion, identity and health in Northern Ireland. He illustrates how in Northern Ireland religion forms the basis of culture and cultural differences. He examines how Northern Ireland is a 'region of serious health concerns'. This can partly be explained by poverty and lifestyle but Moore shows the links between religious identity and health, which have not previously been studied. In this chapter the research carried out by him in 1996 for the Department of Health and Social Services is examined in greater detail and used as a starting point for a discussion of the links between religion, identity and health.

Chattoo and Ahmad (Chapter 2), through their research with people facing advanced cancer, attempt an understanding of how such people deal with the disruption to identity caused by the threat of terminal illness. This is made more complex in the context of membership of an imagined moral community (ethnic group). They contend that the intersubjectivity of self comprised of demographic features and connections are not taken for granted truths but have to be constantly negotiated and managed within the progression of illness and treatment and changes occurring to the body. The re-negotiation of identity is seen as particularly difficult in relatively young communities where the experience of cancer is much less common than in the white population. Their mixture of lively narrative accounts balanced with insightful commentary on brief reviews of theoretical literature makes for interesting reading.

Is the construction of a homosexual identity more complex than in other groups such as ethnic minorities or the disabled? Until the latter part of the twentieth century, homosexuality was a diagnosable psychiatric illness and, despite the emergence of a more open, liberal and pluralist society, many lesbian and gay men in Britain face considerable difficulties in achieving an identity not distorted by guilt and shame. King and McKeown (Chapter 8), through their very recent research with lesbian and gay men with mental health problems, examine the encounter between these women and men and psychiatric services. The authors explore a world where heterosexuality is assumed. They examine the impact of these assumptions and how the suppression of a key narrative aspect of identity has a negative impact on mental health.

Blaxter's chapter is also based on narrative accounts which show how identity is constructed, and how 'identity is shown as a grid through which health and illness are perceived and given meaning'. What is also of interest in this chapter is the well-informed discussion of 'story-telling conventions and the purpose of narrative accounts'. The discussion of the theoretical approaches of Frank, Denzin and Bury are used to generate what becomes a comprehensive review of the literature on narrative. This is then used to frame an analysis of her own data, examining how in the thirty-five

narrative accounts of her sample past, present and future are inextricably linked in the construction of identity.

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Identity and illness

Michael P. Kelly and Louise M. Millward

Introduction

This chapter examines the concept of identity with particular reference to illness. In sociological terms, identity relates to a host of criteria that are called in to play in interaction when assessing oneself and others. It is multi-faceted and has been described in relation to almost every aspect of knowing about oneself and others. Sociologically, identity is understood through visible aspects of the person and all the various points of reference that these might entail, such as skin colour, height, weight, attractiveness, blemishes, deportment, accent and dress attire, for example. It is also understood in relation to abstract ideas, like those that designate communal arrangements, such as status, roles and an almost endless number of group affiliations, such as gender, religion and culture. Conceptually, the term 'identity' consists of two essential types: one regarding others and the assessment of others and one regarding self and the assessment of self. To distinguish these forms the terms 'social or public identity' and 'personal identity or self' are often used.

The development and definition of the concept of identity

It is undoubtedly the case that the idea of identity has exerted a very significant influence on the sociological study of illness and especially chronic disease. By and large, writers dealing with identity have worked within a micro-sociological framework with a focus on interaction. Identity has become a dominant motif within certain strands of medical sociology, especially in Britain. In particular, the study of illness and identity has come to represent an approach to the analysis of ill health in which writers have sought to present the 'authentic' experience of sufferers and give voice to that experience. Because of a commitment to authenticity, phenomenologically and subjectively informed methodologies have been pre-eminent. There is a very rich vein of material dealing with a variety of diseases such as

arthritis, diabetes, Parkinsonism and colitis, for example (Anderson and Bury 1988).

The concept of identity has its roots in psychology. However, contemporary social psychology and its concerns with identity have had very little influence in medical sociology. The ways in which sociologists tend to use the term belongs to much older psychological and philosophical literature that has its intellectual origins in the work of William James, John Dewey, Charles Horton Cooley and George Herbert Mead (Kelly 1992). The dualism in the sociology between public identity and self or private identity is present in the original writings of Mead, James and Cooley, and is found subsequently in the work of Goffman (1969) and Rosenberg (1981) and in many other writers associated with the symbolic interaction perspective in sociology (Rose 1962) or, what has sometimes been called sociological social psychology (Rosenberg and Turner 1981).

It is helpful to delineate the dualism at least analytically (even though not all the authors who use the terms identity and self are careful to maintain the distinction). Public identity describes the way we are known, defined and constructed as social beings in interaction with others, and, private identity or self, is the way we are known, defined or constructed by our selves in interaction. Ball (1972) has helpfully distinguished between ego as known to others (identity) and ego as known to ego (self). While obviously these two aspects of person overlap and reinforce each other, given their common roots in social interaction, they can and do diverge, and in the case of chronic illness, that divergence is very important empirically (Kelly 1992).

The following propositions can be derived from this body of work:

1. individuals interactively emerge under social conditions, whereby in relation to others a sense of self is acquired, which consists of a central 'I' and an interactive 'me' (Szacki 1979:406; Denzin 1992:4);
2. mental life is an accessory, rather than an instrumental force; however interactions form certain customs that nurture the mind (Dewey 1922:155; Szacki 1979: 407–10);
3. 'sympathetic introspection' (Meltzer *et al.* 1975:10) permits people to imagine how they are seen by others (Cooley 1972); and finally
4. through abstract and reflexive language, self arises as a social object that can be interpreted in much the same way as can other objects, whilst retaining an individualistic 'I' (Szacki 1979:425–30).

'Self' or personal identity is not a physical location, it is a cognitive termini borne upon the private sphere of personal thought and language, privately through personally concealed knowing and being and reflexively through one's own appraisal of oneself as seen by others (Kelly and Dickinson, 1997). Charmaz captures the essence of this when she remarks, 'From a sociological view, the self refers to all those qualities, attributes, values and

sentiments, including feelings of moral worth, that a person assumes to be his or her own' (Charmaz 1999). Although it is in a constant state of flux, it has a central core against which new information is assessed. The problem of self is that it has to mediate with that which is socially conferred; that which is termed 'social identity'. Social identity is an individual's identity as perceived by others. Social identity can also be accessed, however, through seeing self as others might see self. The notion of James' 'interactive me' describes this idea. The 'interactive me' is the location of 'social identity', namely ones' identity as perceived by others, however through reflexivity it is also the location of self as perceived by self. Social identity concerns the assignment of shared meanings by others. Shared meanings are evident in Dewey's idea of interactions forming certain customs that nurture the mind. These shared meanings can be configured in numerous ways. They might be positive or negative, fleeting or more grounded, structurally determined or personally defined. The problem of social identity is that it is has the potential to fracture previously held conceptions of self and this can be a real issue in chronic illness.

In summary, what has been referred to as personal identity concerns the self; a private cognitive entity of concealed knowing and being that can reflexively appraise itself as seen by others. What has been referred to as social identity, is the product of others' external assignments, which through appraisal, might be subsumed as part of self. Presentation of self as known to self in socially interactive relations where conferred identities align with self are largely unremarkable. Where, however, an individual is continually subject to alternative modes of information that question the essence of self, self must be reappraised. Avenues of alternative modes of information and reappraisals of self are notable events in individuals who experience chronic illness (Kelly 1992).

The ambiguity that is sometimes found in the literature between the individual and social aspects of the person (between self and identity) tends to get reinforced by another characteristic of this literature, which is the absence of an explicit theorising of social structure. Almost all the work on identity and illness focuses on the human agent and on human agency and not on social systems. Of course society is not denied, but it tends to assume either a kind of residual status in the analysis, important as background, rather than an integral part of the processes described, or as constituted within a micro world of face to face interaction. Consequently the agency structure question remains sociologically under-analysed in the literature on the experience of illness and the construction of identities therein.

Sociological descriptions of identity differ from the mainstream social psychological work in a number of ways. General social psychological accounts of identity range from a focus on the cognitive aspects of identity formation and the ways in which people subjectively come to perceive a mature concept of themselves (Erikson 1968; Marcia 1964, 1966) to the

ways in which identity can emerge from socially induced individual differences, marks or persuasions. On a wider group level, aspects of identity have been interpreted in various ways such as using occupational status as an anchor for identity (Laliberte-Rudman 2002). The social psychological material tends to focus on the ways in which perceptions and motivations influence various types of identity (see, for example, Salazar 1998). This literature attempts to describe the concept of identity using a multitude of factors that are examined at numerous levels of analyses (see, for example, Worchel *et al.* 1998; Tesser *et al.* 2000; Côté and Levine 2002), but with principal consideration being given to the examination of personality within the parameters of introversion/extroversion, agreeableness, conscientiousness, emotional stability/neuroticism and openness to experience (Ouellette 1999). The real difference between this and the sociological work is the sociologists' emphases on social experience as the basis of identity, rather than its locatedness within cognitive processes or personality traits. The cognitive processes are not ignored in the sociology, in the sense that human beings are seen as thinking beings, but the nature of social experience as it shapes meaning in interaction leading to identity development is given priority in the analysis. This perhaps reflects disciplinary preoccupations rather than any kind of absolute division (see, for example, Honess and Yardley 1987).

Identity and illness experience

Perhaps the best way to understand and define the unique contribution of sociology to the study of identity is to examine the way in which the ideas about the nature of illness experience, as the driver of identity construction, have evolved. Illness experience as a focus of analysis emerges as a means of articulating a difference, sociologically, between disease and illness (Field 1976). Disease relates to physical organic pathology and a biomedical model that does not encompass social, psychological and behavioural aspects of illness (Fitzpatrick 1984). In contrast, illness 'refers to all the *experiential* aspects of bodily disorder which are shaped by cultural factors governing perception, labelling and explanation of the discomforting experience' (Kleinman *et al.* 1978). The experiential nature of illness often transcends the organic realm of disease. This is evident in, for example, situations where diagnoses are conferred in the absence of symptoms but where experiencing the act of a diagnosis is consequential. Illness can be both historically and culturally variable, as is evident in past and present natural, religious and/or spiritual conceptions of illness. In respect of recent work in the context of cultural differences in health, Hillier and Kelleher (1996) note that, 'people's meanings and needs can be better understood by listening to what they say about their own health' (Hillier and Kelleher 1996). In a similar vein, Kihlstrom and Kihlstrom (1999) suggest that consultations with individuals

who experience somatisation could be improved by embracing the self-concept of these individuals (1999:33).

The ways in which illness is understood are important for at least four reasons: First, beliefs about illness shape both individual and group experiences of illness. Second, beliefs about illness influence individual and group responses to symptoms (Fitzpatrick 1984). Third, beliefs and potential responses to illness have epistemological links to the ways in which the world is understood through biological, behavioural/psychological and social/environmental realms of knowledge. For example, illnesses such as coronary heart disease are associated with hypertension and cholesterol levels, smoking and physical inactivity, and socio-economic status and social support, respectively (Anderson 1999). Fourth, the relationship between illness and identity is not one-dimensional. Although both self and identity can influence the ways in which illness is perceived and responded to, illness states themselves, in turn, have consequences for self and identity. Illness has the potential to fracture both previously held self conceptions and the perceptions that others might hold of individuals and this is likely to be particularly salient in forms of prolonged chronic illness, as opposed to fleeting episodes of acute illness.

What is undeniable is that one of the major contributions of medical sociology has been to provide a platform for the sociological articulation of the 'authenticity' of the experience of illness. From some of the earliest work by Strauss and colleagues (1984) to the contributions of Bury (1982), Williams (1984), Pinder (1990) and Kelleher (1988), there is a large amount of descriptive material which documents what it feels like to have a particular condition, what it means in social and personal terms, what the impact is on everyday life and what the implications are for the future and the past. Furthermore, this documentation is done largely via the medium of the accounts of the sufferers themselves. The concept of illness careers and the associated identity constructs have helped to place before professional and lay audiences subjective experiences of chronic illness. The ways in which people change about how they feel about themselves and the ways others feel about them, such as how their identities are mediated by these experiences, are described very precisely.

The importance of this is twofold – publicly and theoretically. The theoretical issues we return to later, but by publicly we mean that this literature has been one of the places where the voice of patient experience could be found and was given a public exposure. Before sociologists began to document these processes in this way, the only genres through which such accounts appeared were autobiography or literature. Both are very powerful as a means of conveying the charge of emotional experience, but the sociology added important analytic discipline and purchase as well as academic legitimation. For some writers, the importance of the sociological endeavour in this regard was simply a way of providing a conduit for the voices of

sufferers, which were traditionally unheard within professional discourse. So the task of the sociology was simply to lay before new audiences like carers and doctors the true experience of suffering. In doing so the investigations were a means of drawing to the attention of professionals the true nature of the experience of different conditions, in order to bring about change in professional behaviour and practice. (It might also provide further ammunition in the war of attrition with the medical profession, which certain sociologists have prosecuted for the last several decades.) Whatever the intent, one of the unifying themes was that sufferers and carers could readily recognise the accounts as the *real* experience of *real* people struggling with a personal burden of ill health.

But there is another dimension relating to experience in this literature which is seldom articulated sociologically but which seems to us to be deeply embedded within it. This is a concern to describe human suffering, not just as a product of illness, but also as essential to the human condition. Goffman's work (1961; 1963), for example, is shot through with a concern to explore much of the sheer awfulness of the human condition and this existential angst pervades a good deal of the writing on illness and identity. In many of the narratives of illness experience, illness is a metaphor for the experience of life, and an experience of life which is essentially tragic, but (in the Judeo-Christian tradition) there is a kind of redemption through that experience of suffering. Or in Nietzschian vein, the literature contains the Dionysian notion that the true essence of what it means to be human can only be known through suffering, in this case, in severe illness (Benedict 1935).

These latter themes more often than not have their clearest exposition in the accounts offered by the sufferers themselves and reported by the sociologists. These sociological reports have tended to report Dionysian accounts as representative of the experience of illness, *not* as representing the nature of the human condition. Interestingly, the fact that sufferers not infrequently invoke ideas in their accounts of their illness that draw upon the great meta narratives of Christianity or Greek mythology, has tended to go unremarked by the sociologists (Kelly and Dickinson 1997). The idea that chronic illness takes people beyond the normal existential limits leading to greater self knowledge and hence exerting fundamental effects on identity, rings out loud and clear in the patient accounts in the literature. The sociological implications of this, however, are seldom explored. The Nietzschian possibility that the true nature of being is revealed and a deeper self-understanding acquired through illness, tends not to be taken very seriously, even though the voices of the sufferers suggest that it should be.

Theoretically and empirically the importance of identity lies in its critical role in introducing subjectivity into discussions about illness in the face of the dominance of the sick role paradigm established by Parsons (1951). In fact, we would argue that Parsons' depiction of the sick role, for all its

detractors, is one of the most significant and important pieces of theorising about the social nature of illness of the last century. His idea that sickness was a form of social as well as biological deviance, that societies developed very precise mechanisms to manage the deviance, and that in the case of modern western industrial societies, these mechanisms took very specific forms and patterned very well defined behaviours, were immensely important. It demonstrated the social as well as the biomedical dimensions of illness and it laid out an agenda for much of the subsequent sociological work on illness.

The concept of illness identity develops, it seems to us, in direct response to several of the perceived inadequacies of the Parsonian system. Identity establishes the primacy of human subjectivity and human agency in the face of the determinism of the social system or of social roles. The concept of identity, as against the concept of role, acknowledges the importance of human agency and interaction in structuring human interaction and leads us away from the apparently prescriptive nature of the Parsonian principles. Identity also acknowledges, especially with its connectedness to the nature of career, the evolving nature of the relationships between doctors and patients which the Parsonian principles tend to under emphasise or at least rather tend to leave in the background of the analysis.

However, above all else, we suggest that the real distinguishing feature of the sociological contribution to the study of illness using the concept of identity, was to give a new sharpness and to illuminate that with which we as lay members of society were already familiar. The ability of sociology to render that which is at once recognisably familiar and yet to shed new light on it, has been a major contribution. Some of the key papers, especially those appearing in the journal *Sociology of Health and Illness*, have done precisely that. So the emphasis on identity in this genre in medical sociology might be conceptualised as a response to Parsons or an elaboration of certain things within the Parsonian framework requiring more attention, especially chronic conditions. In an important sense the idea of identity goes hand in hand with Parsons in establishing an important *raison d'être* for the social, as distinct from the biomedical, in respect of understanding illness. But it also goes beyond Parsons in highlighting the familiar but also profound experience of human suffering, which many illnesses engender.

The processes whereby the social became part of the analysis was however not immediate, even in the wake of Parsons, and the application of the idea of identity played an important role in foregrounding the social. So initially the idea was that disease had social, psychological and economic consequences. (Visotsky *et al.* 1961; Shontz 1975; Albrecht 1976; Platt 1979). In public health circles, the idea that an episode of illness might have economic precursors such as poverty or poor housing was also widely acknowledged (Acheson and Hagard 1984). However, the idea that social and psychological factors were not merely contextual and background residual

epiphenomena, but were an integral part of the being, meaning, causes, consequences and experience of illness, owes its debt to Parsons. Identity theory applied to illness by sociologists provided the explanation of the ways in which such things could be theorised and drew out the essential self reflexive nature of the experience of illness and its significance to the wider human condition.

The conceptual journey is in itself quite informative. Two papers, which have charted the history of the way sociologists have dealt with illness experience and identity, are those by Lawton (2003) and Pierret (2003). In reviews of articles in *Sociology of Health and Illness*, over a twenty-five year period, they provide a narrative of the way these ideas have evolved. What these two authors describe is the gradual broadening of interest by sociologists in their concerns about identity and the experience of illness. The interest expands from simple descriptions of the experience as a set of stages operating in chronological sequence, to a concern to illuminate the meaning of experience. In other words, the idea of *chronos,* of linear sequential time, gives way to the idea of *kairos,* concerned with the fusion of past, present and future in biographical significance. The idea that experience is more than the chronicle of a series of events is displaced by the notion that experience is socially located and constructed, on the basis of interpretation and understanding, and that events can come to have different meanings in retrospect and in prospect. The idea that identity simply moves through a series of discrete stages or progressions is replaced by the idea that identity is malleable and plastic and bounded by social structures but not determined by them. Bury's seminal paper (1982) on biographical disruption perhaps best exemplifies this position. A couple of years later, Williams' paper on the linguistic accounting processes which accompany biographical disruption and repair (1984) moved the focus of the analysis still further from time sequences towards an understanding of the language of the sufferers of illness and the subtle nuances which language brings to bear on the experience and its retrospective and prospective understanding.

Subsequently, the question has arisen as to whether the discovery of these linguistic elements of story telling or narratives of illness is little more than a methodological artefact rather than the core of identity. In other words the identification of processes which are fundamentally linguistic are identified as the product of a methodology – the use of in depth interviewing – which requires subjects to produce accounts about themselves, with themselves at the centre of the narrative. As new evidence emerges it also becomes clear that a focus on chronic illness as against acute illness leads to an overemphasis on issues of disruption and biography, and that acute illness and indeed some forms of chronic illness do not share these kinds of characteristics. The most interesting development though has been the recognition that an over emphasis on language and the construction of meaning can in turn lead to a description in which the body and bodily processes are over-

looked. The fact that the management of bodies that do not function in the way that people either want or which society deems to be age and gender appropriate, is at the heart of the experience of illness and the construction of public identity (Kelly and Field 1996). Changes to the body are at the centre of visible changes in identity and the way people feel about themselves. So a stream of literature, which has explored the relationship between the body and identity in illness, has also emerged (Millward and Kelly 2003a). This in its turn has led to the development of the idea that the material and physical world should be reintegrated into the understanding of identity (Lawton 2003; Pierret 2003; Kelly 2001).

Illness, identity and the biological and social world

In chronic illness, self and identity gain salience. It is the biological realm of the physical body that prompts this process. The physicality of the body is important for self and identity because it is inextricably associated with self and with identity. Whilst an essential link between the body and self and identity relates to the body's capacity for cognitive thought, the body is important for self and identity in a number of other respects. Bodily characteristics are part of what individuals perceive themselves to be and influence the ways in which cognitive thought by self and by others are configured. Bodily characteristics are relative to private and public perceptions in relation to both the aesthetic physicality of bodies and the functioning physicality of bodies (Kelly 1992); categories that are not entirely mutually exclusive. Private personas of self and others' perceptions of individuals are constructed upon a range of aesthetic bodily qualities, such as being attractive, ugly, tall, short, fat, thin and such like, and a range of functional bodily qualities which span both capacities of physical functioning such as being able to run, jump, reach, climb, and capacities of cognitive functioning, such as the ability to learn, to remember, or to recognise. The crux of the relationship between the body and identity is that where there are chronic alterations in the aesthetics and/or functions of the body, the self that is configured upon that body must also change. The potential for an altered identity, however, is contingent upon the nature of the bodily changes and whether these come to be subject to public gaze (Millward and Kelly 2003a). These ideas are highlighted in various patient accounts. For example, for subjects who had had ulcerative colitis cured by major surgery, the experience of bodily pain, changes in bodily symmetry, the addition of a 'new body part' and profound changes to sanitation routines resulted in compulsory permanent changes in both private conceptions of self and in tensions arising between the choices of revelation and secrecy in public management and presentation of self (Kelly 1992). For these subjects, appliances were not only a private matter, the permanent demands of attaining and mastering secrecy and the potential for exposure were located in the