

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

Identity and Health

Edited by David Kelleher
and Gerard Leavey



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...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 term 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 one's 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 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

ences, 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

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 Nietzschean 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 Nietzschean 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 Hagarad 1984). However, the idea that social and psychological factors were not merely contextual and background residual

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

social world (Ketty 1992). Similarly, individuals with diabetes, a metabolic condition, have experienced, or are at risk of experiencing, a range of physical bodily changes such as impaired vision, infected wounds, tiredness and impotence (Kelleher 1988).

For these individuals, the chronically ill physical body was associated with self and identity in at least four ways:

- because the impact of physical bodily changes altered the image that individuals had of themselves;
- because to maintain physical equilibrium and prevent further physical risk sequelae, the physicality of the body itself required a special and unique form of physical maintenance not required by majority groups;
- because the routines of managing the body impinged upon previously routinised ways, a recurrent theme that Kelleher referred to as 'loss of spontaneity' (Kelleher 1988); and finally
- because the chronically ill physical body had the potential to invoke extended meanings that assaulted and ruptured a previously held conception of self.

A common thread between both of these groups of individuals and others who have chronic illnesses is the way in which public spheres of life become the site of intense negotiation with huge implications for self and identity. In public spheres the self not only seeks social legitimation, acceptance and integration, but does so equipped with stocks of shared knowledge about the kinds of conduct that are necessary for these events to occur. Bodies that 'malfunction' deviate from norms in both a private and public sense. Public management, however, concerns the social world and the attribution of identity. In the social world it is not just the physicality of the body that has to be managed; far more overwhelming and difficult to influence, predict and control are the cognitive appraisals of others in relation to presentation of self and yet these also have to be managed.

Whilst the previous paragraphs noted how the salience of self and identity in chronic illness is prompted by the biological realm of the physical body, this section notes how the salience of self and identity in chronic illness can be maintained by the social realm of interaction. The social world is where the generation of meanings has profound consequences for self and identity. The social world judges the physical and cognitive presentation of individuals in relation to cultural conventions, and shortcomings are defined by the societal standards therein. The links between illness and identity are illuminated in the social world largely because chronic illnesses and their maintenance have the potential to deviate from social standards. This deviation has the potential to occur within the ways that society is structurally configured and within societal configurations of individual agency. In both of these realms, society manages this deviance by the use of stigma and labelling techniques.

Labelling is a reaction to groups and/or individuals who, through chronic illness, cannot uphold the networks of physical and cognitive behaviours that social etiquette demands. The problem of this labelling for self is that these labels have the potential to become internalised.

One of the key ways in which illness links to identity is through the legitimation of a medical condition by a member of the medical profession. This legitimation might be sought after or undesirably imposed. In both cases the professionally conferred identity is drawn from a recognised classification of disease states that bears consequences for the ways in which particular illnesses and their severity are afforded different statuses and the ways in which these might lead to such things as access to additional resources. Often overlooked, however, are the ways in which medical professionals also invoke a range of other identities and themselves engage in stereotypical processing.

Goffman (1961) highlighted how psychiatric professionals required the removal of individuals' clothing and its replacement with hospital attire and discouraged any references to their personal life. At the same time encouraged adaptation to their new location. This stripped individuals of their very essence of self and avowed a hospitalised patient identity. The importance of this for patients with mental illness was that the resulting patient behaviour reinforced their identity as a mentally ill patient. These links between illness and identity are described in Lemert's (1951) primary and secondary deviance thesis. Primary deviance concerns changes in self that are induced from minimal tensions between self and the environment. In primary deviance, self is largely unaltered. Secondary deviance concerns profound changes in self that are induced through a progressive process of tensions between self and environment. Plummer described secondary deviance as 'a process of shifting and negotiations that gradually build a deviant self' (1979:105). The key issue in secondary deviance is that persistent narrowing of choices, as for example being a mental patient, sets limits on conduct. This unwittingly reinforces the identity being conferred. Secondary deviance is where individuals adopt a socially conferred identity as part of self and come to behave in ways that are associated with their new self.

The notion of the Parsonian sick role discussed earlier (Parsons 1951) offers another idea of how medical professionals can invoke a range of alternative identities and engage in avowing stereotypical identities onto patients. In brief, a patient's occupation of the sick role is legitimated by doctors who, for temporary illness states, and as long as individuals pursue the goal of recovery, grant these individuals exception from their normal social duties. Because, however, chronic illness is not a temporary illness state, legitimation of illness and the rights and obligations therein are not always warranted by the sick role. Sociologically, this is an important event because patients who do not fit a 'legitimate patient identity', and therefore the sick role, often fail to legitimate the doctor's own role in the encounter. It

only the often-continued presence of the chronically ill patient, but also the possibility of their own role being called into question. What is at stake is that some patients deny the role of the professional (Kelly and May 1982:154) and the issue of problem patient becomes bound up with professional identity (May and Kelly 1982:292). The method by which doctors respond to this dilemma is through the use of labelling as, for example, is exemplified in the notion of 'heartsink patients'. Patients become associated with a host of stereotypical labels such as demanding, uncooperative and manipulative; qualities that are not necessarily inherent in the patient; rather they are qualities that, through frustration and defeat, the doctor comes to assign to the patient (Millward and Kelly 2003b). These labels are a situational response to a therapeutic dilemma that concerns the nature of the doctor's role and where, within the doctor-patient encounter, that role is not legitimated (Millward and Kelly 2003b). In doctor encounters, social etiquette demands that the patient fulfils a number of socially defined criteria and failure to do so heightens the potential for labelling. These labels confer an identity on to the chronically ill patient. An identity that the patient is often aware of.

Charmaz (1999) provides a critique of the sick role in this context, arguing that its application does not highlight essential links between illness and identity. For Charmaz, the sick role fails to acknowledge that recovery is not always possible; it assumes a lack of culpability for illness that does not account for the stigma and blame that can attach to illness; it provides exemption from social roles whereas chronically ill individuals might opt to preserve roles, and it assumes a hierarchical doctor-patient relationship, whereas chronic management can involve shared information and decision making. The problem, for Charmaz, is that, 'An abstract role analysis fails to account for subjective experience and its meaning for patients' (1999:230). What Charmaz fails to note, however, is that it is difficult to expect any one role to cover the full spectrum of subjective experience and meaning for patients. Individuals occupy several roles simultaneously and although one role might be salient at a particular moment in time, illness identities are configured using numerous roles and numerous phenomena.

The links between illness, identity and human agency are bound up in day-to-day social interactions and their meanings are rendered precarious by the various physical and/or cognitive limits that chronic illness invokes. These limits are subjective in the sense that they are relative to the pre-illness self. In chronic illness, the numerous personal identities that constitute self and the socially induced meanings that attach to these identities, such as what it means to be male, a mother, a teacher, an employee and so on, are disrupted. Bury (1982) used the term 'biographical disruption' to describe how chronic illnesses induce a profound disturbance of the taken-for-granted aspects of everyday life that straddles cognitive and material

modes of thought and mobilises concerns about uncertainties, resources and lay and professional modes of thought (Bury 1982). In biographical disruption, it is difficult for self to remain intact.

Focusing on a sample of chronically ill males, Charmaz (1994) describes how the biographical disruption of illness induces dilemmas for self and identity. She notes the ways in which self consists of several personal identities, which for men, link to social networks of meanings that are bound up with masculinity, such as male athlete, the competitive businessman and the 'Viet Nam' veteran. Other identities, however, related to age, being a husband and so on. These identities are part of self and in chronic illness, are forcibly reassessed. For example, for heart attack or stroke patients, relatively simple everyday events, such as bathing and grooming, now had to be mastered; a situation that threatened their masculinity. Illness can also set limits on some identities, such as those that are tied to the labour market (Lalibert-Rudman 2002). People can also use illness identities as a reasoning strategy. For example, in Charmaz's (1994) study identities tied to the life-cycle were used to explain away illness as a mid-life crisis. In this respect, illness prompted the links between self and the ageing process; a process that has its own identity formations (Coleman 1996).

In illness, identities can unwittingly become reaffirmed. For example, Charmaz (1994) found that the identity of chronically ill married men was reinforced by the attention, comfort and care of their wives and families. This also reinforced their status within the household and their links with the pre-illness self, a feature not evident in the accounts of single men. On the other hand, an identity could become denied. Where individuals lost hope of influencing the degenerative course of illness and cognitively separated the illness from mainstream life, and thus from self, significant others could sometimes refuse to engage in this 'bracketing' (Charmaz 1994).

A problem of chronic illness for self and identity is the extent to which human agency can keep illness concealed by successfully accomplishing covering and passing. Scambler and Hopkins' (1985) subjects accomplished 'passing' by citing alternative reasons to epilepsy to account for why they could not drive; 'covering' was accomplished by referring to minor seizures as 'fainting fits'. In Charmaz's study one subject did not attend swim or cocktail parties in order to conceal his restricted diet and dialysis shunt (Charmaz 1994). Linked to passing and covering is the idea of 'information control', whereby parents of children with epilepsy did not use the term epilepsy outside the home environment to prevent the child's awareness of the social connotations of the term (Scambler and Hopkins 1985).

Visibility is a key feature for identity markers, which typically becomes a master status and a master identity. 'It is master status because this position overrides and subsumes others; it is a master identity because it defines every other identity' (Charmaz 1994:48). Even where physical or cognitive

subtly transmit social identity. 'Felt stigma' is more pervasive than 'actual' stigma because it is generated through shared meaning and renders individuals on constant guard.

In some circumstances an illness identity is readily accepted because of the secondary gains that it entails. On a basic level, these gains can include enhanced caring and attention of others and access to resources, such as financial or more suitable housing. Acceptance of an illness identity can also help individuals to accomplish successful social relationships. Scambler, for example (1991:190) notes Higgins' (1980) converse notion of avoidance, whereby individuals with hearing impairments extended their 'stigmatised' attribute by also acting mute as this permitted them to rely on the written word which eased social relationships.

Identity dilemmas described above appraise self in relation to past, present and future in a combination of ways. Armstrong and colleagues (1998), for example, describe how the process of genetic counselling which provides patients with a genetic identity, that in contrast to other identities, is an old one that is newly revealed; an identity that is reconstructed in the past as well as in the future. In contrast, Orona (1990) describes how Alzheimer's disease involves a loss of identity that results in a self that resides only in the current. In Alzheimer's the ability to recall past selves is lost, an event that also prevents the individual validating the identity of others.

A range of personal identities is tied to the very core of self. These identities are laden with social meanings. Chronic illness questions the claim to these identities. In males, for example, 'With each identity loss from chronic illness, preserving valued past "masculine" identities becomes more difficult' (Charmaz 1994:52). There are some suggestions that the impact of illness symptoms are evaluated in relation to their impact on the identities that individuals consider to be more salient, rather than in relation to pre-existing knowledge about illness representation (Levine and Reicher 1996; Levine 1999). This is an interesting point as it helps to indicate some of the ways in which individuals might refute a particular identity. For example, a study of disabled individuals found that the vast majority did not accept a disabled identity because impairment was not considered an important aspect of their sense of self or personal identity (Watson 2002). The crucial matter here is the extent to which individuals can successfully incorporate or challenge socially induced identities and where this is not possible, the extent to which individual agency can accomplish minimising or concealing techniques that forestall or prevent negatively attributed identities.

Conclusion

This chapter has appraised the links between illness and identity using the sociological concepts of self and identity in relation to biological and social

modes of being. The relationship between illness and identity is not unilinear; it is multiplex and relates to biological, social and physical worlds. In chronic illness, the self-persona, its presentation and public negotiation merge with these worlds through bodily attributions, socially structured institutions, 'doing' routines of daily interaction and through the resources of the material world. This idea captures the ways in which these worlds are saturated with identities. For 'normals', these identities often have a dormant quality. For individuals who experience chronic illness, however, their dormant status becomes volatile and their potential to actively impact on the lives of sufferers is intensified.

Previous attempts to understand the experiences of chronic illnesses, including the impact of deviant identities and statuses have used particular notions of an illness career (see, for example, Goffman 1961; Fabrega and Manning 1972). For Goffman, the term 'career' was bound up with the concept of institutionalisation and how experiences of hospitalisation, for example, strip individuals of a self. For Fabrega and Manning (1972), 'A career implies a potential beginning, intervening stages with distinctive properties, and equally important, an end' (1972:103). Whilst the career model of illness has been useful for gaining insight into a range of illness-related phenomena, illness identities do not reside solely in chronological time as implied by these models. Illness identities are constant features of biological, social and physical modes of being. They are malleable and constant, they exist in linear time and in social experience constructed and reconstructed in language and interaction. They develop out of experience and the constituent public and private identities, identity and self, themselves interact and evolve. The experience of illness, especially chronic illness, tends to exert a force that separates self and identity empirically as well as analytically. In understanding the tension between self and identity we are able to get a view of the experience of illness which captures the finer nuances of that experience and which helps to reveal the elemental nature of the biological, social and physical modes of suffering and say something quite profound about the very nature of human existence itself.

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The meaning of cancer: illness, biography and social identity

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Theoretical background

This chapter is an attempt to understand the narrative reconstitution of self for people facing advanced cancer, especially when the bodily integrity of self is threatened by terminal illness, marking the self as discontinuous and fractured. We then go on to explore how legitimacy of certain forms of practical strategies and symbolic styles (cf. Bury 2001) might be central to restoration of self and identity, enabling people to 'keep a narrative going' (cf. Giddens 1991) despite biographical discontinuities and disruptions. We also explain how claims to membership of an imagined moral community such as an ethnic group, often perceived as a well defined whole, might be fragile and rest on contested meanings and values underpinning illness narratives that are shaped by a complex interplay of biographical features of ethnicity, gender, age and socio-economic position. It is our contention that intersubjectivity of self, that cuts across ethnic, gender, age and class affiliations, is negotiated differently in relation to the uncertain and changing nature of the illness and treatment. Hence, both temporality and biographical context are central to how identities are threatened and/or maintained in the face of a life threatening illness.

We take the example of advanced cancer since it brings into sharp relief the notion of self as discontinuous at various levels, and how continuity is forged through particular narratives informed by larger discourses and collective representations to sustain particular identities. Our biographical approach (see Radley 1993; Williams 2000:53) can potentially address how a particular appropriation of an illness narrative might provide a critique of existing relationships and biographical circumstances, moving between the existential, inter-subjective, the cultural as well as structural dimensions of the illness (and caring) experience.

It is important, at this point, to reiterate the specificity of advanced cancer as a disease category before we move on to specific issues of illness and identity. Cancer shares much with other illnesses characterised by chronic, acute as well as terminal features where temporality is marked by

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