



HAL
open science

The illness experience: State of knowledge and perspectives for research

Janine Pierret

► **To cite this version:**

Janine Pierret. The illness experience: State of knowledge and perspectives for research. *Sociology of Health and Illness*, 2003, 25 (Silver anniversary issue), pp.4-22. hal-00195373

HAL Id: hal-00195373

<https://hal.science/hal-00195373>

Submitted on 10 Dec 2007

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.

**The illness experience:
State of knowledge and perspectives for research**

Janine Pierret

Centre de Recherche Médecine, Sciences, Santé, Société
CNRS/INSERM/ÉHÉSS, Paris

Abstract Over the last quarter century, research on the illness experience has thrived. Publications on this subject are reviewed in relation to three themes: subjectivity; coping actions and strategies for managing everyday life; and the social structure. *Sociology of Health and Illness* has contributed significantly to this field. In conclusion, research perspectives are suggested for tackling the problems in passing from a micro to a macro level of analysis.

Keywords: illness, experience, subjectivity, everyday life, coping, strategies, social structure.

Assessing the advances made in scientific research on a specific subject, namely the experience of illness and health, is a perilous task. But doing this to celebrate the 25th anniversary of *Sociology of Health and Illness* makes the venture even more hazardous. The writer is in jeopardy of failing to report as accurately as possible on the work accomplished. What if a major article were overlooked? What if the report were partial in both senses of the word? To quiet such worries, a procedure had to be found for obtaining consistent results; and an analytical framework, for organising them.ⁱ

Analytical framework and procedure

Since Strauss and Glaser's (1975) pioneering work, interest in studying the meanings and experience of chronic illness has grown, especially in British circles. This field of research has received substantial reviews in the United Kingdom (Anderson and Bury 1988, Bury 1991, Williams 2000) and United States (Conrad 1987, Roth and Conrad 1987, Charmaz 2000). Initial studies of the illness experience explored the patient's "subjectivity" and the meanings that individuals gave to their experience of illness through the metaphors, cognitive representations, and images that they developed after learning of their condition. These studies often centred around the notions of stigma, sense of shame and loss of self. For several years now, research in this field has been using "illness narratives", a phrase arousing much debate. A second point of focus has been how illness upsets patients' interactions with persons close to them and leads to organising family and occupational activities around it. All this has usually been grouped under the label of coping actions and strategies. A third focal point should be the interactions between the illness experience and the social structure, in particular the effects of the latter on former.

After having consulted major works in this fieldⁱⁱ as well as the articles published in two older journals — *Journal of Health and Social Behavior* and *Social Science and Medicine* — the contributions made by *Sociology of Health and Illness* were selected on the basis of their relevance to the following points: *a*) an *insider's orientation* that, in line with the perspective of the persons directly concerned (the patients or persons close to them: parents, spouses, etc.), leads to examining how these people live with and in spite of illness; *b*) a *chronic illness* that lasts long enough to become life itself — this excludes acute illnesses (Rier 2000); *c*) the *materiel, affective and subjective consequences* of the illness on how persons organise their lives and interpret what is happening to them.

The final selection, listed among those in bibliography, counts 47 articles and 2 review essays published in *Sociology of Health and Illness*.

Ray Jobling's editorial in the first issue of *Sociology of Health and Illness* in June 1979 insisted on the journal's international, multidisciplinary intentions. More than half the selection of publications on the illness experience come from Great Britain; and the others from Canada (7), the United States (4), Australia (2), the Netherlands (2), France (2), Israel (2), Belgium (1) and Sweden (1). Although most of these articles are sociological, the disciplines of social anthropology and public health are also present in this sampling. The huge majority of these publications report on the experience of a specific illness: epilepsy, Alzheimer's, rheumatism, polio, heart disease, cancer, HIV-infection, etc. Very few articles focus on the "health experience", even though, while making the selection, I took the term "health" in a very broad sense so as to include topics such as menstruation, abortion and breast-feeding. All these articles have an insider's orientation; and most of them analyse data from semi-directive interviews.

Given the regularity with which it has published articles of quality on the illness experience, *Sociology of Health and Illness* occupies a central place in this field. Its output can be compared with that of *Journal of Health and Social Behavior* and *Social Science and Medicine*. These two journals have, since 1955 and 1966 respectively, run articles in the behavioural sciences about social, psychological and biological factors in the aetiology and development of disease, but with a slant toward quantitative surveys. Although mention will be made of articles from these two other journals in relation to certain themes or periods of time, the focus will be on the *Sociology of Health and Illness's* contribution over the past 25 years to this field of research,.

Emergence of the illness experience in research

As attention was turning toward chronic illnesses, this field of research emerged in reaction to the Parsonian and interactionist approaches. During the 1960s and 1970s, several social scientists sought to clarify and broaden Parsons' (1951) conception of illness and the sick role (Berkanovic 1972, Gallagher 1976, Gerson 1976, Gerhardt 1979a). In the 1980s, studies on illness behaviour were still being conducted along the lines of these concepts (Alonzo 1984) but they now took into account social and demographic variables as well as factors such as stress, coping and life-events (Mechanic 1995). These studies dwelled on

the determinants of illness behaviour and on the quality of life; and devised scales, such as the “social readjustment rating scale”, for measuring behaviour. In parallel, sociological case studies were being made of how people lived with and made sense of conditions such tuberculosis (Roth 1963), polio (Davis 1963), visible disabilities (Goffman 1963) and dying (Glaser and Strauss 1965, 1968). This shift initiated new inductive analyses for moving from the individual, interactional level to the institutional level. Sociology, social anthropology, psychology and public health fostered studies of the illness experience, a topic reaching across the bounds of academic disciplines. Studies of long-term chronic conditions have come to prevail in this field.

As a journal of medical sociology, *Sociology of Health and Illness* evolved in parallel with the *Journal of Health and Social Behavior* and *Social Science and Medicine*, which dealt with similar themes but from different theoretical approaches. For instance, the meaning of illness was analysed with reference to causes (Cook Gotay 1985) and conceptualised by distinguishing between self and contextual meaning (Fife 1994). Another example of differences in theoretical approaches can be found in studies of stigmatisation. Albrecht *et al.* (1982) measured the perceived social distance between the stigmatised (deviants and disabled) and health professionals but from only the latter’s point of view; but this had little to do with the illness experience approach which seeks to understand the meaning of stigmata and their consequences for patients and persons close to them. In a special issue “Forty years of medical sociology”, *Journal of Health and Social Behavior* devoted one paragraph to the illness experience (Brown 1995: 45-47). Starting with the articles by Robinson (1990) and Kohler Riessman (1990) in a special issue edited by Gerhardt “Qualitative research on chronic illness”, *Social Science and Medicine* broadened its perspectives by, for example, running articles on narrative analysis in psychosocial research (Viney and Bousfield 1991), anthropology (Mattingly and Garro 1994) and sociology (Ezzy 2000, McIntosh and McKeganey 2000).

From its foundation in 1979, *Sociology of Health and Illness* showed special interest in questions of a theoretical or conceptual sort (*e.g.*, Gerhardt 1979*b*) and in qualitative studies (Williams 1981*a* and *b*). Pointed out for the first time by Gibbons (1980:349) in her review of Reynolds and Farberow’s, *Endangered hope: Experience in psychiatric aftercare facilities*, the illness experience perspective was then formulated and conceptualised by Bury (1982). That very same year, *Social Science and Medicine* published a special issue “Sociocultural factors in chronic disease” (McQueen and Siegrist

1982) and, a few months later, an article where Stewart and Sullivan (1982) raised questions about applying the sick role in cases of chronic disease and drew attention to the importance of negotiations in a less normatively controlled situation (the prediagnosis of multiple sclerosis).

Bury, however, stood out owing to his emphasis that chronic illness is an experience that disrupts the patient's everyday life and the forms of knowledge underpinning it. Bury analysed three aspects of what Giddens (1979) had called a "critical situation": "First, there is the disruption of taken-for-granted assumptions and behaviours; the breaching of commonsense boundaries. [...] Second, there are more profound disruptions in explanatory systems normally used by people, such that a fundamental re-thinking of the person's biography and self-concept is involved. Third, there is the response to disruption involving the mobilisation of resources, in facing an altered situation" (1982: 169-70).

Working on thirty semi-structured interviews with rheumatoid arthritis patients, Bury sought to discover how and when the first "signs" of this hard-to-detect condition were recognised. What was the status of the illness — was it a felt or diagnosed condition? How to recognise an illness with intermittent symptoms? How certain or uncertain was medical knowledge? By thus conceptualising disease as separate from the individual's self, Bury could inquire into the relation between causes and meanings. As we shall see however, uncertainty affects not just medical know-how but, in the case of chronic illness, the patient's whole life — uncertain symptoms, treatments with uncertain effects, uncertain durations. In relation to the socio-economic context, Bury analysed how patients mobilise resources and maintain normal activities and relationships (friends, family, occupations). In conclusion, he suggested seeing medicine "as a cultural system, as both an important resource to people in times of distress and pain and as a constraint in their search for the deeper meaning of experience" (1982: 179). Organised around, on the one hand, the illness context and, on the other, interactions between cultural factors as understood by professionals and lay persons, this framework has served as a reference mark for many other studies. Nonetheless little consideration has been given to the social structure.

The book Bury edited along with Anderson related the chronic illness experience to "environmental conditions, material resources and the demands of contemporary culture and social structure" (Anderson and Bury 1988:2). The themes running through this book are: stigmatisation, the impact of illness on family life and

employment, its effects on personal identities; the use of the health system; and medical regimens. The illness conditions that were studied included: stroke, Parkinson's disease, arthritis, heart attack, diabetes, epilepsy, rectal cancer, renal failure and psoriasis. These themes and illnesses would lie at the centre of the studies reported in the pages of *Sociology of Health and Illness*.

Given that “meaning and context in chronic illness cannot easily be separated”, Bury (1991: 453) tried to further develop his framework. For him, the social context of chronic illness corresponded to: health policy and the roles played by patients' associations, consumerism, charities and the media, which, for clarity's sake, I shall call the “social structure”. Bury (1991: 453) distinguished between two sorts of meaning: “In the first place, the ‘meaning’ of illness lies in its *consequences* for the individual [...] Second, the meaning of chronic illness may be seen in terms of its *significance*. By this I mean that different conditions carry with them different connotations and imagery”. Furthermore, he proposed making a clear distinction between three concepts often applied interchangeably to chronic illnesses: “coping” refers to cognitive processes; “strategy”, to the actions people take; and “style”, to the way people respond. Williams (2000) has discussed these ideas, and Sanders *et al.* (2002) have recently put them to use in empirical research. Although very few social scientists have strictly adhered to Bury's terminology, his framework will provide the outline for presenting my comments on articles in this field of research.

The subjectivity of the illness experience

The irruption of an illness leads patients and those close to them to ask questions about what is happening and to call in question ordinary explanations. This involves images, metaphors and other interpretative devices (Frankenberg 1986). This quest for meaning — Why me? Why now? — has been pursued in studies of the significance of illness and is central to inquiries into the illness experience itself. The consequences of illness on self and identity, on the loss of self or of control, on biographical disruption, and on identity and personal narratives are to be analysed. This inquiry into meaning does not, however, bar references to the discourse of medical professionals. In fact, personal accounts may well incorporate the latter, as illustrated by the “story genre” that women provided about

their menstruating bodies and wherein “me”, the “doctor” and “nature” were key figures (Bransen 1992).

Stigma and shame... borne not just by the patient

Interpretations of the meaning/significance of coming down with an illness have dwelled on the notions of shame and stigma. In his book review of Schneider and Conrad (1983), Williams (1984b) emphasised that it comes as no surprise that sociologists interested in the social construction of meaning have dwelled on stigmatised illnesses such as epilepsy. Differing with the standard point of view, which sees the public’s ignorance about epilepsy as the cause of its negative and discriminatory attitude toward persons suffering from this condition, Scambler and Hopkins (1986:33) reworked the idea of stigma so as to make it pertinent to their study of life with epilepsy: “Enacted stigma refers to instances of discrimination against people with epilepsy on the grounds of their perceived unacceptability or inferiority [...] Felt stigma refers principally to the fear of enacted stigma, but also encompasses a feeling of shame associated with ‘being epileptic’”.

Shame was central to interpreting the meaning both of Parkinson’s disease, as patients tended to withdraw from the “public domain” (Nijhof 1995), and of unwanted pregnancies, experienced as a rare event accompanied by feelings of lack of control and loss of status (Harden and Ogden 1999). In all cases, the “discredit” experienced by patients varies depending on the “discreditor”, as well as the circumstances and intensity of the “discredit” (Charmaz 1983). Discredit reaches beyond the patient and has repercussions on care-givers in the family and even on other family members. The stigma was borne by men as well as women in infertile couples (Greil *et al.* 1989) and by the parents (in particular, mothers) of autistic children (Gray 1993).

Social variables increasingly taken into account

Quantitative and qualitative studies have not taken social and demographic variables into account in like manner. Quantitative studies may use such variables to obtain a “sample” (whether representative or based on predefined quotas) of the population to be studied; and these variables are used, when analysing data, to stratify respondents or make log linear models. In qualitative surveys, persons may be recruited using criteria for ensuring social diversity; and the results may be interpreted by comparing two or three subgroups.

Qualitative studies have increasingly taken into account social variables. More and more of them examine how the patient's age, gender and social class affect the meaning given to illness and its consequences. Since Blaxter and Paterson (1982), the generation effect on the relations between women and health or illness have been well documented. Charles and Walters (1998) have laid emphasis on the generation variable in women's health experiences. Age and social class have been used to interpret the stroke experience — for elderly persons who had a hard life, "It's 'not so bad' and stroke is a normal crisis" (Pound *et al.* 1998). Arthritic symptoms were a "normal" and full part of biographies in old age (Sanders *et al.* 2002). Young people who were undergoing chelation therapy for thalassaemia major interpreted their treatment differently as a function of their age and ethnic group (Atkin and Ahmad 2000). By taking into account age, gender, class, ethnic group and social context, middle terms have cropped up for explaining the relations between meanings and consequences, since illness does not always lead to a loss of self or a biographical disruption (Charmaz 1983, Bury 1982).

For patients (the young in particular), maintaining meaning or finding a new meaning for their disrupted lives involves the quest to establish continuity as they learn how to cope with the illness by: redefining the self, reconstructing biographies or renegotiating identities (Mathieson and Stam 1995). When the patient's condition worsens and the body bears more and more marks (as in advanced cancer or incontinence in old age), the body's "boundedness" is menaced. For Lawton (1998), this experience of "bodies without boundaries" leads patients to a loss of self and affects their sense of identity. "Normalisation", a form of coping for Bury, entails either acting as if illness has no impact and thus putting it between parentheses, or else integrating it into one's life. Any illness that severely handicaps the person or is highly visible can become a source of tension between the person's private self and public social identity (Kelly 1992).

The linkage between meanings and consequences requires further study so as to take other factors into account: timing and context, norms and expectations, and the "emotionally expressive body" (Freund 1990, Kelly and Field 1996, Williams 2000). The complexity of this linkage can be seen in the case of ileostomy, an illness so serious that it affected the patient's "private self" by modifying the awareness of his/her body (Kelly 1992). Another example of this complexity has to do with what could more appropriately be called a health than an illness experience. It corresponds to a rather common situation that arises when feeding babies in a context where norms in general and those, in

particular, related to women working have thoroughly changed, but the degree of change depends on the social group. For some mothers, breast-feeding, confined as it is to the private domain of the household, has become a disrupted, disconnected experience with a loss of self (Schmied and Lupton 2001).

From personal accounts to illness narratives

Research on lay persons' beliefs and explanations and on the meanings of illness to them has been based on the "stories" or accounts collected during interviews. Prolonging work on "illness adjustment" (Radley and Green 1987), Radley (1989), a social psychologist, used the notion of style to refer to the forms or patterns in their accounts about how they cope with chronic illness. While discussing private and public accounts, Radley and Billig (1996: 222) stated, "People use health beliefs to make themselves accountable *to others* and to articulate *for others* their own position in the world." Given the quite particular context, "others" referred, here, to the social scientist conducting the interview. The whole set of conditions wherein interviews take place — the research program (for example, whether or not it is part of a medical protocol), its objectives, the interview itself, etc. — must be kept in mind while analysing patients' accounts. However studies have focused more on the "narratives" themselves than on the conditions underlying the research and their impact on the type of account furnished by the patient.

People's beliefs about the causes of their afflictions fit into a comprehensive process of "narrative reconstruction" in "an attempt to reconstitute and repair ruptures between body, self, and world by linking up and interpreting different aspects of biography in order to realign present and past and self with society" (Williams 1984a: 197). Since Williams, this theme has often had echoes, in particular among anthropologists (such as Kleinman 1988) and psychologists (such as Mishler 1986 and Radley and Billig 1996). Despite its various meanings (Hydén 1997), the "narrative" has acquired a key place in studies of the illness experience. For some, it refers to reconstructing a life story and a sense of self (Charmaz 1983); for others, questions of identity should now be subordinated to the concept of a "narrative" (Mathieson and Stam 1995). The "narrative" was also used to explain a collective experience via the accounts provided by individuals (Carricaburu and Pierret 1995).

Bury made this confused debate clearer by distinguishing between three forms of illness narratives. "Contingent narratives" have to do with "beliefs and knowledge about

factors that influence the onset of disorder, its emerging symptoms, and its immediate or 'proximate' effects on the body, self and others" (Bury 2001: 268). Such contingent narratives — or "illness as narrative" (Hydén 1997: 54) — tell how patients and those close to them have reckoned with the illness's symptoms and consequences. Bury (2001: 271) has referred to this as the practical and emotional consequences of managing symptoms in everyday life. "The moral narrative introduces an evaluative dimension into the links between the personal and the social" (Bury 2001: 274). Such a narrative presents moral (Williams 1984a, Pound *et al.* 1998) or religious (Greil and Porter 1989) considerations or tells about shame (Nijhof 1995) or blame (Pinder 1995). Finally, "core narratives" are brought to light by taking into account language, referents and symbols so as to identify a narrative's form — epic/heroic, tragic, comic, romantic. This third type of illness narrative might, in my opinion, lead to concentrating too intensely on the form with the risk of losing sight of the meaning.

Strategies of coping: The illness experience in everyday life

By upsetting everyday routines, becoming ill and being ill are causes of uncertainty for patients and those close to them. This uncertainty affect various activities or even the person's whole existence. Patients work out strategies for coping with this upheaval and use various resources to reorganise their lives. *Sociology of Health and Illness* has made an undeniable contribution to this discussion. By way of comparison, the other two journals of behavioural science mainly ran articles on stress, coping, life events and social support in relation to chronic illnesses and their consequences on behaviours. Although Gerhardt (1979b) had shown how conceptualising coping as a social action could help reconstruct the life-event approach, the illness experience was still being seen from a holistic perspective. This perspective, from the patient's viewpoint, focused on the diversity of experiences of living with illness: how are patients active in everyday life? How are their lives shaped by the social context? How do they help change this context?

Becoming ill and being ill

Becoming ill is the result of a rather long process wherein patients seek help, in particular medical help, for identifying the trouble. This can lead to difficult dealings with doctors (Pinder 1992). The medical profession and women's movements have debated the topic of menopause (Kaufert 1982), since its not very specific "symptoms" — mood swings, hot flashes, night sweats — may be set down to other causes (Ballard and Green 2001). A medical diagnosis might not tally with the patient's experience (Radley 1989). When it is not accepted (Pinder 1992), negotiations take place for the purpose of obtaining a less frightening diagnosis (Scambler and Hopkins 1986). An uncertain diagnosis, itself related to the state of medical knowledge, causes, once it has been made, uncertainty for the patient. How long will things remain uncertain? How will the illness evolve? Do treatments exist? Do they work? What will life be like from now on? Uncertainty about the medical diagnosis can plunge patients into "existential uncertainty" (Adamson 1997). In the late 1980s, announcing a positive HIV test amounted to delivering a death sentence with a short, uncertain time left for living (Weitz 1989, Crossley 1998, Pierret 2001).

As a consequence of being ill, everyday activities are threatened, and the persons risks being stigmatised. Managing the stigma entails working out strategies as a function of social circumstances and situations. A "felt stigma" more often precedes an "enacted stigma" rather than ensuing from it; and its consequences more seriously disrupt lives. It might be learned in the family (Scambler and Hopkins 1986) and give rise to strategies of "selective concealment" in the workplace or in relations with others. The disclosure of epilepsy might be made to "close friends" and future spouses in carefully thought out and staged circumstances, such as during trips or long moments spent with friends. In his study on epilepsy, Faircloth (1999:223) pointed this out while commenting on Susan's narrative, who had a "plan of disclosure well-articulated". John, another case covered by Faircloth, pursued a selective strategy with his doctor by reporting not all of his seizures but only those he thought the doctor needed to know. The family members of persons diagnosed with Alzheimer's disease adopted various strategies for coping with the stigma; some of them avoided stigmatisation — by covering up the discreditable condition, medicalising misbehaviour and condemning the condemners — while others did not (MacRae 1999). This study of the repercussions on the family interestingly points out that medicalisation provided a positive way to manage the stigma in the case of an illness with which the general public was not familiar.

A chronic illness's consequences on the organisation of everyday life vary depending on the seriousness of the condition and the patient's age (Locker and Kaufert 1988, Mathieson and Stam 1995, Pound *et al.* 1998, Atkin and Ahmad 2000, Sanders *et al.* 2002). A long-term illness usually entails "living a restricted life in social isolation and becoming a burden" (Charmaz 1983). Such changes might be independent of the sort of illness itself. They might be strongly felt in relationships during menopause (Ballard *et al.* 2001), but on the other hand, an HIV-positive test result might not lead to any major changes in life at the workplace (Crossley 1998, Pierret 2001). Yet another example, tensions might arise at work and undermine trust (Pinder 1995) or become so strong that patients withdraw from social relations and even from public (Nijhof 1995). This isolation was more intensely felt when the person lived alone or did not want to depend on relatives (Sanders *et al.* 2002).

Potential and actual resources

The impact of illness on everyday life has been at the centre of many studies that have focused on the resources that patients actually and potentially tap.

The chronic illness of one of its members impacts the family or household, and forces them to reorganise activities. The family undoubtedly represents the first line of affective and material support, essential to helping the patient cope with disruptions. The mother, wife or women in general are usually the primary care-givers when the patient is a child, spouse or sick parent (Gray 1993, MacRae 1999). Ailing elderly women had strong feelings about no longer being able to assume their roles as mothers, wives, daughters or workers (Charles and Walters 1998). The household shows even more concern when the patient needed assistance for the performance of everyday gestures (Pound *et al.* 1998, Sanders *et al.* 2002) or when life depended on techniques for which help was needed (Locker and Kaufert 1988). This support can lead to reorganising each household member's role and position (Radley 1989). Not enough research has been carried out on young patients, specifically on how they cope with overprotective parents so as to be able to lead a "normal" life (Atkin and Ahmad 2000).

A small number of articles in *Sociology of Health and Illness* have been devoted to self-help groups as resources for patients. Damen *et al.* (2000) have, in contrast, pointed to the gap between the informative and emotional aspects of self-help groups in the case of persons with breast cancer. Although some self-help organisations are caught up in a

tension between the individual and collective spheres, they provide an alternative to the medical viewpoint. As places where information circulates, they offer support that can help shape bonds of solidarity between patients or... that shut the ill up in their individuality (Williams 1989). In the case of the HIV epidemic, we have observed the transformation of self-help groups into patients' associations (Crossley 1998). The transition from a self-help movement to an organisation has opened new ways for patients to intervene in the media and with public authorities in the fight against stigmatisation. It has even enabled them to act on medical research and therapy.

In his book review of Schneider and Conrad (1983), Williams (1984b) expressed surprise about how little interest members of self-help movements showed in medical professionals. In line with Bury (1982), we wonder whether patients see medicine as a resource or constraint. Medicine is not just a "cultural system". It represents a mandatory reference to a body of knowledge and know-how, but it also refers both to a group of professionals with quite different educations and statuses and to the means for performing diagnoses and providing therapy, means based on an ever more sophisticated technology. In recent years, studies have focused on the place of medicine in the lives of the chronically ill. "Medical talk" became a full part of cancer narratives and helped people renegotiate their identity as patients (Mathieson and Stam 1995). In contrast, the judgmental, normative attitudes of some professionals negatively increase feelings of shame and guilt when young women, who already felt they had suffered a loss of status and of control over the situation, chose an abortion for unwanted pregnancy (Harden and Ogden 1999). For Crossley (1998), medicine represented a burden for the HIV-positive who refused the sick role with its duties and chose an "empowerment ethos".

Changes in medical technology that lead to a condition being seen as an illness can help patients in the fight against stigmatisation. Technological developments for treating infertility, for instance, have limited the effectiveness of religious values and explanations (Greil *et al.* 1989). Medicine gives the chronically ill reason to hope even as it produces limitations with which these persons have to live by making adjustments to meet everyday requirements. Breathing is taken for granted, but for people with post-respiratory poliomyelitis, this indispensable life-giving action became work. By comparing existing techniques (rocking beds, positive pressure machines with a mouth tube, or tracheotomies), light was shed on the strategies whereby patients made a "trade-off" in order to live with their condition. They thus "both solved problems and became problems for themselves and

their close associate” (Locker and Kaufert 1988:37). Chelation therapy for young people with thalassaemia major was not just a matter of compliance; it called for continually striking a balance between body, daily life, family relationships and self (Atkin and Ahmad 2000).

To cope with disruptions so as to live as normally as possible, patients have to tap existing resources or invent new ones (Carricaburu and Pierret 1995). Religion was a resource for young people who had to cope with demanding therapeutical practices (Atkin and Ahmad 2000). But what does living as normally as possible imply? What does it mean given ethnic origins or living conditions (Anderson *et al.* 1989) or “role-settings” in the couple (Radley 1989)? Other analyses of the consequences of chronic illness on everyday life have tried to relate “body condition” and “social constraints” via the notions of adjustment (Radley 1989) or strategies (Locker and Kaufert 1988).

The illness experience and social structure

This macrolevel of analysis has not been studied as much, and may well be the hardest to study. Here, the central question in sociology arises about the interrelation between subjectivity, cultural factors and social structure. Research on how the macrosocial level impinges on the illness experience must do more than simply examine social and economic factors; it must show how these factors shape the illness experience. This entails linking subjectivity, context and social structure.

The illness experience tells us much about the socioeconomic context wherein patients used to live and are living (Anderson *et al.* 1989, Pound *et al.* 1998). It also reveals how contemporary society views ageing (Sanders *et al.* 2002), the ageing body and the role of hospices (Lawton 1998). Although the medical orientation given to the quantitative data collected about health, the menstrual cycle, hormone replacement therapy and the experience of symptoms might have influenced women’s responses, their spontaneous comments showed that they placed menopause in the whole of their lives and saw it as marking a “change of life”. Midlife is an important stage “where a number of competing status passages are experienced”: care for elderly relatives, changes in employment or in marital status, etc. (Ballard *et al.* 2001: 420). Although roles in the couple and for sharing household tasks affect the adjustments made to illness in general (Radley 1989), the illness experience is also shaped by: health policies, the system of care,

the state of medical knowledge, patients' associations and the media. For instance, changes in hospital policy (reducing the number of beds, redefining long- and short-term stays, etc.) directly affect the type of admissions (Lawton 1998). The impact of medical technology on the patient's life ought, as Locker and Kaufert (1988) suggest, to be analysed in terms of patients' careers and quality of life. In discussions on the sick role and patient empowerment, or on the outsider/insider views of illness, Crossley (1998), insisting on the interactions between patients and medicine, has pointed out that the HIV-positive, whose lives so depended on advances in medical knowledge, played the role of informant with their doctors.

To assess the impact of the social structure on the illness experience, the factors (such as ignorance and fear) motivating stigmatisation must be analysed; and the effort, made to better understand the "stigmatisers" (MacRae 1999). However, national campaigns for fighting against stigmatisation have not always had the expected results (Navon 1996). The media's role should be evaluated given its more pressing impact on health matters, as it diffuses values and norms and presents new models of body and health. Discrimination against certain ill or disabled persons can be fought by proposing a "more discriminating approach to discrimination" itself so as to analyse "ambiguous relationships between physical differences and 'environments' as mutually constitutive" (Pinder 1995: 627-8).

Crossley (1998: 528) formulates the question of the relation between subjectivity and social structure in terms of "the need to 'go beyond' this individual perspective and take account of the potential implications for the wider 'social body'". However she has analysed only the limits of the empowerment discourse, which, undergoing institutionalisation, has shifted its accent toward individual freedoms and rights without raising the more general issue of the individual's duties and responsibilities and of the society's needs. Conducting an analysis in similar terms, Pinder (1995: 627), while recognising that the struggle for social and political rights is essential, has stated that full citizenship requires "a corresponding commitment to obligations and duties". To relate the microlevel of subjectivity and the macrolevel of social structure, inquiries must be made into the long-term illness experience as a function of various factors in the social structure. How do the organisation of care, the media attention given to illness, and patient movements and organisations affect the subjective experience of illness?

Research perspectives

As we have just seen, progress in studying the illness experience has been made over the past twenty-five years in the concepts used for referring to meanings, biographical disruptions, narratives, senses of self and identity, and coping. This oversight also provides us with a glimpse of the intensity and liveliness of the “body image” debate in the British context (Kelly and Field 1996, Williams 1996, Kelly and Field 1997) and of discussions of chronic illness as biographical disruption (Williams 2000).

As shown, themes have enlarged beyond the patient to cover the couple, household or primary social group; and more attention is being paid to the effects of age, gender, social class, ethnic group and the general context. Studies of the resources that the patient taps have also broadened, but work remains to be done on the role of patients’ organisations and the impact of the media. New challenges are arising for science as a result of the interrelations between subjectivity and the social structure. The sociology of illness can significantly contribute to sociology in general by focusing on the interrelations between biology, emotions and the body in the experience of illness and disability.

A range of illness conditions have been examined using qualitative data gathered through autobiographical (Adamson 1997) or case studies (Anderson *et al.* 1989, Pinder 1995, Faircloth 1999) or, even more often, through semi-structured interviews with small numbers of patients selected following definite procedures. Couples (Radley 1989, Greil *et al.* 1989, Gray 1993) and family members (MacRae 1999) have also come under study. Other methods have also been devised: long-term participant observation in care-giving centres (Lawton 1998), the quantitative analysis of spontaneous comments provided to questionnaires distributed year after year to large numbers of people as part of a longitudinal survey (Ballard *et al.* 2001), and freely given responses to twenty questions used to rate the degree of adjustment to illness (Radley and Green 1987). Nevertheless, the relation between in-depth-interviews and quantitative surveys is not always easy to establish (Pound *et al.* 1998), a difficulty undoubtedly linked to the problem of passing from the micro to the macro level of social analysis.

While working on the interrelations between subjectivity and social structure, questions crop up about whether research procedures and the data obtained enable comparisons over time and space. Comparisons over time necessitate time series and

follow-up surveys, as Ballard *et al.* (2001) have done by following over several years a single cohort and including open questions in their procedure, or as Bury (1982), Radley (1989), Anderson *et al.* (1989), Atkin and Ahmad (2000), and Schmied and Lupton (2001) have done by using qualitative methods based on recurrent interviews during the evolution of illness. Cross-sectional research, by studying the same illness condition several years later using the same methodology, can help shed light on how individuals' experiences differ as a function of social, political or other changes. I am thinking, for example, of how the HIV-positive manage since the introduction of antiretroviral treatments. Comparisons over space could arise out of studies of a single illness in social, economic and political structures that differ as to the organisation of care or the ethnic and social origins of patients. Two illness conditions could also be compared that, such as cancer and HIV-infection, contrast because patients' organisations or the media have reacted differently. Although research procedures do not solve theoretical problems as such, methodologies must be worked out so as to contribute toward the construction of a theory of the illness experience.

In all the studies reported herein, all results seem to end in the social structure as the problem to be analysed. The challenge is to define a paradigm and methodology for handling the problems related to the social structure. This entails working out theories about the interrelations, reciprocal effects and feedback between subjectivity, cultural factors and social structure.

References

From Sociology of Health and Illness

Adamson, C. (1997) Existential and clinical uncertainty in the medical encounter: An idiographic account of an illness trajectory defined by Inflammatory Bowel Disease and Avascular Necrosis, *Sociology of Health and Illness*, 19, 133-59.

Anderson, J.M., Elfert, H. and Lai, M. (1989) Ideology in the clinical context: Chronic illness, ethnicity and the discourse of normalisation, *Sociology of Health and Illness*, 11, 253-78.

Atkin, K. and Ahmad, W. (2000) Pumping iron: Compliance with chelation therapy among young people who have thalassaemia major, *Sociology of Health and Illness*, 22, 500-24.

- Ballard, K., Kuh, D. and Wadsworth, M. (2001) The role of the menopause in women's experiences of the 'change of life', *Sociology of Health and Illness*, 23, 397-424.
- Bransen, E. (1992) Has menstruation been medicalised? Or will it never happen..., *Sociology of Health and Illness*, 14, 98-110.
- Bury, M. (1982) Chronic illness as biographical disruption, *Sociology of Health and Illness*, 4, 167-82.
- Bury, M. (1991) The sociology of chronic illness: A review of research and prospects, *Sociology of Health and Illness*, 13, 451-68.
- Bury, M. (2001) Illness narratives: Fact or fiction?, *Sociology of Health and Illness*, 23, 263-85.
- Carricaburu, D. and Pierret, J. (1995) From biographical disruption to biographical reinforcement: The case of HIV-positive men, *Sociology of Health and Illness*, 17, 65-88.
- Charles, N. and Walters, V. (1998) Age and gender in women's accounts of their Health: Interviews with women in South Wales, *Sociology of Health and Illness*, 20, 331-50.
- Charmaz, K. (1983) Loss of self: A fundamental form of suffering in the chronically ill, *Sociology of Health and Illness*, 5, 168-95.
- Crossley, M. (1998) 'Sick role' or 'empowerment'? The ambiguities of life with an HIV-positive diagnosis, *Sociology of Health and Illness*, 20, 507-31.
- Damen, S., Mortelmans, D., and Van Hove, E. (2000) Self-help groups in Belgium: Their places in the care network, *Sociology of Health and Illness*, 22, 331-348.
- Faircloth, C.A. (1999) Revisiting thematisation in the narrative study of epilepsy, *Sociology of Health and Illness*, 21, 210-27.
- Freund, P. (1990) The expressive body: A common ground for the sociology of emotions and Health and illness, *Sociology of Health and Illness*, 12, 452-77.
- Gerhardt, U. (1979b) Coping and social action: Theoretical reconstruction of the life-event approach, *Sociology of Health and Illness*, 1, 195-225.
- Gibbons, J. (1980) Review of D.K. Reynolds and N.L. Farberow, *Endangered hope: Experience in psychiatric aftercare facilities*, London: University Press of California, 1978, in *Sociology of Health and Illness*, 2, 349.
- Gray, D.E. (1993) Perceptions of stigma: The parents of autistic children, *Sociology of Health and Illness*, 15, 102-20.

- Greil, A.L., Porter, K.L., Leitko, T.A. and Riscilli, C. (1989) Why me? Theodicies of infertile women and men, *Sociology of Health and Illness*, 11, 213-29.
- Harden, A. and Ogden, J. (1999) Young women's experiences of arranging and having abortions, *Sociology of Health and Illness*, 21, 426-44.
- Hydén, L.C. (1997) Illness and narrative, *Sociology of Health and Illness*, 19, 48-69.
- Kaufert, P. (1982) Myth and the menopause, *Sociology of Health and Illness*, 4, 141-66.
- Kelly, M. (1992) Self, identity and radical surgery, *Sociology of Health and Illness*, 14, 390-415.
- Kelly, M.P. and Field, D. (1996) Medical sociology, chronic illness and the body, *Sociology of Health and Illness*, 18, 241-57.
- Kelly, M.P. and Field, D. (1997) Body image and sociology, a reply to Simon Williams, *Sociology of Health and Illness*, 19, 359-66.
- Lawton, J. (1998) Contemporary hospice care: The sequestration of the unbounded body and 'dirty dying', *Sociology of Health and Illness*, 20, 121-43.
- Locker, D. and Kaufert, J. (1988) The breath of life: Medical technology and the careers of people with post-respiratory poliomyelitis, *Sociology of Health and Illness*, 10, 23-40.
- MacRae, H. (1999) Managing courtesy stigma: The case of Alzheimer's disease, *Sociology of Health and Illness*, 21, 54-70.
- Mathieson, C. and Stam, H.J. (1995) Renegotiating identity: Cancer narratives, *Sociology of Health and Illness*, 17, 283-306.
- Navon, L. (1996) Beyond constructionism and pessimism: Theoretical implications of leprosy destigmatisation campaigns in Thailand, *Sociology of Health and Illness*, 18, 258-276.
- Nijhof, G. (1995) Parkinson's disease as a problem of shame in public appearance, *Sociology of Health and Illness*, 17, 193-205.
- Pierret, J. (2001) Interviews and biographical time: The case of long-term HIV nonprogressors, *Sociology of Health and Illness*, 23, 159-79.
- Pinder, R. (1992) Coherence and incoherence: Doctors' and patients' perspectives on the diagnosis of Parkinson's disease, *Sociology of Health and Illness*, 14, 1-22.
- Pinder, R. (1995) Bringing back the body without the blame? The experience of ill and disabled people at work, *Sociology of Health and Illness*, 17, 605-31.

- Pound, P., Gompertz, P. and Ebrahim, S. (1998) Illness in the context of older age: The case of stroke, *Sociology of Health and Illness*, 20, 489-506.
- Radley, A. (1989) Style, discourse and constraint in adjustment to chronic illness, *Sociology of Health and Illness*, 11, 230-52.
- Radley, A. and Green, R. (1987) Illness as adjustment: A methodology and conceptual framework, *Sociology of Health and Illness*, 9, 179-207.
- Radley, A. and Billig, M. (1996) Accounts of Health and illness: Dilemmas and representations, *Sociology of Health and Illness*, 18, 220-40.
- Rier, D.A. (2000) The missing voice of the critically ill: A medical sociologist's first-person account, *Sociology of Health and Illness*, 22, 68-93.
- Sanders, C., Donovan, J. and Dieppe, P. (2002) The significance and consequences of having painful and disabled joints in older age: Co-existing accounts of normal and disrupted biographies, *Sociology of Health and Illness*, 24, 227-53.
- Scambler, G and Hopkins, A. (1986) Being epileptic: Coming to terms with stigma, *Sociology of Health and Illness*, 8, 26-43.
- Schmied, V. and Lupton, D. (2001) Blurring the boundaries: Breast-feeding and maternal subjectivity, *Sociology of Health and Illness*, 23, 234-50.
- Williams, G. (1984a) The genesis of chronic illness: Narrative re-construction, *Sociology of Health and Illness*, 6, 175-200.
- Williams, G. (1984b) Review of J.W. Schneider and P. Conrad, *Having epilepsy: The experience and control of Illness*. Philadelphia: Temple University Press, 1983, in *Sociology of Health and Illness*, 6, 371-7.
- Williams, G. (1989) Hope for the humblest? The role of self-help in chronic illness: The case of ankylosing spondylitis, *Sociology of Health and Illness*, 11, 135-59.
- Williams, R.G.A. (1981) Logical analysis as a qualitative method I: Themes in old age and chronic illness, *Sociology of Health and Illness*, 3, 140-164.
- Williams, R.G.A. (1981) Logical analysis as a qualitative method II: Conflict of ideas and the topic of illness, *Sociology of Health and Illness*, 3, 165-187.
- Williams, S.J. (1996) Medical sociology, chronic illness and the body: A rejoinder to Michael Kelly and David Field, *Sociology of Health and Illness*, 18, 699-709.

Williams, S.J. (2000) Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept, *Sociology of Health and Illness*, 22, 40-67.

From other sources

Albrecht, G.L., Walker, V.G., Levy, J.A. (1982) Social distance from the stigmatized: A test of two theories, *Social Science and Medicine*, 16, 1319-1327.

Alonzo, A. (1984) An illness behavior paradigm: A conceptual exploration of a situational-adaptation perspective, *Social Science and Medicine*, 19, 499-510.

Anderson, R. and Bury, M. (eds.) (1988) *Living with chronic illness. The experience of patients and their families*, London: Unwin Hyman.

Berkanovic, E. (1972) Lay conceptions of the sick role, *Social Forces*, 51, 53-64.

Blaxter, M. and Paterson, E. (1982) *Mothers and daughters: A three-generational study of health attitudes and behaviour*, London: Heinemann.

Brown, P. (1995) Naming and framing: The social construction of diagnosis and illness, *Journal of Health and Social Behavior*, special issue "Forty years of Medical Sociology", 35-42.

Charmaz, K. (2000) Experiencing chronic illness, in G.L. Albrecht, R. Fitzpatrick and S.C. Scrimshaw (eds.) *The handbook of social studies in health and medicine*, London: Sage Publications, 277-92.

Conrad, P. (1987) The experience of illness: Recent and new directions, in J.A. Roth and P. Conrad (eds.) *Research in the sociology of health care: The experience and management of chronic illness*, Vol. 6 Greenwich, CT: JAI Press, 1-32.

Cook Gotay, C. (1985) Why me? Attributions and adjustment by cancer patients and their mates at two stages in the disease process, *Social Science and Medicine*, 20, 825-831.

Davis, F. (1963) *Passage through crisis: Polio victims and their families*, Indianapolis, IL: Bobbs-Merrill.

Ezzy, D. (2000) Illness narratives: Time, hope and HIV, *Social Science and Medicine*, 50, 605-617.

Fife, B.L. (1994) The conceptualization of meaning in illness, *Social Science and Medicine*, 38, 309-316.

- Frankenberg, R. (1986) Sickness as cultural performance: Drama, trajectory, and pilgrimage root metaphors and the making social of disease, *International Journal of Health Services*, 16, 603-626.
- Gallagher, E. (1976) Lines of reconstruction and extension in Parsonian sociology of illness, *Social Science and Medicine*, 10, 207-218.
- Gerhardt, U. (1979a) The Parsonian paradigm and the identity of medical sociology, *Sociological Review*, 27, 2, 229-251.
- Gerson, E. (1976) The social character of illness: Deviance or politics?, *Social Science and Medicine*, 10, 219-224.
- Giddens, A. (1979) *Central problems in social theory*, London: Macmillan.
- Glaser, B. and Strauss, A. (1965) *Awareness of dying*, Chicago: Aldine.
- Glaser, B. and Strauss, A. (1968) *Time for dying*, Chicago: Aldine.
- Goffman, E. (1963) *Stigma*, Englewood Cliffs, NJ: Prentice Hall.
- Kleinman, A. (1988) *The Illness narratives: Suffering, healing and the human conditions*, New York: Basic Books.
- Kohler Riessman, C. (1990) Strategic uses of narrative in the presentation of self and illness: A research note, *Social Science and Medicine*, special issue, "Qualitative research on chronic illness", 30, 1195-1200.
- Mattingly, C. and Garro, L. (eds.) (1994) Narrative representations of illness and healing, *Social Science and Medicine*, special issue, 38, 771-860.
- McIntosh, J. and McKeganey, N. (2000) Addicts' narratives of recovery from drug use: Constructing a non-addict identity, *Social Science and Medicine*, 50, 1501-1510.
- McQueen, D. and Siegrist, J. (eds.) (1982) *Sociocultural factors in chronic disease*, a special issue of *Social Science and Medicine*, 16, 353-498.
- Mechanic, D. (1995) Sociological dimensions of illness behavior, *Social Science and Medicine*, 41, 1207-1216.
- Mishler, E.G. (1986) *Research interviewing: Context and narrative*, Cambridge: Harvard University Press.
- Parsons, T. (1951) *The social system*, Glencoe, Il: Free Press.

- Robinson, I. (1990) Personal narratives, social careers and medical courses: Analysing life trajectories in autobiographies of people with multiple sclerosis, *Social Science and Medicine*, special issue, "Qualitative research on chronic illness", 30, 1173-1186.
- Roth, J. (1963) *Timetables*, New York: Bobbs-Merrill.
- Roth, J. and Conrad, P. (eds.) (1987) The experience and management of chronic illness, in J.A. Roth and P. Conrad (eds.) *Research in the sociology of health care: The experience and management of chronic illness*, Vol. 6 Greenwich, CT: JAI Press, 1-32.
- Schneider, J.W. and Conrad, P. (1983) *Having epilepsy: The experience and control of illness*, Philadelphia: Temple University Press.
- Stewart, D.C. and Sullivan, T.J. (1982) Illness behavior and the sick role in chronic disease. The case of multiple sclerosis, *Social Science and Medicine*, 16, 1397-1404.
- Strauss, A. and Glaser, B. (eds.) (1975) *Chronic illness and the quality of life*, St. Louis: Mosby.
- Viney, L and Bousfield, L. (1991) Narrative analysis: A method of psychosocial research for AIDS-affected people, *Social Science and Medicine*, 32, 757-766.
- Weitz, R. (1989) Uncertainty and the lives of persons with AIDS, *Journal of Health and Social Behavior*, 30, 270-281.

Notes

ⁱ I could not have conducted this study satisfactorily without the help of Prof. Joseph Lévy of the University of Quebec in Montréal (UQAM), who did the library research, and of Christiane Fiset, a student at UQAM, who photocopied the articles. I warmly acknowledge my indebtedness to them. I would also like to thank Isabelle Baszanger and the reviewers for their comments on preliminary versions. This article has been translated from French by Noal Mellott (CNRS, Paris).

ⁱⁱ In particular: Fitzpatrick, R., Hinton, J., Newman, S., Scambler, G. and Thompson, J. (1984) *The experience of illness*, London: Tavistock; Conrad, P. and Kern, R. (eds.) (1986) *The Sociology of Health and Illness. Critical perspectives*, New York: St Martin's Press; the collection *Research in the sociology of health care* (especially volume 6 on *The experience and management of chronic illness*, 1987, edited by Roth and Conrad); Anderson, R. and Bury, M. (1988) *Living with chronic illness: The experience of*

patients and their families, London: Unwin Hyman; Gerhardt, U. (1989) *Ideas about illness: an intellectual and political history of medical sociology*, New York: New York University Press; volumes 1 and 2 of *Advances in medical sociology*, edited by G. Albrecht; Charmaz, K. and Paterniti, D. (1999) *Health, illness, and healing: Society, social context and self, an anthology*, Los Angeles: Roxbury Publishing Company; and, more recently, Albrecht *et al.* (2000) *Handbook of social studies in health and medicine*, London: Sage Publications.