

Illness and narrative

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Abstract The article gives a review of the last ten years' of research on illness narratives, and organises this research around certain central themes. Four aspects of illness narratives are discussed: 1. a proposed typology giving three different kinds of illness narratives – illness *as* narrative, narrative *about* illness, and narrative *as* illness; 2. considerations of what can be accomplished with the help of illness narratives; 3. problems connected with how illness narratives are organised; and 4. the social context of telling and its influence on the narrative. It is argued that as social scientists we can use illness narratives as a means of studying not only the world of biomedical reality, but also the illness experience and its social and cultural underpinnings.

Keywords: narrative, illness experience, medical sociology, voice.

Introduction

The speech of patients has traditionally been accorded a somewhat ambiguous status in modern biomedicine. Doctors from the turn of the century onwards have been inclined to treat the reports of their patients with considerable scepticism. The clinical gaze of the medical profession was focused on the inner bodily world of the patients. How patients spoke about their ills, symptoms and problems was regarded as best as a pale reflection of the language of the organs and tissues and their pathological changes (see Armstrong 1984). And yet, doctors had to depend on these reports in order to investigate and diagnose the disease.

This sceptical attitude to the speech and narrative activity of patients was adopted by social scientists in their studies of the social reality of biomedicine and illness. When such studies were first initiated, the biomedical definition and conception of illnesses constituted the natural starting point. The patient's views and actions were linked to this conception by means of terms like 'illness-behaviour' or 'lay-perspective'. Then,

when a distinction was made between illness and disease, the possibility opened up for the study of the patient's speech acts as an integral and important part of the course of the illness. And then, when the focus of attention shifted from the illness to the accompanying suffering and its transformation in diverse social contexts, the foundation was laid for conceiving the patient's speech acts as a voice that was strong enough to stand up against the voice of medicine.

One of our most powerful forms for expressing suffering and experiences related to suffering is the narrative. Patients' narratives give voice to suffering in a way that lies outside the domain of the biomedical voice. This is probably one of the main reasons for the emerging interest in narratives among social scientists engaged in research on biomedicine, illness and suffering.

The aim in the present article is to give a review of the last ten years' of research on illness narratives and to relate this research to certain central themes. To begin with, the development of the interest in illness narratives is traced and the relationship between illness and narrative is discussed. Thereafter, there is a discussion of illness narratives in four respects: 1. a proposed typology giving three different kinds of illness narratives – illness *as* narrative, narrative *about* illness, and narrative *as* illness; 2. considerations of what can be accomplished with the help of illness narratives; 3. problems in connection with how illness narratives are organised; and 4. the social context of telling and its influence on the narrative.

Narratives in social and medical science

The increasing reference to narratives in social scientific studies of medicine and illness is a specific example of the widespread interest in narratives now being shown by the social science community. A debate that has sprung up in recent years, particularly among philosophers, has concerned the possibility and value of grand theories and grand narratives. A number of authors have pointed out that the old grand narratives – the theories of Marx and Marxism to give an example – are no longer able to formulate and express experience and knowledge in a world that is becoming increasingly fragmented, polycentric and mobile (Lyotard 1984). This development is paralleled in the field of medical studies by doubts about the possibility of biomedicine to explain and cure illness and relieve suffering.

The philosophers Taylor (1989) and MacIntyre (1982), and others like them, argue that we create frames for understanding and judgement and link them to the everyday circumstances of our lives by drawing on diverse moral and political discourses. The narrative's importance lies in its being one of the main forms through which we perceive, experience, and judge our actions and the course and value of our lives.

Social scientists began to consider narratives as one of the ways in which we create and give meaning to our social reality. To earlier generations of social scientists, the narrative was merely one of many forms of representation (Somers 1994). Little interest was attached to the narrative *per se*, rather its value lay in the knowledge it could generate about the reality 'behind' the narrative. The more recent conception of narratives posits that it is 'through narrativity that we come to know, understand, and make sense of the social world' (Somers 1994).

Consequently, the interest of researchers concerned with narratives and narration is being focused on *how* people talk about and present events – and not only on *what* is said. There is a growing conviction that the narrative is not merely a more or less transparent and neutral medium for conveying something that lies beyond language and the story (Riessman 1993, Bruner 1990, Geertz 1983). Rather, the form of the narrative, its presentation and organisation, also conveys something of the self-image that the narrator hopes to convey to others:

The stories people tell are important not only because they offer an unmatched window into subjective experience, but also because they are part of the image people have of themselves. These narrative self-representations exert enormous power. They shape how we conduct our lives, how we come to terms with pain, what we are able to appropriate of our own experience, and what we disown – at the familiar price of neurosis. (Ochberg 1988)

The narrative concept has come to be used in a variety of ways (for a review, see Mishler 1995) and contexts (for a review, see Somers 1994). In general, most researchers define the narrative as an entity that is distinguishable from the surrounding discourse and has a beginning, a middle and an end. A narrative can be understood in a highly specified sense, for example as two or more time-regulated sentences that depict ordered temporal events (Labov 1972). Other researchers share the view that the life history interview, to give one example, can be seen as a type of narrative that is seldom well demarcated, but is nevertheless defined and held together by common themes that unfold in relation to time (Agar 1982, Mishler 1986). Common to most definitions of the narrative is an emphasis on the temporal ordering of events that are associated with change of some kind.

When the narrative concept first began to appear in studies of medicine and illness at the beginning of the 1980s, it was generally subordinated theoretically to concepts like identity and self. Today, in the mid-1990s, the place of illness narratives in the work of medical sociologists and anthropologists is undisputed. In almost every issue, leading journals in the field like *Sociology of Health and Illness* and *Culture, Medicine, and Psychiatry* include articles dealing with narratives and narrativisation. In

the past ten years or so, the use of the narrative concept in the field of medicine and illness has changed in at least three respects: thematically, theoretically and methodologically.

Thematically, interest in the narrative has shifted since the beginning of the 1980s; today less attention is being given to its use in the study of the clinical practice and experiences of doctors and more to patients' experience of suffering.

Traditionally, the act of narrating as part of clinical practice has been a focal point for observations and discussion (Berger and Mohr 1967, Cassell 1985, Slaveney and McHugh 1984, Charon 1986). The 1970s saw a growing interest in narratives in connection with attempts to formulate a hermeneutic position on medical science and the patient. Several authors suggest that we conceive the patient as a text that can be 'read', which actualises the narrative perspective (Daniels 1986, Gogel and Tery 1987). From a more critical perspective, written narratives in the form of medical case journals have been studied in order to understand how first of all doctors construct patients as part of the social reality (Barrett 1988, Brown 1993, Stoeckle and Billings 1987, Hydén 1997).

Narratives have gained importance in the study of chronic illness as a means for understanding the attempts of patients to deal with their life situations and, above all, with the problems of identity that chronic illness brings with it. Bury (1982) points out in an early article that especially chronic illness can be looked upon as a disruption of a person's ongoing life, thereby also entailing a disruption of the person's identity. Chronic illness alters the relationship between the patient's body, self and surrounding world. Thus, for the chronically ill, the reconstruction of one's own life story is of central importance (Williams 1984). Narrativising the chronic illness within the framework of one's own life history makes it possible to give meaning to events that have disrupted and changed the course of one's life (see also Williams 1993, Bury 1991).

By directing attention to the aspect of *suffering*, Kleinman, in his book *Illness Narratives* (1988), has given the narrative concept a broader definition. For Kleinman the narrative is the form in which patients shape and give voice to their suffering. In the 1990s a number of writers – Frank (1995) among them – have shown how narratives not only articulate suffering but also give the sufferer a voice for articulating the illness experience apart from how illnesses are conceived and represented by biomedicine.

Theoretically, the narrative concept formerly occupied a peripheral position in the social scientific study of illness. Today it plays a far more central role in that it captures central aspects of illness experiences and their social contexts.

In earlier studies the illness narrative itself was a secondary concern. The main focus was on other aspects such as how narratives figure in the identity-work of chronically ill patients, and whether doctors engaged in

clinical work can, through illness narratives, become better able to attend to what their patients say. But just as narratives gradually came to occupy an increasingly centralised position in social science generally, so also has their importance in illness research grown. A central aspect of the narrative concept is that, besides being an important knowledge form, it is able to represent and reflect illness experiences in daily life. Today the narrative concept enjoys the pivotal position once assigned to concepts like identity – it could even be argued that the identity concept has become subordinate to the narrative concept (see for example Mathieson and Stam 1995).

The growing theoretical importance of the narrative concept in the field of illness research is most probably a reflection of the change and expansion of the illness concept towards a greater emphasis on suffering as a point of departure in social scientific studies of illness. This makes it possible to study the patient's illness experience and illness world as a social reality apart from the conception and definition of illness as formulated by biomedicine.

Methodologically, earlier views on illness narratives were based on the idea that identity could be conceived in terms of one individual life history. We have become increasingly aware, however, that situational factors play a decisive role in the construction of narratives and that we continually produce new narratives in new contexts. Thus, it seems all the more evident that it is not a question of *the* narrative, but rather of different possible narratives which are determined by situational factors, particularly by the interaction between narrator and listener. Several writers have shown how factors of this kind may affect the way in which the illness is presented (Clark and Mishler 1992).

Narrative and illness

Any illness constitutes a disruption, a discontinuance of an ongoing life (Bury 1982). The current of daily life is obstructed, perhaps blocked altogether. Illness may revise our conceptions of what is changeable, and we may be forced to change the premises upon which we plan and evaluate our lives (Charmaz 1992).

Acute illness, in the best of cases, has only a temporary significance in our lives: it constitutes a transitory and limited disruption; an acute illness may cause us to re-examine our lives in the light of our own frailty. Chronic illness, on the other hand, usually changes the very foundation of our lives because the illness creates new and qualitatively different life conditions. Our range of options no longer seems so wide and varied, we may be forced to look at the future from a totally different angle. Thus, even the past acquires new meaning: as a part of lived life.

All types of illnesses thus affect one of the fundamental aspects of life – its extension in time, its temporality. The experience of continuity and

inner coherence is called into question, perhaps becoming invalid altogether. Illness can be experienced as a more or less external event that has intruded upon an ongoing life process. At first, the illness may seem to lack all connection with earlier events, and thus it ruptures our sense of temporal continuity – and if the rupture is not mended, the fabric of our lives may be ripped to shreds (Bury 1982).

It is in this context that narratives become particularly interesting. Narratives offer an opportunity to knit together the split ends of time, to construct a new context and to fit the illness disruption into a temporal framework. Narratives can provide a context that encompasses both the illness event and surrounding life events and recreates a state of interrelatedness. The French philosopher Paul Ricoeur, expresses this sentiment when he says that ‘time becomes human to the extent that it is articulated through a narrative mode, and the narrative attains its full meaning when it becomes a condition of temporal existence’ (1984:52). In other words, narratives recreate a temporal context that had been lost, and thereby takes on meaning as part of a life process.

Depicting illness in the form of narratives is a way of contextualising illness events and illness symptoms by bringing them together within a biographical context. By weaving the threads of illness events into the fabric of our personal lives, physical symptoms are transformed into aspects of our lives, and diagnoses and prognoses attain meaning within the framework of personal life – what Early (1984) calls the ‘customisation’ of the illness. Narrativising illness enables other people to comment on the narrative and to offer new interpretations and suggestions. Thus, narratives serve as arenas or forums for presenting, discussing, and negotiating illness and how we relate to illness. By means of the narrative mode it becomes possible to articulate various events and to discuss their meaning.

Types of illness narratives

Illness narratives are concerned – in a broad sense – with illnesses, illness episodes, or illness experiences, and even with experiences considered to be unhealthy. Narratives can be constructed and presented by the person who is ill, by his or her family, or by the medical professional. The common denominator is the narrative’s theme, namely, illness.

The typography of illness narratives I am suggesting here differs from that of, for example Frank (1993, 1994, 1995) and Robinson (1990). Frank classifies illness narratives in accordance with three ‘storylines’ (‘restitution’, ‘chaos’, and ‘quest’) which he has identified and which typify the understanding of the illness, its course and process and its relation to a person’s own life (Frank 1995). A similar scheme is proposed by Robinson (1990) who has identified three different life trajectories in illness narratives (‘stable’, ‘progressive’ and ‘regressive’). Part of the problem

with this kind of typology is that it is based on a limited set of narrative genres ('progressive', 'chaos') and on a meta-narrative on illness: from 'chaos' to 'quest'.

The typology being suggested here is based on the *formal* aspects of illness narratives, namely the relationship between narrator, narrative and illness. There are at least three ways in which narrator, illness, and narrative may be interrelated, resulting in three *types* of illness narratives: illness *as* narrative, narrative *about* illness and narrative *as* illness.

In the first case, narrator, illness, and narrative can be combined in one and the same person. The illness is expressed and articulated in and through a narrative. The narrative plays a central role both in the occurrence of the illness and in shaping the manner in which it impinges on the life of the individual. In a sense, we could say that the illness *is* the narrative. This kind of illness narrative closely resembles what is usually called 'personal experience narratives' (Labov 1972). That is to say, the narrative depicts events that have been experienced personally and pose problems for the individual in one way or another. The narrative is thus a way of integrating or solving the problems that confront us.

The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering . . . The personal narrative does not merely reflect illness experience, but rather it contributes to the experience of symptoms and suffering. (Kleinman 1988:49).

The illness narrative makes it possible to integrate the symptoms and the consequences of the illness into a new whole. This whole becomes part of a new social reality, a new world of illness.

In the second case, the narrative is primarily *about* the illness – that is, the narrative conveys knowledge and ideas about illness. Examples are situations in which doctors and other professional care staff talk *about* the patient's illness. Several authors (for example, Brody 1987 and Hunter 1991) have suggested that the narrative has a central place in medicine as a means of formulating and conveying clinical knowledge. Illness narratives that focus on unusual or deviating clinical images of illness throw into relief those aspects of the narrative that are concerned with describing the illness within the framework of particular types of illnesses and the typical forms of their appearance, but also with a practical or instrumental attitude to the illness (Hunter 1986).

Brody (1987), like Sacks (1993), emphasises the importance of the illness narrative as a means by which doctors acquire a more detailed clinical picture of the patient. The medical practitioner must become versed in the patient's narratives, not only in order to make a correct diagnosis, but also in order to propose a treatment programme that is acceptable to the patient. Becoming acquainted with the patient's illness narratives also plays an important role in determining how the communication between

doctor and patient develops (Clark and Mishler 1992), and how the patient experiences the information conveyed by the doctor (Lind *et al.* 1989, Good *et al.* 1994).

Third, there is narrative *as* illness, by which is meant situations in which a narrative, or an insufficient narrative, generates the illness. A case in point is the patient suffering from a brain injury which impedes his/her ability to use the medium of the narrative to connect experiences with particular events. Another example is the patient who lacks sufficient narrational means for expressing or articulating past or present experiences and events.

Neurologist Oliver Sacks (1985) describes the case of a patient who had developed Korsakow syndrome as a result of brain injury and thereby lost the ability to formulate narratives. Instead, he was forced to constantly invent new stories in an attempt to create a context for his actions and his self. This is an example, not of narrative *about* an illness, but of narrative *as* illness.

Psychoanalyst Roy Schafer (1983, 1992) points to the same phenomenon when he defines the central problem of neurotic people as being their struggle to understand their lives through narratives that exclude central events in their lives. It may be events from early childhood (abuse, for example), or an inability to understand actual events and experiences (such as phobias), or an overpowering sense of one's future as being totally bereft of possibilities and choices (as in depressive states). In each case, the person's narratives are inadequate to articulate events and experiences, and it is this lack that is the basis for the suffering. Similar ideas have been advanced by Shay (1994) and Herman (1992) in the interpretation of psychological trauma, and by Capps and Ochs (1995) in their analysis of agoraphobia.

What can the illness narrative accomplish?

A tradition in narration research is to explore narratives in terms of the written, literary and formalised story. Focusing on the oral narration of illnesses reveals the narrative in its aspect of social event (Mattingly 1994). An important question in this connection is what does the narrative accomplish, both with respect to the individual's interaction with others and to his or her construction of social realities.

Here, five uses that can be made of the illness narrative are highlighted: 1. to transform illness events and construct a world of illness; 2. to reconstruct one's life history in the event of a chronic illness; 3. to explain and understand the illness; 4. as a form of strategic interaction in order to assert or project one's identity; and lastly, 5. to transform illness from an individual into a collective phenomenon.

1. *The narrative construction of an illness world*

The symptoms and consequences of illness, such as the loss of functionality, are not purely objective phenomena, but rather are phenomena that take on meaning for each individual: 'The illness is experienced by the patient not so much as a specific breakdown in the mechanical functioning of the biological body, but more fundamentally as a disintegration of his "world"' (Toombs 1988). The narrative provides a medium whereby we can articulate and transform the symptoms and disruptions of illness into meaningful events and thus relate them to our lives and life courses. Through the narrative, the experience of illness is *articulated*, especially the suffering associated with illness. By arranging the illness symptoms and events in temporal order and relating them to other events in our lives, a unified context is constructed and coherence is established.

In this sense, then, the illness narrative creates something *new* – it does not merely reflect a self-perpetuating pathological process. What is new is that suffering is given a form. That is to say, the illness is articulated and positioned in time and space, and within the framework of a personal biography. The narrative transforms symptoms and events into a meaningful whole, thereby creating the world of illness (Radley 1993).

One example of this is how patients who suffer from chronic pain use narratives to give form and meaning to their experiences (Good 1992, Garro 1994). Through the use of the narrative form, the pain is given a specific starting point and the circumstances precipitating the outburst of pain are delineated. The unfolding of pain and its everyday consequences are portrayed in small examples and stories depicting its invalidating aspects. And finally, by assigning possible outcomes of the pain in terms of, for instance, successful treatment, the longed-for cessation of pain is envisaged.

2. *The narrative reconstruction of life history*

Chronic illness forces us to face fundamental existential, moral, and psychological issues – these overshadow the whole of our lives and call into question our individuality, competence, identity and life projects. We are forced to revise our personal identities and life histories in terms of the illness. In that sense, illness narratives are concerned to a great extent with change, with the *reconstruction* of identity and personal life (Frank 1993). The American sociologist Charmaz (1983) goes so far as to speak of a 'loss of self', particularly in connection with chronic illness. This loss is accompanied by fundamental changes in the individual's life and life style: increasing physical handicap, declining capability, or extreme sensitivity to certain chemical substances or certain types of social situations.

Our efforts to create continuity in our life histories, or to 'reorient' ourselves when our lives have been disrupted by particular events, can be summarised as the attempt to *reconstruct* our personal life histories

(Williams 1984). By uncovering a means of interpreting the illness, we become better able to re-establish the relationship between the self, the world and our bodies. Thus, the narrativised reconstruction is concerned with two things: first, with gaining meaning and import to the illness by placing it within the context of one's own life; and second, with reconstructing the narrative of the self.

The illness becomes an epiphany, that is to say, a repetitive event around which all change revolves and where cause is situated. In some respects, it could be said that in this kind of illness narrative, life is seen in the light of the illness. The illness is the vantage point from which all other events are viewed and to which all other events are related. The reconstruction of the narrative of one's life and the ego follows a series of rhetorical patterns (Frank 1993, Hydén 1995b), showing how, for example, the self in the narrative undergoes change and how continuity is maintained or a change is produced.

An example of narrative reconstruction is how athletes with career-ending injuries describe the loss of their identity as active athletes (Brock and Kleiber 1994). In an analysis of these narratives, Brock and Kleiber show that the athletes present their injuries as being related to their sport activities in order to maintain a connection between their present life and their former sports career.

To be an athlete means to participate in an activity that engages several other persons, such as coaches and trainers. It also means being the centre of attention for these and other persons. In that sense, to be an athlete is to be part of a collective endeavour. An injury is something that befalls the individual athlete and threatens his identity. It is important for the athlete to be able to show, with the help of a narrative about the injury, that it was directly caused by sports events and that the injury can be seen and inspected by others. In that way it is possible for athletes to maintain both their identities as sports persons and their relationships to significant others in the world of sports.

3. *The narrative explanation and understanding of illness*

The illness event poses a series of questions for the individual: Why me? Why was I the one afflicted? How will the illness affect the functioning of my body? We seek to understand the causes of the illness and to relate the illness to our personal lives. We also seek to establish some kind of practical relationship to the illness, that is to say, to deal with the practical problems caused by the illness. The illness narrative can be seen in this context as a medium for *discussing* possible *explanations* for the illness and perhaps even for finding a *way of relating* to the illness. The discussion of the causes of the illness and how the illness affects the life of the afflicted is concerned with linking individual symptoms and the individual context with a shared cultural context (Garro 1994, Good and Good 1994). The anthropologist E.A. Early has pointed out that an

important aspect of the illness narrative is that it deals with practical ways of relating to illness, what Early calls the therapeutic narrative about how to confront the illness. Such narratives are based on cultural ideas.

The therapeutic narrative employs the web of common-sense explanations that links the unique, somatic event with shared cultural knowledge about illness. These explanations serve both to evaluate therapeutic activities and to make sense of experience. They situate illness within the socio-economic reality which sets the parameters of therapeutic action. (Early 1984).

Illness narratives can, in other words, incorporate and build upon cultural ideas about the causes of illness and about the illness itself as a way of transforming the illness into a part of one's own life – something which also makes the illness part of the shared culture. In this respect, illness is also concerned with shared cultural ideas and conceptions, illness models that are used in the construction of the illness narrative. These are then tested in order to 'customise' (Early 1984) the illness, to transform it into a part of one's own life and culture.

But illness can also be discussed in terms of moral causes, that is to say, in relation to our earlier lives. The event of an illness forces us to ask ourselves if there is a connection between the illness, on the one hand, and our moral values and how we live our lives, on the other. The very fact of the illness forces us to evaluate our lives in moral terms (Hydén 1995a, Williams 1993). Causes of this kind are concerned not so much with cultural factors as with examining our own lives within the framework of our life histories, in order to see what kinds of circumstances, actions and attitudes on our part may have influenced or given rise to the illness.

The illness narrative as a moral testing of our basic moral premises is concerned with finding a framework within which the illness can be discussed. That is to say, we test various hypotheses for the onset of the illness: for example, illness as a genetically determined and therefore unavoidable event, or illness as an event caused by our own negligence or attitudes to life (smoking, for example) and which has been proved to have had negative consequences.

An example of this is the case of a former psychiatric patient who was treated in hospital for long-term depression and survived several suicide attempts; the man struggled to understand the 'causes' or reasons for his problems (Hydén 1995a). To him a central question was to what extent he himself was responsible for his situation or whether there were causes outside his control. This concerned both his moral responsibility for his depression and suicidal behaviour, and the question of whose moral standards he was trying to emulate.

By telling narratives about his parents and his family, he examines his own suffering from different perspectives: as a disease inherited from his

father's side of the family; as a result of his own all-too high expectations of himself and his own abilities; or as a result of trying to live up to his mother's high expectations of him with respect to his academic career and social success. In his narrative the different perspectives are brought together in an ongoing dialogue with himself and others about his precarious life situation.

4. *The narrative as a strategic device*

Illness narratives can, in some contexts, be used as *strategic narratives*. That is to say, they can be used to achieve certain effects in the social interaction. Baruch (1981) shows how parents of children who have fallen ill can construct narratives about the maltreatment their children suffered at the hands of care professionals in order to assert their own moral value as parents or to justify their own actions. Dingwall (1977) has shown how different groups of professional staff use the same kind of narrative in order to assert their own positions and knowledge in relation to professional people who occupy positions above them in the medical hierarchy.

Descriptions of illness can also be used for strategic purposes, for example in order to excuse or explain actions or behaviour, Riessman (1989, 1990) has shown how men and woman in the process of divorce can seek to excuse their behaviour by blaming it on illness. In their narratives the men in the study made use of a shared cultural conception of illness as something that befalls one, thereby attempting to disclaim any responsibility for their actions in connection with the divorce.

5. *Transforming individual experience into collective experience*

Traditionally, illness narratives concern the *individual's* experience of illness. But AIDS, which to a large extent is a form of epidemic that often afflicts people who have a marginal standing in society, poses the question of whether the narrative is able to *collectivise* the illness experience and asks what are the social implications of illness. An early example of this kind of endeavour is the book by Irving Zola, *Missing Pieces* (1982), in which he traces the relationship between his own life, disability and the collective experience of being disabled.

In their analysis of men living in France who have been diagnosed as HIV-positive, Carricaburu and Pierret (1995) show how these men reconstruct their identities and incorporate the cultural experiences of homosexual men into their life histories. Other researchers have shown that in the narratives of people with AIDS, the social consequences of the illness are given prominent importance (Viney and Bousfield 1991, Marshall and O'Keefe 1994). The illness experience is removed from the private sphere and becomes a part of an all-encompassing, political and social narrative and context. Through the narrative, the illness experience becomes a collective experience.

Illness narratives about AIDS differ in this respect from narratives about pain where the central theme seems to be the search for an opportunity to articulate one's experience and to find ready listeners (Hilbert 1984, Brodwin 1992).

Telling about illness and organising the narrative

To tell something means to relate an ordered sequence of events to one or more listeners. The narrator selects certain events and arranges them in such a way as to form a whole – with a beginning, a middle and an end – that is imbued with meaning. To listen to the narrative is to take an active part in its construction in order to be able to understand what it is all about and how it can be expected to develop. The narrator creates the 'plot' and the listener tests various ways of listening to and understanding 'the unfolding story' (Bruner 1986).

Literary and cultural conventions help both narrator and listener to construct the narrative. One such instrument is genre (Bakhtin 1986). A research worker in comparative literature, Anne Hunsaker Hawkins, has shown that there is a common pattern to many illness narratives (Hawkins 1990, see also Robinson 1990 and Frank 1994). She calls such narratives *pathographies* which, in her view, constitute a separate narrative genre. Pathographies are, quite simply, patients' narratives about their illnesses and their struggles to overcome them. Of central importance in these narratives is the concept of 'regeneration'; that is to say, the patient has suffered a severe crisis in life and come through it, emerging as a new or regenerated human being. The narratives were divided as a rule into three parts: 1. the time before the onset of the illness, which more often than not was marked by an unhealthy life style and a rejection of the whole tenor of one's life; 2. the onset of the illness and the illness crisis, which has now become a matter of life or death; and 3. regeneration, the resolution of the crisis and the emergence into a new life with a new appreciation of the world.

Hawkins's thesis is that narratives of this kind have replaced earlier stories of religious conversions which depict how a 'sinner' has met God face to face, undergone conversion and now lives a God-fearing life (Hawkins 1990). Furthermore, such narratives also extend back to an ancient Christian narrative pattern. In this, after having first lived a life of sin, there comes the realisation of its sinfulness, and the experience of regret and awakening to a new life. (Freccero 1986). What Hawkins is referring to here is the narrator's ability to make use of established genre and narrative techniques in order to configure his or her life and illness in culturally recognisable and acceptable patterns.

Like many life histories, illness narratives are by nature ambiguous because they do not have a clear and foreseeable *end*. It has frequently

been pointed out that narratives always presuppose an end: the end must be known in order to know the middle and the beginning. In other words, the ending gives meaning and orientation to a narrative, and makes it possible to arrange events in a particular order and in accordance with their inherent relationship, and to separate the essential from the non-essential.

Good (1994) has pointed out that a central problem in illness narratives is that they often lack an ending in the sense that when a person falls ill or contracts a chronic illness, how the situation will develop is largely unknown: will the illness lead to death, to slow deterioration or to eventual recovery? The absence of an ending makes it difficult to evaluate and understand illness symptoms and illness events because there is no temporal horizon to give them meaning.

When events are rearranged to fit into the narrative mode, a 'plot' is created. Written narratives, that is to say formal narratives, often have a given 'plot' which the reader looks for. What characterises the oral narrative, however, engendered as it is and presented in social interaction, is that both the narrator and the listener are active participants in the creation of an *emplotment* (Mattingly 1994). That is to say, both are looking for a way to understand and articulate the illness and the illness events as a meaningful whole.

The lack of an 'ending' gives rise to a central problem with respect to illness narratives: they are narratives forever in search of meaning. This means that, in contrast to many other kinds of narratives, the illness narrative builds upon and relies on the possibility of a new or different ending, which means in turn that the illness narrative is always ambiguous, a continual negotiation (Good 1994). In that sense, illness narratives are constantly changing and being renegotiated, depending on changing perspectives and other changes in the illness process.

Emplotment is also a useful tool in therapeutic work (Mattingly 1991, 1994). Occupational therapists, doctors and others can actively 'struggle to shape therapeutic events into a coherent form organised by a plot' (Mattingly 1994). An example is when seemingly everyday repetitive and tedious events (work training, memory training) are given new meaning by linking them to ongoing therapeutic treatment. A treatment whole is created in which separate events become linked and thus acquire new meaning, thereby making them endurable. It is also possible through 'therapeutic emplotment' to change the patient's time horizon. By establishing a link between the course of the illness and concomitant medical intervention and thereby establishing a time horizon for the illness, hope of a possible cure, and thereby the continuation of life, may be engendered (Good *et al.* 1994).

Still another aspect of this problem in connection with illness narratives has to do with formulating the narrative perspective or the 'narrative's voice'. It is striking that in illness narratives the narrator tries to depict his/her illness from two diametrically opposed perspectives: an illness

perspective and the perspective of the healthy person (Wiltshire 1994, Ingram 1991). Often the narrator vacillates between these two perspectives in one and the same illness narrative.

To speak in the illness voice is to depict the illness 'from the inside', from the vantage point of the suffering person's ongoing situation. To speak in the illness voice is to identify with the illness and accompanying suffering. It is to talk like a person who is, in fact, 'ill'. To speak in the voice of the healthy is to talk about the illness as something extraneous, something that has invaded one's life from the outside; or also it is to talk about something that has been, something that had befallen one earlier in life.

Examples of this way of shifting between different perspectives or formulations of the narrator's voice can be found in most descriptions of psychosis, dating from the early 1700s to the present (Ingram 1991). In some narratives, the narrator speaks 'from inside' the psychotic world and relates experiences and suffering from the vantage point of the psychotic world. Other narratives depict the psychosis from the perspective of recovery, and the psychotic experiences are interpreted or given meaning in the light of the actuality of the individual's recovery.

The choice of perspective and formulation of the narrator's voice can also be seen as the narrator's struggle to define how his/her illness narrative is to end. As Good (1994) points out, this is exactly what characterises the illness narrative.

The narrative in a social context

Illness narratives can be found in a range of social contexts, all of which determine in different ways who narrates for whom, and for what purposes. Both narrator and listener may find themselves in what is usually called *institutional contexts*, that is to say, in a medical care environment, or something of the kind (Agar 1985). It can also be a clinical situation in which a patient tells the doctor or the therapist about his/her illness symptoms or problems in order to obtain confirmation of the experience or to seek help. Professionals in various institutional contexts make use of illness narratives when they talk with each other about their patients or clients. Illness narratives also occur in *everyday contexts*, for example when a person in daily life tells someone else about his/her illness (Early 1984). Lastly, illness narratives occur in various kinds of *elicited contexts*, for example when a researcher asks interview subjects for narratives dealing with illness or some such similar event.

In the study of illness narratives – and other forms of narratives for that matter – it is important to distinguish between different narrative contexts because the context influences the narrative's form, presentation and interpretation. Unfortunately, studies in which illness narratives are situated in a wider social and cultural context are quite rare (see, however, Good and Good 1994, Hunt 1994, Mathews *et al.* 1994).

The encounter between patient and doctor takes place in an institutional context. The clinical encounter is generally structured in such a way as to hinder the patient from relating his/her illness narrative. Mishler (1984) has expressed this problem as the conflict between the 'voice of medicine' and the 'voice of the lifeworld'. In the interaction between doctor and patient, the patient has difficulty in making the voice of the lifeworld heard because it is the doctor who dominates the interaction. In order for the patient to be able to present his/her illness in this setting, there has to be a realignment of the social relationship typically enacted in the clinical encounter, such that the doctor becomes a more active listener and encourages the patient to speak (Clark and Mishler 1992, Mishler *et al.* 1989).

Mishler and his co-workers have shown that patients, in their interaction with the doctor, construct, broadly speaking, two kinds of narratives. The traditional rendition of the illness is in the form of a chronicle in which various illness symptoms are positioned in a temporal context. Against this, there is the narrative which in addition to having temporal context also links this context to the patient's own action to remedy it and to the patient's experience of the illness. In the language of this review, it is possible to conceptualise this as a conflict between narratives *about* illness, as something promoted by the biomedical context, and illness *as* narrative, furthered by the lifeworld context of the patient.

How the doctor relates to the narrative told by the patient is crucial. The patient seeks to find an explanation for and to understand his or her illness in order to find an ending for the illness narrative. In this endeavour the doctor is pivotal to the patient (Good, M-J. *et al.* 1994, Cassell 1985). This is apparently an important therapeutic goal of the medical interview. The different ways of conducting the clinical interview also affect the rest of the medical investigation and the kind of treatment programme devised. Treatment can be understood as being either a continuation within the framework of the patient's illness narrative, or as something that the doctor brings in from the outside (Long 1986, Brody 1994).

In everyday contexts the primary goal of illness narratives seems to be to communicate and negotiate the world of illness, the afflicted's pain and suffering, and the possible causes of the affliction (Early 1984). It is the illness *as* narrative that is in focus. The narrative depiction of the illness makes it possible to share the illness experience with other persons and to discuss possible interpretations of the illness. Remedies can be suggested and discussed.

In the research interview as an example of an eliciting context, a central problem is whether the interview subject presents a narrative *about* illness or a narrative *as* illness. The ambition of research interviewers is generally to elicit an illness narrative reflecting the lifeworld of the patient and not different biomedical explanations of the illness (Mishler 1986).

Final comments

The narrative is one of several cultural forms available to us for conveying, expressing or formulating our experience of illness and suffering. It is also a medium for conveying shared cultural experiences. This review of how social scientific studies of illness and biomedical studies, undertaken during the past ten to fifteen years, have made use of the narrative concept indicates that there is wide variety of *types* of narratives and similarly that narratives can have widely divergent *functions*.

Illness narratives are encountered in different *forms*, as oral narratives or as written, textual narratives, and in various (social) forums ranging from contexts in which experience is made communal through collective oral narratives to individualised narrative situations, as in interviews and medical examinations or during self-reflection. The form of the narrative, and the forum in which it is related are subject to historical and temporal changes – which underlines that both the narrative and the telling of it are linked to social and cultural contexts.

Illness narratives have different functions: to construct an illness experience, to reconstruct life history, to make disease and illness understandable, and to collectivise the illness experience. It has also been indicated in this review that a main characteristic of illness narratives is that they formulate and express a central aspect of being ill in modern society, namely the difficulty of giving voice both to suffering and to the lifeworld context of illness. This is clearly expressed by Frank (1994) when he argues that modern illness narratives are built around three central tensions: first, to gain a public voice in order to relate a private experience; second, to sustain the primacy of one's own voice in relation to the voice of medicine; and third, to balance the illness experience against the scheme of one's own life.

This review would seem to indicate that research into illness narratives is still in its infancy. Little research has been devoted to making comparative studies of the different cultural patterns of illness narratives (an exception is Good 1994), just as there are few studies of the relationship between grand narratives about illness as conveyed by, for example, the mass media and illness narratives constructed by the afflicted themselves. Few comparative studies have been made of the illness narratives of patients exposed to different kinds of suffering. Only a few studies have been made of the relationship between how biomedicine represents illness and the narrative representation that develops in the interchange between doctor and patient. And there have been hardly any comparative studies at all over time, and of how illness narratives may vary depending on the social context. Naturally there are many more unexplored areas of inquiry that could be added to this list.

The advantage of studying illness narratives is that they make it possible to study the experience of illness from a number of vantage points: as

a social and cultural construct, as a transformation and expression of bodily suffering, and most of all as the suffering person's attempt to construct his or her world, to find his or her own life-work and life context.

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