

Narrative and Experience: Telling Stories of Illness

Jennifer M. Levy

*Department of Anthropology
McMaster University*

Abstract

Narratives of illness have a central role in medical anthropology and have illuminated the personal and social experience of suffering. Problematizing the relationship between narrative and experience, narrative is viewed not simply as a reflection of experience. Illness narratives are seen as intersubjective products that create meaning and coherence in an otherwise fractured life. Moreover, narratives are not simply about what was, or what is, but about what will be. Thus, narratives create experience and are directed toward future action in the world.

Introduction

In this paper, I focus on the experience of being ill and the way in which individuals come to tell of those experiences through narrative. Narratives have had a central place in anthropology. While not always explicitly studied as such, a great deal of the cultural material that anthropologists gather come to them through the stories people tell about themselves and their societies (Garro and Mattingly 2000:4). In times of illness, individuals are particularly inclined to tell stories about their suffering and the location of their present experience within their life. Not solely about narrative, this paper is also about experience. However, the relationship between experience and narrative is not unproblematic. What narrative is and the relationship between narrative and experience is taken up and elaborated throughout this paper and is the focus of the first section of this paper. As a starting point, however, I offer a view of narrative not simply as a story about what was, or about what is, but about what will be. Narratives create experience and are directed toward future action in the world. Therefore, narrative is not seen simply as a reflection of experience nor is it simply a text. Rather, narrative is seen as an intersubjective product that creates meaning and coherence in life.

The desire to narrate one's experiences is not particular to illness,

however, narratives seem to flow more rapidly, and urgently, in times of crisis. Indeed, being out of the ordinary is a major element of what makes a story and, moreover, what makes a story worth telling (Linde 1993).

Labov's research (Garro and Mattingly 2000:3) on storytelling among urban youth in the United States shows that narrative must answer the implicit question "so what?" without it ever having to be asked. Beyond storytelling, narrative also plays a role in making sense out of the unexpected, and in giving shape to untoward events. As I elaborate in the second section of this paper, narrative is viewed as a way in which individuals come to understand their experiences in the world and share these with others.

Narrative, however, should not be viewed exclusively as an individual enterprise. Narrative is grounded in cultural understandings of what it means to live, experience, and be ill.

This is particularly illuminated by research reviewed in the third section of this paper, which focuses on commonalities in stories of illness. Narratives of illness experience have a central role in medical anthropology. (Cain 1987 Ezzy 2000, Davies 1997, Frank 1995, Good 1994, Steffen 1997). While cautious not to be overly deterministic, these works clearly articulate the relationship between culture and the experience of illness. Striking similarities in the way stories are told bring attention to issues of power, structure, and agency and the potential use of narrative as a form of control.

Finally, in the fourth section, I examine narrative as oriented toward the future. Thus, storytelling is performative. In this process, storytellers aim to become the narratives they tell about themselves. The action-orientation of narrative makes it possible to reshape the life course. This is done through attempting to influence the behaviour of others through narrative and also in resisting one's location in the life world. Illness, as a liminal period, and narrative, as essential in the construction of self and in the presentation of self to others, create an opportunity for fundamental change.

Narrative

Within anthropology and life in general, the experiences of others come to us predominantly in the form of narrative. Ochs and Capps describe narrative as a "fundamental genre in that it is universal and emerges early in the communicative development of children" (Ochs

and Capps 1996:19). While Wikan may argue that it is “story” which is experience-near and universal – “only academics can find narrative” (Wikan 2000:217) – “story” or “narrative” has a well-established place in anthropology. Kleinman’s (1988) book on illness narratives marks the importance of narrative for medical anthropologists (Steffen 1997:99). In medical anthropology, narratives of illness have illuminated the personal and social experience of illness and suffering.

The proliferation of interest in narrative, however, is not accompanied by any consensus regarding what narrative is or how it should inform theory and method. There is even criticism that narrative has been given an inordinate place in studies of illness at the expense of observation. Wikan relays, “I have deplored the downplayed role of observation in making sense of a person’s experiences, arguing that we need observation of real-life events to anchor and also offer resistance to person’s telling-it-as-it-was” (Wikan 2000:220-221). Wikan’s position raises questions about the nature of narrative and its association to experience. Recognition of the questionable relationship between experience and narrative has led to a profusion of approaches to narrative. In a review article on narrative, Peacock and Holland (1993) differentiate the dominant approaches to the study of life story and narrative as a “life” versus a “story” focus. At one end of the “life”/“story” spectrum, narrative is considered a perfect window on experience, at the other end there is no reality save narrative itself. The divide, of course, is not as stark as the dichotomy presented. Below, I outline the various perspectives on the relationship between life and story, experience and narrative.

Theories that propose a close relationship between life experience and narrative can be differentiated in terms of those that focus on the representational quality of narrative and those that argue for a semiotic structure to life.

The “life” or “mimetic” approach to the study of narrative is concerned with what the narrative tells us about life, critics label this perspective “naïve realism” (Mattingly 2000:183). Within this approach, narrative is seen to have a tight grasp on the “reality” of life. Two formulations within the “life” focused approach highlight the two different realities accessible through narrative (Peacock and Holland 1993). The first of these is interested in accessing events external to the narrator; that is, objective facts about the world. The second is interested in the subjective experience of narrators in their

lived life. Whichever is emphasized, “a presumed reality external to the narration is paramount” (Peacock and Holland 1993:369).

Lived experience and narrative also have a close relationship for those who argue that cultural action plays out pre-existing cultural scripts or narrative texts. This is sometimes referred to as a semiotic approach to narrative. Narrative, within this perspective, is not a retrospective approach to life but, rather, a script that guides lived life and meaning making. Good (1994:88-115), for example, explores the complex semiotic relations of a young woman’s complaint of rectal bleeding. Based in her Jehovah’s Witness belief system she symbolically opposes “blood as the essence of life” and “blood as filthy” (for a second example see Littlewood 1983).

The anti-mimetic or “story” focus, labelled the formalist perspective by Peacock and Holland (1993), attends most directly to the form of the narrative itself rather than approaching it as a window on experience. This approach criticizes naïve realism by arguing that life is simply not like narrative. Those who focus on the correspondence between life and experience, this position argues, do not attend to the constructed nature of narrative. Indeed the very nature, or art, of a good story is “its capacity to dramatically transform lived experience” (Mattingly 2000:183). One fundamental component of narrative is plot, which is dependant on a beginning, middle, and end. Indeed, it is knowledge of the end that shapes the story, including, what is told and what is left out (Mattingly 2000:184). While life also has a chronology, it does not have a plot and is missing a clear ending. Life, unlike narrative, also lacks a narrator. “It is the narrator’s vision of events that allows for narrative configuration. When narrative theorists describe narrative as something told rather than lived, they especially have in mind the function of the narrator as arbitrator of perspective” (Mattingly 2000:185). Narrative, therefore, has more coherence and order than life. In life individuals are better viewed as characters in a story or readers of it than the narrators. Thus, there is both a gap, between life as lived and narrative, and a distortion. Narrative theory understands narratives as “fictions” – constructing, rather than referring, to a world (Mattingly 1994:811).

A number of medical anthropologists interested in and utilizing narrative approaches are aware and critical of the way in which some manifestations of narrative analysis, particularly those most concerned with narrative as text, undermine the importance of the social and

performative elements of narrative (Mattingly 2000; Wikan 2000). They claim that narrative simplifies social action and is blind to non-verbal forms of communication and meaning. Performance approaches instead focus on context dependent action and are concerned with the specificities from which action is derived. The performance approach gains strength from phenomenology and both have a particularly strong critique of semiotic analysis. Csordas writes,

The dominance of semiotics over phenomenology, and hence concern with the problem of representation over the problem of being-in-the-world, is evident in the relation between the parallel distinction between 'language' and 'experience'... I would argue that the polarization of language and experience is itself a function of a predominantly representationalist theory of language. One need conclude neither that language is 'about' nothing other than itself, nor that language wholly constitutes experience, nor that language refers to experience that can be known in no other way. One can instead argue that language gives access to a world of experience in so far as experience comes to, or is brought to, language.

(Csordas 1994:11)

For phenomenologists, such as Csordas, language and experience both emerge from being-in-the world and, thus, language is experience near. Moreover, what the phenomenological approach offers to medical anthropology and the study of narrative is the way in which narratives are embodied and spoken through the body (Frank 1995:2). Performance and phenomenological approaches will be elaborated below as synthetic approaches to narrative and experience.

Peacock and Holland (1993) propose a dialectical approach, which they term "processual," to the study of narration. "The telling of life stories, whether to others or self alone, is treated as an important, shaping event in social psychological processes, yet the life stories themselves are considered to be developed in, and the outcomes of, the course of these and other life events" (Peacock and Holland 1993:371). This approach variously emphasizes narrative as (1) a culturally mediated phenomena important in psychological processes and self-formation; (2) important in the "formation and maintenance of social relationships and collective identity;" (3) a product of interaction between narrators and listeners; and, (4) an outcome of cultural and collective dynamics and a "gripping formulation of beliefs, values, and ideas basic to a cultural tradition" (Peacock and Holland 1993:371-373). In the processual view, narrative is never static; rather, it is an active process central to human development.

An example of a processual approach comes from the cognitive psychologist Jerome Bruner (1987). Bruner proposes narrative as the only descriptive possibility for lived time and sees a two-way mimesis between “life so-called and narrative.” Therefore, just as narrative imitates life, life also imitates narrative (Bruner 1987:13). Bruner’s approach is grounded in the hypothesis that narrative is a fundamental mode of cognitive functioning and that “world making” is the principal function of the mind (Ochs and Capps 1996:26). Bruner describes life story as a cognitive achievement, rather than a “crystal recital of something given,” which in the end is a narrative achievement (Bruner 1987:13). Bruner argues that initially, narratives, as grounded in culture and language, reflect “prevailing theories about ‘possible lives’” (Bruner 1987:15). Eventually, Bruner proposes, “the ways of telling and the ways of conceptualizing that go with them become so habitual that they finally become recipes for structuring experience itself, for laying down the routes of memory, for not only guiding the life narrative up to the present but directing it to the future” (Bruner 1987:31). Thus narrative is a central element in life-making.

Finally, through an anthropological study of occupational therapists and patients, Mattingly (1994, 1998, 2000) proposes “emergent narratives” or “therapeutic emplotment.” Mattingly creates a view of stories as “not told so much as acted, embodied, played, even danced” (Mattingly 2000:181). In certain occasions, Mattingly argues, “time itself takes on narrative shape.” (Mattingly 2000:181). While anthropologists like Victor Turner have traditionally studied the dramatic and narrative elements of time through ritual, Mattingly (2000:181) describes narrative time as not clearly marked as extraordinary time but, rather, as coming about unexpectedly. Mattingly (1994:181) argues that actors make stories in the midst of acting, creating a sense of meaningful purpose in life. Dramatic narratives, for Mattingly therefore, illuminate what makes life worth living. Mattingly finds that the intersubjective creation of narrative relates to the need to locate a desire to engage in the future possibilities of life.

Medical anthropological interpretations variously exploit the terrain of narrative possibilities. However, the literature reviewed here illustrates that various processual approaches are the most compelling to medical anthropologists and consistently inform their understandings of illness narratives. Therefore, a number of general

propositions, which will be elaborated throughout the rest of the paper, can be made about the ways in which medical anthropologists understand narrative. First, while narrative is often proposed as an individual exercise for making meaning out of fractured lives, narratives are more aptly described as intersubjective, emerging from negotiations between the narrator and interlocutor. These occur in the context of community and culture. Secondly, illness narratives are not only reflexive accounts of the past, but also create future possibilities. Illness narratives are action oriented and performative. Finally, illness narratives are not only about the ill body but are spoken through the ill body (Frank 1995:2). They are fundamentally experience near and about giving voice to the being of an ill body in the world.

Why do “The Sick Bleed Stories”?

Broyard writes, “the sick bleed stories” (Wikan 2000:217). This section explores the experiences of illness and asks why stories are important in such times. What is the work of stories for the sick? “Almost every illness story,” describes Frank, “carries some sense of being shipwrecked by the storm of disease, and many use this metaphor explicitly. Extending this metaphor describes storytelling as repair on the wreck” (Frank 1995:54). In my exploration, I first examine the experiences of change brought to the life world by illness, and then consider the role of narratives in restructuring lives.

The specificities of illness experiences are numerous and dependant on many factors including, the type of illness, whether it is chronic or acute, the length of suffering, the impact on one’s life, and the extent to which the illness necessitates significant life change. Despite this, a number of general propositions can be made about illness, which relate in general to the liminal quality of illness (Becker 1997, DiGiacomo 1987, Hoybye 2002, Murphy 1987, Paget 1993). Victor Turner, expanding on van Gennep’s description of the phases of rites of passage, elaborates on the liminal period. In the liminal period “the state of the ritual subject (the ‘passenger’) is ambiguous; he passes through a realm that has few or none of the attributes of the past or coming state” (Turner 1979:235). Good (1994:124-126), drawing on the work of Alfred Schultz, outlines three ways in which the experience of illness significantly differs from the usual, taken-for-granted perception of the world. As is elaborated below, in illness,

common-sense realities are unmade as perceptions of self, world, and time change.

Schultz (Good 1994:124) has analyzed the way that people construct “common-sense” realities. Good (1994:124) shows how, through experiences with illness, these realities are “unmade” or deformed.

In the everyday world, the self is experienced as the “author” of its activities, as the “originator” of on-going actions, and thus as an “undivided total self.” We act in the world through our bodies; our bodies are the subject of our actions, that through which we experience, comprehend, and act upon the world. (Good 1994:124)

In illness, a dichotomy is experienced between self, and body as the site of illness. The body becomes something that is perceived to be no longer within the control of the self. The result is a loss in the feeling of totality – the feeling of being a whole person. Wikan (2000:214) describes the experience of giving a lecture just prior to an operation for a detached retina. Wikan wore a bright pink sweater (the only colour she could clearly make out) to “keep in touch” with herself. Ellen, who suffers with temporomandibular joint (TMJ) pain, described to Garro her conscious awareness of her body and her limited control over her actions:

I don’t recognize the way my body won’t react at certain times...It’s not responding and I have to think about doing certain things as opposed to just doing it...To have to think about how I’m going to eat that thing, to have to think about having to talk, to have to think about how I’m going to rest my head, you know. (Garro 1994:782)

Pain is experienced as an “it” having a reality outside the self (Brodwin 1994:92). The Cartesian division between mind and body, dominant in western culture (Scheper-Hughes and Lock 1987), is brought to particular attention in illness. “Illness negates this lack of awareness for the body...the body can no longer be taken for granted, implicit and axiomatic, for it has become a problem” (Murphy 1987:13). The ability to participate in everyday life as a whole person becomes a difficult task, rather than a taken-for-granted reality.

People are oriented to the world with a belief that the world they inhabit is the same and experienced in the same way as those around them (Good 1994:125). With severe illness, this assumption is called into question by both the feeling that the world of illness is unknowable by others and by the consuming nature of illness. Due to this, there is the sense that the world of the ill is fundamentally

different from that of those around them (Good 1994:125). One of the components of otherworldliness relates to time.

For those with life-threatening illness, the limited quantity of time takes on a new perspective. Paget, a sociologist, writes of her own experience with a rare cancer and notes her altered perception of time. "I feel the delicacy of life very keenly now and know that others feel it less because they are less endangered by nothingness than I, less close to it. This is I am sure one of the markers of my status as a liminal" (Paget 1993:100). The knowledge that others experience time differently from oneself creates a sense of an uncommon reality. Those suffering from illness and pain also experience discordance between their lived perception of time and the lived perception of time by other people. This is the experience of Brian, as recorded by Good. Brian explains,

For me,...time...seems to be spreading out, almost like I can't say anything is happening now. I have no way of pigeon-holing a specific span of time which I can get a few things done. Seems like I'm usually losing track of it. I can't keep up with it. Or, it's all, everything's caving in on me at once; the past, the present are coming together all at one time...episodes that repeat over and over again: you know, physical episodes of pain that seem to repeat. (Good 1994:126)

In illness, time is perceived as being experienced differently because of both the increased meaning of time, particularly in terminal illness; and a desynchronization between inner time and outer time (Good 1994, Murphy 1987, Paget 1993). As the above brief overview illustrates, illness has a life changing quality that challenges commonsense notions of self and the experience of self in the world.

The reviewed literature describes narrative as a formative process in the creation of self. In illness, notions of self and expectations for self are challenged. In confronting illness, therefore, narrative plays an essential role in the reconstruction of self. The work of narrative is in creating continuity between past, present and future, and maintaining connections with others. If, as Frank describes, illness is the loss of the destination and map, then "stories have to repair the damage that illness has done to the ill person's sense of where she is in life, and where she may be going. Stories are a way of drawing new ways and finding new destinations" (Frank 1995:53). The reparative work of narratives in situating illness in the life processes is the focus of the following discussion.

Narrative is also a critical process in the creation and maintenance

of a viable self in western cultural settings (Linde 1993, Monks 1995, Ochs and Capps 1996, Price 1995). "Self is here broadly understood to be an unfolding reflective awareness of being-in-the world, including a sense of one's past and future... We come to know ourselves as we use narrative to apprehend experience and navigate relationships with others" (Ochs and Capps 1996:20-21). Storytelling during illness engages oneself immediately in the world and challenges discontinuity and the lost sense of self created by illness (Price 1995:465). Arndt describes (Hoybye 2002:7) engagement in the world, through being seen and heard, as essential to the maintenance of humanness. Through narrative, images of self are conveyed and negotiated with others (Linde 1993:98). While the creation of self is always a continual and evolving process, the need for new meanings is particularly acute when illness calls for radical revisions.

Becker (1997:5; see also Becker 1994, Frank 1995, Good 1995) describes a universal human need for continuity through life, while giving attention to the cultural shaping of the meaning of continuity. The western emphasis on linearity creates a need to restructure the life story when confronted by illness. Indeed this is necessary because illness happens in a life that already has a story (Frank 1995:54). For a sense of continuity to be achieved, the life story must be restructured in light of new circumstances. This process involves reorganization of the story and a change in emphasis between what is foregrounded and backgrounded. This is necessary in order to maintain a connection between the past, the present, and the future, an exercise in what psychoanalyst Donald Spence calls "narrative truth" (Frank 1995:60-51). This is the process of emplotment "that draws a configuration out of a simple succession. Emplotment brings together heterogeneous factors such as agents, goals, means, interactions, and unexpected results and renders the story's contents intelligible" (Becker 1997:27). The process of emplotment is performative insofar as people learn their stories by telling their stories and hearing the reactions of others (Becker 1997:153, Frank 1995:1). Stories may create a range of possible interpretations rather than certain truths and thus leave open diverse possibilities for future action (Good 1994:138, Migliore 1994).

This literature gives attention to metaphor as a major cultural resource for social communication and the creation of continuity after disruption (Becker 1994, 1997, Brodwin 1992, Hoybye 2002,

Kirmayer 1992). Brodwin argues that metaphors provide a powerful way to express, through a common language, experiences of pain. Metaphors “transpose meaning between two radically different domains” (Brodwin 1992:77-78). Brodwin’s example of the migraine sufferer who describes her head as feeling as though “it’s made out of glass,” makes qualities of pain comprehensible to others at the same time as she creates new meaning. She communicates fragility and a need to be handled with care. For scholars, including Lakoff and Johnson (Becker 1997:52), metaphor is embodied and attends to the interconnection of body and mind, self and world. Metaphors frame structure and meaning and therefore provide a bridge in life reorganization. New meanings are made as metaphors, as vehicles, move topics from one context and meaning to another (Kirmayer 1992:332).

As the preceding review outlines, illness is a potentially self-changing event as it disconnects the self from both the former self and the commonly shared life world. Insofar as illness shatters self, narrative reconstructs it. This is done through narratives, which create a life tradition in the way that stories are told, events are structured, and meanings are made. As is elaborated below, this is a social and cultural process, where self is communicated to others at the same time that the very ideas of self are negotiated in such interactions.

From Where Stories Come

This section explores the influence of culture on illness experiences and narratives and how people come to tell particular, and often similar, stories about their illnesses. From the case studies below it is clear that individual perspectives on illness often come from, or are influenced by, local cultural systems (Kleinman 1988:27). In times of crisis people draw on their cultural resources. For Migliore (2001:103) these consist of:

- (1) A number of verbal and nonverbal cues people can use to express their suffering,
- (2) various cultural concepts that provide individuals with a basis for interpreting and explaining their experiences or the experiences of others, and
- (3) various preventive and therapeutic rationales people can employ to guide them in their attempts to deal with illness and misfortune. (Migliore 2001:103)

The influence of culture in shaping experience should not, however, be viewed as an overly deterministic process. As this section illustrates,

when prevailing cultural themes are inadequate in assisting individuals in making sense out of their lives, new cultural themes are enacted. One site where this is played out is in self-help groups (see Janzen 1982 for a cross-cultural discussion of therapeutic communities). “Groups amend normalizing ideologies to reflect their particular views, and because these amended ideologies carry particular moral force for group members and buffer them from more generalized ideologies of normalcy, they facilitate agency” (Becker 1997:202). Self-help groups often also have their own powerful narratives that shape the experiences of members. As Garro and Mattingly point out “narratives offer a powerful way to shape conduct because they have something to say about what gives meaning, what is inspiring in our lives, what is dangerous and worth taking risks for” (Garro and Mattingly 2000:12). The examples below illustrate how anthropologists and others have made sense of the relationship between culture, experience, and story.

Cain (1991) and Steffen (1997) have studied Alcoholics Anonymous (AA) in the United States and Denmark respectively. AA and AA members view alcoholism as an incurable disease that affects all areas of life. The drinking alcoholic is powerless in the face of alcohol and the only way to reclaim control of life is to stop drinking. In order to stop drinking, the alcoholic must turn life and will over to a higher power (this may be God or the AA group). However, this can only be done when an individual is ready for complete surrender (Cain 1991:213-214). AA thus initiates not only a change in behaviour but also a transformation in identity from a drinking non-alcoholic to a non-drinking alcoholic. This requires a new understanding of self and a reinterpretation of past experiences (Cain 1991:210). Thus, as Steffen (1997:106) describes, AA is a local moral world where the experiences of members are shaped by social interaction.

Telling personal stories is essential in the transformative process of AA. In group meetings, AA “old-timers” tell their life stories and drinking histories. Steffen (1997:107) describes, the standard content of AA stories include: the member’s first drinking experience, feelings of difference, the struggle to build a normal career, denial of a problem, loss due to alcohol and life threatening event, “hitting bottom,” and the process of recovery. Cain argues, “as the AA member learns the AA story model, he learns to tell and to understand his own life as an

AA life, and himself as an AA alcoholic” (Cain 1991:215). In this way, the AA model guides past and present understanding and future action. Steffen (1997:106), however, is careful to point out that the AA narrative is not a rigid framework producing stereotyped stories. Nevertheless, socialization into the group is the aim. Cain (1991:234) notes that longer engagement with AA is correlated with the creation of stories that more closely reflect the ideal AA story structure.

The accounts of AA make clear that stories are a powerful way to socialize individuals into a group. Storytelling by “old-timers” provides control over which stories are told. The moral voice of these stories is that they tell about how life ought to be lived and how stories ought to be told. What is not clear in these accounts is if these become totalizing narratives for structuring experience in all areas of life or are tied to the context of story-telling in AA.

Good’s (1994) study of illness narratives related to epilepsy in Turkey finds a particular cultural shaping to the way that stories are told and how they are emplotted. In Turkey, “fainting” rather than epilepsy is the descriptor of choice, as it does not carry the same stigma – epilepsy is culturally associated with madness (Good 1994:138). Fainting, however, is additionally associated with seemingly general distress. For Good (1994:138), this brings into relief the difficulty in differentiating the illness experience from culturally appropriate modes of expression and, it seems, rarely to be clear if someone indeed does have epilepsy.

In general, the stories gathered focus on a “predicament” that preceded the illness, life suffering, and the quest for cure. The stories are not complete – they are told in the midst of illness. In many cases, the stories leave open the possibility for future alternative readings of events. Good describes this as “subjunctivizing” elements, “imagistic elements that suggest indeterminacy, an openness to possibility and the potential; for change and healing in the lives of the sufferer” (Good 1994:146). Good describes the illness experience of epilepsy as emplotted within five typical narrative structures. The most common story begins with an initial fainting brought on by a severe emotional trauma. In subsequent years the fainting continues. These narratives focus on the traumatic event and the quest for cure. The second most common description of illness begins with a childhood fever or injury that leads to a life of seizures. Unsuccessful attempts at treatment are highlighted in these narratives as well as

guilt on the part of mothers for not being able to protect their children. The third group of stories focus on seizures that began with no apparent cause. Good characterizes these as “unplotted” narratives; they focus on the suffering caused by the seizures but neither the beginning nor potential end of the seizures. The fourth narrative type describes a life of sadness, poverty, and suffering accompanied with fainting. Extensive care seeking was absent from these illness experiences. The final illness narrative locates the onset of illness in evil eye or possession with Jinn spirits.

These plot types give stories order and coherence and “make the accounts recognizable to others in the society” (Good 1994:146-148). While told collectively, largely in families, the stories were not exclusively those of the afflicted. Various family members gave voice to the experiences of illness. For Good (1994:160), this raises the question of who can tell stories, as well as what stories can be told. These narratives show that in Turkey, as elsewhere, power and gender relations determine who tells the stories and the content of stories. Ochs and Capps (1996:33) refer to the silencing of alternative stories as a form of “linguistic oppression.” “Narrative asymmetry” is apparent in the privileging of certain versions of stories and specific ways of recounting experience. In the Turkey illness narratives, mothers tell children’s stories and older women and men tell younger women’s stories. As researchers, we must be aware of the stories that are not told and the voices that are not heard.

Frank (1995) outlines three narrative types drawn primarily from written accounts of illness in North America and Europe (see also Davies 1997 and Ezzy 2000 whose analyzes of the narratives of those living with HIV/AIDS also utilize plot types). For Frank, “narrative types are the most general storyline that can be recognized underlying the plot and tensions of particular stories” (Frank 1995:75). Frank is clear that while people tell their own stories, they also draw on cultural resources when story-telling. “The shape of the telling is moulded by all the rhetorical expectations that the storyteller has been internalizing ever since he first heard some relative describe an illness, or she saw her first television commercial for a non-prescription remedy” (Frank 1995:3). Frank proposes three narrative types as tools to aid listeners in hearing the stories told by the sick.

The “restitution narrative” is the dominant narrative that Frank (1995) finds underlying the narratives of both the recently and

chronically ill. The storyline of the restitution narrative can be summarized as “yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again” (Frank 1995:77). Modernist societal expectations of healing reinforce this future oriented lineal trajectory. Parson’s notion of the sick role parallels this narrative, which describes health as the norm and the work of the sick as the regaining of health (Frank 1995:81). The second narrative type, “chaos narratives,” are, like the name suggests, stories or non-stories told in a chaotic manner and lacking in narrative order. Frank believes that those who are living the chaos cannot tell their story, as storytelling (even chaotic storytelling) requires reflexivity only achievable through distance. “Events are told as the storyteller experiences life: without sequence or discerned causality” (Frank 1995:97). They are antithetical to modernism in their “vulnerability, futility and impotence” (Frank 1995:97). They are based in the present with no memorable past or anticipated future. The belief within the chaos narrative is that the situation will never change – one will never be well. “Quest narratives,” the third narrative type, “meet suffering head on; they accept illness and seek to use it” (Frank 1995:115). The ill person believes that something will be gained through the experience of illness. In the quest narrative, the ill person’s voice is rescued from both chaos and the dominant medical system, which seeks to use the story as just another success story. Patient advocacy and making changes in one’s own life are characteristics of the quest narrative.

In reading these narratives, I am struck by the way in which the agency of the patient differs in each of these three story types. In the restitution narrative, the patient’s action is limited to taking medication and getting well – being a “good” patient. The chaos narrative is resistant in that it refuses to see life as ordered and illness as having a simple fix. Unfortunately, the very resistance will leave those with chaos narratives marginalized by a biomedical system content on order. The storytellers in quest narratives are moral agents who speak of the ability to transcend illness. The danger of quest narratives is their authority in constructing illness as transformation and growth.

The preceding case studies have illustrated the context of the creation of illness stories as being social and cultural. This parallels the analysis of narratives in other contexts. Ochs and Capps (1996:33) illustrate the way in which institutionalized storylines, dominant narratives in education, religious, legal, and medical settings, give

moral voice to particular world views. Culture thus influences what sorts of stories get told by which kind of people in each particular circumstance (Garro and Mattingly 2000:25). The construction of illness experiences is thus political and relates to specific relations of power. While there is some perception that illness stories are empowering, this is not necessarily the case. We need to be more critical.

Is such storytelling (finding its contemporary manifestations predominantly in self-help groups, therapy, everyday life and social science interviews), just another of Foucault's 'technologies of the self,' one of the ways in which power operates by convincing people to seek certain parts of themselves and institute practices (e.g. confession, diet, physical/spiritual exercise, therapy) to effect a transformation of self? (Crossley 1999:1686)

While individuals may be able to resist normative role constructions, agency can also be supplanted by dominant "ideals" about the life course and moral predilections for "healing". For example, Price's (1995) study of the use of life history among terminally ill patients warns that life story could become reified, commodified, and standardized if it were to become a more formal part of the therapeutic process. Although attention to power is important, the action and agency of individuals must also be recognized. The cases presented in the next section illustrate that in some situations people actively work against dominant constructions and resist roles through the stories they tell.

To Where Stories Go

Narratives are not simply stories about the past, but also actively change current situations and project specific possibilities for the future which may then be enacted. The case studies in this section highlight narrative as performative and as a tool in the creation of future life. This is particularly true in the first case study of occupational therapy where therapists and clients create stories and dramas that focus on the future payoffs of hard work. The next two case studies also highlight the way in which narratives are future oriented at the same time as they are resistant and an active tool in reordering problematic social relationships. In these cases, narrative accomplishes a clear and specific presentation of the self. People are thus able to indirectly challenge the dominant social order while

maintaining their social position.

The first case study is an example of Mattingly's "emergent narratives" as discussed in the first section. The case describes a situation where time itself takes on narrative qualities and thus transforms a routine therapeutic encounter into a dramatic event (Mattingly 2000). This example involves a paediatric occupational therapist, Ellen, and a nine-year-old girl, Sarah, with vestibular problems. Sarah's sessions are designed to teach her body to sense the world in a normal way. At Sarah's initiation, the therapy session of touching, swinging, whirling, and jumping is transformed into an Olympic sport. "The actions of child, therapist, and camera person all contribute to the development of a plot, one in which the child is not a disabled patient undergoing treatment but a brilliant athlete performing her breathtaking feats for an admiring audience" (Mattingly 2000:191). The narrative transcends the ordinariness of the occupation therapy session and creates a grander vision of possible life (Mattingly 2000:196). While Sarah took the lead in this case, occupational therapists also actively attempt to emplot therapeutic activity to address larger commitments and concerns in life. The goal is to create meaningful narratives which create engagement in a meaningful life (Mattingly 2000:202).

The second case study attends to the future orientation of illness stories in shaping social relationships and interactions. Migliore's (2001) study of "nerves" among Sicilian Canadians is less interested in finding a definition for the elusive "folk" illness than showing the multiplicity of meanings of the idiom "nerves" and the diverse ways in which this concept is mobilized or used. In addition to expressing bodily suffering and distress, "nerves" also has broader communicative potential.

"Nerves," for example, can be used as part of a moral commentary on "self" and "other;" an impression management technique; a social control mechanism; both a status enhancing and stigmatizing label; an expression of ethnic identity; a form of resistance or protest against the overwhelming power of certain cultural, social, and economic forces present within a community; and a source of humour that can be commercialized. (Migliore 2001:104)

Migliore presents a number of narrative accounts which illustrate (1) the utilization of "nerves" to change the behaviour of others, and (2) "nerves" serving as an explanation for behaviour. In each of these

cases the threat of “nerves” seems equal to actually suffering with “nerves.” Examples of each of these are presented below.

In the first case a mother uses the idiom of “nerves” as a means of expressing her concern about her family and as a means of social control (Migliore 2001:110-112). Zia Spinto tells her son a number of stories of divorce and separation in their Sicilian Canadian community, including a specific example where the mother had no idea that there were any problems in her daughter’s marriage. In this story, the daughter spent the whole day with her mother without telling her that she had just left her husband. It was not until they were going to bed, and the mother again asked about the daughter’s husband, that the daughter finally disclosed. In this story, the mother chastises the daughter and tells her that she will get “nerves” because the daughter has not given the mother time to get this distressing news out of her system. In the end, they spent the whole night talking in order to “get it out.” Zia Spinto uses this story and others as a way of inquiring into her son’s marriage. She is also informing him of the consequences, his mother getting “nerves,” of not sharing important information with his mother.

“Nerves” is also used within Sicilian Canadian society to explain one’s own or someone else’s behaviour. Migliore (2001:113-115) identifies (1) disclaimers, (2) excuses, and (3) justifications as three examples of this use. The story below illustrates nerves being used as an excuse for otherwise unacceptable behaviour. In this case, Zia Lenireuses uses “nerves” as an excuse for her friend’s, Signora Alfonsini, behaviour. After the loss of her son in a car accident, Signora Alfonsini had to spend many hours at the funeral home and cope with many visitors. Signora Alfonsini was clearly sad and upset. After the funeral, relatives and friends returned to her house. People ate, drank, and talked, and Signora Alfonsini was very busy catering to the men, who became increasingly loud. Signora Alfonsini became very angry and got “nerves.” She exploded and yelled at everyone: “What do you think this is a show? Is this what you want?” As she said this she exposed one of her breasts. Within her cultural context, Alfonsini’s behaviour is considered unacceptable and a failure in upholding her role as an “adult woman” and “good wife.” The use of nerves brings attention to Signora Alfonsini’s distress and thus to her need for care and support. Further, the idiom of “nerves” also excuses her behaviour, she is relinquished of responsibility and remains a

respectable woman. In this case “nerves” is also used to contest male insensitivity (Migliore 2001:113-114).

The final example is Hunt’s (2000) study of cancer narratives in Mexico. In this account, Hunt attends to the way in which narratives of illness can restructure social identity as one reintegrates into the life world. In situations where problematic social relations characterize pre-illness life, continuity will not be the desired outcome of illness narratives. In these cases, Hunt proposes, individuals restructure identities to address relational power dynamics and gender constructions of ideal roles. “Illness narratives may thus respond to the disruption of identity, creating a new place in the social world that resolves conflicts and difficulties rooted in the broad context of the teller’s life” (Hunt 2000:90). The case studies presented by Hunt show the way in which the removal of part of the reproductive organs gives way to narrative that challenge normal gender constructions.

At twenty-five Roberto Juarez faced a number of challenges related to his fulfillment of the role of a “good man” and provider for his family. Roberto was not married and had no children but was single-handedly supporting his parents, five younger siblings, alcoholic brother-in-law, and his nieces and nephews by working their two small plots of land as well as maintaining a part-time job as a bricklayer. Testicular cancer halted Roberto’s ability to work. While the cost of the surgery was prohibitive, the sacrifice would mean that Roberto would be able to contribute to the family again. And, thus, his family sold some of their few belongings and a plot of land to pay for surgery for the highly treatable cancer. As Hunt (2000:97) describes, “Roberto’s narrative is structured in a way that foregrounds his obligation as caretaker.” However, the expectation of Roberto’s return to the service of his family is still unfulfilled a year and a half later. Roberto explains:

Now I don’t have the tumour, but I still can’t work. It made it harder because I can’t lift heavy things, I can’t. I can’t work like I did before...What I think is that since they cut the testicle out of me. I can’t anymore...I try to be like everyone else, but...I’m not the same as I was before I was born. (Hunt 2000:97)

Roberto’s loss of strength and stamina is related in the narrative to the loss of his testicle. Through this narrative Roberto negotiates traditional gender roles and redefines his role in the household without losing the reputation of a “good son.”

These accounts illustrate the strategic use of narrative in creating a world. They also refer again to the complex relationship between lived experience and narrative. In this view, as well as a story being about past action, it also expresses the desire for specific future interactions in the world. Moreover, it communicates future expectations to others. In order for narratives to be understood, they use the language available within specific cultural settings. These examples show that people use cultural resources to achieve specific goals. It appears from the narratives that the narrators will be successful in reaching their desired ends, however narratives are negotiated intersubjectively. At future points, these narratives may be contested and new narratives will be created, or alternatives possibilities existing within these narratives foregrounded, to make new possibilities in complex and changing lives. Indeed, many narratives leave open a range of possible interpretations and meaning making.

Conclusion

Narratives of illness experience occupy a central role in medical anthropology. However, they are explicitly utilized most extensively in works that deal with the condition of illness in North America society. The conclusion is not that “others” tell fewer stories in illness. Rather it seems that anthropologists either (1) do not elicit such narratives to the same degree in their work among other cultures, or (2) that they are read less problematically and enter the literature not as narratives, but as an explanation of experience. The first section of this paper articulated the relationship between narrative and experience. Narrative is variously viewed as a window to experience and as a complete construction. Predominantly, medical anthropologists rest between these extremes. As I have elaborated in this paper, medical anthropologists focus on the work of narrative in bridging the disruption caused by illness and making sense of the life world. Moreover, narrative is created in the context of culture, utilizing cultural modes of expression. Narrative is created intersubjectively and expresses shared meaning between the narrator and the interlocutor. In creating meaning, narrative proposes a future life by suggesting possibilities for the behaviour of self and others.

Narrative seems to be fundamentally connected to the creation of self and the sharing of ideas of self with others. This component of

narrative creates narrative urgency when past narratives are interrupted by illness. Illness leaves one disconnected from past life and the world around oneself. Illness creates a heightened awareness of the body at the same time as the body feels estranged from the self. Narrative bridges the disruption and creates new possibilities. Metaphor has particular force in illness narratives in that it communicates, using social resources, bodily experience of illness.

Although narrative is seemingly personal and independent, the literature illuminates the intersubjective and cultural elements of this process. The latter is the former writ large. The normal flow of conversation and the dialogic telling of stories gives light to the collective creation of stories. Cultural resources, symbols, and modes of expression also influence the way in which stories are told. In some cases this is prescriptive, to be an AA alcoholic you must tell an AA story. In other cases, people creatively use the categories available to them to diverse ends, as is the case of “nerves” among Sicilian Canadians. Concomitantly, not all stories may be told, either because specific people or narratives are silenced. In some situations this may be context dependant, like the well-documented example of doctors’ preference for stories that get to the point. This is also clear in the restitution narratives, which see “good patients” as compliant and focused on getting better. In other cases the silence is complete, as in the case of the young Turkish woman who was given no voice in her husband’s family to express her own distress.

Finally, narration is an active process where meanings are made and futures are created. This also explains the “wreck” of illness in shattering the possibilities expressed in previous narratives. However, some narratives are flexible and allow for contingencies and alternative readings. Narrativity can also be an active form of resistance. Illness in this case provides an opportunity to initiate reordering. Moreover, it creates a specific situation where one can still emerge as a good person. Illness can act as an excuse or an explanation for why things have changed. As Migliore’s study of “nerves” points out, the potential of illness is in some situations enough to influence the behaviours of others. Narrative emerges from the above exploration as a dynamic process in culture where stories express the self to others at the same time as they propose guidelines for future actions.

References

Becker, Gay

1997 *Disrupted Lives: How People Create Meaning in a Chaotic World*. Berkeley: University of California Press.

Becker, Gay

1994 Metaphors in *Disrupted Lives: Infertility and Cultural Constructions of Continuity*. *Medical Anthropology Quarterly*. 8(4):383-410.

Brodwin, Paul

1994 Symptoms and Social Performance: The Case of Diane Reden. In *Pain as Human Experience: An Anthropological Perspective*. M. Delvecchio Good, P. Brodwin, B. Good and A. Kleinman, eds. Pp. 77-99. Berkeley: University of California.

Bruner, Jerome

1987 Life as Narrative. *Social Research*. 54(1):11-32.

Cain, Carole

1991 Personal Stories: Identity Acquisition and Self-Understanding in Alcoholics Anonymous. *Ethos*. 19:210-253.

Crossley, Michele

1999 Stories of Illness and Trauma Survival: Liberation or Repression. *Social Science and Medicine*. 48:1685-1695.

Csordas, Thomas, ed.

1994 *Embodiment and Experience: The Existential Ground of Culture and Self*. Cambridge: Cambridge University Press.

Davies, Michele

1997 Shattered Assumptions: Time and the Experience of Long-Term HIV Positivity. *Social Science and Medicine*. 44:561-571.

DiGiacomo, Susan

1987 *Biomedicine as a Cultural System: An Anthropologist in*

the Kingdom of the Sick. In *Encounters with Biomedicine: case studies in medical anthropology*. H. Baer, ed. Pp. 315-346. New York: Gordon and Breach Science Publishers.

Ezzy, Douglas

2000 *Illness Narratives: Time, Hope and HIV*. *Social Science and Medicine*. 50:605-617.

Frank, Arthur

1995 *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago Press.

Garro, Linda

1994 *Narrative Representations of Chronic Illness Experience: Cultural Models of Illness, Mind, and Body in Stories Concerning the Temporomandibular Joint*. *Social Science and Medicine*. 38:775-788.

Garro, Linda and Cheryl Mattingly, eds.

2000 *Narrative and the Cultural Construction of Illness and Healing*. Berkeley: University of California Press.

Good, Byron

1994 *Medicine, Rationality, and Experience*. Cambridge: Cambridge University Press.

Hoybye, Mette Terp

2002 *Storytelling of Breast Cancer in Cyberspace: On-Line Counteractions to the Isolation and Demeaning of Illness Experience*. Copenhagen: University of Copenhagen Press.

Hunt, Linda

2000 *Strategic Suffering: Illness Narratives as Social Empowerment among Mexican Cancer Patients*. In *Narrative and the Cultural Construction of Illness and Healing*. C. Mattingly and L. Garro, eds. Pp. 88-107. Berkeley: University of California Press.

Janzen, John

1982 Drums Anonymous: Towards an Understanding of Structures of Therapeutic Maintenance. In *The Use and Abuse of Medicine*. M. De Vries, R. Berg and M. Lipkin, eds. Pp. 154-165. New York: Praeger.

Kirmayer, Laurence

1992 The Body's Insistence on Meaning: Metaphor as a Presentation and Representation in Illness Experience. *Medical Anthropology Quarterly*. 6(4):323-346.

Kleinman, Arthur

1988 *The Illness Narratives: Suffering, Healing and the Human Condition*. New York: Basic Books, Inc.

Linde, Charlotte

1993 *Life Stories: The Creation of Coherence*. New York: Oxford University Press.

Littlewood, Roland

1983 The Antinomian Hasid. *British Journal of Medical Psychology*. 56:67-78.

Mattingly, Cheryl

2000 Emergent Narratives. In *Narrative and the Cultural Construction of Illness and Healing*. C. Mattingly and L. Garro, eds. Pp. 181-211. Berkeley: University of California Press.

1998 *Healing Dramas and Clinical Plots: The Narrative Structure of Experience*. Cambridge: Cambridge University Press.

1994 The Concept of Therapeutic 'Emplotment.' *Social Science and Medicine*. 38:811-822.

Migliore, Sam

2001 From Illness Narratives to Social Commentary: A Pirandellian Approach to 'Nerves.' *Medical Anthropology Quarterly*. 15(1) 100-125.

Monks, Judith

1995 Life Stories and Sickness Experience: A Performance Perspective. *Culture Medicine and Psychiatry*. 19:453-478.

Murphy, Robert

1987 *Body Silent*. New York: Henry Holt and Company.

Ochs, Elinor and Lisa Capps

1996 Narrating the Self. *Annual Review of Anthropology*. 25:19-43.

Paget, Marianne

1993 *A Complex Sorrow: Reflections on Cancer and an Abbreviated Life*. Philadelphia: Temple University Press.

Peacock, James and Dorothy Holland

1993 The Narrated Self: Life Stories in Process. *Ethos*. 21(4):367-383.

Price, Laurie

1995 Life Stories of the Terminally Ill: Therapeutic and Anthropological Paradigms. *Human Organization*. 54(4):462-469.

Scheper-Hughes, Nancy and Margaret Lock

1987 The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology. *Medical Anthropology Quarterly*. 1(1):6-41.

Steffen, Vibeke

1997 Life Stories and Shared Experience. *Social Science and Medicine*. 45:99-111.

Turner, Victor

1979 Betwixt and Between: The Liminal Period in Rites de Passage. In *Reader in Comparative Religion: An Anthropological Approach*. W. Lessa and E. Vogt, eds. Pp. 234-243. New York: Harper and Row.

Wikan, Unni

2000 With Life in One's Lap: The Story of an Eye/I (or Two).
In Narrative and the Cultural Construction of Illness and
Healing. C. Mattingly and L. Garro, eds. Pp. 212-236.
Berkeley: University of California Press.