

## Essay 2. Illness Narrative as a Lens into Societal Understanding. Derek Soled

*Essay prompt, same as for essay 1: ‘What can illness narratives and medical case histories tell about society?’*

A severe illness is a gaping rift in one’s life story, one with significant effects on the sufferer, whose experience is forever etched in memory. In medical anthropology, scholars often use illness narratives to explore how individuals stitch this gap. Such narratives embody the memory of an illness experience. This is a contrast to traditional medical case histories that present patients’ illnesses as generalized diseases with a focus on the characteristic symptoms and relevant pathological processes. Illness narratives differ from medical case histories because narratives specifically focus on the patient's subjective experience and understanding of the illness, and they can highlight the social and cultural factors that may have influenced the symptoms (and their interpretations). Indeed, illness narratives are ‘performed’ by patients who are characters in their ongoing stories, actors constantly influenced by their social environments. Thus, studying illness narratives and medical histories can provide insights into a patient’s society, specifically 1) how group experience moulds individual experiences, 2) how cultural values and social relations shape the body’s illness experience, 3) how societal influences may trigger the body’s memory of an illness, and 4) how the society helped create illness. Together, these narratives offer a lens into a patient’s sociality, as well as providing a more holistic understanding of a patient’s condition, illustrating the ultimate causes of suffering and helping determine more productive ways to help the patient.

First, illness narratives can reveal how a collective, societal experience moulds individual experiences. Consider the ethnographic work of Vieda Skultans (1997) concerning the health of the Latvian people after the collapse of the Soviet Union. As Skultans notes, ‘These accounts of the Soviet invasion and its long aftermath constitute a hybrid genre which unites personal and collective experience’ (ibid.: 761). While studying neurasthenia (an ill-defined medical condition characterized by lassitude, fatigue and emotional disturbance), Skultans observed that the narratives she heard were intended by their authors to provide a literal representation of the past, but the stories were actually potent carriers of literary and cultural meanings, which confirmed personal identities and national loyalties; in other words, the illness narratives brought together the past, present and future. Skultans describes how her encounters with life stories in Latvia encompassed violent and terrible events that occurred

half a century ago, which the Latvians use as foundations to construct their life stories, functioning as a catalyst for their anxieties about and hopes for the future. Narrators drew upon stories and fragments of stories to translate their brutal tales into a meaningful story, and Skultans could identify cultural values and knowledge of identity through individual accounts. Moreover, the narratives functioned as testimonies to both personal and social memory. Informants wanted to speak about their arrests, imprisonments and deportations, and when they felt they could not offer greater insights, they would send Skultans to someone who could. Skultans was 'taken aback by the power and fluency with which many people spoke and sustained literary quality of their narratives' (ibid.: 763). Testimonies came from witnessing awful events, but in doing so, the informants speak from solitary experience and yet 'paradoxically, also speak for others' (ibid.: 766). As Arthur Kleinman (1988) repeatedly implies throughout his book on illness narratives, it is as though there is sedimentation of socio-political-historical realities in the experiencing body. The fault lines of societal trauma are commemorated in the lived experiences of individuals who are suffering.

Most of the narratives that Skultans heard involved the informants framing themselves as heroes or heroines in a romantic quest, and they relied on literary traditions to do so. As Skultans comments, 'Many Latvian narratives appear to be underpinned by medieval paradigms of romance and quest which would be familiar to all my informants through collections of fairy tales' (1997: 768). For instance, Milda, a country woman from north Vidzeme, used a biblical paradigm to hold her narrative together: 'We travelled forty days and nights in cattle trucks...we were hungry the first day, we were hungry the second day, on the third day we were no longer hungry, only thirsty' (ibid.: 771). The Israelites were forty years in the desert, Jesus was forty days in the wilderness, and the three days of hunger recall the three days between Christ's crucifixion and his resurrection. In another story, there was an element of fantasy and quest. Sent to Siberia in exile, Regina describes how 'somewhere in the distance I could see a little light shining... And I walk some more and run after that woman [by the light] [...] Suddenly someone screams 'Regina!' and as I go inside the light falls on me and she [the woman] recognizes me' (ibid.: 774). These tales become almost interchangeable in their form, as they follow the same pattern. In the stories, the Latvian people approach and move away 'from the desired goal state [of independence out of past suffering] ...to achieving a sense of directionality' (ibid.: 768). It is through these common narrative forms that one can better understand the personal and social memory of a given people within a society, as well as their collective experience.

Secondly, illness narratives and medical histories reveal how cultural values and social relations may manifest themselves in the sick body. As Kleinman notes, ‘embodied memory emerges through the interaction of culture, structure, and the body, realised through “sociosomatic processes” that shape everyday embodied experience’ (Kleinman 1988: 36) and can be learned through narrative representations of illness. For instance, consider Byron Good’s ethnographic accounts (1994) of people suffering from seizure disorder in Turkey. The study was initially designed to look at the prevalence of epilepsy and the social disability associated with it, yet, through the stories he heard, Good learned much more about the sufferers. He conducted one interview with a lady named Meliha Hanim. When asked how her illness (‘fainting’ spells) began, she said that when she was a young woman, she had resisted her father’s wish for her to marry a specific man and instead chose another husband far away. When ‘she saw her father with a knife in his hand, she received a “shock,” she was frightened, and from that day until today, she has been fainting’ (ibid.: 136). This woman’s story revealed more than a traditional biomedical diagnosis. Questions arose as to whether the woman’s ‘fainting’ was caused by epilepsy or some culturally specific form of the disease that biomedical models label epilepsy, or whether her episodes stemmed from the initial psychological trauma or some other medical condition. Note that Meliha never even used the word ‘epilepsy’ in her narrative. Her use of the word ‘fainting’ instead of ‘epilepsy’ reveals something about the society in which she lives, as ‘fainting is associated with a more general semantic domain that includes fainting occurring in times of acute distress or in the context of a life of suffering, and is less stigmatized than the term “epilepsy”’ (ibid.: 136).

The narratives heard would also frequently take a common form like that of Meliha’s, as narrators would ‘emplot’ themselves in a distinctive cultural form rooted in Turkish popular medical culture in which there was a major emotional trauma that produced future fainting. From this study of seizures in Turkey, other ethnographies reveal more of the society’s traditional folklore and beliefs. For instance, a man by the name of Kerim shared his fainting stories with obvious spiritual influences (*jinn*s) that he credited to his illness: ‘A sound came from the cat, like a new born baby was crying ... Before, one of our friends had gone to that place [with the cat] ... as a joke they told him there is a *jinn* there ... soon after I fell down [in a seizure] ... which saved me from a hot stove nearby where I would have burned myself’ (ibid.: 157). This story illustrates how a society’s conventional and traditional beliefs may shape perceptions of how a condition began.

The way an illness narrative is told can also reveal power relations, as exemplified in some of the ethnographies from the same seizure study in Turkey. One instance concerned a

woman named Emine, a low-class female whose illness narrative was told by her more powerful sister-in-law. As Good notes, 'Emine's voice was appropriated by the family. She was not allowed to tell her story, perhaps even to have a story. She was the daughter-in-law, an outsider in a powerful family, only a year past being the youngest bride. Her story evoked a previous husband. She was fat. She had pain' (ibid.: 160). Such a story, and many like it, informed the listener of local power relations, and how relations of power and gender are expressed not only in the story's structure but in its point of view as well. Good's main argument is that illness cannot be represented all at once or from a single vantage point, as illness is a 'network of perspectives' (ibid.: 157). Listening to these narratives and the common themes of how one 'emplots' oneself in a given narrative and questions the future is indicative of the social and institutional relationships and practical activities in that society. It makes one question what the true relationship is between a story and actual illness, showing how experience is cultural to the core and influenced by societal networks, beliefs and traditions.

Thirdly, illness narratives and case histories may reveal not only how suffering is situated in an individual's world, but also how it might be triggered by broader societal influences. Those who were severely ill at one point in their lives will struggle to be fully 'healed,' as a severe illness will leave an experience that is hard to shake. There is a memory (revealed by illness narratives) that is etched in the present (and embedded in current experiences), and the past comes into the present through forms of 'sensation' learned during the illness. For example, consider Eli's ethnographic work (2016) examining Israeli women who had recovered from eating disorders. Eli notes how one of her subjects, Grace, had to eat every five or six hours, or else her body would give her a terrible malaise, with shivering, sudden hypoglycaemia and a sense of almost fainting. It was as though her body 'remembered' the pain of her former anorexia even in the moments when she consciously did not. In this instance the drive for food was internal rather than external, but in other cases, external societal influences are the drivers of body remembrance. In the case of Tamar, a recovered anorexic, social pressure to exercise caused her body to remember her troubled past. She and her partner started a new training programme, years after she was classified as 'recovered,' until one day she realized what she was doing to her body: 'I said, like, where did you bring yourself? What are you doing? Run away; this is fire. And that moment I just quit ... And then the central tenet of my life occurred to me – you have the virus, be careful not to trigger it' (ibid.: 75). Embodied memories of an illness, like an eating disorder,

constitute a mode of dynamic integration, bridging the past disorder with present-day recovery and vigilance.

Many severe disorders can in fact operate like a virus, such as Tamar describes. While one may be 'healed,' the sickness is simply dormant until the right societal influences ignite it again. What illness narratives thus reveal are not only how a disease manifests itself in one's own world (such as Grace and the need to eat at set time intervals), but the societal-*cum*-sensory pressures that may activate it. Of all the women interviewed, there was a salience of the social milieu in which their eating disorders developed, namely the Western ideal of thinness. The more women were exposed to this ideal (watching movies, shopping, etc.), the greater tendency there was for the body to 'remember' the past eating disorder and for the individual to relapse. There was also a commonality with how the women remained vigilant against their disorders reoccurring when other positive societal values (like motherhood) were placed before them; in Israel the mark of 'responsible' citizenship for expectant mothers is extensive engagement with foetal genetic testing, measuring and continuous monitoring of the body. Thus, 'since motherhood is constructed as the path to 'good' feminine citizenship in Israel, such discourses and practices shape girls' attention to and interpretation of embodied experience' (ibid.: 80-1). What these narratives inform us as listeners are the societal and social pressures that trigger the body to remember and react. They also reveal ways in which the body may respond outside of conscious control, thus having significant implications for how society may influence individual agency for those who were previously ill.

Finally, when they are shared with others in society, illness narratives can provide a way for individuals to find meaning in a disorder and gain insight into how society may have helped create the sickness. The key ethnography that drives this point is that by Steffen (1997). Through various interviews with members of a Danish organization of Alcoholics Anonymous (AA), one can see the purpose of illness narratives in merging individual and group experiences in a therapeutic process that gives meaning to the individual sufferers' lives. As Steffen notes, 'The telling of life stories in AA illustrates that personal narratives are neither mere reflections of life as lived nor made-up fiction. Personal narratives are products of complex interactive social processes, and they constitute powerful and dynamic means of communication' (ibid.: 110). In this work, Steffen recounts short summaries of several individuals who lost part of their lives due to excessive drinking. After each narrative, together they would recite the prayer: 'G-d grant me serenity, to accept the things I cannot change, courage to change the things I can, and wisdom to know the difference' (ibid.: 103). Telling a story helps an individual process what happened, processing events being the first

step towards recovery; such openness is a therapeutic necessity as well as a moral duty for members, who find solace in knowing that their story is quite similar to the stories of those around them.

Moreover, the AA narratives reveal that the same social experiences of loneliness and worthlessness (regardless of an addict's class and background) affected their illnesses and their views of themselves. Implicit in the narratives is the idea that society does not prioritize 'openness,' and thus the AA setting highlights a major cultural value about what information deserves to be made public and what kept private. Accordingly, illness narratives provide an opportunity to see the common thread in situations that are all the result of having the same feelings of being shunned by society (exemplified through the homogeneity of most stories), thus revealing the societal tensions and ailments that may indirectly cause suffering. Stories 'begin in the experience of one person, but others make it related to themselves and give it new uses and interpretations' (ibid.: 103). Illness narratives reveal what people in a given society see as within their control (and what is out of their control, such as the AA members described), and how they might find meaning in their lives through collective suffering and controlling what they can.

Illness narratives are performative acts in which individuals present their stories and experiences surrounding their condition. The narrative 'emplots' human action in a story with (often) no conclusion. By contextualizing meaningful events, illness narratives contribute to the understanding of individual experience by showcasing social relations and cultural values. In this regard, they offer much more than a brief medical history of a patient; instead, they offer patient perspectives not only about the illness but about the patient's perceived role in society. They also allow for a better understanding of the ultimate causes of a disease that cannot be boiled down to mere pathological description. Finally, they demonstrate how society becomes embodied in illness, and which societal values may outweigh others in the shaping of an illness experience. Narratives show how collective societal experiences mould individual experiences, how values may embed themselves in the body in periods of sickness, and how suffering is tied to larger societal triggers.

### *References*

- Eli, K. (2016). 'The Body Remembers': Narrating Embodied Reconciliations of Eating Disorder and Recovery. *Anthropology & Medicine* 23(1): 71-85.
- Good, B. (1994). *Medicine, Rationality, and Experience: An Anthropological Approach*. Cambridge: Cambridge University Press.

- Kleinman, A. (1988). *The Illness Narratives: Suffering, Healing, and the Human Condition*.  
New York: Basic Books.
- Skultans, V. (1997). Theorizing Latvian Lives: The Quest for Identity. *Journal of the Royal Anthropological Institute* 3: 761-780.
- Steffen, V. (1997): Life Stories and Shared Experience. *Social Science and Medicine* 5 (1):  
99-111.