

Essay 1. Interlaced Illness Narratives. Cathryn Klusmeier

Essay prompt: 'What can illness narratives and medical case histories tell about society?'

One of the first Alcoholics Anonymous groups in Denmark began with a glass of water. A Danish man named Jens, who grew up in Jutland in the years after WWII, was having dinner with an American business companion. Since his late twenties, Jens had a drinking problem. Though he was known as a 'jolly fellow' in his friendships, he often felt that he 'had to drink to feel normal and was scared to expose his real character, if he did not drink' (Steffen 1997: 104). Despite the drinking, Jens had managed to maintain a family, a house, a dog and a swimming pool. For fifteen years, however, he had been in and out of hospitals for 'detox, periods of medication with antabuse, aversion therapy, psychiatric treatment, and so on, until he broke his leg after a binge ending in a blackout' (ibid.: 104). Going to the hospital yet again, he experienced a 'spiritual awakening' that made him 'feel free,' sensing a 'strange overall meaning of life' (ibid.: 104). 'From that moment he intuitively knew that he would never drink alcohol again' (ibid.). Which led him to said glass of water. He ordered it during dinner with an American businessman, only to discover that the American had also ordered water, and by explanation, said the words: 'I'm an alcoholic' without hesitation (ibid.:104). These were revelatory words for Jens, who asked the American about it, only to discover that this man came from an Alcoholics Anonymous (AA) group, and he then went on to tell Jens his life story. Jens, in turn, reciprocated by telling *his* life story. Soon afterwards, Jens started a new AA group in Denmark and opened the first Minnesota Model treatment centre there five years later (Steffen 1997).

Here, it is important to deconstruct this scene and look at the parts. On the surface, it seems like a very simple story. One man, an alcoholic, who has decided that he will no longer be an alcoholic, meets another man with the same desire, though neither realizes it at the time. They both order water with their meal, and it is this moment that signifies to the American—who is familiar with the AA model—that this is the space in which he can tell his 'life story' to the man in front of him. This process of 'telling the narrative' is central to the AA model. It is the process by which the (sometimes tattered) narrative threads that tie one life together become the very mechanism for healing and community.

In this paper, I intend to flesh out this notion of 'telling the narrative' and further examine the ways in which narrative constructs meaning and potentially allows for healing. I

argue that, while narratives often seem to operate on an individual level, with each person having their own ‘life story’ that interacts with others, in fact, as shown through descriptions of alcoholism and Alzheimer’s stories, many illness narratives are *shared* narratives, expanding the scope of illness narratives including both the individual *and* the collective experiences of illness and disease.

‘We tell ourselves stories in order to live,’ writes Joan Didion in the opening sentence to her seminal essay, ‘The White Album’ (Didion 1979: 11). The importance of telling stories and paying attention to narratives *as a way to live* is not simply delegated to the realm of writers: medical practitioners and medical anthropologists such as Byron Good and Arthur Kleinman have also emphasized the importance of patient narratives and personal stories in their work. This was not always the case, however. As Lars-Christer Hyden, in his article ‘Illness and Narrative,’ describes it:

Doctors from the turn of the century onwards have been inclined to treat the reports of their patients with considerable skepticism. 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 at best as a pale reflection of the language of the organs and tissues and their pathological changes. (Hyden 1997: 49)

This turn in roughly the last forty years towards incorporating a narrative perspective into medicine pushes against that strictly biomedical model which saw a patient’s narrative as that ‘pale reflection’ compared to the language of malfunctioning tissues and organs. Narrative inherently resists Michel Foucault’s notion of the ‘clinical gaze’ and instead places the emphasis on story, context, and ultimately the possibility of meaning:

Narrative provides a medium whereby one 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. (Hyden 1997: 56)

It is the establishment of this ‘unified context’ and ‘coherence’ which is the real strength of the narrative medium. It is not meant to completely deny the biomedical, nor the language of tissues and organs, necessarily; rather, it provides the context upon which the biomedical rests. ‘In this sense, 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. The narrative transforms symptoms and events into a meaningful whole, thereby creating the world of illness' (ibid.: 56).

This is what AA aims for in their work: the transcendence of the strictly individual narrative towards a collective narrative that engenders meaning.

The telling of life stories in AA shows 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 (Steffen 1997: 110).

As Steffen furthermore writes, 'The illness account becomes a narrative of lived experience to the benefit of everybody, and the narrator's experience of pain and suffering loses its meaninglessness and gains value as collective knowledge' (ibid.: 106). Narrative is about constructing meaning through this performative structure. In AA, the narrative structure offers a mechanism for creating meaning out of pain and suffering. The exchange takes place on multiple levels, affecting both parties in turn:

Thus the illness narrative fulfils the purpose of helping both the narrator and the listener, whose experience becomes the object of renewed reflections resulting in reconsiderations and a revised memory. Telling your story in AA brings thoughts and emotions into form in a process where listening and performing goes hand in hand. (Steffen 1997: 106)

In AA, whether you are the person telling the story or the person who has a story told to them, you are nevertheless *intersubjectively* involved in this dynamic activity, which in turn creates a *new* story, one where there are multiple actors. The act of telling and retelling life stories in the context of AA provides all the actors with a mechanism for being involved in a new story, one that is not singular, but a tapestry of multiple stories. Drawing on Byron Good's work, Steffen writes:

Both narrator and listener engage in the creation of synthesis through which the story gradually comes into being, and both contribute to the 'emplotting' of illness, through which an ordered story is sought and authored. Thus, the plot of the story may both be seen as an underlying structure and a dynamic activity unfolding in the process of making sense of the story, providing it with narrative intentionality and direction. (Steffen 1997: 106)

This particular example of AA is important to our understandings of illness narratives because of its ability to work on the individual and interpersonal scale simultaneously, while also taking place outside some of the more traditional ‘medical’ constructs. You can only come to the meetings if you are also an alcoholic or specifically invited. It is not necessarily a medicalized space, nor does it necessarily want to be. It is a performative space for the telling of stories and for the making of *new* stories by interactions with the collective through the back and forth dynamic of narrating and listening in turn:

Expressing experience in a narrative form apparently implies a process in the individual, where feelings of fragmentation and alienation are overcome and replaced by congruence and direction. Confusing personal experiences become coherent and well-structured narratives. Partly this is an introspective process, where individual meaning is created as experience is forced into verbal expression. But on the other hand it is important to remember that these experiences are expressed in groups of listeners—that is, in a context of interpersonal relationships between fellow-sufferers. This interplay between individual self-reflection and community response is captured in an AA slogan: You alone can do it, but you can’t do it alone. (Steffen 1997: 105)

In the context of AA, narrative allows for people to share experiences. Together, in the group, the ‘confusing personal experiences become coherent and well-structured narratives’ (ibid.: 105). For Didion, this is an excellent example of her notion. In order to live, we tell ourselves stories. Her notion works on the group level, as well as on that of the individual. For an alcoholic, in order to live, you must tell your story: you cannot do it alone. We share stories so that we can become a part of one another’s stories and then make sense of our own again.

But what happens when the person suffering from the illness – to go back to Didion – in fact cannot tell themselves stories anymore? What happens when illness narratives can no longer be articulated by the individual who is sick? Who, then, tells their story? Byron Good says: ‘An “illness” has a narrative structure; although it is not a closed text, it is composed as a corpus of stories’ (Good 1994: 164). But what happens when the person with the illness seems to be a ‘closed text’ and unable to create new stories?

Leslie Burke (2014), in her paper ‘Oneself as Another: Intersubjectivity and Ethics in Alzheimer’s Illness Narratives’, pulls from the ever-growing body of literature that details the ‘Alzheimer’s epidemic’ as told by those closest to the person with the disease. Like AA, the literature on Alzheimer’s involves discussions of intersubjective, shared narration. And although aspects of modern medicine such as the impetus to speak of individual ‘symptoms’

seem to isolate individuals based on their illness, Kleinman notes that the experience of illness itself is often shared, reaching ‘beyond the bodies of ill persons to saturate the lifeworld of those around them’ (Kleinman 1988: 186, quoted in Burke 2014: 30).

Burke notes that, ‘Alzheimer’s raises inescapable questions about the way we conceptualize the boundaries between self and other and about the ethical dimensions of memorial practices’ (Burke 2014: 30). She points out that in this growing body of literature, with books such as Michael Ignatieff’s (1994) *Scar Tissue*, ‘the narrator’s relationship to the disease, and to the ill person, is experienced as a kind of trauma that disrupts his or her own sense of identity’ (ibid.: 31). In Sue Miller’s account of her father’s disease, she describes herself as ‘altered ... in some of the very same ways’ as her father is by his illness: ‘made bland and callous, reduced’ (Miller 2004: 137). Burke addresses the inherent complexities involved in writing about narrative through the lens of Alzheimer’s disease:

Lives and selves become entangled in these Alzheimer’s memoirs—to write of another is necessarily to write of oneself. And this is an ambivalent undertaking: less an act of healing than a form of mourning, less an act of self-realization than an elegiac reflection upon the fragility of all identity and its undoing (Burke 2014: 32).

Because ‘the impact of dementia upon memory, cognition, mood and behavior makes an engagement with questions of the meaning and definition of personhood unavoidable’ (ibid.: 39), Alzheimer’s narratives are tricky to define individually. While these narratives, which are oftentimes taken up by family members, tend towards the collective as well, they do so in different ways than the AA narratives. In AA, the focus on narrative allows individual stories to interact with one another to construct new stories and provide meaning – it’s constructive. However, in the face of Alzheimer’s narratives, it is not a case of interacting stories so much as entangled, complicated narratives, with unclear understandings of what these narratives are constructing. In *Scar Tissue*, Michael Ignatieff’s wife at one point asks: ‘Why do you think that writing about it [his mother’s disease] will make any difference?’ He replies: Because ‘I need to do something, anything’ (Ignatieff 1994: 8). His need is to pick up the threads of her narrative when she can’t tell her story anymore, yet in doing so he begins to feel sick himself, at one point totally convinced that he, too, was getting dementia. He takes on her story as a co-author. ‘Like her, he becomes increasingly isolated, lost in the fracturing logic of her cognitive decline’ (Burke 2014: 40). The narrative traces the dismantling of both his and his mother’s lives as a consequence of her disease. As her story starts to erode, so does his:

This is a very common story in Alzheimer's narratives. Burke argues that in dementia stories, there is an underlying 'shared authorship' of life narratives. This 'shared authorship' allows one to envisage the construction of life narratives as a shared enterprise rather than as the province of a monadic entity. It also erodes the distinction between inner and outer selves pointing to a far leakier or permeable relationship between the two' (Burke 2014: 36).

One could argue that this theme of 'permeable relationships' is also the case in the interpersonal narratives surrounding AA. In the group setting, do the barriers between the 'selves' start to erode as well in these narratives as they create 'new' narratives together? However, in Alzheimer's narratives, 'one of the difficulties that resonates through Alzheimer's life writing is the collapse of mutual recognition wherein the identities of both parties are thrown into crisis by the failure of one to recognize the other' (ibid.: 38). In the context of AA, the intersubjective stories are told with recognition of one another as a distinct, yet interacting part of the group's narration. However, where Alzheimer's narratives depart is in the moment when there is a collapse of the mutual recognition of each party involved. Instead of an interaction *between* life narratives creating an atmosphere of collective storytelling, in Alzheimer's narratives that space *between* individuals seemingly collapses, causing individuals to 'co-author life narratives of those no longer able to do so themselves' (ibid.: 37). In both of these cases, however, there is still a tendency towards a *shared* narration of these illnesses—towards an interpersonal experience. In both of them too, this understanding of largely individualized medicine and narratives is challenged. In AA, the storytelling in the group provides a space for the creation of new, shared narratives that provide meaning for the individual as a member of a strictly demarcated group. In Alzheimer's studies, there is a similar tendency towards shared experience, with the erosion of barriers between individual narratives. Not only has the propagation of illness narratives begun to move the conversation away from the 'language of organs and tissues' (Hyden 1997: 48), but going still further, I argue that illness narratives further widen the lens of our understanding of the scope of illness beyond individual narratives alone into the realm of the social.

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