

# When Patients Tell a Story We Have Not Yet Learned to Hear

Stephen Hibbs<sup>1</sup>

**Correspondence:** Stephen Hibbs, *HemaSphere* Scientific Editor (s.p.hibbs@qmul.ac.uk).

*The danger for ill people is that they are taught how to be ill by professionals. Illness is not presented to the ill as a moral problem; people are not asked, after the shock of diagnosis has dulled sufficiently, what do you wish to become in this experience? What story do you wish to tell of yourself? How will you shape your illness, and yourself, in the stories you tell of it?.*

-Arthur Frank, *The Wounded Storyteller*<sup>1</sup>

Her first concern was the assignment deadline. I could soothe that worry—a diagnosis of acute leukaemia is a watertight excuse for late coursework in the eyes of most universities. But then she collided with the deeper implications of the diagnosis. Her diary, her aims, her hopes and her story itself all began unraveling in a flood of words. Her mother turned to me with pleading eyes, entreating me to say something that would make this better. Slowly and calmly, I began my explanation:

Yes, this is a life-changing diagnosis.

But there is hope.

We have good treatment.

You are in an expert centre.

We will do all that we can to cure you.

There were a few traps that I was careful to avoid. I had learned elsewhere about the dangers of military metaphors—evocative phrases like “invading cells” or “fighting the leukaemia.” These are routinely used in conversations between cancer doctors and patients,<sup>2</sup> but can worsen feelings of fatalism and depression in patients who internalise them.<sup>3</sup> Furthermore, if you see your relationship with cancer as a war, then on the day that focus moves to palliation, are you capitulating to an evil foe? I also avoided any suggestion that she should “stay positive,” which can lead patients to blame their own negative thoughts if the cancer comes back. But despite my carefulness, I would soon discover that there was more implied by my choice of words than I realised at the time.

The following day, a book arrived through my door entitled *The Wounded Storyteller*<sup>1</sup> (I still have no idea who sent it to me). As I began to read, I felt the book was reading me—probing into my work, including my consultation with the student the previous day. The author, Arthur Frank, is a sociologist who was treated for aggressive testicular cancer as a young man, and who became fascinated by how patients and clinicians tell stories of illness. In *The Wounded Storyteller*, Frank describes 3 types of stories which I had regularly heard, but never recognised.

The first is *restitution*—a category that encapsulates nearly all I have heard from clinicians since medical school: “you are ill now, we are going to do something about it, and we are going to get you better.” “Better” ideally means cure, but it might mean remission for a time, or at least to reduce the rate of decline. Many patients and their families come expecting this story, ready to put life on hold and entrust themselves to deeply unpleasant treatments if order and normality can be restored. Cancer charities use the same script: “we will beat blood cancer,” “we will find a cure,” and we are “saving the lives of people with blood cancer” (these are all direct quotes from recent campaigns). I know that the restitution narrative is where I will look first if

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<sup>1</sup>Queen Mary University of London, United Kingdom  
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I am diagnosed with blood cancer. Restitution is the narrative that I gave the young woman with acute leukaemia that day.

But Frank points to some of the harm of relying on restitution narratives alone. Conversations during Frank's own treatment "positioned the physician as the protagonist and relegated [Frank] to being the object of that protagonist's heroism."<sup>1</sup> In other words, your story centres around your doctors and treatment, rather than being truly your own. And if a doctor and patient have exclusively made sense of the cancer with a story of treatment and remission, then what happens at the end? Those who rely upon the restitution story "have nothing left to say to a person who has no further use for the language of survival."<sup>1</sup> We have all seen this enacted where the dying person is still receiving blood products, antimicrobials, and sometimes even chemotherapy, long after futility has been reached. This is the logical conclusion for a sufferer who has only understood their illness in terms of restitution.

The second type of story is *chaos*. Chaos is the story my patient began before I brought the conversation back to the restitution narrative of treatment plans and the expert centre. Chaos is a stream of present tense experience, stuck in the now, that feeds on "the sense that no one is in control."<sup>1</sup> The person's story has lost all coherence. It sounds like "and then... and then... and then... and this problem... and this as well." Very few listeners can endure a chaos narrative for long. We rush to contain a person's illness testimony into something more orderly, something more hopeful. An overwhelmed and traumatised patient who is naming components within the barrage of assault they experience in their body will soon be prompted by an uncomfortable doctor to return to a conversation about pills, about blood tests, about next steps. Yet there is an honesty and authenticity to the chaos narrative that the clinician can meet by *being present* to their patient's suffering.

The third story is *quest*. Quest stories are those in which a patient finds meaning and courage in the face of their illness,

regardless of whether treatment is successful. There are millions of different quest stories: they are created by anyone who finds meaning in life that doesn't solely rely on getting better. They are not stories about the wonders of haematology and medicines. The restitution narrative sees suffering as a puzzle to be solved (primarily by the clinician), whereas the quest narrative sees suffering as a mystery to be faced. A person will still hope for cure or remission, but they also answer the question of "How do I rise to this occasion?"<sup>1</sup> The quest narrative is the only way that a patient can recreate their own story. A patient does not give their story to the medical system (as in restitution) or remain story-less (as in chaos), but establishes their own story that provides "courage to live after losing the world where it was possible to aspire to certain values and forms of excellence."<sup>1</sup>

So, what do we do with this awareness of stories? After all, it is our place to treat, to try and cure, to seek restitution for our patients. It is *not* our place to lead patients to a deeper sense of meaning, to a transformed sense of self. But the great value of Frank's work to us is to remind us that patients are doing the hard work of remaking sense of their own stories, now that they have been interrupted by illness, and they might not tell the same story that we do. As clinicians, our reliance on the restitution narrative risks crowding out other stories that our patients are telling us. Perhaps some of the patients who frustrate us most by their lack of understanding or appreciation of our care are trying to tell us a completely different story to the one we are used to. How do we respond in a way that does not diminish their story, their sense of self?

I do not think I did a terrible job on the day I met this young woman with acute leukaemia. For that day, my words did enough, and the narrative of restitution from acute leukaemia has served many patients well. But on the day of her final relapse, when even the CAR-T cells have failed, I do hope she has had time to build a more fitting story, a story to give her the courage that she needs.



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#### REFERENCES

1. Frank AW. *The Wounded Storyteller: Body, Illness, and Ethics*. 2nd ed. University of Chicago Press; 2013. Available at: <https://press.uchicago.edu/ucp/books/book/chicago/W/bo14674212.html>. Accessed January 15, 2022.
2. Casarett D, Pickard A, Fishman JM, et al. Can metaphors and analogies improve communication with seriously ill patients? *J Palliat Med*. 2010;13:255–260.
3. Hauser DJ, Schwarz N. The war on prevention II: battle metaphors undermine cancer treatment and prevention and do not increase vigilance. *Health Commun*. 2020;35:1698–1704.