

LITERATURE, NARRATIVE MEDICINE AND THE WISH NOT TO DIE IN THE HOSPITAL

GUSTAVO KUSMINSKY

Hospital Universitario Austral, Buenos Aires, Argentina

E-mail: gkusmins@cas.austral.edu.ar

BZ, a 53-year-old man, was admitted to the hospital with relapsed acute myeloid leukemia (AML) after hematopoietic transplantation. He was from a small town in Entre Ríos province and had spent his whole life doing farm work, employed on a rural estate. He lived with his partner on a small family farm; his three adult daughters lived in another city. When intermediate risk AML was diagnosed, two induction regimens were needed to achieve complete remission. He received a myeloablative allogeneic transplant from an HLA-identical, ABO-incompatible sister, with post-transplant cyclophosphamide, tacrolimus and mycophenolate mofetil as immunosuppression. Complete donor chimerism was observed by day 60 after transplant. However, there was no red-cell engraftment, and a bone marrow aspirate showed pure red cell aplasia. Rituximab was planned, but in the meantime, four months after the transplant, the patient relapsed, with many blasts in peripheral blood, and he was admitted. Salvage therapy with azacitidine and venetoclax produced no response. His general condition deteriorated rapidly, with multiple organ failure, sepsis and pulmonary aspergillosis. Palliative care was considered and limitation of therapeutic effort was proposed and accepted by the patient and his family. Discharge was not possible because of his dependence on in-hospital care. His clinical condition worsened quickly, and five days after the decision to limit therapeutic effort, the patient died in hospital.

On the previous day he was intermittently lucid, with persistent fever and a tendency to

hypotension. When the physician entered his room in the morning, he found him asleep in the companion's armchair, not in the hospital bed, covered with a light blanket he had brought from home, with one of his daughters beside him, the two of them embracing and holding hands. Although no noise had been made, the physician's presence woke him. The patient looked at him and, in a voice full of emotion, told his doctor that he had been dreaming he was walking across the fields of his home country, and that on waking, confused, he had believed he was truly on his farm, with his partner and his daughters; and he stated emphatically that this was what he would have wished for that moment.

In "El Sur" ("The South"), the short story Jorge Luis Borges added to *Ficciones* in 1956, Juan Dahlmann, a librarian, cuts his forehead on the edge of a freshly painted casement as he hurries up the stairs to read a copy of *Arabian Nights*. The wound becomes infected, fever consumes him, and Dahlmann ends up in a hospital with sepsis. Borges narrates the hospital stay as a succession of medical assaults on a passive body: "they undressed him, shaved his head, fastened him with metal to a stretcher, lit him until he was blind and dizzy, auscultated him, and a masked man stuck a needle in his arm"¹. In the days that followed, "Dahlmann meticulously hated himself; he hated his identity, his bodily needs, his humiliation, the beard that bristled on his face"¹. Afterwards Dahlmann recovers, or so it seems, and travels by train to the South of Buenos Aires province, where he had kept a much-loved family estate. The story

leaves traces of an unreal atmosphere. On the train he travels “as if he were two men at once”, one of them “imprisoned in a sanatorium and subject to methodical servitudes”¹. Dahlmann gets off at a station that is not his usual one and reaches a *pulpería*, a country general store. The owner resembles one of the sanatorium employees. There, some half-drunk locals provoke him to fight. An old gaucho, in whom Dahlmann sees “a cipher of the South (of the South that was his)”¹, throws him a “dagger”, a word Borges uses significantly. Dahlmann, who does not know how to fight, picks it up to face them. As he crosses the threshold, Borges writes that dying this way “would have been a liberation for him, a joy and a feast, on the first night in the sanatorium, when they stuck the needle in him. He felt that if he, then, had been able to choose or to dream his death, this is the death he would have chosen or dreamed”¹.

In the prologue, Borges warned that the story, perhaps his best as he himself maintained, could be read as a direct narration of novelistic events but also “in another way”². In a later interview with Ricardo Piglia and Mario Szichman he was more explicit, stating that whoever rereads *El Sur*, will notice that Juan Dahlmann is not saved, that he does not return to the South, and that he dies under anesthesia, in the last dream he has³. Dahlmann, too, never left the sanatorium. The wish for another death is, here, the character’s own wish for a heroic death rather than one in the misfortune of hospitalization.

In the poem “Isidoro Acevedo”, Borges evokes the death of his maternal grandfather, who had fought at the battle Cepeda and Pavón during the civil wars, and died in a house on Calle Serrano, in the burning summer of nineteen-hundred-and-five⁴. The poet admits he knows nothing about his grandfather except some names and dates, “frauds of the word,” and Borges writes in his poem that he has rescued and imagine how was his last day, “not the one the others saw, his own”⁴. What the others saw was a sick man with pulmonary congestion who spoke aloud and wanted to sit up. What the poem sees is something else: “When a pulmonary congestion was sweeping him away / and the inventive fever falsified the face of the day for him, / he gathered the burning archives of his memory / to forge a dream”⁴. It was a battle in which “he assembled an army of

Buenos Aires shades / so that they would kill him”⁴. The poem takes care to deny that this vision is a symptom: it was a visionary act that his faith required, not one imposed on him by weakness⁴. The wish for another kind of death no longer belongs to a character; instead and marvelously, it is an elaboration by Borges himself, the first-person narrator, who in turn dreams that his grandfather dreams that death.

In “La noche boca arriba” (“The Night Face Up”) by Julio Cortázar, a motorcyclist injured in an accident is taken to the hospital. A man in white, a doctor, approaches him “with something that gleamed in his right hand” and, from that moment on, the character begins to dream that he is a Moteca warrior hunted by the Aztecs during the Flowery Wars⁵. Each time he wakes, the hospital receives him like a refuge. The man in the next bed reassures him: “It’s the fever”⁵. At the end, the reading is inverted. Laid out on the sacrificial stone, the Moteca understands that he will not wake, “that the marvelous dream had been the other one”⁵, the dream of the city, the motorcycle and the ward. No one here wishes for the other death; the Moteca flees from it. But the story replaces the anonymous hospital death with a death that is fought and, at the same time, meaningful. The anonymous one is that of a nameless person, with the X-ray on his chest “like a black tombstone”⁵. The other will remain inscribed in sacred time and in a collective war.

These texts produce three degrees of a single wish, not to die in hospital, to die another death. In all three, the imagined death is active, belongs to a personal, family or collective history, and preserves the name of the one who dies. And in all three the threshold is clinical: the needle, the anesthesia, the fever. Fiction had already figured what the patient BZ recounted on his last day.

Reflecting along these lines is a clinical exercise. From the perspective of narrative medicine, Arthur Kleinman distinguished the sickness recorded in the medical chart (*disease*) from the one the patient lives (*illness*), and noted that the latter becomes visible only when someone listens to the story the patient builds about it⁶. Arthur Frank showed, in turn, that serious illness, and often the institution itself, strip patients of their voice, and that narrating is a way of recovering it⁷. In “El Sur”, Dahlmann strapped to the stretcher is

the exact image of that dispossession. Rita Charon, one of the founders of narrative medicine at Columbia University, called narrative competence the capacity to recognize, absorb, interpret, and be moved by the stories of illness⁸, and organized it into three movements she defined as attention, representation and affiliation⁹. John Launer brought this into the everyday conversation of the consulting room¹⁰, and Maria Giulia Marini, for her part, conceived of it as a bridge between evidence and the humanities, not as an alternative to them¹¹. What literature trains is not so much empathy. It is something more uncomfortable, the distrust of the first reading. *"It's the fever"* is a first reading. Borges's poem proposes another. Through these exercises, literary discourse becomes also an interference with medical discourse.

In Argentina, dying in hospital is the rule. Of the cancer deaths registered in 2017, 80.5% occurred in hospital, one of the highest proportions among twelve Latin American countries. In that study, patients with solid tumors were more likely to die at home¹² than those diagnosed with hematologic malignancies. A systematic review and meta-analysis showed that the likelihood of dying in hospital for patients with hematologic malignancies is more than twice that for other cancer types¹³. Yet a review of 210 studies in 33 countries showed that most people would prefer to die at home, and that about four in five patients maintain that preference as the disease progresses¹⁴. Between what happens and what is wished for lies a distance that statistics measure but do not explain.

The patient BZ inhabited that distance. The team was planning his return to the farm, and that destination never came. The day before, he had dreamed another ending. Like Dahlmann, he dreamed of his land. Like Isidoro Acevedo, he forged that dream from the archives of his own life's memory, the fields, his partner, his daughters. Like the Moteca, he woke without knowing on which side wakefulness lay. A dream like this rarely reaches the medical record, and, naturally, it appeared neither in the chart nor in the discharge summary written after his death. Reading such summaries confronts us with an account of the moment of death wholly stripped of the meaning it holds for the patient or the family. The word *"demise"* appears almost exclusively in these records of death, alongside a language devoid of all sensitivity. And yet the dream was probably the truest thing that could be known about his end. Listening to it and reflecting on it was also an important part of care, placing attention on the narrative of the patient's last vision, his last day; producing a representation of that moment; and forging a bond with the memory of this patient after his death. An ending different from the one recorded by those who completed the discharge summary. An ending that the care team who followed him considered BZ's own, the ending he dreamed.

Se ha empleado IA para la traducción al inglés del texto original en castellano, que luego fue supervisada y corregida por el autor.

References

1. Borges JL. El Sur. In: Obras completas. Vol. 1. 5th ed. Barcelona: Emecé Editores España, 1996, p 524-9.
2. Borges JL. Prólogo [a Artificios]. In: Obras completas. Vol. 1. 5th ed. Barcelona: Emecé Editores España, 1996, p 483.
3. Piglia R, Szichman M. Entrevista a Jorge Luis Borges [undated]. In: Piglia R. Borges por Piglia. Portas D (ed.). Buenos Aires: Eterna Cadencia, 2024, p 171.
4. Borges JL. Isidoro Acevedo. In: Obras completas. Vol. 1. 5th ed. Barcelona: Emecé Editores España, 1996, p 86-7.
5. Cortázar J. La noche boca arriba. In: Cuentos completos. México DF: Alfaguara, 1996, p 386-92.
6. Kleinman A. The illness narratives: suffering, healing, and the human condition. New York: Basic Books, 1988.

7. Frank AW. *The wounded storyteller: body, illness, and ethics*. Chicago: University of Chicago Press, 1995.
8. Charon R. Narrative medicine: a model for empathy, reflection, profession, and trust. *JAMA* 2001; 286: 1897-902.
9. Charon R. *Narrative medicine: honoring the stories of illness*. New York: Oxford University Press, 2006.
10. Launer J. *Narrative-based primary care: a practical guide*. Abingdon: Radcliffe Medical Press, 2002.
11. Marini MG. *Narrative medicine: bridging the gap between evidence-based care and medical humanities*. Cham: Springer, 2016.
12. Dannenberg A, Cohen J, Deliens L, et al. Place of death of people with cancer in 12 Latin American countries: a population study using national death registers. *Cancer Med* 2025; 14: e70996.
13. Howell DA, Roman E, Cox H, et al. Destined to die in hospital? Systematic review and meta-analysis of place of death in haematological malignancy. *BMC Palliat Care* 2010; 9: 9.
14. Gomes B, Calanzani N, Gysels M, et al. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care* 2013; 12: 7.