THE EUROPEAN JOURNAL OF LIFE WRITING

VOLUME XII (2023) GA 7–32

The Violent ‘Trojan Horse’: a Comparative, Transnational Reading of Two Paralysis Narratives

Isabel Durán Giménez-Rico
Universidad Complutense de Madrid

Abstract

This article proposes a comparative analysis of two ALS narratives: one written in 2017 by the Spanish businessman and author Francisco Luzón, *El Viaje es la recompensa* (*The Trip is the Reward*) and the other published in 1999 by American sociologist Albert B. Robillard, *Meaning of a Disability: The Lived Experience of Paralysis*. Both ‘autopathographies’ present detailed testimonies of the increasing emotional crisis, stigmatization, and feeling of helplessness of two powerful and eminent men left paralyzed in mid-life by a cruel illness. The European and the American outlook on this perverse malady, as experienced on two different continents, will enable us to explore issues related to wasted bodies, the daily struggle against a body and a mind bent on destroying themselves, the battle against fear and anger, the memories of an intense life and of a life journey worth travelling, even when narrated from ‘the kingdom of the ill.’

Keywords: Francisco Luzón, Albert B. Robillard, ALS, pathography, medical humanities.

Resumen

Este artículo propone un análisis comparativo de dos narrativas de ELA; la escrita en 2017 por el empresario y escritor español Francisco Luzón, El Viaje es la recompensa, y la publicada en 1999 por el sociólogo estadounidense Albert B. Robillard, Meaning

https://doi.org/10.21827/ejlw.13.41314

of a Disability: The Lived Experience of Paralysis. Ambas ‘autopatografías’ presentan testimonios detallados de la creciente crisis emocional, estigmatización y sentimiento de impotencia de dos hombres poderosos y eminentes que quedaron paralíticos a mediana edad a causa de una cruel enfermedad. La mirada europea y americana sobre esta perversa enfermedad, sufrida en dos continentes diferentes, nos permitirá explorar cuestiones relacionadas con los cuerpos enfermos, la lucha diaria contra un cuerpo y una mente empeñados en destruirse a sí mismos, la batalla contra el miedo y la ira, y los recuerdos de una vida intensa y de un viaje existencial que ha merecido la pena recorrer, aunque narrado desde ‘el reino de los enfermos’.

Palabras Clave: Francisco Luzón, Albert B. Robillard, ELA, patografía, humanidades médicas.

Introduction

Stephen Hawking (1942-2018), the British theoretical physicist and cosmologist, was an icon for the struggle against ALS, or Amyotrophic Lateral Sclerosis, also known as Motor Neuron Disease (MND), a neurodegenerative disease that results in the multiple and progressive loss of motor neurons that control voluntary muscles. At the age of 21, Hawking was diagnosed with ALS. As his condition worsened over the years, he was left almost completely paralyzed, forcing him to communicate through a voice-generating device. He was the longest-lived person post-diagnosis with this disease, surviving 55 years, when the average life expectancy is about three to five years. His case still puzzles neurologists.

To sum up in brief a plethora of scientific mysteries, early symptoms of ALS include stiff muscles, gradually increasing weakness and muscle wasting. Motor neuron loss progresses until the ability to eat, speak, move, and finally the ability to breathe is lost. ALS eventually causes paralysis and early death, usually from respiratory failure. In other words, unlike MS (Multiple Sclerosis), ALS is a deadly disease with no cure, and most treatments focus on alleviating the various symptoms caused by the disease.

Moreover, ALS remains a much-neglected disease still today. As Francisco Luzón puts it, its most immediate reality remains unknown: how it affects those who suffer from it and the people around them; what emotional care they require; and how the victims are to be cared for. No specific training is given to specialists, nor are there many health policies developed to support research. Moreover, the drastic reduction in quality of life also generates intense psychological distress and predisposes sufferers to mental illness and, in more severe cases, to suicidal behavior or the request for euthanasia. No evidence has been found to explain what causes the disease, and any estimate about its future development lacks a scientific basis. To make things worse, the scientific community, the health systems, and society in general consider ALS a minor disease because it affects a relatively small number of people. It is, in Luzon's words, an 'invisible disease'.[1]

This article proposes a comparative and transnational analysis of two ALS narratives, which can be described as 'autopathographies', adopting Thomas Couser's term:[2] *El Viaje es la recompensa (The Journey is the Reward)*, written in 2017 by the Spanish economist and author Francisco Luzón, and *Meaning of a Disability: The Lived Experience of Paralysis*, written in 1999 by American sociologist Albert B. Robillard. Both narratives are detailed testimonies of the experiences and observations of two men, both highly distinguished in their professions, who became paralyzed in mid-life. The European and the American outlook at this perverse disease, as experienced on two different continents, will enable us to explore issues related to wasted bodies, the daily struggle against a body bent on destroying itself, the battle against fear so that it does not overtake the soul, the memories of an intense life, and, eventually, a journey that has been worthwhile and that, in some ways, has been a reward in itself.

Many texts on the Medical Humanities and Illness Narratives seem to be addressed to physicians, medical educators, or medical students,[3] with multiple goals in mind: helping 'develop in physicians and healthcare professionals through the study of literature and narrative *habits of attentive listening* with the patients',[4] bridging the gulf between science and human experience, educating more humane physicians, and recapturing the notion of medicine as a learned profession rather than simple vocational training. That is, its main intention is to help re-humanize medicine.[5] But what aims do we, literary scholars and humanists, pursue when studying illness narratives, pathographies, or artistic expressions that represent illness? Just like gender studies (which developed in response to sexism) or age studies and humanistic gerontology (which developed in response to ageism), or black and ethnic studies (which developed in response to racism and xenophobia), medical humanities grew up alongside and in association with the patient's rights movements in the 1960s and 1970s, and it is concerned with questions of power and justice, broadly conceived.[6] That is, if literature teaches us questions related to love, hate, race, sex, politics, loss, hope, trauma, everyday manners, (in)justice, ideals, dreams and nightmares, human relations, psychological intricacies, and every possible aspect of the human experience, illness stories also teach us, general readers as well as scholars, the biopsychosocial experience of the diseased body as experienced and suffered by human beings in general. In other words, 'reading narratives of illness […] can heighten our powers of perception, deepen our self-knowledge, and broaden our understanding of what it's like to suffer through an illness or cope with an injury'.[7] Moreover, reading pathographies enhances our sense of empathy.

Francisco Luzón (1948-2021) was an economist and banking professional. He participated in the transformation of Spanish and Latin American banking over the last forty years, assuming important responsibilities, especially in Banco Santander. In 2016, he announced that he had suffered from ALS since his diagnosis in 2013 (he was then in his mid-sixties). He also announced the creation of the *Francisco Luzón Foundation* (https://www.ffluzon.org/) to fight the disease and support research. He died in 2021 at the age of 73, eight years after diagnosis.

Albert Robillard (1943-2015) was Professor of Sociology at the University of Hawaii at Manoah, and author of *Social Change in the Pacific Islands*. His original training was as an ethnomethodologist at UCLA. He was diagnosed with ALS in his early 40's (around 1985) and after 1988 was wheelchair-bound. He died at 72 in 2015, some thirty years after being diagnosed with ALS.

Like Hawking, both Luzón and Robillard were born in the 1940's and they both died of ALS in their early seventies. Biographical coincidences apart, this chronological data reveals that they were almost exact contemporaries; they both lived through the same decades, and thus had the same technological and scientific advances available to them to fight their paralysis. Likewise, both had resources—financial, intellectual, and emotional—to fall back on. Yet, their approach to their deadly illness was quite different, and this transnational comparative analysis will not only reveal differences in narrative intentions and strategies, and differences in the ways they came to terms with their wasted bodies, but also the different cultural and sociological issues that arise in the two countries and their health systems. To achieve my aim, I will be making a thematic comparative analysis of both autopathographies, inspired by the landmark works in this area provided by authorities in the field of Health Humanities, such as Thomas Couser, Anne Hunsaker Hawkins, Arthur Frank, and Thomas Cole, among others.

Types of (auto)pathography

In *Reconstructing Illness: A Study of Pathographies*, Anne Hunsaker Hawkins explains that a pathography 'restores the person ignored or canceled out in the medical enterprise, and it places that person at the very center. Moreover, it gives that ill person a voice'. An offshoot subcategory of pathography is autopathography. This literary subgenre of life-writing has been defined by Thomas Couser as an autobiographical narrative of illness or disability that becomes a cathartic act in what Suzette Henke (1998) has termed scriptotherapy, 'by heightening one's awareness of one's mortality, threatening one's sense of identity, and disrupting the apparent plot of one's life'. The term autopathography is useful to distinguish first-person illness narratives from those told by another, in the third person. Its focus is typically not on the medical condition or details of treatment; rather, it critiques social constructions of the disabled body and incorporates a counternarrative of empowerment that reclaims the individual's body from the social stigmatization and the impersonalization of medical discourse.

Hunsaker Hawkins presents pathographies as complementary to the medical history of the patient. While the medical chart concerns illness as 'a particular biomedical condition,' the pathography describes how an experience was understood. In place of the chart's presentation of 'symptoms and body chemistry,' the pathography situates illness in the author's life and reflects on 'the *meaning* of that life'.[8]

Hunsaker's emphasis on the 'meaning of that life' takes me to the title of one of the texts to be analyzed, Robillard's *Meaning of a Disability: The Lived Experience of Paralysis*, the personal story of a highly trained observer forced to confront simultaneously the limits of the disabled person's social world and the unspoken assumptions about meaningful interaction. As told in his narrative, after his loss of speech, Robillard was forced to communicate through a lip-reading system developed by his wife and student assistants. Restricted by this form of communication and his paralysis, he soon learned the frustrations of making his meaning known. Finding himself isolated due to his lack of both mobility and vocalization, Robillard threw himself into his academic work and began to develop settings and methods where he could satisfactorily interact with others.[9]

As such, the voice that predominates in the account and study of his paralysis is that of the social scientist who considers his own experience a sociological case, where he tries to discover the personal, but also the ethnomethodological *meanings* of his disability, and of disability in general. After his initial three-month hospitalization for pneumonia in 1991, he decided to turn to writing about living inside a disabled, weak, and mostly paralyzed body. He felt that, as a person who could not communicate in what was a commonsense notion of 'real time'[10] and was isolated by his caretakers and by his interaction with them, he had to return to ethnomethodology as a way of making sense of his experience and his living with it.[11] The scientific outlook on his illness gives rise to a quite distant memoir, in which he interweaves his own experience with critical scientific analysis, frequently quoting fellow scholars. In fact, chapter four, entitled ‘Anger’ was published as a critical essay as ‘Anger in the Social Order’ in the journal *Body and Society* (1996), and his memoir includes four pages of works cited, and a thematic index, in the manner of academic books.

Spaniard Francisco Luzón takes a wholly different approach to the same problem. If we reflect on its title, *The Journey is the Reward*, and examine some of its arguments and thoughts, we may conclude that, for Luzón, his life has been a journey for which he is grateful, despite all the sorrows that now torment him: ‘My life journey follows a new course since ALS became my inseparable companion. Now I search for thoughts, arguments, I inquire about life and death, about the whys and wherefores’.[12]

It is evident that the voice we hear is much more subjective and intimate than Robillard’s; it is less distanced and much more personal and emotional. Luzon’s inexplicable gratefulness contrasts with Robillard’s detached, critical views that verge on anger. ‘I am an expert on anger’, he says at one point, and continues: ‘Not only can I assemble anger on a routine basis, I can see and talk about the sequential and socially concerted steps building toward an outburst before it happens’.[13]

This quote and the spirit that permeates the book leads me to categorize Robillard’s text as a clear instance of what Hunsaker Hawkins has called ‘angry pathographies’, one of the four different groups of pathographies she identifies as emerging when one analyzes them according to authorial intent. The authors of ‘angry pathographies’ are motivated by a strong need to point out deficiencies in various aspects of patient care. Nearly always, the main concern is about lack of empathy and professionalism in medicine:

> Pathographies of this kind are important in alerting all of us to important problems in medical practice. They vividly depict how an ill person today can be at the same time the beneficiary and the victim of a healthcare system whose very excellence – its superb technological and pharmacological achievements-is at the same time potentially dehumanizing.[14]

As Thomas Couser has warned, ‘the claim to expertise rests on the prestige of science, but the scientific tendency to objectify and quantify human experience may obstruct the profession's humanitarian intent’.[15] Indeed, Robillard openly expresses his anger against the intelligence, motivations, and dehumanized sensitivity of his medical caregivers and against the irrationality of the entire health care delivery system, particularly in Hawaii. In chapters two and three he launches a crusade against two particular physicians for having poor patient communication, and for how their uncaring statements are made without preparing the patient:

> What the family practitioner did, in his statements, was to present me and my wife with a close horizon, a lesser form of existence, denigrated by illness and a prognosis of death. There is something about having a fatal disease, an officially diagnosed fatal illness, that immediately renders the diagnosee less worthy, and having fewer prospects, than others. This image of the life of the fatally ill leads to comments like the physicians telling me to go home, take Valium, get death counseling, and prepare to die.[16]

In the same chapters he is also scornful of nurses, particularly what he calls 'flying nurses', who use their profession to do professional tourism, a specific problem of Hawaiian hospitals:

> Most of those in the ICU were visiting nurses from the U.S. mainland […] These nurses call themselves "flying nurses"; they sign short-term contracts to work for from three months to a year […] Most worked three twelve-hour shifts each week and would have four days off to enjoy Hawaii […] The national need for intensive care nurses was so great that some were able to spend years working the circuit of resort areas in the United States.[17]

Given this temporary hiring system, the nurses never really make any close personal connections with the patients; they may know their medical history, but not the particular personal circumstances and ailments of their patients, which Robillard decries. He also criticizes the 'blame the patient' rhetoric of the nurses, asking him to 'be a good boy' while staying at the ICU: 'What does it mean to be a "good boy"? It means to be a patient who does not express symptoms requiring the attention of a nurse. Such reasoning trades on an assumption that patients have some motivational control of their symptoms, or at least should have'.[18]

One need not want to undermine the authority of physicians to be uneasy with many aspects of medical discourse, such as its tendency to infantilize patients ('be a good boy'), typify illness, and medicalize experience. To support his view, Robillard actually quotes American sociologist Talcott Parsons, who said that one of the properties of the sick role was being exempt from responsibility. This exemption includes responsibility for the present illness:

> The sick, instead of being allowed to suffer in quiet, are addressed with supposed reasons they have become sick—for example, "You could not control your eating

> and drinking". For the chronically ill, the comments will often be directed at how the person is a burden, requiring constant care; some remarks will be directed at the cost of care; and a few formulations will focus on the person's lack of will, as seen in the comment directed at an individual having trouble standing— "What is wrong with you, why don't you stand up?"[19]

Robillard's anger is also addressed at how the American system does not provide financial support to buy the very expensive devices an ALS patient needs, such as electronic wheelchairs, or to face the almost omniprevalent social pressure to obtain and use computers and other assistive devices, such as the artificial-voice machines. Because of his professor's salary, he does not qualify for state assistance in the purchase of equipment: 'The constant barrage of requests to purchase assistive equipment to help yourself and your family makes you feel inadequate at first for not having the necessary funds. This feeling of inadequacy quickly turns to anger'.[20]

Turning now to Francisco Luzón's text, we perceive that he never expresses this sort of anger, or displays a demanding attitude. However, he does try to suggest alternative ways of approaching the treatment of ALS. In this sense, Hunsaker Hawkins proposes a second type of pathography that she calls 'alternatives pathography,' which is also critical of the medical system, but without angry denunciations or doctor-bashing:

> Like their angry counterparts, these pathographies stem from dissatisfaction with medicine. They differ in that the author is concerned not so much with criticizing traditional medicine as with finding alternative treatment modalities.[21]

In this sense, *The Journey is the Reward* is written, so Luzón explains, with the aim of changing the professional understanding of this illness, and how to fight it, as something that requires a coordinated team of specialists. He proposes an alternative policy for handling ALS, which is to concentrate all the physical and psychological treatment of the patient in a few hospitals with specialized ALS units, since the treatment of this illness requires from the outset a multidisciplinary model that truly makes the patient the center of gravity, which implies that specialists -neurologists, psychologists, speech therapists, physiotherapists, traumatologists, nutritionists, nurses and pneumologists- must be together in a specific, well-equipped physical space: 'Is it so difficult to understand that we are patients with reduced mobility, that we are not able to make a long pilgrimage from doctor to doctor in different hospitals and for several days?'[22]

Luzón's text often utters a collective and relational voice, in so far as he talks about a community of ALS patients, and not just himself. In this sense, it would also be more in tune with the third kind of pathography that Hunsaker Hawkins names 'didactic,' as a narrative motivated by the explicit wish to help others, 'based on the assumption that the author's experience can serve as a mirror or a model (whether positive or negative) for prospective readers'.[23] This could likewise be linked to what Arthur Frank calls 'an ethic of solidarity and commitment,' expressed when the storyteller offers his voice to others, not to speak *for* them, but to speak *with* them as a fellow-sufferer who has a chance to speak while others do not.[24]

The purpose of writing his autopathography, so Luzón states, is more philanthropic than denunciatory: to commit himself to other ALS patients, their families, hospitals and medical specialists, public administrations, patient associations, and society in general. Well aware that opening his disease to the public implies taking responsibility, soon after being diagnosed with ALS in 2015, he started to give shape to the *Francisco Luzon Foundation* 'for the benefit of my fellow travelers':

> Consciente del curso de la enfermedad, decidí tomar cartas en el asunto, mojarme, devolver a la sociedad lo que esta me había dado. Y a pesar de que la ELA ha seguido su marcha imparable y demoledora, me puse manos a la obra […] Con la enfermedad pisándome los talones a diario, decidí crear la Fundación Luzón con vocación de largo plazo […] Yo seré su alma y ese es el motivo por el que le he puesto mi nombre, no por narcisismo, sino como expresión de mi compromiso con la sociedad para el resto de mi vida.[25]
>
> Aware of the course of the disease, I decided to take action, get involved, and give back to society what society had given me. And although ALS continued its unstoppable and devastating march, I got down to work […] With the disease nipping at my heels every day, I decided to create the *Luzon Foundation*, with a long-term vocation [...] I will be its soul and that is the reason why I have given it my name, not out of narcissism, but as an expression of my commitment to society for the rest of my life.

Luzón describes how his ALS progresses, how it follows its path at a steady pace despite medication, care, strength of mind, physical and respiratory exercises, and the sessions with different specialists. But, unlike Robillard, he only has words of recognition and thankfulness for the medical profession at the Carlos III Public Hospital in Madrid, where 'I am treated with such professionalism'.[26] He also has praiseful words for the nurses who, he says, are diligent, treat him and the other ALS patients with kindness and efficiency, are skillful, and make sure all the patients are well attended to. One particular case is Nurse Yolanda: 'Yolanda, redheaded, affectionate, cheerful, is a great professional who welcomes us with a huge smile and an affectionate question: "How are you, honey?" And she is referring to me. I thank her so much, with the same sincerity and affection that she transmits to me, I give her back the best of smiles'.[27]

Embodied selves

Illness in pathographies is not just the topic of the story; it is the condition of the one telling that story. In Arthur Frank's words, the illness story is not just *about* illness: the story is told *through* a wounded body. In other words, the body is simultaneously 'cause, topic, and instrument' of illness stories.[28] As Frank further explains, one of our most difficult duties as human beings is to listen to the voices of those who suffer. The voices of the ill are easy to ignore, because these voices bespeak conditions of embodiment that most of us would rather forget our own vulnerability to. Thus, as readers of pathographies, both the medical professions and the general readership engage in a fundamental moral act, when participating in the 'ethics of listening' to the wounded voice of the storyteller.[29]

In *The Wounded Storyteller*, Frank proposes four general problems of embodiment: control, body-relatedness, other-relatedness, and desire.[30] Within this matrix, he further proposes four typical ill bodies: the disciplined body, the mirroring body, the dominating body, and the communicative body. Clearly, the four body types cannot be either mutually exclusive or exhaustive. Logically, the value of the four types is to describe the extreme moments of these shifts, thus providing some parameters for hearing the body in the story. Without getting into a detailed description of Frank's categorization, which would be beyond the scope of this essay, I propose that Robillard's and Luzón's bodies-as-selves fit into two particular body types: the dominating body and the communicative body, respectively.

'The dominating body defines itself in *force*', Frank states,[31] and, usually, this body-type displaces rage against contingency onto other people (spouse, parents, care-takers, children, etc.). In Robillard's case, much of his rage is displaced onto his Filipino wife and caretaker, Divina. *Meaning of a Disability* actually constitutes a pathography within an autopathography, for, as Robillard writes, as he was concluding the narrative of his illness, his wife was diagnosed with breast cancer, and she underwent a radical mastectomy.[32] But just a brief paragraph is devoted to this terrible event:

> When she came in she immediately said, "I don't have good news. The lump I removed was cancerous and the surrounding tissue was cancerous." We were desolated. Divina and I were both thinking, ' "We have enough coping to do with one illness. This is too much." As the surgeon went on, explaining the need for a modified radical mastectomy, we were too numb to follow her.[33]

What follows is not an account of his wife's suffering, as might be expected, but quite a distant description of how his wife's surgery entailed some readjustments in his own daily care, since during Divina's hospitalization, he needed full-time home nursing care to assist him. The focus of his rage now falls on the problems he had with his health insurance company, when they bargained over the number of hours of in-home nursing, and how this meant that they had to recruit private nurses through an agency.[34]

Bent on their own paralyzed bodies, some patients tagged by Frank as 'dominating bodies' actually become emotionally abusive in their possessiveness of their spouses, and the climax of this abuse often comes when they expect them to give up their jobs, and become full-time caregivers.[35] This is the toll that Robillard's wife had to pay, when she was forced to put her career and doctorate 'on hold'[36] in order to perform the daily routine he describes, of which I will only give a brief account:

> When I awaken, around seven or eight, I begin watching CNN […] At eight-thirty, after *Divina* eats breakfast, we start with the first breathing treatment of the day. I am on a ventilator, which pumps a medical mist into my lungs to loosen the mucus. After the breathing treatment, I am turned on my left side, while *my wife* uses a percussor to loosen the mucus from my right lung […] Then *Divina* shaves me […] After the shave, I get a bed bath. Then I am fed […] After I am fed, *my wife* cleans my trache. Then *she* will do range-of-motion exercises on my arms and legs […] When I come to work, I transfer from my car to a wheelchair. *My wife*, or sometimes a friend, drives.[37]

If we take note of the number of times his wife is mentioned in this short paragraph, we may get a hint of why caring for a partner with a progressive neurological illness has been recognized as being a source of burden and psychological distress. The negative effect of the patient's disease on the caregivers' quality of life, social life, work activities, and health can be very high. Caregivers are at high risk of developing stress, anxiety, and depression, sometimes even more than that of their patients, to the point that the caregiver is often defined as 'the hidden patient,' one whose needs are often underestimated.[38] Robillard explains that one day a doctor unleashed the following remark, without provocation: 'You are lucky you have a wife who stuck by your side. Most people in your condition have had their wives split long ago,' a comment to which his wife immediately replied, 'You see, you see!'.[39] Indeed, Robillard admits that Divina has taken excellent care of him, and that she is the single reason he is still alive, defying all predictions. But immediately afterwards, he states that such long-term care cannot be without complaint:

> My wife has complained, on bad days, that my illness has drained her, that constant pressure of taking care of me has ruined her life and the life of our son. She has asked me to be creative in thinking of ways, within our limited means, to free her from the constraints of having to be around me constantly.[40]

Without explicitly saying it, it seems that Robillard's dominating body-self is in some way complaining that his wife may have the right to complain for having become a full-time caregiver.

Although the various body types overlap and exist at different moments of their being, turning now to Francisco Luzón, we may conclude that his falls more into Frank's category of a 'communicative body', that which accepts its contingency as part of the fundamental contingency of life, since here lies the sense of obligation toward the other that grounds Schweitzer's 'brotherhood of those who bear the mark of pain'.[41] That is, the dyadic nature of the communicative body means 'that it never belongs to itself alone but constructs its humanity in relation to other bodies', and its ethical ideal is that of existing for the other; of joining with other suffering bodies.[42] In this sense, Luzón understands from the beginning of his illness that, while some of his muscles are paralyzed, his brain continues to boil. And it makes him wonder if it was worth living such a hectic life to end up like this. His answer is a definitive 'yes':

> Durante toda mi vida he tenido la convicción de que no debía resignarme nunca, la enfermedad no ha hecho más que afianzar dicha convicción. Y cuando una nebulosa amenaza mi mente, me pilla desprevenido o sin recursos, siempre me digo a mí mismo: 'Paco, piensa en el día de hoy, nadie ha vivido mañana'.[43]

> All my life I have had the conviction that I should never give up, and the disease has only strengthened this conviction [...] And when a nebula threatens my mind, catches me unawares or without resources, I always say to myself: 'Paco, think about today, *no one* has lived tomorrow'.

Indeed, his allusion to 'no one' locates his contingency in communication with all human beings; the ill and the healthy. And, while he mourns the sense of isolation to which his illness has condemned him, he tries to find a meaning in his existence, which again, speaks of engagement and inclusion of the others that surround him. These are his reflections on a Christmas Eve:

> Uno, un solo sentido. Compartir ese tiempo con la familia. Observarles, disfrutar a través de su gozo. Oírles cantar. Verles reír. Intuir lo que van a hacer los jóvenes con sus amigos. Sentir su felicidad, la de Julia, la de los más pequeños que alborotan al abrir sus juguetes. Claro que es bonito, claro que provoca placer. Y dolor [...] No voy a dejar paso a la autocompasión. Soy el mismo Paco de siempre, pero con una visión de la vida algo diferente. A medida que mi cuerpo se ha debilitado, mayor ha sido mi compromiso en la lucha diaria.[44]

> One, only one meaning. To share this time with my family. To watch them and to feel happy through their joy. To hear them sing. To see them laugh. To intuit what the young ones are going to do with their friends. To feel their happiness, Julia's happiness, that of the little ones who make a fuss when they open their presents. Of course, it's fulfilling, of course it's pleasurable. And painful […] I will not admit self-pity. I am the same Paco as always, but with a slightly different outlook on life. As my body has weakened, the greater my commitment to the daily struggle has become.

Moreover, Luzón's communicative body-self is very aware that the victims of ALS may be isolated, but they are not alone, if they generate a communal strength. That is why in his narrative he invites other ALS victims to find each other, to come together and to build a fortress to protect themselves from the 'Trojan horse', the term he finds to define this disease, as an aggressive attack of unstoppable violence.[45] As in Homer's *Odyssey* or Virgil's *Aeneid*, the wooden horse has sneaked into Troy, it is only a matter of days to know when and how it will attack the city. Defeat is inevitable, he is well aware, but ALS victims, if united, can still defend themselves, minimize the damage, face the destructive process and gain time. So, he invites the 'brotherhood of those who bear the mark of pain' to find dignity in defeat, facing the disease as a community. This, he confesses, is his goal and the battle that keeps him going.

As for his beloved wife and caregiver, María José, whom he considers his 'spirit', the one who makes him 'live, breathe, dream,'[46] Luzón listens to his inner voice, and finds strength in his determination not to be too much of a burden for her, or his larger family:

> 'Paco, no tires la toalla', escucho. 'Todavía te queda fuerza exterior e interior. Has de lograr que el camino al precipicio sea cada vez más largo y lo recorras sin perder ánimo ni ilusión. Y sobre todo, sin dañar la vida de María José ni la de la familia. Pelea hasta el último minuto, aunque estemos ya casi en la prórroga'.[47]

> 'Paco, don't give in', I listen. 'You still have external and internal strength. You have to travel the road towards the precipice without losing courage or illusion. And above all, without harming María José's life or that of the family. Fight until the last minute, even if you have reached overtime'.

Illness as a Journey: Quest Narratives

'Illness is the night-side of life, a more onerous citizenship', is the line that opens Susan Sontag's seminal book 'Illness as Metaphor.' And she continues, using a metaphor, explaining the evidence that:

> Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.[48]

Susan Sontag's metaphor of illness as a transit or journey from one kingdom to the other, gives us grounds to describe our two pathographies as journeys that eventually become quest narratives. Despite the differences in typology pointed above, both Luzón's *The Journey is the Reward* and Robillard's *Meaning of a Disability* could be catalogued as cases of what Arthur Frank terms 'quest narratives'. These stories, Frank explains, meet suffering head on; they accept illness and seek to use it. That is, illness is the occasion of a journey that becomes a quest: 'Quest stories tell of searching for alternative ways of being ill. As the ill person gradually realizes a sense of purpose, the idea that illness has been a journey emerges. The meaning of the journey emerges recursively: the journey is taken in order to find out what sort of journey one has been taking'.[49]

Arthur Frank obviously recurs to Joseph Campbell's monomyth in his classic 1949 work, *The Hero with a Thousand Faces*, and uses his reduced three-part structure for the hero's journey (departure, initiation, and return), as applied to illness narratives. I will follow in Frank's footsteps and test how the 'hero's journey' can be applied to our cases.

As is well-known, the first stage, *departure,* begins with a call. In illness stories the call is the symptom: in the case of our ALS patients, the initial difficulty with speech, stiff muscles, clumsiness when moving, and so on. Both Luzón and Robillard offer a detailed description of their departure from 'the kingdom of the well' (Sontag), and their entrance into 'the first threshold' of the unknown 'kingdom of the ill' which, in both cases, is their first hospitalization and the learning of their tragic diagnosis. This is how Luzón describes this departure stage as a 'blackout':

> Y comenzó el apagón, no fue repentino, pero ahí arrancó la desconexión. Desconectaron aquellas que habían forjado parte de mi ser. El cerebro está bien […] pero las neuronas del bulbo que conectan el cerebro con los músculos de la boca, sobre todo la lengua y la garganta se iban muriendo […] Tan solo veinte meses más tarde comenzaba la mala pronunciación […] Después, mi cara iría poniéndose más rígida. Todas las mañanas sentía como si los labios hubiesen pasado la noche en el desierto. Mi lengua, cada vez más inmóvil. Notaba sensaciones extrañas en las piernas, algunas noches tuve problemas de respiración […] Paco habitaba en un cuerpo que le provocaba percepciones desconocidas, extrañas, pero era yo.[50]

> And so the blackout began, it was not sudden, but there began the disconnection [...] They disconnected those that had forged part of my being. The brain is fine […] but the neurons in the bulb that connect the brain with the muscles of the mouth, especially the tongue and throat were dying […] Only twenty months later the slurred speech began […] After that, my face would get stiffer and stiffer. Every morning I felt as if my lips had spent the night in the desert. My tongue, more and more immobile. I felt strange sensations in my legs […] Some nights I had breathing problems […] Paco now lived in a body that caused him unknown, strange perceptions, but it was still me.

Crossing the threshold commences the second stage, *initiation*. Narrators of quest stories use the metaphor of initiation implicitly and explicitly. Campbell calls initiation 'the road of trials,' easily identified in any illness story as the various sufferings that the disease involves, not only physical but also emotional and social. Both Luzón and Robillard amply dwell on this second stage and often coincide in how they narrate their corporeal transformation, the psychological burden brought by the stigmata that ALS entails, the sense of isolation and helplessness, and the anguished sense of being totally dependent on their caregivers, more specifically their wives. As further examples, this is how Robillard narrates the great daily changes, adaptations and transformations that he has to endure:

> Grunting, perspiring, breathing in deep gulps, shaking, sometimes going into muscle spasms with painful cramps, I was rewarded with the violent rotation of the room. What had been an effortless act, getting out of bed, had become a monumental achievement. What I had done for over forty years, completely without notice, had become an obstacle. I became aware of movements and relationships between movements that had remained unconscious for many decades.[51]

A most poignant trial that these wounded 'heroes' have to face is stigmatization; the social discrediting shared by those who suffer from visible disabilities and deformities. In fact, when talking about his illness, Robillard prefers the more socially ambiguous term '*Motor Neuron Disease*,' for it does not suggest the stigmatizing time horizon of *Lou Gehrig's disease* or ALS.[52] Moreover, he mentions more specific instances of stigmatization, as, for example, people's cruel reactions to the bib he often has to wear to absorb his incontinent salivation: 'The wearing of the idiot bib leads to deductions that I am incontinent, deaf, and otherwise socially incompetent. When we have visitors, I ask Divina to remove it. Often, for one reason or another, the bib stays on. This almost always has the effect of socially stigmatizing me'.[53]

As Arthur Frank has also explained, illness is about learning to live with lost control, and 'contingency is the body's condition of being subject to forces that cannot be controlled.[54] In our case, incontinent salivation at the least, impossibility to control one's speech or legs, at worst. In some ways, this contingency re-assembles ALS patients into infantile bodies. However, when adult bodies lose control, they are expected to attempt to regain it if possible, and if not then at least to conceal the loss as effectively as possible; because loss of this control is stigmatizing. Stigma, Coffman points out, 'is embarrassing, not just for the stigmatized person but for those who are confronted with the stigma and have to react to it'.[55] Thus, the work of the stigmatized person is not only to avoid embarrassing themselves by being out of control, but also to avoid embarrassing others, who should be protected from the vision of the loss of body control. In some ways, then, as Robillard suggests, society blames the victim for their stigmatizing loss of control.

However, the most painful psychological burden both authors describe is the sense of solitude and isolation. Luzón speaks of the isolation in which he lives, locked inside his body that he describes as a jail, which has transformed him into a different man. He cannot share family meals or celebrations, for 'eating has become an intimate and solitary act'; he can barely communicate with his offspring and grandchildren; and even his old 'good friends' have stopped visiting him, to preserve themselves from a difficult social situation. Likewise, Robillard mourns his isolation which he compares to that described by anthropologist Robert F. Murphy, the first to describe this process of social isolation in his 1987 book, *The Body Silent*. Murphy had a spinal cord tumor and was eventually paralyzed at and below the level of the tumor. In his book, Murphy details the dual process of the progression of his illness and the gradual loss of friends, colleagues, and visits by neighbors and family. His condition, Murphy sates, 'has visited upon me a disease of social relations no less real than the paralysis of the body'.[56] That is, as he lost physical functions, he increasingly found himself alone, just as Robillard does:

> As my disease progressed, I began to notice that I had become invisible to many friends and colleagues at the university where I am a professor. People with whom I had worked for many years and men and women with whom I had been friends for decades would pass by my wheelchair and not notice who I was […] The texture and identity generated by daily face-to-face interaction with colleagues and friends has been absent from my life for years.[57]

Additionally, both authors mention the emasculation of the patriarchal figure in the family, which implies a confrontation between their illness and the myths of masculinity. It is wrongly assumed that ALS affects the sexual function in men, creating what Robillard calls 'The Myth of Sexual Dysfunction', and he clarifies: 'It does not matter that my penis is one of the last things working properly';[58] still, the wives of paralyzed men are pitied for living not only a life devoted to care giving, but also a life devoid of sex. Moreover, both Robillard and Luzón have to accept their total dependence on their wives (actually, second wives in both cases), and acknowledge their relentless dedication to their care and welfare, especially true in Luzón's case.

Finally, to go back to Campbell's monomyth and its application to illness narratives, the last stage is the *return.* The storyteller, Frank remarks, 'returns as one who is no longer ill but remains marked by illness'.[59] Obviously, this third stage cannot be covered by patients with a terminal illness, as is our case, for they will never return to the 'kingdom of the well.' And yet, they finish their journey through the nightmare of their paralysis and their perseverance, sharing with the reading public what Campbell calls a 'boon,' usually some insight that must be passed on to others which, in the case of pathographies, is the ill person's responsibility of being a witness, and of proclaiming what lessons they have learned throughout their journey.[60]

In Robillard's case, in spite of his angry and spiteful mood in the initial chapters, he devotes his last chapter, aptly entitled 'The Trip', not only to explaining the actual difficulties involved in his mobility, but also to come to terms with some of the 'gifts' that his metaphoric journey through paralysis, silence and seclusion have brought forth. As a professor, one of those gifts is being able to concentrate in the life of the mind:

> My paralysis has added a new dimension to my concentration on work. When I was an able-bodied sociologist, I used to spend the major portion of the working day chatting in others' offices and attending meetings [...] The stillness of a paralyzed body increased my powers of concentration. I started to publish more than before, and I organized my classes down to the last detail.[61]

A second gift, besides his wife's endless struggle to provide him with a life of dignity, have been his colleagues and research assistants. Of the latter he says that they 'are my legs, arms, and whole bodies. They are also my trusted colleagues'.[62] When, as a Spanish scholar, I read of Robillard's dedication to his academic life even after he became fully paralyzed, I cannot but marvel at this crucial difference between the US and Spain. Robillard spends many pages describing the Dean's support (offering assistants or co-teaching with supportive colleagues) and the financial support from universities to keep up the academic activity of disabled staff. He names all the helpful assistants who learned the lip-reading system and became his 'translators;' he describes the complex process of being transferred every day from his home to his university office, where he would spend hours doing research and even teaching: 'I sit at the monitor of my computer and lip-sign to a student assistant, who types what I sign, letter by letter […] My co-teacher carries on the 'real time' discussion in the seminar, following my plan'.[63]

I cannot envision a parallel situation in the Spanish academia, and in many other professions in the public system. In Spain, a university professor with an advanced case of ALS would not be offered assistants to provide both physical and intellectual support, let alone financial aids to keep up his or her academic activity. A Spanish Robillard would simply receive from his physician a certificate of 'definitive functional disability,' which would enable him to apply for permanent sick leave, signaling the end of his active academic career. In 2019, a study carried out by the Spanish newspaper *La Vanguardia*, estimated that in Spain, the socio-health cost of this disease is 50,000 euros per patient, per year.[64] Providing extra-medical support to help patients maintain their careers would increase that amount: something that the system is not willing to face. Conversely, it must be said, as Luzón readily suggests, that Spain is the country with one of the best healthcare systems in the world, a privilege shared with Singapore, Hong Kong and Japan, as reported by the competitiveness index presented by the World Economic Forum for the year 2019, which gives the highest possible score to the four states.[65]

Finally, my comparative reading of a Spanish and an American illness narrative also offers me grounds for mentioning the importance given to religion (Catholic in the Spanish case), and of how faith is related to the lessons learned throughout the journey. Robillard discards resorting to faith and prayer altogether in a short paragraph:

> Although it is nice to be on others' minds and feel them pulling for you, to hear repeatedly that you are the subject of a request for divine intervention is a bit tiring. I say tiring, as much as I appreciate the prayers, because it is the only form of message I receive from the well-intentioned aunts. Being always and only addressed as the subject of prayers limits who I am and focuses my attention on myself as a person of pity.[66]

On the contrary, Luzón finds comfort and consolation in his faith, and devotes a whole chapter, entitled 'Dioses y Hombres' ('Gods and Men') to what for him is a crucial issue, for he acknowledges that in a situation of illness with a life expectancy of four or five years, it is difficult not to look for a spiritual resource that may serve as a sort of consolatory bargaining. 'When medicine and science do not have the right answers to find a solution,' Luzón says, 'it is almost impossible not to raise one's eyes to heaven to ask for help from supernatural forces; it is also difficult not to ask for explanations to an Almighty being when we find the situation unintelligible'.[67]

In her 1970 book *On Death and Dying*, Elizabeth Kübler Ross proposes five 'stages' of dying that have been subsequently simplified beyond recognition. Well-known, but overworked to the point of banality, the five stages of the journey towards death that she proposes are denial, anger, depression, bargaining and, finally, acceptance. Bargaining, Kubler-Ross explains, is the least well-known but equally helpful to the patient. If we have been unable to face the sad facts in the first stage and have been angry at people and God in the second phase, maybe we can succeed in entering into some sort of an agreement which may postpone the inevitable happening: 'If God has decided to take us from this earth and he did not respond to my angry pleas, he may be more favorable if I ask nicely.' The bargaining, she continues, is really an attempt to postpone; and 'most bargains are made with God and are usually kept a secret'.[68]

In line with this argument, while Robillard, as said, seems to be trapped in the 'anger' stage, we may conclude that Luzón does enter the 'bargaining' stage, which leads to 'acceptance', propounded by his faith in God and in Virgin Mary, as the following lines demonstrate:

> Siempre había hecho la misma petición a la Virgen. — 'Señora, quiéreme como yo a ti. ¡Cúrame!' — le requería. Y le solicitaba, con fervor y quizá con cierta angustia, que mi enfermedad no avanzase […] no estaba ante su imagen para rogarle mi curación, pero sí le iba a pedir ayuda para dos cosas: una, que la enfermedad avanzase lentamente y la otra que no sufrieran los míos, mi mujer, mis hijos, mis familiares, mis amigos. No, no le pedí por mí, fue por los otros, porque quería — quiero — que mi yo generoso, mi yo más bondadoso, prime sobre el yo que estaba destacando desde que la ELA se apoderó de mi mente.[69]
>
> I had always made the same request to Our Lady. –'Lady, love me as I love you. Heal me!' - I asked her. And I asked her, with fervor and perhaps with some anguish, that my disease did not progress […] I was not in front of her image to pray for my healing, but I was going to ask for her help in two issues: one, that the disease would advance slowly and the other that my family, my wife, my children, my relatives, my friends, would not suffer. No, I didn't pray to her for me, it was *for others*, because I wanted -I want- *my generous self*, my kinder self, to preside over the self that was standing out since ALS conquered my mind.

Again, this reference to the 'others' and to his more 'generous self', further demonstrates the communicative body-self that we have attributed to Luzón above.

Conclusion

As Couser rightly asserts, one of the things that reading pathographies reveals is 'the wide variation in tolerance of permanent severe disability'.[70] Our comparative, transnational analysis of two wasted bodies has taken us along the paths of various degrees in tolerance, of different types of narrative, of diverse aims and body-types, and through some of the stages of the victims' journeys. Likewise, it has taken us through anger, hope and hopelessness, isolation, stigma, fear and anguish; it has revealed how different health systems work; how physicians react and respond to this illness; how relatives, friends, colleagues and society in general cope with the suffering of the disabled. But, most importantly, it has enhanced our sense of empathy for the wounded storytellers, because literature excites our empathy; healthy observers thereby can understand and communicate with the unhealthy. Because literature makes visible the invisible; opens the private to the public; and destroys the frontier between literature itself and life.

One could even argue that these two autopathographies require a different strategy of reading; one that could be described as an empathetic reading, since the reader´s empathy with the writing subject is not so much a *reading strategy* as a required *way of reading*; required, because the illness that is described could potentially strike anyone.[71] As a result, this new 'autobiographical pact' (Lejeune) with the reader goes even beyond empathy and is one of potential *identity* between reader and writer. Indeed, as Luzón and Robillard have demonstrated by the end of their journeys, the experiences of ALS, with the bodily and spiritual abjection and waste they entail, 'can still be a gateway, however cruelly won, into the tapping and expansion of (one's) own power and knowing'.[72]

In the end, reading pathographies about this cruel and invisible disease has helped us understand that a single patient deserves the same level of quality care as thousands of patients diagnosed with more common diseases; the same primary care and the same resources for research. Human dignity does not belong to the masses, but to individuals. And as long as there is only one ALS patient, that single patient will have the same right to the hope of being cured someday.

Works Cited

Bleakley, Alan, *Medical Humanities and Medical Education: How the Medical Humanities Can Shape Better Doctors*, New York: Routledge, 2015.

Campbell, Joseph, *The Hero with a Thousand Faces* (1949), Princeton: Princeton UP, 1972.

Charon, Rita, *The Principles and Practice of Narrative Medicine,* Oxford: Oxford UP, 2016.

Cole, Thomas R, *Medical Humanities: An Introduction*, Cambridge: Cambridge UP, 2015.

Couser, Thomas, *Recovering Bodies: Illness, Disability, and Life-writing*, Madison: U of Wisconsin P, 1997.

Couser, Thomas, *Signifying Bodies: Disability in Contemporary Life Writing*, Ann Arbor: The U of Michigan P, 2009.

Couser, Thomas, *Vulnerable Subjects: Ethics and Life Writing*, Cornell: Cornell UP, 2003.

Durán, Isabel, 'Autoscriptotherapy: Cancer Diaries as Battle Diaries', in: Nieves Pascual, and Antonio Ballesteros (eds.), *Feeling in Others: Essays on Empathy and Suffering in Modern Culture,* Vienna & Berlin: LIT Verlag, 2008, 51–65.

Frank, Arthur, *The Wounded Storyteller: Body, Illness, and Ethics*, Chicago: The U of Chicago P, 1997.

Henke, Suzette, *Shattered Subjects: Trauma and Testimony in Women's Life-Writing*, London: Macmillan, 1998.

Hunsaker Hawkins, Anne, 'Pathography: patient narratives of illness', in: *Culture and Medicine* 171 (1999) 127–129.

Hunsaker Hawkins, Anne, *Reconstructing Illness: Studies in Pathography*, West Lafayette, Ind.: Purdue UP, 1993.

Jurecic, Ann, *Illness as Narrative*, Pittsburgh: U of Pittsburgh P, 2012.

Kendal, Evie, *Teaching Medicine and Medical Ethics Using Popular Culture*, New York: Palgrave Macmillan, 2017.

Kübler-Ross, Elisabeth, *On Death and Dying* (1970), Abingdon: Routledge, 2009.

Lejeune, Philippe, *Le pacte autobiographique*, Paris: Seuil, 1975.

Lorde, Audre, *The Cancer Journals*, San Francisco: Aunt Lute Books, 1980.

Luzón, Francisco, *El viaje es la recompensa*: *mi lucha por la vida*, Madrid: La Esfera, 2017.

Marini, Maria Julia, *Narrative Medicine: Bridging the Gap between Evidence-Based Care and Medical Humanities*, New York: Springer, 2016.

Mediavilla, Jesús, 'El Foro Económico Mundial da a España el título de mejor sanidad del mundo', *Redacción Médica,* February 2020, https://www.redaccionmedica.com/secciones/sanidad-hoy/espana-cuenta-con-la-mejor-sanidad-el-mundo-segun-el-foro-economico-mundial-8476 , date accessed: 15 October 2023.

Murphy, Robert, *The Body Silent: The Different World of the Disabled*, New York: Norton, 1990.

Pagnini, Francesco et al., 'Mindfulness as a Protective Factor for the Burden of Caregivers of Amyotrophic Lateral Sclerosis Patients,' *Journal of Clinical Psychology*

72:1 (2016) 101–111, https://onlinelibrary.wiley.com/doi/10.1002/jclp.22235, date accessed: 15 October 2023.

Robillard, Albert B, *Meaning of a Disability: The Lived Experience of Paralysis*, Philadelphia: Temple UP, 1999.

Robillard, Albert B, 'Anger in the Social Order,' *Body and Society* 2:1 (1996) 17–30, https://acortar.link/6EQ5fR, date accessed: 15 October 2023.

Schleifer, Ronald and Jerry B.Vannatta, *Literature and Medicine: A Practical and Pedagogical Guide*, Cham: Palgrave Macmillan, 2019.

Schleifer, Ronald, *The Chief Concern of Medicine: The Integration of the Medical Humanities and Narrative Knowledge into Medical Practices*, Ann Arbor: The U of Michigan P, 2013.

Sontag, Susan, *Illness as Metaphor and AIDS and its Metaphors*, Picador, 2001.

About the Author

Isabel Durán Giménez-Rico (https://orcid.org/0000-0002-6026-0184) is Professor of North American Literature at the English Department of the Universidad Complutense de Madrid (UCM). She was Vice-Provost for International Affairs at the UCM (2015-2019); President of SAAS (Spanish Association for American Studies) until 2019, Chair of the Department of English (2013-2015), and an elected member of the General Council of ASA (American Studies Association 2008-2011). Her research and publication record on gender studies, literature, autobiography and ethnicity include the edition of an eight-volume Gender Studies collection, in addition to more than ninety articles and book chapters. She is the Director of the Complutense Research Group "Gender Studies in the anglophone World". She has supervised 12 Doctoral dissertations. She has been a Fulbright scholar (2000), and a postdoctoral researcher at Harvard University (2012) and UCSB (2019). She has been PI in several national research projects and is currently leading the project entitled "Gender and pathography from a transnational perspective" (2021-2024).

Acknowledgement

This publication resulted from research supported by Research Project "Gender and Pathography from a Transnational Perspective" (Spanish Ministry of Science and Innovation . Reference: PID2020-113330-GBI00).

Notes

[1] Luzón, Francisco, *El viaje es la recompensa*: *mi lucha por la vida*, Madrid: La Esfera, 2017, eBook, chapter 5.

[2] Couser, Thomas, *Recovering Bodies: Illness, Disability, and Life-writing*, Madison: U of Wisconsin P, 1997: 5.

[3] See, for example, Schleifer, Ronald and Jerry Vannatta, *Literature and Medicine: A Practical and Pedagogical Guide*, Cham: Palgrave Macmillan, 2019; Bleakley, Alan, *Medical Humanities and Medical Education: How the Medical Humanities Can Shape Better Doctors*, New York: Routledge, 2015; Charon, Rita, *The Principles and Practice of Narrative Medicine*, Oxford: Oxford UP, 2016; Jurecic, Ann, Jurecic, Ann, *Illness as Narrative*, Pittsburgh: U of Pittsburgh P, 2012; Kendal, Evie, *Teaching Medicine and Medical Ethics Using Popular Culture*, New York: Palgrave Macmillan, 2017; Marini, Maria Julia, *Narrative Medicine: Bridging the Gap between Evidence-Based Care and Medical Humanities*, New York: Springer, 2016.

[4] Schleifer and Vannatta, *Literature and Medicine*, 5.

[5] Cole, Thomas R, *Medical Humanities: An Introduction*, Cambridge: Cambridge UP, 2015, 1.

[6] Idem, 3.

[7] Idem, 125.

[8] Hunsaker Hawkins, Anne, *Reconstructing Illness: Studies in Pathography*, West Lafayette, Ind.: Purdue UP, 1993, 13.

[9] Robillard, Albert B., *Meaning of a Disability: The Lived Experience of Paralysis*, Philadelphia: Temple UP, 1999, back cover.

[10] Idem, 48.

[11] Idem, 158.

[12] 'Mi viaje vital sigue un rumbo nuevo desde que la ELA se convirtió en mi compañera inseparable. Ahora busco pensamientos, argumentos, indago sobre la vida y la muerte, sobre los porqués'. Luzón, *El Viaje*, eBook, chapter 1 (all the translations provided henceforward are mine).

[13] Robillard, *Meaning of a Disability*, 64.

[14] Hunsaker Hawkins, Anne, 'Pathography: patient narratives of illness', in *Culture and Medicine* 171 (1999) 127–129, 128.

[15] Couser, *Recovering Bodies*, 21.

[16] Robillard, *Meaning of a Disability*, 43.

[17] Idem, 53–54.

[18] Idem, 36.

[19] Idem, 38.

[20] Idem, 131.

[21] Hunsaker Hawkins, 'Pathography: patient narratives of illness', 128. „

[22] '¿Es tan difícil comprender que somos enfermos con la movilidad reducida, que no estamos en condiciones para realizar un largo peregrinar de doctor en doctor por distintos centros hospitalarios y durante varias jornadas?' Luzón, *El Viaje*, eBook, chapter 5.

[23] Hunsaker Hawkins, *Reconstructing Illness*, 128.

[24] Frank, Arthur, *The Wounded Storyteller: Body, Illness, and Ethics*, Chicago: The U of Chicago P, 1997, 132.

[25] Luzón, *El Viaje*, eBook, chapter 5.

[26] Idem, eBook, chapter 3.

[27] 'Yolanda, pelirroja, cariñosa, alegre, es una gran profesional que nos recibe con una enorme sonrisa y una pregunta llena de afecto: "¿Qué tal estás, bombón?" Y el bombón soy yo. Se lo agradezco tanto, con la misma sinceridad y afecto que ella me transmite, le devuelvo la mejor de las sonrisas'. Luzón, *El Viaje*, eBook, chapter 5.

[28] Frank, *The Wounded Storyteller*, 2.

[29] Idem, 25.
[30] Idem, 30.
[31] Idem, 46.
[32] Robillard, *Meaning of a Disability*, 33.
[33] Idem, 174.
[34] Idem, 175.
[35] Frank, *The Wounded Storyteller*, 47.
[36] Robillard, *Meaning of a Disability*, 118.
[37] Idem, 85 (italics added).
[38] Pagnini, Francesco et al., 'Mindfulness as a Protective Factor for the Burden of Caregivers of Amyotrophic Lateral Sclerosis Patients', in *Journal of Clinical Psychology* 72:1 (2016) 101–111, 101.
[39] Robillard, *Meaning of a Disability*, 39.
[40] Idem, 179.
[41] Quoted in Frank, *The Wounded Storyteller*, 49.
[42] Frank, *The Wounded Storyteller*, 49–50.
[43] Luzón, *El Viaje*, eBook, chapter 1 (italics added).
[44] Ibidem.
[45] Luzón, *El Viaje*, eBook, chapter 2. Interestingly, a 'Trojan Horse' virus in computing is a type of malware that downloads onto a computer disguised as a legitimate program. As in Luzon's metaphoric use, the term is derived from the ancient Greek story of the deceptive Trojan Horse that led to the fall of the city of Troy.
[46] Idem, eBook, chapter 8.
[47] Idem, eBook, chapter 15.
[48] Sontag, Susan, *Illness as Metaphor and AIDS and its Metaphors*, Picador, 2001, n.p.
[49] Frank, *The Wounded Storyteller*, 117.
[50] Luzón, *El Viaje*, eBook, chapter 8.
[51] Robillard, *Meaning of a Disability*, 45.
[52] Idem, 113.
[53] Idem, 99.
[54] Frank, *The Wounded Storyteller*, 31.
[55] Quoted in Frank, *The Wounded Storyteller*, 49.
[56] Murphy, Robert, *The Body Silent: The Different World of the Disabled*, New York: Norton, 1990, 4.
[57] Robillard, *Meaning of a Disability*, 82–83.
[58] Idem, 121
[59] Frank, *The Wounded Storyteller*, 118.
[60] Ibidem.
[61] Robillard, *Meaning of a Disability*, 164.
[62] Idem, 162.
[63] Idem, 159.
[64] Anonymous, 'La ELA en cifras', https://www.lavanguardia.com/vida/20190621/463018584225/la-ela-en-cifras.html , date accessed: 15 October 2023.
[65] Mediavilla, Jesús, https://www.redaccionmedica.com/secciones/sanidad-hoy/espana-cuenta-con-la-mejor-sanidad-el-mundo-segun-el-foro-economico-mundial-8476, date accessed: 15 October 2023.
[66] Robillard, *Meaning of a Disability*, 116.
[67] 'Cuando la medicina y la ciencia tienen las respuestas tan ajustadas para hallar una solución, es casi imposible no alzar la vista al cielo para solicitar ayuda a las fuerzas sobrenaturales; también es complicado sustraerse a pedir explicaciones a un ser Todopoderoso cuando nos resulta ininteligible la situación que acontece'. Luzón, *El Viaje*, eBook, chapter 9.

[68] Kübler-Ross, Elisabeth, *On Death and Dying,* Abingdon: Routledge, 2009, 66.

[69] Luzón, *El Viaje*, eBook, chapter 9 (italics added).

[70] Couser, Thomas, *Vulnerable Subjects: Ethics and Life Writing,* Cornell UP, 2003, 149.

[71] See Durán, Isabel, 'Autoscriptotherapy: Cancer Diaries as Battle Diaries', in: Nieves Pascual, and Antonio Ballesteros (eds.), *Feeling in Others: Essays on Empathy and Suffering in Modern Culture,* Vienna & Berlin: LIT Verlag, 2008, 51–65.

[72] Lorde, Audre, *The Cancer Journals*, San Francisco: Aunt Lute Books, 1980, 54.