

Antje Kley

## **Vulnerability and Masculinist Notions of Control in Late Capitalist Societies. Reading Paul Kalanithi's Autopathography When Breath Becomes Air (2016)** 2022

<https://doi.org/10.25969/mediarep/19709>

Veröffentlichungsversion / published version  
Zeitschriftenartikel / journal article

### **Empfohlene Zitierung / Suggested Citation:**

Kley, Antje: Vulnerability and Masculinist Notions of Control in Late Capitalist Societies. Reading Paul Kalanithi's Autopathography When Breath Becomes Air (2016). In: *Kulturwissenschaftliche Zeitschrift*, Jg. 7 (2022), Nr. 1, S. 49–69. DOI: <https://doi.org/10.25969/mediarep/19709>.

### **Erstmalig hier erschienen / Initial publication here:**

<https://kulturwissenschaftlichezeitschrift.de/ausgaben/ausgabe-2021-3/#moisi-warum-sie-nicht-gegangen-ist-beitrag-zu-einer-wissensgeschichte-der-gegenwart>

### **Nutzungsbedingungen:**

Dieser Text wird unter einer Creative Commons - Namensnennung - Weitergabe unter gleichen Bedingungen 4.0/ Lizenz zur Verfügung gestellt. Nähere Auskünfte zu dieser Lizenz finden Sie hier:

<https://creativecommons.org/licenses/by-sa/4.0/>

### **Terms of use:**

This document is made available under a creative commons - Attribution - Share Alike 4.0/ License. For more information see:

<https://creativecommons.org/licenses/by-sa/4.0/>

Antje Kley

# Vulnerability and Masculinist Notions of Control in Late Capitalist Societies

Reading Paul Kalanithi's Autopathography *When Breath Becomes Air* (2016)

**ABSTRACT:** This article lays out how Kalanithi's international bestseller and Pulitzer Prize finalist uses the infrastructures of literature to negotiate the infrastructures and the masculinist values of the medical system. The text chronicles how a promising young male neurosurgeon becomes a terminal patient himself. This radical change of perspective is represented in ambivalent terms of embodiment, vulnerability, and relational being, and as a fall from the masculinist grace of medical discursive power. The text presents the medical hospital as a social space that, in its high-tech efficiency, is ill-equipped for the negotiation of the personally and culturally contradictory process of dying that, in late capitalist societies since the 1980s, predominantly takes place in its confines. With its literary means, the text explores a critical perspective on late capitalist societies' high-tech medical system that is geared towards the control of disease and cost at the expense of a supportive view of life's end. With its literary address of a neurosurgeon's experience of dying, *When Breath Becomes Air* offers an alternative form of knowledge production to currently dominant medical, care, insurance and legal discourses on death, and it advocates an ease of narrowly masculinist notions of control as key to more resonant social relations.

**KEYWORDS:** literature; medical system; vulnerability; illness; death; masculinity; relationality; resonance

## 1. Notions of vulnerability: an introduction

This article seeks to shed light on how Kalanithi's autobiographical text, prompted by the author's experience of fatal illness, uses the infrastructures of literature to negotiate the infrastructures and the masculinist values of the medical system.<sup>1</sup> My reading of the text is part of a larger project, entitled »Death Becomes Us«, concerned with US-American stories of the end of life since the 1980s.<sup>2</sup> The project is concerned with how

---

<sup>1</sup> I want to thank my anonymous reviewers for their careful readings, helping me to clarify and strengthen the article's argument. Any remaining weaknesses are of course my own.

<sup>2</sup> I am grateful to the *Knowledge Infrastructures Research Network* of the *Regensburg Center for International and Transnational Area Studies* (CITAS) as a stimulating context for this work and to

fictional and autobiographical writing socially embeds the experiences of dying and of losing a loved one. It argues that literary forms of knowledge production around mortality and death meet an acute social need in highly competitive capitalist performance societies: they connect professionally separate discourses of the body and the mind and develop a vocabulary to negotiate human vulnerability and mortality.<sup>3</sup> My study draws on and seeks to contribute to the fields of the medical humanities, narrative medicine, age and disability studies as well as cultural thanatology.<sup>4</sup>

With such diverse critics as Judith Butler and Ralf Schnell, I take the concept of vulnerability to denote the constitutive character of socially bound, embodied beings. In the more narrow but culturally dominant sense, »vulnerability« designates undesirable physical, mental or psychic limitations. Vulnerability in the wider and more all-encompassing sense precedes the distinction between healthy and ill bodies (Schnell 17-21, Butler 2020). »Vulnerability is not just the condition of being potentially harmed by another«, as Butler explains. »It names the porous and interdependent character of our bodily and social lives« (2020: 1). Assuming vulnerability as anthropologically given reminds us of the interdependence of living beings. The psychologist Kenneth Gergen speaks of »relational being« and recent work in palliative care and medical ethics has developed notions of »relational autonomy« (Gómez-Virseda, Welsh/Ostgathe/Frewer/Bielefeldt) to redescribe acts and initiatives that we tend to ascribe to solipsistic individuals instead as socially embedded results of co-action, co-creation and dialogical developments in decision-making. Butler, Gambetti and Sabsay clarify that vulnerability does not imply passivity or social withdrawal: vulnerability is not »the opposite of resistance« and may be conceived as part of resistant practices (2016: 1-11, here 1).

---

the *Fritz-Thyssen-Stiftung* for its funding of a 6 months *LeseZeit* stipend in the summer 2020. The title »Death Becomes Us« is used by a growing number of articles and cultural productions concerned with a close examination of dying. Two examples are the journalist Pamela Skjolsvik's exploration of jobs related to death and the Presbyterian Minister Douglas E. Baker's review of McCullough's 2018 book *Remember Death: The Surprising Path to Living Hope*.

- 3 The cultural historian Anne Harrington bespeaks the need for connecting separate discourses of body and mind, science and experience in her well and widely received study *The Cure Within: A History of Mind-Body Medicine* (New York: Norton, 2008) 243-255. Literature is a discourse well-equipped to contribute to building such connections. The German literary critic Jürgen Link has described literature as an interdiscourse. Interdiscourses build bridges across compartmentalized bodies of knowledge and subjectivities. In this view, literary writing is engaged in remaking as it reports; it selects, accentuates, combines, and inflects partial bodies of knowledge from particular, historically changing discourses and areas of expertise – as, e.g., the medical system –, and it renders them relevant within particular cultural frames of reference. Readers may use these interdiscursively fictionalized worlds as models from which to extrapolate generatively intelligent clarification of the discursive interdependencies in their own past and present. See Kley 2016.
- 4 For work not mentioned elsewhere in this article, which historically and theoretically frames my concerns see Banerjee, Charon, Gilbert, and Kunow.

According to them, vulnerability implies the need for »collective forms of resistance and social transformation« rather than »the need for protection and the strengthening of paternalistic forms of power« (Butler, Gambetti, Sabsay 2016: 1). In this wide sense, the concept of ›vulnerability‹ implies reachability and relationality, a willingness to acknowledge and listen to others, an epistemic potential and attitude as well as a critique of sovereign power and control. *When Breath Becomes Air* undertakes a reevaluation of human vulnerability in this relational sense. The text connects this reevaluation with a critique of masculinist notions of control, which tend to cast vulnerability, embodiment and mortality in a decidedly negative light, presenting them as weaknesses to be fought.<sup>5</sup>

## 2. Illness as ›an agent of change‹

In his 1988 study *Disease and Representation: Images of Illness from Madness to AIDS*, Sander Gilman explains that, across time and cultures, imaginative representations of illness function as an antidote to the audience's fear of their own physical demise. According to Gilman, the audience's fear of a loss of control is kept in check as the representation bans it within its confines. Consuming the representation allows the recipient to develop a fantasy of wholeness and control that soothes his or her deeply rooted experience of exposure, instability, and vulnerability with the assertion that they are not affected by the harm depicted.

To some degree, Kalanithi's text participates in this pattern of containment, but it also significantly shakes it up, giving rise to an understanding of illness as »an agent of change«.<sup>6</sup> It does so by presenting a paradoxically positioned narrator-protagonist who is both a successful neurosurgeon and a terminally ill patient, telling his own story of illness as both a fall from the grace of medical credentialing and as a ›re-enchantment‹ of his own life and the lives of those close to him in and outside of the hospital. *When Breath Becomes Air* thus interweaves and overwrites a narrative pattern of restitution – »Yesterday I was healthy, today I am sick, but tomorrow I'll be healthy again« (Frank

<sup>5</sup> In his 1991 essay »Autopathography: Women, Illness, and Lifewriting«, Thomas Couser emphasizes the gender codification of illness and its suppression inscribed in Western discourse: »the suppression of illness in literature has its subtext in the domination of discourse by masculinist assumptions [...] the Western privileging of mind over body, the tendency to deny the body's intervention in intellectual and spiritual life« (68). This is not – at least not primarily – an argument about men and women. It is an argument about masculine and feminine codifications of certain qualities of habitualized thought and action.

<sup>6</sup> This phrase comes from Eve Ensler's 2013 autopathography *In the Body of the World*, where the narrator speaks of cancer not as an enemy, but as »an alchemist, an agent of change« (8).

2013: 77) – with a pattern of undergoing a fundamental change of seeing and *being in* the world.

As a consumable popular book, *When Breath Becomes Air* does offer closure – provided by the author’s wife who wrote the epilogue after her husband’s death – and, with it, at least some measure of the reassurance to the reader that Gilman speaks about. But it also has a far more interesting, even if disturbing dimension. More than generically soothing a sense of vulnerability on the part of the reader, who may distance himself from the fate represented, the text prompts readers to join the dying narrator-protagonist, who cannot finish writing his account himself, in *reassessing the status of vulnerability* in a more general sense. The main indication for this other dimension of the text is its refraining from talking about disease in terms of an enemy to be defeated. *When Breath Becomes Air* questions this culturally pervasive rhetoric, which may frequently be found in patients’ accounts of their encounters with life-threatening illness as well as in presentations of, e.g., cancer research.<sup>7</sup> The narrator recalls the bellicose but brittle reaction to bad medical news – »[w]e’re gonna fight and beat this thing« – as an unrealistically optimistic form of crisis-denial and a knee-jerk »alternative to crushing despair« (96). The social theorist Laurent Berlant speaks of such optimism as »cruel.« »Cruel optimism« substitutes for a reckoning with one’s own situation, »the built and affective infrastructure of the ordinary« (49). It indicates a »survival scenario« which, because of its cover-up nature, is in itself problematic: it keeps the threatened subject from »assess[ing] what’s unraveling there« – here in the absorption of a fatal diagnosis – and thus from actually »measuring the impasse of living in the overwhelmingly present moment« (49).

In step with Berlant, Kalanithi’s text exposes the rhetoric of »fighting disease as an enemy« as a fundamentally helpless gesture. The narrator-protagonist himself accepts his fatal diagnosis with considerable ambiguity. On the one hand, as soon as he possibly can, he seeks to assert the masculinist sense of control that his profession bestows upon him. Insofar, he follows his father’s insistence not to capitulate, an insistence in line

---

<sup>7</sup> On the basis of the expansive readings he conducted for his 1997 study *Recovering Bodies*, Thomas Couser explains that the narrative pattern of the patient success story and its demand for a positive ending dominates the literary market. He speaks of »the tyranny of the comic plot« (Couser 2016: 4), which marginalizes narratives that do not tell a successful overcoming of illness and the restitution of a previous state of health. The medial sociologist Arthur W. Frank categorizes illness narratives into three corresponding patterns: »restitution« (Frank 2013: 75-96), »chaos,« (97-114), and »quest« (115-136). Frank explains that the »restitution narrative« may shade into the »quest narrative« when the confrontation with contingency is presented as a test to be mastered. »The risk of quest stories is like the risk of the Phoenix metaphor: they can present the burning process as too clean and the transformation as too complete, and they can implicitly deprecate those who fail to rise out of their own ashes« (Frank 2013: 135). Frank’s view is explicitly reiterated in Anne Boyer’s 2019 autobiography *The Undying*.

with the narrative of restitution the protagonist had been explicitly puzzled by time and again (127). Picking up on the ›cruelly optimistic‹ rhetoric of fighting disease, his father had stated that his son »was going to beat this thing, [he] would somehow be cured« (127). However, the doctor as patient, or the patient as doctor, feels forced to at least begin to look at his own life and his professional ambitions in ways *not* shaped by the logics of competition. He begins to relocate himself socially and affectively, in particular in relation to his family, shifting the scope of stories and encounters he invests his energies in. He thus defers the narrative of »restitution« with its rhetoric of masculinist self-assertion and success in the face of testing times. Knowing that he cannot win, he defers the ultimately cruel narrative of the »quest« for renewal, together with its tendency to romanticize or placate. Instead, the narrator-protagonist exposes himself *to* and engages *with* the experience of contingency and of *not* knowing »what life is in death,« as the epigraph by the Elizabethan poet and statesman Fulke Greville has it (ix). Kalanithi exposes himself to his own mortal being and channels his controlling energies, again with Fulke Greville, into an address of his audience: »Reader! Then make time, while you be,/ But steps to your eternity« (ix). There will be occasion to come back to the issue of time at the end of section 3. My point here is, though, that, with the decisive shift in perspective of its narrator-protagonist, the text blurs rather than reinforces the distinction between health, masculinist strength and control on the one hand and illness, weakness, emasculation and loss of control on the other. His narrative advocates a profoundly relaxed relation to time at the end of life.

Pacing the narrative pattern of restitution, the text engages a narrative pattern which closely examines desperation, the notion of the normal, radical change, as well as the protagonist's own bodily being and his relation to other people. The text still participates in, but also questions and begins to shed, the culturally dominant narrative pattern of restitution. This narrative pattern of battle, which is coded masculine in Western discourse, conceptualizes the body in technical terms as a mechanical entity that might have to be (and can be) repaired. This pattern casts illness as a bodily interruption of an entrepreneurial self that will rise like Phoenix from the ashes;<sup>8</sup> and the patient remains a monad or an autonomous entity complete in itself. Shedding a critical light on this rhetoric, while still being drawn to it at times, *When Breath Becomes Air* articulates a visceral witness account and a reevaluation of the *physical experience* as well as the *epistemology* of vulnerability, which are conventionally coded feminine and frequently marginalized in Western discourse in general and in the physicalist medical system in particular. As a patient the protagonist finally begins to understand the degree to which he – as much as others – has never been an autonomous entity complete in himself. As much as others, he is a manifestation of »relational existence«:

---

<sup>8</sup> On the political sociology of the entrepreneurial self, see Broeckling.

his autonomy emerges from relations, community and co-ordinated action (Gergen 396-403).

### 3. Deflating masculinist notions of control in *When Breath Becomes Air*

The neurosurgeon and author Paul Kalanithi dies of lung cancer at the age of 37 in 2015 before he can publish the autobiographical account of his illness. The author's wife, the internist Lucy Goddard Kalanithi, sees the book through publication in January 2016. It remains #1 on the New York Times nonfiction bestseller list for 68 weeks, becomes a finalist for the Pulitzer Prize for auto/biography in 2017 and is translated into over 40 languages (lucykalanithi.com). The text chronicles how the promising young neurosurgeon, after a decade of training and ready to take up a position at one of the country's leading research universities, becomes a terminal patient himself.

The two-part narrative opens its prologue with the »obvious diagnosis« (3), before circling back through the previous year of denial (3-16). As the doctor-patient flips through the CT scan images, the narrator routinely comes to his conclusion: »Cancer, widely disseminated. I was a neurosurgical resident entering my final year of training. Over the last six years, I'd examined scores of such scans, on the off chance that some procedure might benefit the patient./ But this scan was different: it was my own« (3). In Kalanithi's text, as in many autopathographies and in medical realities (Couser 2004; Boyer 15-16; Maio 2020: 45-66), the diagnosis fundamentally puts into perspective a lived life, its unspoken assumptions and stabilizing convictions. It shakes up all coordinates in time, space, and relation which used to orient the patient in his environment. It catapults him into an intensively experienced present giving rise to conflicting emotions of fear, courage, devastation and happiness, as well as desires for meaningful agency, recognition, companionship, »for public life and civil society, for inclusion [and] purpose,« all of them frequently buried underneath a crowding plurality of daily routines and concerns (Solnit 1-10, here 6).

This fundamental shift in perspective is heightened here by the fact that the devastated patient is also a physician in the know. The formerly unspoken assumptions and stabilizing convictions of the doctor-patient Paul Kalanithi include research-driven and practically exercised world-class expertise in dealing with the issue of impending death in acute situations. These, too, are momentarily crushed: »Severe illness wasn't life-altering, it was life-shattering,« the narrator states. »My carefully planned and hard-won future no longer existed. Death, so familiar to me in my work, was now paying a personal visit. [...] yet nothing about it seemed recognizable. [...] as if a sandstorm had erased all traces of familiarity« (120-121). The patient's sensibilities thus question his own professional take on death. His take on statistics also becomes a different one as soon as he is required to look at his own life in terms of their logics: »The angst of facing

mortality has no remedy in probability« (135). As conversant as he was as a doctor with his patients about impending death, he is at a loss, almost as much as them, when he, »so authoritative in a surgeon's coat« finds *himself* in the »meek« role of the patient (5, 6, see also 12, 180). As a patient, he experiences the lack of control that the protocols of his professional expertise had so efficiently covered over.

The memoir's »Part I: In Perfect Health I Begin« is dedicated to the build-up of the narrator-protagonist's medical expertise over two decades, and it connects that build-up with the protagonist's growing sense of ambition and his increasingly tight professional focus – both of them in line with his upbringing, especially with the role of his father. The narrator traces the protagonist's double interest in the philosophical and the scientific pursuit of existential questions concerning the interconnection of mind and brain, the human sense of identity and the biological framework enabling it. »I was driven less by achievement than by trying to understand, in earnest: What makes human life meaningful? I still felt literature provided the best account of the life of the mind, while neuroscience laid down the most elegant rules of the brain« (30-31). Having studied English at Stanford and History of medicine at Oxford, the protagonist decides to start medical school at Yale, even though he had never wanted to become a doctor. The example of his father, a cardiologist, had shown that doctors never had idle time and, for their families, were mostly absent (19-21). Believing that practicing medicine was the arena where »biology, morality, literature, and philosophy intersect[ed]« (41), however, Kalanithi specifically sought out »that direct experience of life-and-death questions,« because he felt that it »was essential to generating substantial moral opinions about them« (43).

The narrative raises significant points of critique concerning both the growing ambition of an intellectually curious young scientist and the medical profession. Going through the »medical rite of passage« of anatomical cadaver dissection, the young protagonist realizes that, for many students, the practice marks the »transformation of the somber, respectful student into the callous arrogant doctor« (44). He understands that it becomes an exercise in alienation:

Anatomy lab, in the end, becomes less a violation of the sacred and more something that interferes with happy hour, and that realization discomfits. In our rare reflective moments, we were all silently apologizing to our cadavers, not because we sensed the transgression but because we did not. (49)

While understanding that »[s]eeing the body as matter and mechanism is the flip side to easing the most profound human suffering« (49), the narrator still insists that »Medical school sharpened my understanding of the relationship between meaning, life, and death. I saw the human relationality I had written about as an undergraduate realized in the doctor-patient relationship« (51). Kalanithi clearly started clinical work

as an idealist. Seeking »to relieve concrete suffering, with patients, not abstractions, as [his] primary focus« (54, see also 77), he did not understand how much cutting-edge medicine is a strictly *physicalist* enterprise (Harrington 15-30) which would severely restrict his possibilities to ponder the relationship between meaning, life and death except in, precisely, the most *abstract* ways. His eyes on the prize of mastery, authority and perfection (71-72, 98), he nurses the ideal of the true doctor's »heroic spirit of responsibility amid blood and failure« (54). Given the placement of this retrospective account of learning after the brief introduction of the diagnosis in the prologue, there is considerable narrative irony mixed into the account of the student's earnest striving. In addition, the young doctor's ambition may be seen as closely tied not only to culturally ingrained US-American senses of progress and individual self-reliance, but also to masculinist notions of rugged individualism, mastery and invulnerability. In the account of his youth, the narrator critically cites his father's conviction that »[i]t's very easy to be number one: find the guy who is number one, and score one point higher than he does« as a »stony pronouncement« (21), typical for his father's »austere diktats« (20). He hadn't thought that he'd ever follow in those footsteps. Later, however, the protagonist's growing ambition becomes more and more pronounced. The narrator admits that, »a life spent in the space between« life and death was supposed to grant him »not merely a stage for compassionate action but an elevation of my own being,« a kind of transcendent escape from everyday materialism and pettiness (81). The narrator thus directly addresses the medical careerism which his idealism had merely covered. He further questions his high ideals when he speaks about the toll taken by up to a hundred hours of work per week, much of it highly intense: He was frequently exhausted (79), either losing focus on the relational foundation of his work (86, 96-97) or feeling vulnerable to crushing guilt if he kept it in place (98). He actually became inured to the suffering he had sought to ease (81). He understands that he had actually been acting as death's »ambassador« in his heroic drive to *save lives* rather than *protect identities* (87). The high medical calling of »saving lives« becomes questionable to the narrator when it becomes untied from the patient's identity, when it attaches the medical doctor's dedication to a pulsing body rather than a comprehensive sense of a patient's life. Speaking about an admired colleague going through cancer treatment, the narrator even remarks: »How little do doctors understand the hells through which we put patients« (102). These more critical observations about the roles and interactions of doctors and patients that the narrator makes in part I of the memoir serve to anchor the text's critique of the unconditional US-American narrative of success that has been prepared in the prologue and is unfolded in »Part II: Cease Not till Death,« which again sets in with the diagnosis.

As a counterweight to the young neurosurgeon's striving for success, the text sheds critical light on the values that had supported the protagonist's professional ethos and in turn validates mortality, embodiment and vulnerability. Up until the diagnosis, and

despite his philosophical interest in relationality and the mutually constitutive interconnection between mind and body, the protagonist's social life had to take a backseat to the narrative of professional success that had scripted his adult life. He had dedicated all of his time, his physical and emotional resources, and his attention to his professional career, postponing his social life. At the end of his residency, he would soon reap the fruit of his strict work ethic: »At age thirty-six, I had reached the mountaintop; I could see the Promised Land [...]. I could see the tension in my back unwinding as my work schedule eased and life became more manageable. I could see myself finally becoming the husband I'd promised to be« (7). At this point of arrival almost within reach, he was not going to give in to the physical ailments he could easily read as serious symptoms. He was so much »determined to persevere for the next fifteen months, until residency ended« (6), that he even refrained from speaking to his wife about his suspected condition, which put considerable extra strain on a marriage bond already worn thin by years of multiple professional obligations. If he didn't speak about it, maybe it would go away: »Things are going to be okay« he tells himself and his estranged wife (9). Informed by these patterns of facing trouble with a potent mixture of denial and perseverance, the surgeon recently become patient can only take his unsought sense of embodiment as a sweeping failure. Even as a dying patient who accepts what is ahead of him, he thus finds himself unable to let go of the masculinist discursive power his professional position within the medical system, »with its unforgiving call to perfection« (71), bestows upon him: »without that duty to care for the ill pushing me forward, I became an invalid« (125). So he returns to the operating room and to his role as a neurosurgical »maste[r] of many fields« (72) as soon as he possibly can, in order to be *in control* once more: »I was calling the shots« (159). For him, returning to work after 18 weeks meant returning to life, shedding the passivity connected to the role of the patient (150). And it meant betting on the most hopeful prognostication of 10 more years of life. But he quickly felt exhausted and the narrator admits that his work had become »joyless« (156). Nevertheless, he clings to the idea of »restor[ing] [his] life to its prior trajectory« (156). Reopening his job search, the narrator reports with considerable irony, he »could almost hear trumpets sounding a victory fanfare« (156). Subsequently the narrator rephrases this victory, confirming the sense of irony in his own hyperbolic pronouncement of triumph, as a desperate *need* to feel triumphant (165).

After conceding that living through terminal illness is a process which entails unstable evaluations, the narrator acknowledges his own »total denial« involved in his return to work (162): »I had striven with every ounce to restore my life to its precancer trajectory, trying to deny cancer any purchase on my life« (164). Recognizing the desperation and fear underlying his denial, he feels compelled to face »a strange and strained existence, challenging [him] to be neither blind to, nor bound by death's approach« (165). Faced with unknown territory under the sign of approaching death,

he seeks to navigate a course between triumphant denial and desperate passivity. He seeks to fight for an inner space of rest rather than against his illness.

As I already indicated, the protagonist experiences this threatening change of perspective, his unsought embodiment and vulnerability, with considerable ambivalence. As his doctor Emma had told him, he needed to figure out what was important to him now. »Emma hadn't given me back my old identity. She'd protected my ability to forge a new one. And, finally, I knew I would have to« (166). In this process of attempting to think of his identity in different terms, the protagonist begins to see his profession critically and his »own hybris as a surgeon stood naked to [him] now« (166): it was his responsibility and power as a surgeon to perform successful crisis interventions, but he never solved those crises:

the patient and family go on living – and things are never quite the same. A physician's words can ease the mind, just as the neurosurgeon's scalpel can ease a disease of the brain. Yet their uncertainties and morbidities, whether emotional or physical remain to be grappled with. (166)

Only as a patient does Kalanithi begin to question his professional position, which had, in the end, *not* allowed him to connect an interest in the body with an interest in the mind: Being a »leading actor« in *other* people's »medical dramas« (73) had been grand. But it did *not* allow him to be »*with* patients in their pivotal moments, I was merely *at* those pivotal moments. I observed a lot of suffering; worse, I became inured to it« (81, italics mine). Reaching back to his own interdisciplinary education, the narrator also relativizes science as *one* form of knowledge production that is ill understood if it is taken to include and thus cancel all others: transcendent revelation, literary or philosophical knowledge production. The scientific »view from nowhere« has, as he admits in his literary view from a socio-culturally and affectively situated standpoint, its own blind spots:<sup>9</sup>

Science may provide the most useful way to organize empirical, reproducible data, but its power to do so is predicated on its inability to grasp the most central aspects of human life: hope, love, hate, beauty, envy, honor, weakness, striving, suffering, virtue.

Between these core passions and scientific theory, there will always be a gap. No system of thought can contain the fullness of human experience. (170)

---

<sup>9</sup> For a heuristic juxtaposition of the scientific »view from nowhere« and the literary »view from somewhere« see Kley 2016.

The narrator concludes:

In the end, it cannot be doubted that each of us can only see part of the picture. The doctor sees one, the patient another, the engineer a third, the economist a fourth, the pearl diver a fifth, the alcoholic a sixth, the cable guy a seventh, the sheep farmer an eighth, the Indian beggar a ninth, the pastor a tenth. Human knowledge is never contained in one person. It grows from the relationships we create between each other and the world, and still it is never complete. (172)

Guided by this idea of the inherent imperfectability of any one perspective, he is able, during the subsequent relapse and feeling weak, to allow his need for control to ease and make room for a sense of conscious and sensitive acceptance of the wealth of the life he has left. His wife confirms, in her posthumous epilogue to the text, how he consciously enjoyed the support of friends and family and »let himself be open and vulnerable, let himself be comforted« (219). She confirms that, in contradistinction to the strenuous time of denial during the year before the diagnosis, her husband remained in sensitive relation to her and to his environment. »Even while terminally ill, Paul was fully alive; despite physical collapse, he remained vigorous, open, full of hope not for an unlikely cure but for days that were full of purpose and meaning« (219). Kalanithi experiences the birth of his daughter, in particular, in ways which affirm and enrich his sense of embodiment and vulnerability: »Feeling her weight in one arm, and gripping Lucy's hand with the other, the possibilities of life emanated before us« (195). Abandoning frantic activity and ambition, Kalanithi's sense of time also changes, as he seems to heed the Fulke Greville line he quotes at the beginning of the book: »Reader! Then make time, while you be,/ But steps to your eternity« (ix). He adopts what he calls a »tor-toiselike approach. I plod, I ponder. Some days, I simply persist« (197). His sense of time changes significantly: Future orientation and delayed gratification wash away into an expansive immediate present.

Needing a communicative examination of death and needing to be present in time are, as Corinna Caduff suggests, effects of the permanent stress experienced by working generations in late modern high-performance societies. Where predominant values tightly circle around performance and efficiency, death is the most radical disruption of ›normal life‹ and facing mortality the most radical form of slowing down. Slowing down is a practice frequently evoked but little practiced with any consequence in high performance cultures. It is a symptom of a time that is experienced as passing too fast. As Caduff explains:

In order to develop and embed a consciousness of death, a society must enable the experience of present-ness, the experience of ›having time,‹ of ›being in time.‹ Therefore, new figurations of death might be rooted in our longing for adjourning,

pausing, lingering – in order to experience and become conscious of time. In order to become evanescent (239-241, here 241, translation mine).<sup>10</sup>

Along these lines Kalanithi's text substantiates the connection I see between the serious contemplation of mortality and a profound criticism of late modern forms of economic and social life. Saturated in this new conscious sense of time slowed down, Part II of the memoir ends with the narrator-protagonist addressing a letter to his daughter: »you filled a dying man's days with a sated joy, a joy unknown to me in all prior years, a joy that does not hunger for more and more but rests, satisfied. In this time, right now, that is an enormous thing« (199). The text thus offers a perspective from which it becomes possible to understand that the ideology inscribed in the need to »fight the disease as an enemy« makes it impossible to *live with* the disease. Allowing personal recognition and support are major steps in letting go of the combative take that underlies the desperate need, encouraged by a thoroughly economized hospital system and a competitive culture of achievement, to repair the body to a previous condition. As Kalanithi undergoes this transformation, he is enabled, under first class medical treatment and in the midst of a »death-avoidant culture« (215), to develop new, poignantly meaningful conceptions of a life worth living with cancer.<sup>11</sup>

#### 4. Death-avoidance and new visibilities: Western attitudes toward death

As Philippe Ariès has explained in his 1973 classic study *Western Attitudes Toward Death*, confrontation with death has been spatially and emotionally marginalized in Western societies since the late nineteenth century. And, as the psychologist Pauline

---

<sup>10</sup> The German original reads: »Um ein Todesbewusstsein aktuell zu verankern, muss eine Gesellschaft die Erfahrung von Gegenwärtigkeit ermöglichen, die Erfahrung von ›Zeit haben‹, ›in der Zeit sein‹. Dementsprechend scheinen die neuen Figurationen des Todes nicht zuletzt begründet in unserer Sehnsucht danach, endlich einmal auszusetzen, einzuhalten und zu verweilen – um Zeit wieder erfahren und begreifen zu können. Um vergänglich zu werden« (239-241, here 241).

<sup>11</sup> The fact that the dying patient reconsiders long abandoned Christian values of »sacrifice, redemption, forgiveness« for their compelling stand »against blind determinism« (171) confirms the historian Anne Harrington's claim that the various branches of current mind-body medicine and their critique of a strictly physicalist medical system gain much of their authority from recourse to older religious traditions (245-247). A second set of concerns she identifies as amplifying mind-body medicine's »efforts to talk coherently about what it means to be human« (254) are cultural anxieties about the costs of modernization in general and about material prosperity, masculinity, weakening family and community bonds, in particular (246-247). These concerns surface strongly in Kalanithi's text. For an up-to-date anthropological conception of a trans-religious *ars moriendi* see Leget.

Boss has shown in her work over the past 20 years, the American nation in particular, a nation invested in imagining itself in control of its own and other nations' fate, suffers from what she calls »ambiguous loss« – from individually and collectively unaddressed grief. Boss attributes US-American ambiguous loss to the history of slavery and racism, the Civil War, the history of immigration, the wars in Korea, Vietnam and the middle East, 9/11 and last but not least the Corona pandemic – all of which sent strong and lasting senses of mortification across a country highly invested in making, doing and success. Biomedical development since the end of WWII also extends the repression of death in ambivalent ways: on the one hand, people who enjoy unhindered access to the modern medical system grow much older and encounter death later and less frequently in their lives than earlier generations. But while people in high tech cultures grow older, the experience of aging and dying becomes a stage of life in its own right and it remains under-examined. Speaking about the medical system, the surgeon and author Atul Gawande explains:

Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and denied them the basic comforts they most need. Lacking a coherent view of how people might live successfully all the way to their end, we have allowed our fates to be controlled by the imperatives of medicine, technology and strangers. (9).

Sharon Kaufman confirms in her study of how hospitals shape the end of life in the US, that the hospital has become, since the 1980s, the primary place and institution where, in high tech and high-performance cultures, spatially and psychologically repressed encounters with mortality return with a vengeance in all their personal and cultural ambivalence.

Biomedical progress has normalized longevity and stabilized medicine as a consumer product and practice. It has also brought with it enormous medical and personal complications and frequently a protraction of the process of dying a »natural« death. Under current biomedical conditions, dying frequently becomes a significant and considerably long phase of life in its own right (Carr). In the late 1960s, the intensive care concept of brain death was introduced. Since the 1980s and up to this very day, the concept has been connected to controversial and ongoing public debates around the definition of death both in the US and in Europe. These debates have, together with the increase in longevity and the occurrence of degenerative diseases, contributed to making death and dying a frequent topic of public discussion. In late industrial societies, death thus becomes a public issue of debate at a time when traditional Christian rituals

of mourning have lost authority as a widely shared practice.<sup>12</sup> However, these debates hardly contribute to clarifying how we live content and in dignity all the way to our end.

In line with Kaufman's claim that dying in late capitalist societies predominantly takes place in hospitals, Kalanithi explains that »the questions intersecting life, death, and meaning, questions that all people face at some point, usually arise in a medical context« (70). And he adds that their encounter and address is at least as much a *philosophical* as a biological exercise, emphasizing that the medical system produces or exacerbates problematics it is ill-equipped to address with its own resources (Gawande). Kalanithi finds himself needing, in addition to medical treatment, *words*, i.e. a non-scientific form of abstraction, to go forward:

Lost in a featureless wasteland of my own mortality, and finding no traction in the realms of scientific studies, intercellular molecular pathways, and endless curves of survival statistics, I began reading literature again: [...] – anything by anyone who had ever written about mortality. I was searching for a vocabulary with which to make sense of death, to find a way to begin defining myself and inching forward again. The privilege of direct experience had let me away from literary and academic work, yet now I felt that to understand my own direct experiences, I would have to translate them back into language. (148-149)

With its reach for language, indirection and perspective, Kalanithi's text is an instance of a larger cultural formation insisting on an address and examination of mortality.

Death as a new *cultural* topic began to grow with the development of »personal accounts of illness and dying« after World War II, as the medical profession transformed with the wide availability of antibiotics and vaccines, turning its primary focus from infectious to chronic diseases (Jurecic 4-17). As the health system persistently medicalized human lives from birth to death, patients also became more active medical consumers seeking treatment for conditions previously not considered medical. Many patients, however, also became alienated from the system. Antipsychiatry and the women's health movement picked up on this growing sense of alienation among patients and helped initiate the development of the political or activist patient. Jurecic cites six publications which discursively paved the way for this development and for an increasing number of personal illness narratives resisting the capitalist medicalization of life and the objectification of the patient.<sup>13</sup> These narratives carve out space for the

---

<sup>12</sup> Clearly, and in particular in the US, there are significant fundamentalist counter movements, but it seems safe to say that the loss of a widely shared Christian faith leaves a vacuum in its wake which calls for new and sustainable modes of addressing experiences of death and grief.

<sup>13</sup> On the medicalization of life and death and the medical quest for control of human bodies see Ehrenreich and Gawande.

reflection of existential questions connected to personal health issues that do not have room in medical institutions, which are systematically, and with considerable success, focused on the eradication of disease.

The six trailblazing publications identified by Jurecic are the Swiss-American psychiatrist Elisabeth Kübler-Ross' account of the five stages of grief, *On Death and Dying* (1969); the first edition of the feminist medical bible *Our Bodies Ourselves* (1970); the Christian ethicist Paul Ramsay's first account of bioethics, *The Patient as Person: Explorations in Medical Ethics* (1970); the Austrian-American theologian and critic of progress Ivan Illich's *The Medical Nemesis: The Expropriation of Health*; the American director, author and social critic Susan Sontag's *Illness as Metaphor* (1977) which fought the stigmatization of cancer patients; and finally the journalist Norman Cousins' *Anatomy of an Illness as Perceived by the Patient: Reflections on Healing and Regeneration* (1979). The tide of personal illness narratives in the wake of these publications swelled with the narrative negotiations of the AIDS crisis in the 1980s and 1990s, which produced, in a variety of genres and media, »a thunderous cacophony of voices« by patients, their relatives and friends, journalists, medical personnel, and novelists about »loss, sorrow, struggle, rage, and redemption or its absence« (Jurecic 2, 8-10), i. e. about »matters of concern« (Latour) not addressed in medical discourse.

Since then, cultural productions of the past three or four decades in all media frequently address death, illness, dying and bereavement ushering in a »new cultural visibility« of death in transatlantic cultural geographies (Macho/Marek 9-21, Caduff, Anderson).<sup>14</sup> At the end of the 20<sup>th</sup> century, digital and digitally organized practices of commemoration emerge.<sup>15</sup> The concept of »digital immortality« as well as social debates around digital legacy also gain traction. With digitalization, the understanding and structuring of the experience of death, which is connected to a set of people, particular times, places, as well as culturally specific objects and symbols, also assumes new shape and form (Cutter 105-120, Caduff 173-202). Altogether, this new cultural visibility of death is in part a reaction to, and it collides with, the social denial and repression of death, dying, and mourning I have addressed at the outset of this section. It indicates an ongoing recalibration of the social significance of death.

<sup>14</sup> Cursory examples are photographs like those by Sue Fox, films (like *Death Becomes Her*), TV-series (like *Six Feet Under*, *Dead Like Me*, *C.S.I.*, and more recently *The Good Place* or *After Life*), Comics and Graphic Novels (like those by Alison Bechdel and Tom Hart), Games, Performances, international exhibitions (like the anatomist Gunter von Hagens' *Body Worlds*), autobiographies, novels. Additionally, the ongoing process of digitalization has opened up new »thanatechnological« spaces for an individualized processing of death, dying, loss, and grief.

<sup>15</sup> One example is the practice of conducting non-commercial discussion groups on death, the so-called death cafés which, starting from London, have spread internationally since 2010 ([www.deathcafe.com](http://www.deathcafe.com)).

The internet and, in particular, social media also further amplify the production of multiplied, multimedia and frequently relational or collaborative versions of illness narratives, both offering visibility and enabling selection and surveillance (Bolaki 211-221). Illness narratives may seem self-indulgent or utilitarian in their demand for empathetic engagement with the ›victim‹ of disease. I want to insist, however, with Jurecic and Bolaki that these representations' media-specific formal and generic constructions and their staging of conflicting ideologies »continue to test the possibility that a narrative will do meaningful work in the world« (Jurecic 11, Bolaki 220-221).<sup>16</sup> I choose to join those whose work on illness narratives and representations of dying and bereavement seeks to be both critically discerning and empathetic, employing both hermeneutically suspicious and reparative modes of reading – in order to identify the what and the how of the cultural work they perform. This kind of critical work rejects a deeply problematic divide between embodied everyday experience and unaffected cultural criticism, between the emotional and the rational, between ethics and aesthetics – without assuming they are the same.<sup>17</sup>

### 5. Literary knowledge production: a conclusion

*When Breath Becomes Air* presents the medical hospital as a social space that is inherently ill-equipped for the negotiation of the personally and culturally contradictory process of dying that, in late capitalist consumer societies and since the 1980s, predominantly takes place in its confines. Recent journalistic work (Ehrenreich, Gawande, Mikich) and research in medical history (Illich), medical sociology (Kaufman) as well as medical ethics (President's Council on Bioethics) systematically explores these weaknesses of late capitalist societies' high tech medical systems: they are geared towards the control of disease and cost at the expense of a clear-eyed and emotionally supportive view of life's end. Only on the fringes of the medical system, in medical ethics and the recently developed branch of palliative care, does a more humble but strongly supportive take on the human body and both its physical and mental needs take hold (Maio 2011, Maio 2020, Student 2004).

*When Breath Becomes Air* is a paradigmatic example for the contribution literary forms of knowledge production might provide in a discursive field which, in late

<sup>16</sup> See also Kainradel/Kriebernegg, Kainradl et al. and Oró-Piqueras/Wohlmann.

<sup>17</sup> In addition to the critics already mentioned, I include Jessica Restaino in this open ›we‹. She allows the conceptual walls »between the personal, the academic and the analytic« to become permeable (9). »What happens when we refuse to operate in only one area at a time,« she asks, opening up her work on a friend's death to the experience of *not* knowing – in order to transform what it means to write, to do research, and to be a friend (9-11).

capitalist societies, is securely framed by medical, economic, legal and residual religious protocols. Literary knowledge production has many facets; here I am primarily concerned with »matters of concern« (Latour) that are more poignantly – and with more searching specificity – discussed in literary writing than in medical, care, religious or insurance protocols (Kley 2016, Kley 2018: 9–14, Bolaki 11). With the resources of literary expression (a tragic story and a compelling narrative voice) and equipped with the powers of the business of literature (which place a well-pitched book internationally in both the prestigious and the popular limelight), *When Breath Becomes Air* provides a much-needed perspective on death and hospital culture. It highlights the fundamental contradictions between a thoroughly economized high tech hospital system and the needs of terminally ill patients who require that systems' services. It thus juxtaposes the hospital system's efficient control of cost and disease as well as its masculinist notions of hierarchy and command with the suffering body's need for recognition and physical as well as emotional support. This juxtaposition indicates that the hospital system needs to make room for the perspective it marginalizes in order to *respond* to the needs of the ill body.<sup>18</sup>

By deflating masculinist notions of control and by exploring the alternative qualities needed to face mortality, *When Breath Becomes Air* attends to the issue of human vulnerability the hospital system exacerbates but cannot attend to with its own resources (Kaufman, Gawande). With its literary address of the experience of dying, *When Breath Becomes Air* thus offers an important form of alternative knowledge production to currently dominant medical, care, insurance and legal discourses on vulnerability, mortality and death. At a larger scale the text articulates a critique of late capitalist high tech societies' need for control and their heightened demands on the individual's resources of time, creativity, flexibility, and commitment. Deflating those urgencies, culturally coded masculine, healthy and strong, the text implies the existential need for the strengthening of relationality and solidarity. Under the sign of death, the habituated economic logics of augmentation quickly become unreal. The text thus exposes a longing for a different quality of relation to the world; a relation to the world that is attuned to the body and to the relational nature of knowledge, enquiry, friendship and life; a relation to the world that may »resonate,« as the sociologist

---

<sup>18</sup> In his first study of literary narrative as a resource for medical sociology, *The Wounded Storyteller*, Frank also connects the suffering body's need with the hospital system's deficits and the vital communicative function of stories: »administrative systems [...] cannot take suffering into account because they are abstracted from the needs of bodies. When the body's vulnerability and pain are kept in the foreground [through the telling of witness accounts], a new social ethic is required« (2013: 146). Frank suggests that the »pedagogy of suffering« (2013: 145), which illness witness accounts may provide, significantly contribute to the development of a »new, multivocal clinical ethic« (2013: 147), which seeks to make sure the hospital system is better oriented toward the patient as a person than it has been.

Hartmut Rosa would have it, with the needs of individuals and groups (Rosa 2021, Rosa 2018). A both humble and pleasurable relation to the world that is attuned to the needs of bodies and a broadly inclusive »ethics of vulnerability,« as Martin Schnell develops it at the crossroads of philosophy and nursing, does not have a systematic place wherever growth imperatives are prevalent. Therefore, late capitalist societies are in acute need for artistic reflection and imaginary arrangement of such ethics and relations to the world as *When Breath Becomes Air* enacts it. The text prompts its readers to expand and defer seemingly self-evident notions of ›normal life‹. Dodging the pervasive rhetoric of personal development and the heroic overcoming of pain and grief, the text articulates the contours of a shaken and fundamentally uncertain life and imagines it with all its contradictions as a volatile point of reference.

### Works Cited

#### Primary Source

Kalanithi, Paul (2016): *When Breath Becomes Air*. New York: Random House.

#### Research Literature

- Ariès, Philippe (1973): *Western Attitudes Toward Death: From the Middle Ages to the Present*. Trans. Patricia M. Ranum. London: Marion Boyars.
- Anderson, Inga (2018): *Bilder guter Trauer: Neue Sichtbarkeiten der Trauer in der Psychologie, Philosophie und Fotografie*. München: Fink.
- Banerjee, Mita (2011): *Medical Humanities in American Studies: Life Writing, Narrative Medicine, and the Power of Autobiography*. Heidelberg: Winter.
- Berlant, Lauren (2011): *Cruel Optimism*. Durham, NC: Duke University Press.
- Bielefeldt, Heiner/Frewer, Andreas/Osgathe, Christoph/Welsh, Caroline (eds.) (2017): *Autonomie und Menschenrechte am Lebensende: Grundlagen, Erfahrungen, Reflexionen aus der Praxis*. Bielefeld: transcript.
- Bolaki, Stella (2016): *Illness as Many Narratives: Arts, Medicine and Culture*. Edinburgh: Edinburgh University Press.
- Boss, Pauline (1999): *Ambiguous Loss: Learning to Live with Unresolved Grief*. Cambridge: Harvard University Press.
- Broeckling, Ulrich (2015). *The Entrepreneurial Self: Fabricating a New Type of Subject*. Los Angeles: Sage Publications.
- Butler, Judith/Gambetti, Zeynep/Sabsay, Leticia (2016): »Rethinking Vulnerability and Resistance.« In: Butler, Judith et al. (eds.): *Vulnerability in Resistance*. Durham: Duke UP, pp. 12-27.
- Caduff, Corinna (2013): *Szenen des Todes: Essays*. Basel: Lenos.

- Carr, Deborah/Luth, Elizabeth A. (2019): »Well-Being at the End of Life.« *Annual Review of Sociology* 45, pp. 515-534. <https://doi.org/10.1146/annurev-soc-073018-022524>. Accessed July 10, 2022.
- Charon, Rita (2006): *Narrative Medicine. Honoring the Stories of Illness*. New York: Oxford University Press.
- Couser, G. Thomas (1991): »Autopathography: Women, Illness, and Life-writing.« In: *a/b: Auto/biography Studies*, vol. 6, no. 1, pp. 65-75.
- Couser, G. Thomas (1997): *Recovering Bodies. Illness, Disability, and Life Writing*. Madison: University of Wisconsin Press.
- Couser, G. Thomas (2004): *Vulnerable Subjects: Ethics and Life Writing*. Ithaca/London: Cornell University Press.
- Couser, G. Thomas (2016): »Body Language: Illness, Disability and Life Writing.« In: *Life Writing*, vol. 13, no. 1, pp. 3-10.
- Cutter, Mary Ann G. (2019): *Death: A Reader*. Notre Dame: U of Notre Dame P, 2019.
- Ehrenreich, Barbara (2018): *Natural Causes: Life, Death and The Illusion of Control*. New York: Twelve.
- Frank, Arthur W. (2013): *The Wounded Storyteller: Body, Illness, and Ethics*. 1995. 2nd ed. Chicago: University of Chicago Press.
- Frank, Arthur W. (2010): *Letting Stories Breathe: A Socio-Narratology*. Chicago: University of Chicago Press.
- Gawande, Atul. (2014): *Being Mortal: Medicine and What Matters in the End*. New York: Metropolitan Books.
- Gergen, Kenneth J. (2009): *Relational Being: Beyond Self and Community*. New York: Oxford University Press.
- Gilman, Sander L. (1988): *Disease and Representation: Images of Illness from Madness to AIDS*. Ithaca/London: Cornell University Press.
- Gilbert, Sandra M. (2006): *Death's Door: Modern Dying and the Ways We Grieve*. New York: Norton.
- Gómez-Virseda, Carlos/de Maeseneer, Yves/Gastmans, Chris (2019): »Relational autonomy: what does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature.« In: *BMC medical ethics*, vol. 20, no. 1. 26.10.2019. doi:10.1186/s12910-019-0417-3. Accessed July 10, 2022.
- Harrington, Anne (2008): *The Cure Within: A History of Mind-Body Medicine*. New York: Norton.
- Illich, Ivan (1995): *Limits to Medicine*. London: Marion Boyars.
- Jurecic, Ann (2012): *Illness As Narrative*. Pittsburgh, PA: University of Pittsburgh Press.
- Kainradl, Anna-Christina/Kriebernegg, Ulla (2021): »Bad News? Literarische Care-Beziehungen als Utopien des Alter(n)s.« In: Gronemeyer, Reimer/Schuchter, Patrick/Wegleitner, Klaus (eds.): *Care – Vom Rande betrachtet. In welcher Gesellschaft wollen wir leben und sterben?* Bielefeld: transcript, pp. 97-114.
- Kainradl, Anna-Christina/Kriebernegg, Ulla/Trinkaas, Eva-Maria et al. (eds.) (2021): *Alter(n) und Pflege gemeinsam neu denken: Interdisziplinäre Perspektiven aus Wissenschaft und Praxis*. Wien: facultas.

- Kaufman, Sharon R. (2005): ... *And A Time To Die: How Hospitals Shape the End of Life*. New York: Scribner.
- Kley, Antje (2016): »Literary Knowledge Production and the Natural Sciences in the US.« In: Knewitz, Simone/Klößner, Christian/Sielke, Sabine (eds.): *Knowledge Landscapes North America*. Heidelberg: Winter, pp. 153-177.
- Kley, Antje (2018). »What Literature Knows: An Introduction.« In: Kley, Antje/Merten, Kai (eds.): *What Literature Knows: Forays into Literary Knowledge Production*. Heidelberg: Winter, pp. 9-25.
- Kunow, Rüdiger (2018): *Material Bodies: Biology and Culture in the United States*. Heidelberg: Winter.
- Latour, Bruno (2004): »Why Has Critique Run out of Steam? From Matters of Fact to Matters of Concern.« In: *Critical Inquiry*, vol. 30, Winter 2004, pp. 225-248.
- Macho, Thomas/Marek, Kristin (eds.) (2007): *Die Neue Sichtbarkeit des Todes*. München: Fink.
- Maio, Giovanni (2020): *Den Kranken Menschen Verstehen: Für Eine Medizin Der Zuwendung*. 2nd ed. Freiburg: Herder.
- Maio, Giovanni (ed.) (2011): *Abschaffung des Schicksals? Menschsein Zwischen Gegebenheit des Lebens und Medizin-Technischer Gestaltbarkeit*. Freiburg: Herder.
- Leget, Carlo (2017): *Art of Living, Art of Dying: Spiritual Care for a Good Death*. London/Philadelphia: Jessica Kingsley Publishers.
- Mikich, Sonia (2013): *Warum Uns der Medizinbetrieb Krank Macht*. München: Bertelsmann.
- Oró-Piqueras, Maricel/Wohlmann, Anita (eds.) (2015): *Serializing Age: Aging and Old Age in TV Series*. Bielefeld: transcript.
- President's Council On Bioethics (2003): *Beyond Therapy: Biotechnology and The Pursuit of Happiness*. New York: Regan.
- Restaino, Jessica (2019): *Surrender: Feminist Rhetoric and Ethics in Love and Illness*. Carbondale: Southern Illinois University Press.
- Rosa, Hartmut (2021): *Resonance: A Sociology of Our Relationship to the World*. Medford, MA: Polity Press.
- Rosa, Hartmut (2018): *The Uncontrollability of the World*. Medford, MA: Polity Press.
- Schnell, Martin W. (2017): *Ethik im Zeichen Vulnerabler Personen: Leiblichkeit – Endlichkeit – Nichtexklusivität*. Weilerswist: Velbrück Wissenschaft.
- Solnit, Rebecca (2009): *A Paradise Built in Hell: The Extraordinary Communities That Arise in Disaster*. New York: Penguin.

### Further Sources

- Baker, Douglas E. (2019): »Death Becomes Us.« *Tenth Presbyterian Church*: <https://www.tenth.org/resource-library/tenth-presses/death-becomes-us/>. Accessed May 22, 2022.
- Boyer, Anne (2019): *The Undying. Pain, Vulnerability, Mortality, Medicine, Art, Time, Dreams, Data, Exhaustion, Cancer and Care*. New York: Farrar, Straus and Giroux.
- Butler, Judith/Yancy, George (2020): »Interview by George Yancy: Mourning is a Political Act Amid the Pandemic and its Disparities (Republication).« Springer Link Online / *Bioethical*

- Enquiry* (2020): <https://link.springer.com/article/10.1007/s11673-020-10043-6>. Accessed May 22, 2022.
- Ensler, Eve (2013): *In the Body of the World*. New York: Metropolitan Books.
- Kalanithi, Lucy (n.d.): »Homepage.« Lucy Kalanithi Homepage: <https://lucykalanithi.com/>. Accessed May 22, 2022.
- Skjolsvik, Pamela (2015): *Death Becomes Us*. North Charleston: CreateSpace Independent Publishing Platform.
- Student, Johann-Christoph (ed.) (2004): *Sterben, Tod und Trauer: Handbuch für Begleitende*. Freiburg: Herder.