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TEMPORALITY, READER RECOGNITION AND LITERARY CONSOLATION: A Reading of Paul Kalanithi's *When Breath Becomes Air* with Narrative Medicine

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A quest to establish meaning in the face of illness and mortality from a perspective that includes, yet at the same time exceeds, medical knowledge led neurosurgeon in residence Paul Kalanithi back to a life-long interest in literary fiction and prompted him to write *When Breath Becomes Air*. At the age of just thirty-six, right before finishing nearly a decade's training to become a neurosurgeon, Kalanithi's world came apart as he was diagnosed with widely metastatic lung cancer. A year later, he passed away, living only long enough to see the first few months of his infant daughter's life. The posthumously published memoir recounts Kalanithi's early life, his journey to becoming a doctor, a deep affection for as well as marital squabbles with his partner, and the experience of caring for new life while his own was dwindling. Gluing it all together is Kalanithi's life-long grappling with finding meaning at the intersection between a medically informed worldview and a belief in literature as especially attentive to what makes human life valuable.

In this article, I look closely at Kalanithi's literary approach to illness in relation to key principles from narrative medicine. More specifically, I turn to the significance of temporal norms, and how the onset of serious illness makes Kalanithi come to understand time in an entirely new way. This change in perspective, I argue, can be illuminated by turning to narrative medicine insights, particularly, the field's emphasis on the 'gaps' that exist between scientific approaches to illness and the subjective, lived experiences of illness. Being a medical specialist, perfectly familiar with delivering devastating information and acutely aware of Kaplan-Meier survival curves, Kalanithi navigated a science-based paradigm of treatment and care easily. However, as illness made him slip away from a position of medical control and mastery, he came to reconsider a worldview fixated on ambition and progress – and reflect on the limits of conventional medical care. Patients, he realized, seek a form of assurance that is not offered by any diagram or graph: namely, a path to consolation and authenticity (Kalanithi 2014).

Kalanithi's writing has social and political ramifications, I would argue, in so far as it rattles the doctrine of self-reliance and personal responsibility: being able to organize and plan your own time, his memoir shows, is not bestowed on everyone. People who live with serious illness, or who are caregivers for someone ill or vulnerable, cannot, to the same degree as others, lead well-organized, self-supporting, and ambitious lives. And this is something well-organized, self-supporting, and ambitious people – as Kalanithi personally exemplifies and effectively communicates to readers – need to recognize.

When Breath Becomes Air is structured as a frame story with a coming-of-age tale embedded into an overarching narrative of Kalanithi receiving his fatal diagnosis and reflections on facing death. Dating back to the Book of Thousand Nights and a Night, Decameron and Chaucer – Marcos Asencio notes – the frame narrative often "controls the embedded text" (Asencio 372). On this note, one could argue that the 'frame' of illness and death that surrounds *When Breath Becomes Air* governs the embedded text by dismantling and rearranging key insight from the middle section concerning Kalanithi's early childhood, adolescence and path to medicine. The middle part is brimming with confidence as young Paul experiences answers to grand questions beginning to dawn on him, whereas the prologue and the section "Cease Not Till Death" are marked by a sense of giving up on reaching a "permanent truth" and a description of time as an increasingly "meaningless" concept (Kalanithi 2016, 167, 197).

In this way, the frame story of illness that hems in Kalanithi's coming of age-tale does not work to cement or explain anything. Rather, it undermines Kalanithi's former attitudes and ambitions, and corrodes the picture it is enclosing. In this way, compositional features of the frame story underscore the change in Kalanithi's worldview. Most significantly, time, as Kalanithi used to know it as a promising doctor and researcher – a catalyst of development, skill building and progress – suddenly takes on an entirely different meaning through the lens of fatal disease. It does not form a linear, upward progression but brings disaster, repetition, occasional glimpses of hope, and a "feeling of openness" (Kalanithi 2016 197).

Understandings and experiences of time, we hence learn, do not unfold on a level playing field but are intrinsically linked to privilege and social norms. Julie Cosenza, reflecting on time and power, argues that there is an "able-bodied timeline [that] suggests a linear progression of cultural expectations bound by normative notions of time" (Cosenza, 157). Experiences of time, it follows from this, are saturated in and filtered through a wide array of practices, privileges and parameters. A textile worker, a sleep deprived new parent, and a manager in a large corporation are all bound by different expectations and structures of temporal power and hence relate to the span of ten minutes in vastly different ways. Cosenza goes on to argue that normative interpretations of time – informed by capitalist ideals of optimization and productivity – exert harmful regulatory power over people that do not comply with standard chronologies of work and reproduction (Cosenza, 162). Along similar lines, Elizabeth Freeman has coined the term chrononormativity to describe how a specific conception of time is being widely deployed to standardize and promote productive, and reproductive, citizens (Freeman 3). According to this line of thought, idealized chronologies circulate widely – in popular culture, on the labor market, in the educational system, and in politics – in order to bolster and boost able, straight, economically resourceful, and white bodies.

Prior to becoming fatally ill, Kalanithi fitted into almost all of the above categories. Being Indian American, he was a person of color – but his memoir does not examine the social injuries of racialization. Still, the realization that time presents itself in a radically different

way from a perspective of serious illness is a major topic and concern articulated by *When Breath Becomes Air*. As Kalanithi fails to meet the logic of production and progress he formerly adhered to, he comes to recognize the flow of time as a source of uncertainty and anxiety – as opposed to the fuel that used to help him reap the harvest he planned for and invested in. Certain bodies, it dawns on him, do not have the somewhat dubious privilege of being considered timely and useful. The idea that powerful structures establish realms of normalcy and erase experiences and bodies that do not fit in – offered by disability studies as well as preceding and related schools of thought – help to illuminate what is at stake: the injuries of illness (and disability) are not, or not primarily, about bodily pain or lack, but more so, a socially induced pain of being excluded from the fenced-in domain of normalcy (Davis 2).

In addition to gaining a new perspective on time, Kalanithi's memoir also brings out a different approach to physical pain. For example, he recaps a moment of being paralyzed by unbearable pain in an airport while being ordered by a security guard to move away: "Bad…back…spasms." – Kalanithi stammers out, but the guard is unaffected:

"You still can't lie down here." I'm sorry, but I'm dying from cancer. The words lingered on my tongue – but what if I wasn't? Maybe this was just what people with back pain live with. I knew a lot about back pain – its anatomy, its physiology, the different words patients used to describe different kinds of pain – but I didn't know what it felt like" (Kalanithi 2016, 12).

A lucid example of the epistemic schism between professional training and personal experience, this passage foregrounds a critical theme running through the memoir: the contrast between medical knowledge and individual experiences of illness. Kalanithi also ponders why he is "so meek in a patient's gown" when he used to be "authoritative in a surgeon's coat", and registers the irony of being "wide awake" as a patient in the same hospital bed that he, as a doctor, "in moments of utter exhaustion longed to lie down in" (Kalanithi 2016, 16). Indeed, the very title *When Breath Becomes Air* is emblematic of the discord between subjective perception and medical rationality – what happens when the breath you used to be able to control is replaced by air from a ventilator? For Kalanithi, the experience gives rise to a new awareness of emotional and philosophical aspects of illness that he did not pause to think about before.

Rita Charon argues that the gaps between what medical professionals know and what patients feel come down to a failure to listen to stories. "Sadly, health care professionals are not equipped to listen to such telling of the self with a diagnostic and interpretive ear", she observes, "so that too soon, the narrative is derailed by such questions as, "Is the pain sharp or dull?" or "How long did it last?"" It is Charon's conviction that medical caregivers need to build 'narrative capacity' in order to learn how to properly grasp the sufferings of patients and learn how "to listen, to recognize, to witness, and to be moved to action on behalf of patients through close attention to their situations" (Charon 2016, 8). Often, she argues, narrative medicine can help alleviate much more than just physical symptoms. Stories told between patient and the medical professional, she observes, can have a "redemptive force" and – referring to a specific example – "heal not only the shame and humiliation but also,

almost as a dividend, the eating disorder and the abdominal pain" (Charon 2006, 80). "To listen for stories", she further argues, "we have to know, first of all, that there are stories being told. We have to notice metaphors, images, allusions to other stories, genre, mood—the kinds of things that literary critics recognize in novels or poems" (Charon 2006, 66). A narrative medicine approach, it follows from this, stresses that competent listeners can help alleviate illness and pain, and rests on the assumption that a beneficial process of intersubjective recognition and consolation can happen via narrative telling and listening.

Kalanithi's realization that his medical expertise is of no particular help when it comes to confronting death speaks to the distance between medical and subjective knowledge laid out within a narrative medical framework. "As a doctor", he observes, "I had some sense of what patients with life-changing illnesses faced – and it was exactly these moments I had wanted to explore with them. Shouldn't terminal illness, then, be the perfect gift to that young man who had wanted to understand death? What better way to understand it than to live it? But I'd had no idea how hard it would be, how much terrain I would have to explore, map, settle. I'd always imagined the doctor's work as something like connecting two pieces of railroad track, allowing a smooth journey for the patient. I hadn't expected the prospect of facing my own mortality to be so disorienting, so dislocating" (Kalanithi 2016, 147).

Similar to the passage from the airport where it dawns on Kalanithi that he had never really considered what severe back-pain feels like – despite having studied it for years – this quote speaks to the discouraging experience of having a worldview of meaning and coherence punctuated. Kalanithi cannot utilize his medical knowledge of death, nor, as it turns out, apply his newly found insight of illness and mortality to the vocabulary of medicine; it is far too bewildering and illogical.

Kalanithi's sense of disorientation is, as I have argued, closely connected to a rupture in his understanding of chronology: the slippery slopes between life and death that he thought himself so familiar with, cannot be compared to traveling from A to B or putting together pieces in the right order, and so 'journey' and 'railroad' metaphors lose explicatory force. Ideas of proper chronology might be available to the medical professional, but they do not necessarily present themselves as options for people suffering from terminal illness. Believing that you know exactly when to do what, and in what order, turns out to be a privilege – not a neutral condition.

Emphasizing existential aspects of illness, and the importance of addressing them did not, however, lead Kalanithi to lose confidence in the value of conventional medicine. Rather, he came to know it in a new way; as a vital yet limited approach to illness due to the range of painful experiences, hopes and fears – caused by and entwined with illness – that it cannot describe, let alone remedy. This particular observation fits neatly with the arguments offered by a narrative medical understanding of illness, in which telling and listening to past and present experiences of pain and trauma, beyond issues of somatic pain, are considered critical tools for supplementing standard procedures of medical treatment.

One could argue that Kalanithi's coming to terms with the fact that he can no longer be governed by normative temporalities is beneficial, or even epiphanic: as cancer melts away career ambitions and private aspirations, he comes to appreciate the present moment, rather than plan for the future, and connect with what 'really' matters. The experience of no longer being counted among young ambitious people who hold the privilege to look to the future, however, is no less harrowing and aching in light of the fact that it brings new insight: "A few months ago" – Kalanithi recalls – "I celebrated my fifteenth college reunion at Stanford and stood out on the quad, drinking a whiskey as a pink sun dipped below the horizon; when old friends called out parting promises — "We'll see you at the twenty-fifth!"— it seemed rude to respond with "Well…probably not" (Kalanithi 2016, 198). Not just future reunions, but also small-talk pleasantries, are out of reach for Kalanithi as this point; an observation which illuminates the not-so enchanting and benign implications of living with a heightened awareness and, furthermore, an example of a distinct social pain of living with serious illness.

Reader Recognition and Social Acknowledgment

In spite of enduring social agony and feelings of alienation, Kalanithi did not stand back from trying to communicate his experience to a broader audience. On the contrary, he opted for a strategy of narrating illness and pain and in so doing, I would argue, ultimately engaged in a social struggle for recognition. Viewed in the light of social acknowledgment dynamics, *When Breath Becomes Air* is a text preoccupied with laying out the importance of not imposing standard conceptions of time to vulnerable patients, and a battle cry for narrative approaches to medical care. Rita Felski has convincingly emphasized reader recognition as one potential strategy through which literary texts can demand social recognition of the hardships faced by a particular group (Felski 2008, 36). A range of texts, she observes, have raised awareness by making readers feel addressed, summoned or 'mirrored' and hence, coming to see glimpses of their own lives in the text. Felski's analysis allows us to appreciate that not only can *When Breath Becomes Air* lead readers to recognize Kalanithi's struggle – and, on a broader level, acknowledge how ideals of linearity and productivity are experienced from a perspective of serious illness – it can also incite readers to recognize themselves as potentially caught up in normative conceptions of temporality in which ideals of achievement, progress and control dictate our every move.

The fact that Kalanithi, before receiving his diagnosis, firmly believed that if only he spent enough time on work and made it sufficiently far in his career, he would gain 'back' time and make it up to his family is yet another example of how a certain way of thinking about time disintegrates with the onset of serious illness, and also, how the memoir calls on us to recognize ourselves (Kalanithi 2016, 7). Time can only be spent once, as the advent of illness makes agonizingly clear. Capitalist and chrononormative models of time give us impression that we will acquire time and comfort by placing huge amounts of effort on the labor market, but in reality, we never get it back. "Grand illnesses are supposed to be life-clarifying", Kalanithi ponders, and goes on: "Instead, I knew I was going to die – but I'd known that before. My state of knowledge was the same, but my ability to make lunch plans had been shot to hell. The way forward would seem obvious, if only I knew how many

months or years I had left. Tell me three months, I'd spend time with family. Tell me one year, I'd write a book. Give me ten years, I'd get back to treating diseases. The truth that you live one day at a time didn't help: What was I supposed to do with that day?" (Kalanithi 2016, 161).

The confidence of knowing what to do when, we learn from this passage, hinges on the idea that time is predictable and knowable. For Kalanithi, this illusion gets shattered with the arrival of lung cancer. Meanwhile, his impulse to plan along rational timelines stays intact. Such inclinations to organize, however, turn out to be useless in the face of the brutal contingency sparked by serious illness: Kalanithi realizes the utter futility of trying to rationalize an increasingly messy life. In addition, the arrival of fatal illness uncovers that he, like most of us, ultimately fails to come up with a good answer to the harrowing question: 'What is the most meaningful way of spending a day'? Idealized, normalized timelines of education, work, reproduction, and more work, would normally prevent us from even asking it, but the forceful memento mori inherent to *When Breath Becomes Air* takes a step in the opposite direction. As the dying Kalanithi grapples with how to organize a disintegrating and precarious future, readers are nudged to step outside the realms of mandated normalcy, take stock of what truly matters to them and ask themselves how they really want to spend their time.

When Breath Becomes Air muses on the past as well as a present moment under constant siege from the perils of illness, whereas reflections on the future are almost entirely absent – apart from in mirage-like tableaus written, notably, in the past tense: "At age thirty-six, I had reached the mountaintop; I could see the Promised Land, from Gilead to Jericho to the Mediterranean Sea. I could see a nice catamaran on that sea that Lucy, our hypothetical children, and I would take out on weekends. 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" (Kalanithi 2016, 7).

From being a motivational mental image, the catamaran vision turns into a permanent utopia as Kalanithi's linear strategy of professional and personal advancement falls apart. In connection with a job interview in Wisconsin where the department chairman enthusiastically lists perks associated with the job, Kalanithi has a similar experience: "It was like a fantasy. And in that moment, it hit me: it was a fantasy. We could never move to Wisconsin. What if I had a serious relapse in two years? Lucy would be isolated, stripped of her friends and family, alone, caring for a dying husband and new child. As furiously as I had tried to resist it, I realized that cancer had changed the calculus" (Kalanithi 2016, 164).

These passages show that, before being deprived of futurity in the bleakest sense, Kalanithi loses the privilege it is to be able to talk about, plan for and dream of a future. Consequently, the memoir becomes one of a few genres that Kalanithi can draw on when writing about his life – as looking back becomes his only option. As a literary work, and a widely read one, *When Breath Becomes Air* has nonetheless reached well beyond the temporal limitation of terminal lung cancer and well into the future. Sidonie Smith – analyzing the relation between narrative and self – notes that our "repertoire" of stories defines "ourselves to the extent

that changing our stories changes our memories and our understanding of who we are, who we have been, who we will be" (Smith 93). If we latch onto Smith's notion of an intrinsic connection between memory and self and take it that stories are instrumental for what and how we remember, *When Breath Becomes Air*, and the critical acclaim it received, does not only structure Kalanithi's past but also cements his outlook on life, going forward. Kalanithi remembers – but also makes sure that the world remembers, indeed, recognizes how he went through the world, the ways in which serious illness changed his perspective, and that we need to rethink our approaches to medical care for the critically ill. Kalanithi's memoir, it follows from this, speaks to the social and political potential of literary works on illness: His descriptions of a previous inability to comprehend existential and social aspects of illness morph into a more general plea to get medical caregivers, and broader society, to recognize that hegemonic conceptions of normalcy, including temporal normalcy, affect and harm people living with critical illness.

For the purpose of grasping Kalanithi's strategy of literary representation, I have claimed that the framework of narrative medicine can contribute important insight to his emphasis on subjective storytelling and the need for supplementing conventional medicine with narrative approaches. Literary writing and reading, as it turns out, can – on top of functioning as helpful coping-mechanisms during difficult times – also assist patients, as well as their surroundings, in the continuous struggle for articulating and presenting new visions of care.

Towards the end of the book – and the end of his life – Kalanithi muses about what time means to him in his most fragile state. Noticeably, he suddenly shifts to present tense prose: "These days, time feels less like the ticking clock and more like a state of being" (Kalanithi 2016, 197). The temporal change approaches readers directly and makes Kalanithi's piercing words come through with force: "As a surgeon, focused on a patient in the OR, I might have found the position of the clock's hands arbitrary, but I never thought them meaningless. Now the time of day means nothing, the day of the week scarcely more. Medical training is relentlessly future-oriented, all about delayed gratification; you're always thinking about what you'll be doing five years down the line. But now I don't know what I'll be doing five years down the line. I may be dead. I may not be. I may be healthy. I may be writing. I don't know. And so it's not all that useful to spend time thinking about the future—that is, beyond lunch" (Kalanithi 2016, 198).

The progress-oriented course of medicine has lost significance: time, to Kalanithi, is no longer a 'chase' but a 'state'. Illness brings about this particular recognition, but Kalanithi's eager attention to literature, and, arguably, the process of writing his memoir, fuel it too. The claim that critical illness brings about a new outlook on time is a politically significant insight for readers, as I have argued. Not least, readers who would dismiss bodily and psychological vulnerability as legitimate reasons for not complying with standards of improvement and success. Meanwhile, the memoir also invites readers to recognize their own privilege, and perhaps acknowledge a degree of involvement in or, perhaps, a sense of suffering from hegemonic ideals of how to spend one's time. Along the lines of Rita Felski's advocacy for additive thought, it is my claim that aesthetic features of literary works on the one hand –

including appeals to reader recognition – and their political weight, on the other, do not cancel out or undermine one another (Felski 2019). The fact that a work of art is aesthetically distinct, emotionally biting and potentially mirrors its audience does not automatically make it less politically potent, quite the opposite. Kalanithi's plea that his infant daughter, later in life, will not "discount that you filled a dying man's days with a sated joy, a joy unknown to me in all my prior years, a joy that does not hunger for more and more but rests, satisfied" (Kalanithi 2016, 199) is not a mushy distraction from more important matters, and does not sideline a political analysis of the relation between critical illness and temporality, but rather, enhances the point that time can only be a race when you are fit to run.

WORKS CITED

Asencio, Marcos A. Romero. "Maria de Zayas' Broken Frame: A Brief Study of the History and Evolution of Frame Narratives." *Neophilologus*, vol. 102, no. 3, 2018, pp. 369–386.

Charon, Rita. *Narrative Medicine – Honoring the Stories of Illness*. Oxford University Press, 2006.

Charon, Rita. "The Shock of Attention." Enthymema, vol. 16, 2016, pp. 6-17.

Felski, Rita. "Both/And: A Response to Winfried Fluck." *American Literary History*, vol. 31, no. 2, 2019, pp. 249-254.

Felski, Rita. *Uses of Literature*. Blackwell Manifestos, 2008.

Cosenza, Julie. "The Crisis of Collage: Disability, Queerness, and Chrononormativity." *Cultural Studies ↔ Critical Methodologies*, vol. 14, no. 2, 2014, pp. 155-163.

Davis, Lennard J. *The Disability Studies Reader*. Routledge, 2006.

Freeman, Elizabeth. *Time binds: Queer temporalities, Queer Histories*. Duke University Press, 2010.

Kalanithi, Paul. "How Long Have I Got Left?" newyork times.com, 24 January 2014. www.nytimes.com/2014/01/25/opinion/sunday/how-long-have-i-got-left.html Accessed 9 December 2019.

Kalanithi, Paul. *When Breath Becomes Air*. Penguin Random House, 2016.

Smith, Sidonie A. "Material Selves: Bodies, Memory, and Autobiographical Narrating." *Narrative and Consciousness: Literature, Psychology and the Brain*, edited by Gary D. Fireman, Ted E. McVay, and Owen J. Flanagan, Oxford University Press, 2012, pp. 86-111.

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