

Why do we read illness stories?

*Paul Kalanithi's When Breath Becomes Air (2016)
read in the light of Rita Felski*

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*Why do we read pathographies and why have they become so popular? These are the key questions in our paper. In answering these, we will introduce and discuss Rita Felski's *The Uses of Literature* (2008) in connection to the American bestseller and Pulitzer prize finalist pathography *When Breath Becomes Air* (2016) by Paul Kalanithi.*

*We chose Kalanithi's book because we consider it in many ways typical of the pathographical genre with its first-person narrator, the frequent expression of shock, its reflections on meaning of the illness and the focus on daily life. Rita Felski's *The uses of literature* reflects by means of the four concepts knowledge, recognition, shock and enchantment upon what makes us want to read a certain book or genre. However, when working with Kalanithi's novel we soon found that Felski's four modes were not only meaning-making for enlightening the question on why we as readers turn to this book. We soon also found that recognition, enchantment, knowledge and shock were concepts that were relevant used in connection with Kalanithi's own experience of becoming ill and being a patient. The*

concepts, therefore, seem most useful for reflections on both the reader's response and the author drives of the pathography genre.

Introduction

Autobiographical or biographical illness stories (pathographies) are experiencing increasing popularity for reasons that are not obvious. Narrative theory rests on an acknowledged post-modern fact that is important for human beings to tell their stories, not least those involving illness: *"We make as well as tell stories of our lives and this is of fundamental importance in the clinical world"* (Mattingly 1994: 811). The increased public interest in pathographies may be due to several reasons. One is the general interest in contemporary autobiographical novelists like Karl-Ove Knausgård, Claus Beck Nielsen and Siri Hustvedt, to mention only a few. This hybrid genre resting on the verge of fiction and biography somehow meets the extreme with pathographies rendering people in intimate and existential threshold situations concerning health and wellbeing. Another reason for the popularity of the pathography genre is the growing interest in and openness toward health issues in media and popular culture. Due to the digital revolution around 1995 medical information and knowledge were easily spread, and on-line communities connected to specific diseases were established (Tjora & Sandaunet 2010:37). With the development from Web 1.0 to Web 2.0, the internet became a place for interaction rather than information (ibid). A growing number of people were given the possibility to publish online and soon online health diaries or blogs, as they were named in 1997, flourished on the world wide web (Du & Wagner 2006: 790). The presence of illness blogs might have triggered a latent interest in personal illness stories also published as analogous books. Other reasons might be the stirring of feelings and possible empathy in the readers, the need for readers to gain access to the hope which is often rendered (Ezzy 2000), an enhanced emphasis on the importance of narratives as meaning-making material (Wiltshire 2000) and a growing sense of the inadequacy of medicine to treat the whole human being.

In 2016, this novel sold a million copies and was placed second among Amazon's best sellers, after *"Harry Potter and the Cursed Child"* (Gamerman 2016). It has since been translated and published in more than 30 languages, according to an article in *"Medscape"* from 2016. This book is in many respects typical of the pathographical genre with its first-person narrator, its expression of shock, its reflections on the meaning of the illness and its focus on daily life. At the same

time, we acknowledge that Kalanithi's story in some respects differs from the "ordinary" pathography. One pivotal difference is that he was a medical doctor and thus had privileged information about his medical condition. Another is that he had an MA in English literature in addition to his medical degree, which is seen in his manner of writing. The main reason why we chose to study Kalanithi's book, though, was due to it being such a worldwide bestseller obviously answering some of the claims of the readers to the pathography genre. Another important reason was because of the literary qualities of the text.

The reasons for reading pathographies and the popularity of the genre are the focus of this article. For our theoretical approach, we have chosen Rita Felski's notable work *The Uses of Literature* (2008) in which she summarizes why we choose to read fiction, limiting the answer to four objectives, namely recognition, enchantment, knowledge and shock. Together, Felski's four concepts offer a pragmatic approach to why readers read. The hermeneutics of suspicion and the literary theorists' emphasis on otherness are replaced by a more general understanding of what we experience upon reading a work of fiction or watching a film. Felski's many examples are not only canonical, elitists works of art but also popular fictions and films. By taking a bestseller like Kalanithi's as our example, we use the methodology on a text representing the same popular corpus as Felski likes to highlight. We chose Kalanithi's book because we consider it in many ways typical of the pathographical genre with its first-person narrator, the frequent expression of shock, its reflections on meaning of the illness and the focus on daily life. Felski's four concepts knowledge, recognition, shock and enchantment help bring the methodological tools to reflect upon what makes us want to read a certain book or genre. However, when working with Kalanithi's novel we soon found that Felski's four modes were not only meaning-making for enlightening the question on why we as readers turn to this book. We soon also found that recognition, enchantment, knowledge and shock were concepts that were relevant used in connection with Kalanithi's own experience of becoming ill and being a patient. The concepts, therefore, seem most useful for reflections on both the reader's response and the author drives of the pathography genre.

We will introduce and discuss these four modes proposed by Felski in connection with the American bestseller and Pulitzer Prize finalist, the pathography *When Breath Becomes Air* (2016) by Paul Kalanithi.

However, when working with Kalanithi's novel, we soon found that Felski's four modes did not only make meaning as to why we as readers turn to this book. We also found that shock, recognition, knowledge and enchantment were rele-

vant concepts to Kalanithi's own experience of becoming ill and being a patient. We would like the reader to pay particular attention to the use of Felski's concepts on these two levels; one intended by Felski herself, and one added by us as an interpretative tool.

An American bestselling pathography

Paul Kalanithi's widow, Lucy Kalanithi, was asked in an interview with *The Guardian* whether the book's success was expected:

"It's exceeded our wildest expectations. A month or so before it was published it was getting some critical acclaim but the big question was whether people would actually want to read a book about dying written by a man who had recently died. We weren't sure. But it turns out they do. I think it is because the book is about living as well as dying. And although it is about what happened to Paul it is also about a universal experience – and it is so beautifully expressed."

Pathographies understood as personal accounts of illness are a new genre, even though stories of personal illness have existed at least since the 16th century (Wiltshire 2000: 411). If we include doctors narrating about patients, however, the genre goes as far back as antiquity (van der Horst 2013). Modern pathographies, meaning biographical or autobiographical texts rendering an illness experience, grew as a genre in the USA in the 1950s (Hawkins 1999), in the UK from the late 1970s (Aronsen 2000: 1600) and in the Nordic countries from the late 1960s (Bernhardsson 2010, Henriksen 2014: 115). In line with the growth of the pathography genre during the last fifty years, the texts have become more diverse, including first-person autobiographical accounts, third-person biographical rendering of illness, and documentary texts as well as fiction. There seems to be a trend for modern pathographies to be less accepting and more often "[a] critical patient narrative" (Wiltshire 2000: 412), formulating protests of being transformed into a body rather than being a person within the biomedical system.

When Breath Becomes Air is, however, not a critical pathography, either in its view on health care or in the feelings stirred in the author-patient himself. The biography about illness and dying by the late American neurosurgeon Paul Kalanithi (1977-2016) is marked by the success its author experienced as a doctor and the brave manner in which he faced his illness. Parts of the book were published

as essays at high-profile media outlets like *The New York Times* while Kalanithi was still alive, but the whole book was published posthumously ten months after his death. The book consists of a prologue and two parts. It is framed by a foreword by the celebrated Indian-American physician-author Abraham Verghese, and an epilogue written by the author's wife Lucy Kalanithi. Both the introduction and the epilogue stress the "human touch" of Kalanithi's biography and adds crucial information about him, both from a professional and a private perspective. More pragmatically, the introduction written by a medical celebrity like Verghese gives the book credibility and grandeur that makes it stand out from the majority of other pathographies. The prologue opens with the 36-year-old author flipping through his own CT scans, confirming his suspicions that he is suffering from incurable cancer.

Part one, "In Perfect Health I Begin", is a highly curated selection of the author's life story up to falling ill. Apart from sketched portraits of his Indian parents, this is the author's story of how he first became an English literary scholar, then a doctor, then a neurosurgeon. He cites his motivation for his educational choices as a search for answers to the question: What makes human life meaningful? He soon develops a fascination for the human brain, the biological organ that enables meaning. Finally, he realizes that questions about "life, death and meaning" more often arise in a medical context, and particularly connected to brain damage. In part two, "Cease Not till Death", Kalanithi expresses great disappointment that he has to stop working just as he is about to graduate as a neurosurgeon and was to be appointed an attending professor. His identity as a person is strongly tied to his professional identity; who is he, if not a neurosurgeon? The description of Kalanithi's transition from doctor to patient is pivotal. Apart from the joy of having a baby daughter shortly before his death, Kalanithi does not touch much on the meaning of personal relationships. However, he portrays the doctor-patient relationship as decisively important to him, both as a doctor and as a patient. He praises the value of having a doctor that accompanies him through his entire illness journey, and the meaning of having a continuous and trustful relationship to, in his case, an oncologist. From Lucy Kalanithi's epilogue, we learn more about the meaning of family relationships, both for her and for Paul. Here, she also describes her husband's last weeks and the way he died.

Kalanithi's biography became popular and was reviewed in leading newspapers and medical journals worldwide. Neurosurgeon Henry Marsh said in *The Guardian* that Kalanithi "writes very well, in a plain and matter-of-fact way, without a trace of self-pity, and you are immediately gripped and carried along". In *The Irish Times*,

Paul D'Alton found that "*Kalanithi takes the reader into the heart of life and death. At times this is a place of brutal isolation and at times a place of the most heartbreaking human intimacy imaginable.*" Ann Jurecic and Daniel Marchalik asked in *The Lancet*: When so many doctors have written about the shock of becoming patients and so many patients have written about facing death – is there more to say? Their answer is that because Kalanithi is so reflective, he has something to say and they conclude that reflectiveness should be cultivated in the medical profession, for the sake of both patients and doctors. Janet Maslin in *The New York Times* suggests: "*Part of this book's tremendous impact comes from the obvious fact that its author was such a brilliant polymath. And part comes from the way he conveys what happened to him (...)*" Kalanithi's background gives him the privileged position to tell about illness as lived experience and to be acknowledged and believed, as a doctor, patient and author.

Recognition

According to Rita Felski, *recognition* can mean both "*a cognitive insight, a moment of knowing or knowing again*" and also acknowledgement, or "*a claim for acceptance, dignity and inclusion in public life*" (Felski 2008: 29). This double meaning seems particularly relevant for pathographies. Until patients' stories started to emerge in print and on the screen, their lives and deaths had been silent to all but their close relatives. The writing and reading of pathographies brought acknowledgement of the relevance and importance of patients' and carers' perspectives, and the possibility for readers to align themselves with sick people or family carers all over the world. Patients' stories also created a possibility for physicians to enhance their understanding of what it meant to be sick, enabling them to nuance their responses towards patients. Pathographies also foregrounded the important role of the caregivers. The private village of the sick became a public space, where the authors pleaded for witness and validation.

Susan Sontag coined the famous metaphor of illness and well-being as belonging to two kingdoms, and the idea of entering a different world upon becoming ill still prevails (Sontag 2002). In Paul Kalanithi's book, this is expressed in many ways, for instance where he is talking to a patient he has just realized has terminal brain cancer. The patient, however, still does not know: "*I could see the vastness of the chasm between the life she'd had last week and the one she was about to enter. She and her husband didn't seem ready to hear brain cancer – is anyone? – so I began a couple of steps back*" (Kalanithi 2016: 93). As he himself is terminally ill, he reflects

upon the identical existential disruption the diagnosis brings, reflected in the light of his previous experiences as a doctor being the one to break such news: *"Once again I had traversed the line from doctor to patient, from actor to acted upon, from subject to direct object"* (Ibid: 180). Whereas the genre of medical reports is restricted to facts and a singular perspective, Kalanithi's statement is important as it points to unique characteristics of literature; to add several perspectives and hypothetical versions.

Through the genre of pathographies, sick people can find descriptions, metaphors and styles to express their bodily discomfort, existential anxieties and quests for meaning. Words are sought for sensations that were previously not verbalized. Literature, along with medical science, becomes not only the way to formulate the experience of having illness, but also a manner in which to rebuild the new life that remains. Paul Kalanithi, who held an MA in both English literature and medicine, writes about how this combination is literally meaning-making: *"Torn between being a doctor and being a patient, delving into medical science and turning back to literature for answers, I struggled while facing my own death, to rebuild my old life – or perhaps find a new one"* (Ibid: 139).

Literature becomes particularly important for self-formation *"when other forms of acknowledgement are felt to be lacking"* (Felski 2008: 33). Recognition in this sense means taking into account knowledge not yet fully understood, or not considered important until illness strikes. Kalanithi dwells upon this form of recognition in connection with death. As a neurosurgeon, he had close experiences with death, both communicating about it and making decisions involving the termination of life. Being terminally ill himself, he realizes that his familiarity with death has been pseudo-real: *"Death, so familiar to me in my work, was now paying a personal visit. Here we were, finally face-to-face, and yet nothing about it seemed recognizable"* (Kalanithi 2016: 121).

The experience of illness is individual, existential and lonely. The self is threatened by bodily extinction in ways that are hard to describe and share, and possibly even harder to perceive and understand for the other. *"Recognition is about knowing, but also about the limits of knowing and knowability, and about how self-perception is mediated by the other, and the perception of otherness by the self"* (Felski 2008: 49). Being bodily alone in experiencing illness can lead to a better understanding of what you are: *"The central question that symptoms can open is, Who are you?"* (Frank 1995:140). Kalanithi answers this question by claiming to be not a husband, son or future father, but a neurosurgeon. As he turns ill, his strong identity as a doctor remains. Even in part two, *"Cease Not till Death"*, which deals with the period between

diagnosis and death, professional ambitions prevail. This chapter continues to use the title phrase of the first chapter "In perfect health I begin", a quotation from the first section of Walt Whitman's famous poem "Song of Myself" (1855).

*"My tongue, every atom of my blood, form'd from this soil, this air,
Born here of parents born here from parents the same, and their parents the same,
I, now thirty-seven years old in perfect health begin,
Hoping to cease not till death."*

Turning to Whitman may have seemed obvious, knowing that Kalanithi wrote his MA in English literature at Stanford on the American poet. There is also a tragic irony that the lyrical voice is that of a man of the same age as Kalanithi when he is writing his book. However, the intertextual usage is primarily a way of bringing forth the aspect of recognition. It is present not only as a literary element but also as an existential means of expression, due to the presence of similar feelings across historical times. Kalanithi not only addresses his contemporary readers on today's issues but makes a point about how illness and death are recognizable despite different times, places and identities.

Knowledge

Knowledge is a theme touched upon in most pathographies, and Paul Kalanithi writes several times about his hunger for knowing how much time he has left. As a doctor, he was reluctant to be specific, e.g. informing someone that she had six months left. As a patient, he craves this information. His doctor, however, will not communicate about statistics and probability. After reflection, Kalanithi concludes that the distinction is between medical knowledge and existential hope:

"The reason doctors don't give patients specific prognoses is not merely because they cannot. [...] What patients see is not scientific knowledge that doctors hide but existential authenticity each person must find on her own. Getting too deeply into statistics is like trying to quench a thirst with salty water. The angst of facing mortality has no remedy in probability" (Kalanithi 2016: 134).

Here, Kalanithi takes the perspective of the doctor, yet using a metaphorical, non-medical language. This double perspective is intriguing. David Morris writes in

Eros and Illness (2017) about how modern medicine is driven by logos instead of *medical eros*, a term coined by Morris himself, which “[...] operates in a realm given over to uncertainty, fluidity, and profound lack of knowledge [...]” (Morris 2017: 8). Morris reflects on how medicine leaves little space for what he calls the “not-knowable”, which, however, is a major part of medicine despite its preference for facts, randomized trials and objective observations. Paul Kalanithi is mentioned as an example of an author, doctor *and* patient who assigns the normally entangled different points of view to the different roles: “He writes with deep respect for the science-based biomedical knowledge basic to his profession, but he understands too the limits of such knowledge and the importance of human affiliations that extend beyond the natural histories of disease” (Morris 2017: 84). The attention and valuing given to human connection given by Kalanithi is complex; on the one hand, he reflects upon it in a sophisticated manner, yet the part his family and friends take in his story is clearly minor to that of his profession. Maybe Kalanithi’s Indian background, his ambitious parents and elitist education influenced his autobiographical choices. More commonly, pathographies emphasise family and friends and the role they play during illness.

Reading literature may be a method or manner of reflecting an extra-textual reality. The notion of mimesis, meaning to imitate reality, plays on the connection between the outer world and the world of fiction. Fiction is considered authentic and truthful. However, the notion of truth, according to Felski, may be problematic in connection with fiction: “An entire cluster of terms – knowledge, reference, truth, mimesis – vanished from the higher altitudes of literary theory” (Felski 2008: 81). In contemporary fiction, the claim to truth is not necessarily that of the majority or of the mirrored reality, but rather the subjective inner truth of the individual. The subjective rendering of personal experience of illness compared to the medical description of bodily transformations is precisely the contribution of pathographies to new ways of rendering illness. Truth may also be acknowledged in glimpses, giving the individual and art as a medium a privileged position in gaining this particular knowledge: “Epiphany emerges as a signature mode of modernist aesthetics; the work of art discloses, makes manifest, forces into consciousness, what is otherwise inaccessible to thought” (Felski 2008: 79). Many pathographies render this kind of epiphanic experience and the genre is often characterized as bringing particular wisdom to its readers: “Illness narratives provide a way of knowing what really matters” (Leimumäki 2012: 265). Kalanithi, however, explicitly challenges the myth that illness brings knowledge and certainty to the sick individual. Instead, he finds that being ill gives way to uncertainty, primarily concerning the time aspect: “Grand il-

nesses are supposed to be life-clarifying. 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" (Kalanithi: 161).

Instead of clarity, stability and constancy, values and opinions are in constant motion. The lack of knowledge in Kalanithi's biography is a trait it shares with many recent patient stories. It stresses the importance of the individual and of acknowledging that truth is not necessarily only a biomedical fact but also a vague or subjective phenomenological experience of what it feels like to be ill. Moreover, it shows how pathographies, being autobiographical yet using literary devices form a genre suitable for portraying not only the biomedical facts of illness but, more importantly, the subjective experiences of being a patient.

Enchantment

"Enchantment is characterized by a state of intense involvement, a sense of being so entirely caught up in an aesthetic object that nothing else seems to matter" (Felski 2008: 54). This is seemingly the opposite of the widespread new critical understanding of close reading, which calls for distance and neutrality. However, Felski's aim as such is to supplement the theoretical, skilled understanding of reading by a more pragmatical approach recognizable to the lay reader. She refers to the critic and queer theorist Joseph Boone in addressing close reading as an act that includes involvement with the other:

"For Boone, close reading is about intoxication rather than detachment, rupture rather than disinterestedness. [...] Through the act of reading, he writes, we can experience a condition of "absolute powerlessness, enacting the intense human desire to let go – to be released, to yield to an 'other'" " (Felski 2008: 51).

This manner of reading is crucial when dealing with patient stories; close reading takes place at the same time as involvement as a human being. While close reading often distances readers' emotions, patient stories call for an intense affective and emotional interest with the work of art. Patient stories stand out as realistic texts not fleeing reality but rather brutally confronting lived experience. Felski writes: *"Modern enchantments are those in which we are immersed but not submerged, bewitched but not beguiled, suspensions of disbelief that do not lose sight of the fictiveness of those fictions that enthrall us" (Felski 2008: 75).* The strong pathos of the patho-

graphy genre particularly calls for such a subdued reading. Felski's distinction between old and modern enchantment may, therefore, be particularly relevant to patient stories, aiming for involvement but at the same time benefitting from some critical distance.

Enchantment is relevant to patient stories with regard to their use of other literary works or phrases. Using literary references means invoking other life stories based on aesthetic foundations. Intertextuality as a literary device manifests itself in a variety of forms, including allusion, quotation and references. In Kalanithi's text, the use is explicit and mostly expressed in quotes and epigraphs and we have already mentioned the frequent Walt Whitman allusions. There are, however, several other examples of intertextuality, where he discusses literary works or alludes to literary references. Examples are the mention of T. S. Eliot's "The Waste Land" (31) and some name-dropping, such as Nabokov, Conrad and Sir Thomas Browne's *Religio Medici* (53), Nuland's *How we Die* (52) and biblical references (164). As his condition gets worse, Kalanithi increasingly turns to literature looking for a language in which to formulate his troubled feelings: "*Lost in a featureless wasteland of my own mortality, and finding no traction in the realms of scientific studies, intracellular molecular pathways, and endless curves of survival statistics, I began reading literature again*" (148). "*And so it was literature that brought me back to life during this time*" (149). He remembers Samuel Beckett's play "The Unnamable" (1954) and the famous end-phrase: "*I can't go on. I'll go on*", giving meaning and courage to Kalanithi's hopeless situation. It is not so much literature as enchantment as a way of formulating an extra-realistic experience in which there are no words. By means of the writing process, Kalanithi experiences a certain kind of existential hope: "*Hoping is the enemy of fixity. It introduces a fluidity and even a playfulness in our construction of the world*" (Toombs et al 1995: 48).

Paul Kalanithi's use of literature, literary references and allusions does not have an enchanting effect on the reader. Enchantment involves seeing reality through a veil of wondrousness. Pathographies like *When Breath Becomes Air* are about unveiling reality, bringing forth the brutality of being human. In doing so, the book creates a shock effect for the reader. The associations with beauty and escapism that enchantment may entail are not present when reading Kalanithi's text. The story he presents is instead shocking: "*Shock thus marks the antithesis of the blissful enfolding and voluptuous pleasure that we associate with enchantment*" (Felski 2008: 113).

Shock

“Shock, then, names a reaction that is startling, painful, even horrifying” (Felski 2008: 105). *“...like a slap in the face, an exhilarating assault, equal part intellectual and visceral”* (Ibid: 106). *“...the standard supports and consolations of everyday life are ruthlessly ripped away”* (Ibid: 107). Felski’s definitions of shock in literature could equally have been describing human reactions to the sudden onset of serious illness in loved ones or oneself. Becoming seriously ill is always a shock. No one, no matter what age or gender or physical condition, expects to become critically ill: *“Few people expect to enter what I have called ‘deep illness’, conditions that afford the person little perceived prospect of ever again living a life without some sickness or disability”* (Frank: 2000, 135).

The basis of shock is suddenness: *“Hence a common mode of beginning such books is to represent a kind of tumbling into events – the sudden phone call, the momentous X-ray, the revelation that all is not as it had to be, the breaking into one life of a calamity from another”* (Wiltshire 2000: 414). *When Breath Becomes Air* opens exactly in this manner, with a scene in which Kalanithi and his wife Lucy look at the scans which will turn his life upside down:

“Lying next to Lucy in the hospital bed, both of us crying, the CT scan images still glowing on the computer screen, that identity as a physician - my identity - no longer mattered. With the cancer having invaded multiple organ systems, the diagnosis was clear” (Kalanithi: 2016, 120).

Despite the controlled and calm narrating mode, called a pause in narratology, this is the climax of the story, the turning point in both his and Lucy’s lives. The shock of a fatal diagnosis is followed by several shocking moments, such as the sudden onset of diarrhoea and vomiting on graduation day and suffering from symptoms of multi-organ failure. The shocking moments are mostly rendered in a scenic manner using a calm mode. It is as the perspective of Kalanithi as a physician, his true identity as stated above, still controls his more private and devastated feelings. *“Shock pivots around the quality of what Karl Heinz Bohrer calls ‘suddenness’, a violent rupture of continuity and coherence, as time is definitively and dramatically rent asunder into a ‘before’ and ‘after’”* (Felski 2008: 113). Describing and reflecting on the “before” and “after” are important hallmarks of pathographies, as are attempts at re-ordering chaotic feelings and restoring a sense of coherence. However, the feeling of shock, grief and bereavement in *When Breath Becomes Air*

is less prevalent than the feeling of hard work as an ambitious neurosurgeon. Giving way to thinking about not live to see his child grow up, would presumably enhance the feelings of grief and bereavement. Keeping up with work, however, is a way of maintaining the identity he once had, being well and staying in the present tense. Kalanithi refuses to let the suddenness take over his life, and keeps up his work as a way of melting past, present and future together. Although severely ill, he still manages to return to work, thereby maintaining his mundane life despite the frailty of his body. By doing this, Kalanithi demonstrates his strategy of coping with severe illness.

It may seem odd to mention mundane life as a resonance of shock. Shock normally interferes with daily life and is not present in mundane life. Everyday life is defined by Rita Felski in this way: *“After all, everyday life simply is, indisputably: the essential, taken-for-granted continuum of mundane activities that frames our forays into more esoteric or exotic worlds”* (Felski 2008: 77). Shock and everyday life are described as opposites for most people. Shock is connected to suddenness, whereas everyday life is connected to repetition. However, recent research questions whether chronic or terminal illness necessarily has to involve shock or rupture (Ellis 2013). Having experienced the initial feeling of shock at being told they are severely ill, some patients feel that going back to daily life is the best cure. For these patients, the focus is rather on everyday life and maintaining old routines and habits. Arthur Frank wrote about this state as one of four forms of facing illness, calling it *“illness as daily life”* (Frank 2010). The sociologist Julie Ellis writes about how people facing illness and death tend to hang on to daily routines: *“What it aims to show is that a sense of continuity, a belief in pragmatism and an immersion within mundane matters of the everyday were important to families facing life-threatening illness”* (Ellis 2013: 266).

Why do we read pathographies?

What are the reasons for the large interest these texts generate among readers? This is a broad question which we have discussed with reference to one particular text. We have touched upon how patient stories oscillate between enchantment and shock, between the harsh brutalities of illness and feelings of hope, dreams, escapism, looking back on better times and looking forward to being cured. Parts of Paul Kalanithi’s story are placed between these antipodal positions of dread

and hope, brutality of illness facts and romantic, enchanting glimpses of what life used to be like.

Paul Kalanithi's *When Breath Becomes Air* is in many respects a *Bildungsroman* telling the story of a young man's journey from glory to defeat in the shadow of severe illness. However, Kalanithi tears down some of the myths about illness leading to wisdom, insight, and closeness to family. He is not denying but confronting (Baena 2017: 7) or, as he says himself, he is reversing the Kubler-Ross stages of grief. The use of Rita Felski's four modes of reading literature has been relevant to Kalanithi's text in many respects, illustrating the pathography genre. While stressing the aspect of shock, he gives a true, yet uncomfortable version of what it is like to be terminally ill at the age of 36. He lived the dream but ended up in the nightmare we all want to avoid. The shock of illness does not lead him to greater insight, but to enhanced attention to life.

"As long as we find ourselves prone to evasion, euphemism, and denial, as long as we flinch away from reminders of our material and mortal existence as fragile composites of blood, bone and tissue, shock will continue to find a place in art" (Felski 2008: 130). The popularity of pathographies of various genres, however, indicates a broad interest in topics that do remind us of our mortality. Deep beneath the civilized and sugar-candied surface, we do have an awareness of being creatures of flesh and blood. Irrespective of gender, cultural background, ethnicity, age or social status, these texts render the experience of being human. Doctors are well represented in writing pathographies (Aronsen 2000), even though the majority is written by patients not having a professional medical perspective. Perhaps it is due to the imminent paradox of the ill doctor that these books, like Kalanithi's own, gain such popularity.

So why *do* we read pathographies? What Rita Felski claims as a general description of work of art could equally well have been a poignant description on the peculiarities of pathographies: *"Rather than serving up suffering at a distance, they allow us to witness it close up, magnified to the nth degree, sometimes in lurid and blood-spattered detail"* (Felski 2008: 114). This is true of many first-person accounts about illness, including *When Breath Becomes Air*. Paul Kalanithi becomes close to us. We align with his ambitions, hope for him to succeed, and are shocked by the brutality of his tragedy. This pathography bears the mark of a Greek tragedy, bearing resemblance to Icarus and the theme of hubris. Kalanithi is almost too successful until illness strikes him down. The central function that shock bears in pathographies stresses the resemblance between the genre and classical Aristotelian tragedy: the rendering of a tragic hero making a fatal mistake due to a tragic

flaw and thereby suffering an ill fate. A crucial part of classical tragedy is that the incidents are most often beyond the hero's control, a similarity it shares with pathographies. Ill health and serious diseases are in many cases purely the result of bad luck. Like the readers of Greek tragedies, we are perhaps not only shocked but also cleansed by the shock having had the effect of *catharsis*. The feeling of shock, so central to Kalanithi himself, is transported to us as readers, as are the feelings of recognition, knowledge and enchantment. *When Breath Becomes Air* arouses all these feelings in the reader as well as in the protagonist – on a most profound, existential level. The story of the patient is a genre in which an impressive multiplicity of reader-response is awakened and alarmed. This lays the ground for a strong feeling of empathy, close to identification, with the author-protagonist, which may be one of the reasons for the popularity of the pathography genre.

References

- Aronsen, J.K. (2000). Autopathography: the patient's tale. *British Medical Journal*, 1599-1602. <https://doi.org/10.1136/bmj.321.7276.1599>
- Baena, R. (2017). Narrative empathy and illness memoirs: Arthur Frank's *At the Will of the Body* and Kathlyn Conway's *Ordinary Life*. *Medical Humanities*, 43(3), p.177. <https://doi.org/10.1136/medhum-2016-011052>
- Bernhardsson, K. (2010). *Litterära besvär. Skildringar av sjukdom i samtida svensk prosa* [Literary problems. Descriptions of disease in contemporary Swedish prose]. Stockholm: Ellerström.
- Du, H. & Wagner, C. (2006) Weblog success: Exploring the role of technology. *International Journal of Human - Computer Studies*, 64(9), 789-798. <https://doi.org/10.1016/j.ijhcs.2006.04.002>
- Ellis, J. (2013). Thinking beyond rupture: continuity and relationality in everyday illness and dying experience. *Mortality*, pp.1-19. <https://doi.org/10.1080/13576275.2013.819490>
- Ezzy, D. (2000). Illness narratives: time, hope and HIV. *Social Science & Medicine*, 50(5), pp.605-617. [https://doi.org/10.1016/S0277-9536\(99\)00306-8](https://doi.org/10.1016/S0277-9536(99)00306-8)
- Felski, R. (2000). *Doing time: feminist theory and postmodern culture*, New York: New York University Press.
- Felski, R. (2008). *The Uses of Literature*. Blackwell Manifestos, Oxford, UK: Blackwell Publishing Ltd. <https://doi.org/10.1002/9781444302790>
- Frank, A.W. (2000) Illness and Autobiographical Work: Dialogue as Narrative Destabilization. *Qualitative Sociology*, 23(1), pp. 135-156. <https://doi.org/10.1023/A:1005411818318>
- Frank, A.W. (2010). *Letting stories breathe: a socio-narratology*, Chicago, Ill: University of Chicago Press. <https://doi.org/10.7208/chicago/9780226260143.001.0001>
- Frank, A.W. (2013). *The wounded storyteller: body, illness, and ethics* 2nd ed., Chicago, Ill: University of Chicago Press.

- Gamerman E. (2016). A Book on Life and Death Becomes a Best Seller. *The Wall Street Journal*, 19 Dec. <https://www.wsj.com/articles/a-book-on-life-and-death-becomes-a-best-seller-1482167354> Retrieved 18 Nov 2018.
- Hawkins, A.H. (1999). *Reconstructing illness. Studies in pathography* 2nd ed., West Lafayette, Ind: Purdue University Press.
- Guardian, The (2016). »Lucy Kalanithi: 'Paul's view was that life wasn't about avoiding suffering'«. Interview by Lisa O'Kelly. Read 25 June 2018.
- Horst, C. auf der (2004) »Historisch-kritische Pathographien und Historizität: Eine Kritische Auswertung der Heine-Pathographien am Beispiel Der Syphilisdiagnosen Heinrich Heines.« *Sudhoffs Archiv. Zeitschrift Für Wissenschaftsgeschichte. Beihefte*, no. 54: 121-51. <https://www.irishtimes.com/culture/books/when-breath-becomes-air-review-a-neurosurgeon-s-story-of-terminal-illness-1.2933276>
- Kalanithi, P. & Verghese, A. (2016). *When Breath Becomes Air* 1st ed., London: Random House.
- Lekmumäki, A. (2012). What does falling ill mean? Illness experience as elucidation of experience expertise. In: Cohen, E. *Knowledge and pain*, Amsterdam: Rodopi. https://doi.org/10.1163/9789401208574_014
- Mattingly, C. (1994). The concept of therapeutic emplotment. *Social Science and Medicine*, 38, 811-822. [https://doi.org/10.1016/0277-9536\(94\)90153-8](https://doi.org/10.1016/0277-9536(94)90153-8)
[medscape.com/viewarticle/865258](https://pubmed.ncbi.nlm.nih.gov/10160277/)
- Morris, D.B. (2017). *Eros and illness*, Cambridge, MA and London, England: Harvard University Press.
[nytimes.com/2016/01/07/books/review-in-when-breath-becomes-air-dr-paul-kalanithi-confronts-an-early-death.html](https://www.nytimes.com/2016/01/07/books/review-in-when-breath-becomes-air-dr-paul-kalanithi-confronts-an-early-death.html)
- [sciencedirect.com/science/article/pii/S0140673616006656](https://www.sciencedirect.com/science/article/pii/S0140673616006656) (The Lancet)
- Sontag, S. (2002). *Illness as metaphor and Aids and its metaphors*, London: Penguin Books
[theguardian.com/books/2016/jan/31/when-breath-becomes-air-paul-kalanithi-review](https://www.theguardian.com/books/2016/jan/31/when-breath-becomes-air-paul-kalanithi-review)
[thelancet.com/journals/lancet/article/PIIS0140-6736\(16\)32470-9/abstract](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(16)32470-9/abstract)
- Tjora, A. & Sandaunet A.G. (2010). *Digitale pasienter*, Oslo: Gyldendal akademisk
- Tooms, K., Barnard, D. & Carson, A. (Eds) (1995). *Chronic illness: From experience to policy* (p. 221). Indiana University Press.
- Wiltshire, J. (2000). Biography, pathography, and the recovery of meaning. *Cambridge Quarterly*, 29(4), pp. 409-22. <https://doi.org/10.1093/camqtly/XXIX.4.409>