The Life and Death of Paul Kalanithi:
The Dilemma of Illness Identity in a Physician-Turned-Patient

by

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“Even if I’m dying, until I actually die, I am still living.”

Paul Kalanithi

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Abstract

After his diagnosis of stage IV lung cancer, Paul Kalanithi composed the memoir *When Breath Becomes Air*. Kalanithi's background as a student of literature allows for a well-crafted illness narrative in which he examines his life's journey and his experience with illness. As Kalanithi experiences illness from different perspectives, most notably as a physician and a patient, he offers a poignant look on how a terminal diagnosis can affect a person in every dimension of their life. In this thesis, I study how the many facets of Kalanithi's identity are affected by own his terminal diagnosis. This thesis uses Kalanithi's experience in *When Breath Becomes Air* to explore the role of narrative in medicine, the role of suffering in illness, and the relationship between illness and the sense of self. This thesis helps to address the relative lack of published scholarship on Kalanithi's memoir since its publication.

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Chapter One: Introduction

In May 2013, Paul Kalanithi was diagnosed with stage IV lung cancer. Kalanithi's diagnosis was cruelly-timed: the disease presented itself "after ten years of relentless training" (6), when he was a neurosurgical resident and a neuroscience postdoctoral fellow at Stanford University School of Medicine, with prestigious career opportunities awaiting. Disease, however, does not discriminate. Kalanithi, at only 36 years of age, bore the crushing weight of the prospect of losing the future he had worked so hard to achieve, the family he desired, and the ambitions he had nurtured. Despite everything he had to lose, there was much still to learn. Kalanithi recognized that he was in an opportune, albeit unfortunate, position to learn more about patient care as a patient himself. In discussing a physician's role in illness, Katherine Montgomery Hunter states, "Face to face with a patient, physicians can know disease only indirectly. They depend for its identification on their interpretation of the signs they observe and the story of symptoms the patient tells them" (xvii). In concordance, Kalanithi writes of his experience, "As a doctor you have a sense of what it's like to be sick, but until you've gone through it yourself, you don't really know" (140). His diagnosis was, undoubtedly, devastating. However, from tragedy, he creates beauty and crafts a narrative from which patients and health professionals alike can learn in the form of a memoir, *When Breath Becomes Air*. Kalanithi reminds readers that the person—not just the disease—is important and that medicine must consider both in equal measure.

The multiple dimensions of Kalanithi's identity as a patient, physician, literature student, and writer contribute to the strength of his memoir. In writing *When Breath Becomes Air*, Kalanithi explores illness and medicine and reflects on the patient-physician relationship. As his hopes for overcoming the cancer faded, Kalanithi's desire to share his

observations and self-reflection compelled him to write, savouring each breath until only air remained. His story ended with a final exhalation on March 9, 2015. *When Breath Becomes Air* was a *#1 New York Times* bestseller. It was named one of the best books of the year by *The Washington Post* and *The New York Times.* In 2017, it was a finalist for the Pulitzer Prize in the biography category. Kalanithi's memoir resonated.

The aim of my thesis is to use *When Breath Becomes Air* as a study of illness identity throughout the many stages of Kalanithi's journey, not only focusing on how his diagnosis affects his personal and his professional life, but also looking at how his profession in medicine affects how he conceives of his own illness. He is repeatedly forced to consider and plan for an uncertain future, whether it be focused on his next career steps or the expansion of his family with his wife, Lucy, despite his uncertain prospects. During some of the most trying moments of his life, Kalanithi invites readers to share in his experience of navigating a diagnosis of terminal cancer while completing his medical residency, strengthening his marriage, and welcoming a daughter into the world. With his diagnosis comes a transformation of identity, both personally and professionally. His identity as a husband, a friend, and a physician are not diminished, but his capabilities in these roles are changed due to the suffering and trauma of illness and treatment. While the cancer eats away at his future and devours his living cells, Kalanithi refuses to allow it to consume his day-to-day life, even though he cannot escape its constant presence.

When Breath Becomes Air is a unique illness narrative, in part because of Kalanithi's experience with literature. Kalanithi received Bachelor's and Master's degrees in English literature from Stanford University and even considered completing a Doctorate degree, although he ultimately decided to pursue medical school instead.

Kalanithi's interest and advanced study in English literature is significant to his understanding of illness, as well as to his consideration of identity. His familiarity with literature and knowledge of medicine help shape his thinking on mortality and his philosophy on what it means to be human. Throughout his illness and treatment, Kalanithi turns to literature—as both reader and writer—to better grasp the nuances of mortality that can get lost in the depths of medicine and patient care. To Kalanithi, "Literature not only illuminated another's experience, [but] it provided […] the richest material for moral reflection" (31). "Lost in a featureless wasteland of [his] own mortality," Kalanithi temporarily withdraws from medicine and instead begins to read "anything by anyone who had ever written about mortality" (148). When medicine begins to fail him in his final months, he looks to literature for comfort and finds peace by sharing his love of literature with his baby daughter, Cady. Lucy, who writes the epilogue of *When Breath Becomes Air*, recalls how "Paul would hold Cady in his writing chair, reading aloud works by Robert Frost, T. S. Eliot, [and] Wittgenstein" (218), connecting literature from the past to shape the mind of his daughter—his only link to the future.

Further than simply exploring existing literature, Kalanithi contributes his own narrative in memoir form. In the epilogue, Lucy briefly examines her husband's relationship with literature during his last days, emphasizing the importance that this memoir held to him: "Paul was proud of this book, which was a culmination of his love for literature—he once said that he found poetry more comforting than Scripture—and his ability to forge from his life a cogent, powerful tale of living with death" (220-21). She believes that Kalanithi's composition of this book was "an act that allowed him to live with hope, with that delicate alchemy of agency and opportunity that he writes about so eloquently, until the very end" (221). By structuring a narrative based on his experience

with both literature and medicine, Kalanithi is able to find purpose in illness and meaning in life.

Kalanithi's familiarity with literature and knowledge of medicine provides him with an easier path into "narrative medicine," a phrase coined by Rita Charon that I explore later. Kalanithi's medical training helps him articulate his experience, but not necessarily deal with his own illness. He writes, "As a doctor, I had 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?" (147). Kalanithi approaches illness and death with incredible strength and courage. Although his experience is uniquely singular, as it is with every patient, it still shares common threads of fear, pain, and hope with which many readers can identify. It is Kalanithi's honest telling, profound understanding, and empathetic nature that makes *When Breath Becomes Air* so moving to read and so important to study.

In the second chapter of my thesis, I provide a theoretical framework regarding illness identity and identity theory, drawing on theory by many different authors, most notably Charon, Anne Hunsaker Hawkins, and Arthur Kleinman. I also draw on the larger body of theoretical work on illness narratives, which contributes to my analysis by providing an operative understanding of the nature of illness narratives. As Kleinman writes, each narrative is an interpretation of illness that "[edifies] us about how life problems are created, controlled, made meaningful" (xiii). Illness itself undeniably becomes "a context or frame within which the remainder of [a] person's life can be evaluated and approached" (Radley 110). Kalanithi frames his experience with life and death in *When Breath Becomes Air* by repeatedly considering how his illness affects his

identity: is he a patient? Is he still a physician? Can he be both? If so, how? I study the relationship between illness and the sense of self using theories of illness identity. The larger role of narrative in medicine is also considered, particularly in discussion of how this narrative can provide for a process of discovery. I analyze Kalanithi's contemplation and experience, giving particular attention to the shifting balance of power between his identity as a patient and his identity as a physician.

In the third chapter, I address Kalanithi's understanding of suffering as both a patient and a physician. "Illness narratives explore the existential meaning of illness and the suffering of the patient" (Pierce 26), and Kalanithi furthers these key concepts by exploring the existential meaning of mortality, regardless of illness. Since the trauma resulting from his diagnosis is multifaceted, the dimension of suffering Kalanithi experiences strongly correlates with the idea of suffering explored in Eric J. Cassell's discussion of the multiple aspects of personhood. Cassell writes that "suffering can occur in relation to any aspect of the person, whether it is in the realm of social roles, group identification, the relation with self, body, or family, or the relation with a transpersonal, transcendent source of meaning" (640). This chapter specifically focuses on how illness changes Kalanithi, not only as a physician and a patient, but also as a husband, a father, and a friend. Illness narratives by Anatole Broyard and Arthur Frank are examined alongside Kalanithi's for comparison, particularly in relation to the way different origins of suffering affect a patient.

In the fourth chapter, I evaluate Kalanithi's identity change through each stage of his diagnosis and treatment. As the memoir progresses, Kalanithi transitions from identifying himself as a physician with cancer to identifying himself as a cancer patient, a physician, and increasingly a writer. Incrementally, Kalanithi is rendered powerless as a

physician. The crisis of his identity, however, remains, not only because of his inability to continue his work in the medical field, but also due to the fact that an "ill person [loses his] sense of physical identity. The body that was formerly an instrument of [his] will is now an object of concern" (Pierce 4). The body, however, has long been more than just an instrument of Kalanithi's will; it is the subject of his calling. This chapter examines Kalanithi's role as a patient by considering the change in patient values and identity, as well as the patient-physician relationship between Kalanithi and his oncologist during his treatment. Throughout the transition, the primacy of all he wanted to be reluctantly yields to the inevitability of what he has become.

When Breath Becomes Air is tragic, inspiring, and important, not only for physicians and patients, but for all readers. Kalanithi offers an honest perspective on the human experience of illness and suffering. Throughout the thesis, I use Kalanithi's perspective in *When Breath Becomes Air* to explore how illness affects him medically, professionally, socially, and psychologically. In analyzing this memoir, I aim to establish a better understanding of illness identity and to demonstrate the importance of empathy within the patient-physician relationship. Furthermore, it is important to note the lack of critical examination of this text by literary critics, given that it is such a widely celebrated book. Kalanithi's memoir provides a rich demonstration of how literature and medicine interact; analyzing the text from a literary perspective, the discussion that follows points to the many ways Kalanithi's writing makes a significant contribution to the memoir subgenre of illness narratives, specifically through its discussion of illness identity.

Chapter Two: Illness, Self, and Identity

When a healthy person is stricken with a chronic or serious illness, their former identity can suddenly become less concrete and more complicated and uncertain. Illness, its treatments, and its symptoms can affect patients by influencing their perspective on themselves and their abilities. Illness can also have long-lasting or permanent consequences, both physical and mental, for the patient, their caregivers, and their supporters, especially in cases of chronic illnesses and terminal diagnoses. Michael P. Kelly and Louise M. Millward state that "in chronic illness, self and identity gain salience" (9); illness thus forces new aspects of being on a patient, which can cause dramatic changes in how the ill conceive of themselves. Whether or not the patient realizes it, a diagnosis typically creates the formation of an illness identity, which becomes simply one of many facets to an individual's sense of self. As Kelly and Millward write, "The relationship between illness and identity is not uni-linear" (15). Rather, illness identities are "malleable and constant" in nature because "the relationship between illness and identity… relates to biological, social and physical worlds" (15). At any time during a patient's illness and treatment, their sense of identity through illness can shift: "illness identities are constant features of biological, social and physical modes of being" (15), so the identity can develop as a patient's experience with illness progresses.

In *When Breath Becomes Air*, Kalanithi presents his experience with illness identity and his evolving understanding of self by demonstrating how illness identity interacts with the other dimensions of his identity and self. At times, Kalanithi struggles to define his identity based on his professional and personal circumstances in relation to medicine. In fact, Kalanithi questions his identity the moment his cancer is confirmed:

"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" (119). While attempting to reconcile his familiar physician persona with a newly-realized patient self, Kalanithi seemingly reformulates his identity throughout his memoir. He writes, "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" (139). Kalanithi better understands the complexities of illness identity towards the end of his journey with illness, once he acknowledges that his current identity must consist of a compromise between his past and his future.

Until he becomes a patient himself, Kalanithi's experience with medicine is one-dimensional. As a physician, he understood the importance of respecting and empathizing with patients. However, he still had moments where he "feared [he] was on the way to becoming Tolstoy's stereotype of a doctor, preoccupied with empty formalism, focused on the rote treatment of disease—and utterly missing the larger human significance" (85). As Anne Hunsaker Hawkins writes, "Medicine today has been criticized for its narrow focus on disease and its disregard for the experiencing patient" (11-12). Throughout his career, Kalanithi works between this separation of medicine-focused care and patient-centric care. Upon becoming the patient himself, Kalanithi's strengths as a physician—and later as a writer—balance out his illness-induced vulnerabilities, and vice versa. A physician's role is to facilitate healing and practice medicine, but Kalanithi notes how important it is to remember the patient is "a person, instead of a problem to be solved" (90).

As a physician, Kalanithi is able to understand the importance of empathy, and as a patient, Kalanithi is fortunate to have such profound experience in medicine. However, few patients are in this position of knowledge that allows them to so fundamentally understand their illness, and not all physicians will be unlucky enough to experience the illnesses they treat. Consequently, there is often a deep imbalance in the patient-physician relationship and, further, a strong possibility for miscommunication. Experiencing illness as a patient does not stimulate the patient into becoming naturally competent in interpreting and translating the dimensions of illness. Likewise, physicians are trained to recognize and articulate the development of illness, but they are not always able to truly understand the effects of illness and treatment on their patients. Charon further clarifies the difficulty of understanding and elucidating illness as a patient without training: "If disease is structured like a language, one needs an ear for its inflections to decode its signs, and one needs fluency with which to transmit and receive messages among its native speakers" ("Literary Concepts" 30). In Kalanithi's case, he becomes a better physician for having experienced illness first-hand and a better patient for understanding the nuances of medicine. However, the actualization of this balance comes gradually, as Kalanithi must work through accepting his new illness identity in order to utilize it.

For Kalanithi, the composition of his illness narrative helps him adjust and recalibrate his sense of self. By structuring a narrative, he gives purpose to his illness. However, coming to terms with a new illness identity is not a simple deed for any patient, especially those with a chronic or terminal diagnosis; it is easy to get lost in the labyrinth of illness and lose one's sense of self. This is especially true in cases where it seems that medicine is practiced on the illness rather than the patient. Thomas G. Couser believes, "One source of illness narratives is patients' sense that the language and practice of

traditional medicine translate their concerns into somewhat alien terms and detach the body from its life context" (286). To each patient, an illness, its symptoms, and its required treatment differ, so when an illness is categorized and then separated from the patient, absolute healing cannot occur. It is incorrect, then, to assume that it is a physician's responsibility to simply treat an illness; instead, it is a physician's responsibility to treat a patient. An illness is powerless without a patient, and so the patient must be treated alongside the illness. By "[detaching] the body from its life context," as Couser says, an individual's life story is minimized as they become a patient.

Further, the individual's identity as a patient is devalued when the illness and treatment are prioritized above the patient. Kleinman writes, "Physicians are encouraged to believe that *disease* is more important than *illness*, and that all they need is knowledge about biology, not knowledge about the psychosocial and cultural aspects of illness" (254-55). Diagnosing and treating illness without recognizing the suffering endured by a patient—whether physically, mentally, or emotionally—is a failure of medicine. "Sick people," as Charon argues, "need physicians who can understand their diseases, treat their medical problems, and accompany them through their illness," rather than simply providing a treatment and leaving the patient—and their caregivers—to come to terms with a new illness story in their lives alone ("A Model for Empathy" 1897). Charon writes that "physicians sometimes lack the capacities to recognize the plights of their patients, to extend empathy toward those who suffer, and to join honestly and courageously with patients in their illnesses" (1897). Kalanithi underscores this lapse in judgement from his perspective as a physician, prior to his illness. He admits to "occasions of failed empathy," such as when he "pushed discharge over patient worries" or "ignored patients' pain when other demands pressed" (85). Kalanithi makes it clear

that he values medicine as more than simply treatment of an illness, but the demands of his high-stress job take their toll: "Amid the tragedies and failures, I feared I was losing sight of the singular importance of human relationships, not between patients and their families but between doctor and patient" (86). Even Kalanithi, who consistently outlines his sincere desire to understand the meaning of life, is prone to failure by not demonstrating empathy; however, he recognizes these shortcomings and "swore to do better," as his "highest ideal was not saving lives—everyone dies eventually—but guiding a patient or family to an understanding of death or illness" (86). Kalanithi wishes for patients to be treated as human, with empathy, patience, and respect, rather than simply being defined by their illness.

It is through this distinction between patient and illness that the patient begins to separate how they conceive of themselves from their outward identity. Immediately after diagnosis, for example, Kalanithi is seen as both a patient and a physician by his oncologist, yet he himself admits that "[his] body, and the identity tied to it, had radically changed" (124-25). In studying identity and illness, Kelly and Millward separate identity from the self, wherein identity represents a person's public persona and the self remains private:

> The experience of illness, especially chronic illness, tends to exert a force that separates self and identity empirically as well as analytically… In understanding the tension between self and identity we are able to get a view of the experience of illness which captures the finer nuances of that experience and which helps to reveal the elemental nature of the biological, social and physical modes of suffering and say something quite profound about the very nature of human existence itself. (15)

The separation of one's publicly presented identity and their privately acknowledged self can exert an added psychological and even physiological toll on the patient as they struggle to cope with their twin realities and prevent their new patient identity from usurping their former self. "Narratives of chronic illness [present] particular and probably permanent challenges to identity" (Blaxter 170), so it is plausible that there could be a division between a patient's experience and how they choose to publicly portray their experience. Yet the patient of an illness narrative is able to work through the separation between identity and self by dissecting their illness experience and new identity. As Couser adds, an illness narrative provides the patient with an opportunity to "[reclaim] one's story" and "[re-site] one's illness in the context of one's whole life" (286). Illness, then, becomes simply a part of a structured life story.

Illness narratives are also important in demonstrating how illness affects a patient's identity. Mildred Blaxter states that "identity is shown as a grid through which health and illness are perceived and given meaning, and in turn health and illness construct identity" (170). Of course, identity is tied to more than just physical being; however, as Kelly and Millward argue, "the physicality of the body is important for self and identity because it is inextricably associated with self and with identity" (9). An individual's identity is constructed in part by their physical abilities, and so "where there are chronic alterations in the aesthetics and/or functions of the body, the self that is configured upon that body must also change" (9). Therefore, as Kathy Charmaz concludes, "Serious chronic illness undermines the unity between body and self and forces identity changes" (657).

For Kalanithi, his serious diagnosis complicates an already complex identity. His role as a patient affects every aspect of his life, and it is a new dimension of identity over

which he has no control. He writes, "As a doctor, I was an agent, a cause; as a patient, I was merely something to which things happened" (141-42). Suddenly, he is faced with an inability to put into practice his desire to save the life of his patient: himself. Instead, he tries to have his "doctor-self [remain] responsible for [his] patient-self" (183). He states, "I hadn't ever considered that I could release myself from the responsibility of my own medical care" (182). Much of Kalanithi's text is thus focused on how he navigates this tenuous line between patient and physician: sometimes he separates them from one another; at other times, he simply can't.

Capturing his struggle with illness and mortality, Kalanithi epitomizes Charon's concept of narrative medicine. Charon defines narrative medicine as "medicine practiced with the narrative competence to recognize, absorb, interpret, and be moved by the stories of illness" ("Honoring the Stories" vii). It "provides the means to understand the personal connections between patient and physician" and "enables the physician to practice medicine with empathy, reflection, professionalism, and trustworthiness" ("A Model for Empathy" 1899; 1897). By sharing this introspective narrative, "both physicians and patients can achieve more accurate understanding of all the sequelae of illness, equipping them to better weather its tides" (1899). Kalanithi's application of narrative medicine is unusual: since he plays the role of both physician and patient, he is able to explore two key facets of narrative medicine simultaneously. In the midst of illness, he returns to literature once again to seek a better understanding of life and mortality, writing, "[I found] no traction in the reams of scientific studies, intracellular molecular pathways, and endless curves of survival statistics" (148). Instead, "it was literature that brought [him] back to life during this time" (149), as his knowledge of great literature and his craft as a writer drew him out of "the monolithic uncertainty of [his] future" (149). He writes, "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 led 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" (148-49).

Crafting a memoir is "a pivotal event in the life of its writer" (Charon "Honouring the Stories" 70). Kalanithi states, "Death may be a one-time event, but living with terminal illness is a process" (161). The composition of his memoir is in itself an act of empathy and reflection. It is also an act of acceptance. Charon goes on to say that a patient's decision to narrate their story may allow for a personal cathartic awakening:

> Any time a person writes about himself or herself, a space is created between the person doing the writing and the person doing the living, even though, of course, these two people are identical. Called the "autobiographical gap," this space between the narrator-who-writes and the protagonist-who-acts confers the very powerful distance of reflection, without which no one can consider his or her own actions, thoughts, or life. Within this reflective space, one beholds and considers the self in a heightened way, revealing fresh knowledge about its coherent existence. ("Honoring the Stories" 70)

Structuring an experience of illness into a coherent narrative allows for a more comprehensive understanding of illness and its personal effects. Although Kalanithi states that he "hadn't expected the prospect of facing [his] own mortality to be so disorienting, so dislocating" (148), he records his emotional journey very pragmatically. The narrative isn't chronologically ordered, but it is linear in terms of how Kalanithi conceives of his diagnosis and mortality. He asks questions concerning life's purpose and the nature of

morality; if he doesn't answer them, he at least attempts to work through them. This "examination" of illness and identity through medical and philosophical terms, writes Charon, "is simultaneously a demonstration: it is in the very acts of discoursing about identity that [one identifies] themselves" ("Honoring the Stories" 69).

Besides that of a physician and a patient, there is another aspect of Kalanithi's own identity that is featured in the memoir. As Franklin G. Miller points out, "What [Kalanithi] doesn't write about, but displays in his book, is his new identity as a writer" (585). Although he doesn't explicitly acknowledge this new identity as a writer, as Miller says, Kalanithi does seem to move towards an awareness of this new identity and makes a decision to focus on it, as a return to health no longer seemed likely. Kalanithi's literary education played a diminished role in his life during medical residency—that is, until he was diagnosed with cancer. Kalanithi's "relationship with statistics changed as soon as [he] became one" (135). Suddenly in the role of a patient, Kalanithi found himself unable to find peace and understanding within the bounds of medicine: "While being trained as a physician and scientist had helped me process the data and accept the limits of what that data could reveal about my prognosis, it didn't help me as a patient" (139). Data that previously represented hypothetical patients now represented the reality of medicine, and in that reality, Kalanithi struggles to reconcile the effect of illness and the meaning beyond mortality. His turn to literature signified a change in Kalanithi's values and offers meaning to the data beyond the scientific. Therefore, not only does illness create a dimension of patient identity in Kalanithi, but it also called him back to literature, and so another dimension of identity is created in crafting his narrative. This discussion of identity as shaped by illness is a significant element in Kalanithi's dialogue on mortality, purpose, and the meaning of life. The multiple aspects of his identity as a physician,

patient, student of literature, and writer each plays a role in how Kalanithi conceives of himself in the final years of his life. Further, his profound passion for literature is evidenced by his frequent literary allusions, as well as in his polished, poetic style.

Structuring and composing a narrative worth sharing is not a simple achievement, although Kalanithi makes it seem effortless. As Charon writes, "Narrative competence […] is not a trivial goal. Although everyone grows up listening to and telling stories, sophisticated knowledge of how stories work is not attained without considerable effort and commitment" ("Honoring the Stories" ix). Kalanithi's advanced degree in English allows for a refined, nuanced writing style not always found in illness narratives. As well, Kalanithi demonstrates a deep understanding and profound connection with literature with numerous allusions throughout the text, allusions meant to help himself and the reader work through his diagnosis. He thinks of T. S. Eliot's "The Waste Land" when considering "meaninglessness and isolation, and the desperate quest for human connection" (31). He places import on Nabokov for "his awareness of how our suffering can make us callous to the obvious suffering of another" (31). He considers how Conrad demonstrates "a hypertuned sense of how miscommunication between people can so profoundly impact their lives" (31). Although he chooses to focus his career in medicine and neuroscience, Kalanithi returns to literature when he is weak with illness and "lost in a featureless wasteland of [his] own mortality" (148). He credits literature for "[bringing him] back to life during this time," when "the monolithic uncertainty of [his] future was deadening" (149). When he is "in pain" and "no project beyond breakfast seems tenable," Kalanithi calls on Samuel Beckett's *Waiting for Godot*, repeating to himself, "I can't go on. I'll go on" (149). And he does. Kalanithi's training in literary studies constitutes a significant part of his identity, and in illness, he returns to his passion for literature to help

him better understand and manage his diagnosis. His new identity as a patient and his old identity as a literary scholar allow Kalanithi to become a writer. His ability to articulate his experiences with life, love, literature, medicine, and sickness allows him to create an illness narrative that demonstrates an attempt to balance his different identities and find acceptance in his fate.

Kalanithi's return to literature reflects his method of understanding his situation and coming to terms with all of the possible outcomes of his disease. By sharing his experience, he enlightens readers to the depths of illness and suffering. Kleinman writes that "the study of the experience of illness has something fundamental to teach each of us about the human condition, with its universal suffering and death" (xiii). In a discussion of the function of illness narratives, Kleinman underscores that there is a "difference between the patient's experience of illness and the doctor's attention to disease" (xii). Even Kalanithi admits "How little do doctors understand the hells through which we put patients" (102). Regardless of the narrator's relation to medicine, illness narratives in general offer an understanding of the illness experience to readers. Hunsaker Hawkins more specifically identifies the illness narrative as a type of pathography, that is, "a form of autobiography or biography that describes personal experiences of illness, treatment, and sometimes death" (1). The narrator is attributed "a specific kind of authority" due to their relation to illness: "Because he or she has undergone a serious ordeal and has been confronted with possible death, these texts provide evidence for some kind of survival, be it only in the form of the text" (Gygax 291-92). The possibility of death due to illness "stimulates writers to attempt transgressions towards a theoretical exploration of this very experience" (292).

Illness narratives not only enlighten both writer and reader, but they can also comfort. As Arthur Frank puts it, "Ill persons need others to share in recognizing with them the frailty of the human body. When others join the ill person in this recognition, courage and cheer may be the result […] as a spontaneous expression of common emotion" (71). Critical illness unwittingly forms a community among people that have a shared experience. While every patient's journey with illness is different, commonalities can be found simply in the experience of being ill. Illness narratives can connect patients, physicians, and caregivers by providing exemplars of how others have dealt with illness. As Frank states, "Ill persons can hold out these examples of illness experience to families, friends, and medical staff as proof of all there is to talk about. Talk is not the only way to elevate illness beyond pain and loss, but for most people it may be the most reliable way" (5).

While illness narratives play an important role in creating community, Hunsaker Hawkins notes that they also "have a significant part to play in the movement towards a patient-centred medicine" (xii), and *When Breath Becomes Air* is no exception. The memoir portrays patient-centred medicine from both sides of the stethoscope: not only is Kalanithi caught up in his own illness, but his approach to medicine as a physician also happens to be one of empathy and kindness towards his patients. The act of expressing one's acceptance of their illness identity allows for a genuine and striking exploration of patient care and illness experience. Hunsaker Hawkins believes illness narratives "concern the attempts of individuals to orient themselves in the world of sickness […] to achieve a new balance between self and reality, to arrive at an objective relationship both to experience and to the experiencing self" (2). She also notes that "narrative form alters experience": by structuring illness experience into a narrative, a patient "[gives] it a

definite shape, [organizes] events into a beginning, a middle, and an end, and [adds] drama—heightening feelings and seeing the individuals involved as characters in a therapeutic plot" (15). This structured story of illness can be therapeutic not only for the writer, whether patient or caregiver, but also for the reader. It can "[provide] a kind of vicarious support group, offering some guidance in the bewildering and often frightening terrain of serious illness" (xi). Kalanithi's illness narrative offers understanding and empathy; it provokes sympathy and compassion; it creates community and connection; and it presents a measured acceptance of illness as an inescapable—but manageable—part of life.

Chapter Three: The Role of Suffering

Chronic or terminal illness can affect all aspects of a person's life. Serious illness consists of more than feeling unwell and suffering from the physical effects of illness. In fact, patients can suffer at the hands of medicine itself, in the treatment of an illness, regardless of intention. In "The Nature of Suffering and the Goals of Medicine," Eric J. Cassell examines the effects of suffering, noting that "Even in the best settings and with the best physicians, it is not uncommon for suffering to occur not only during the course of a disease but also as a result of its treatment" (639). Treatment differs with each illness and each patient; however, for chronic or terminal illnesses, it can be lengthy, demanding, and often physically painful. Further, it can be mentally, emotionally, and spiritually distressing. Some of this distress originates from the difficulty in understanding one's new identity alongside illness.

With a diagnosis, a person's sense of self can change immediately, whether or not the diagnosis seemingly impacts the patient beyond their bodily identity. Cassell notes that "[each] person has roles," whether they be personal or professional, and "by middle age, the roles may be so firmly set that disease can lead to the virtual destruction of a person by making the performance of his or her roles impossible" (642). In *When Breath Becomes Air*, Kalanithi has difficulty understanding his roles. Immediately after his diagnosis, he decides to take some time away from medicine to focus on his new journey, believing it impossible for him to continue in his residency. He is unable to perform as a neurosurgical resident and as a husband, at least to the extent he desires, which is consistent with Cassell's claims. Kalanithi's oncologist, Emma, urges him to maintain his identity as a physician. However, he struggles with the reality of his diagnosis and its consequence on his personal and professional future:

> In [Emma's] office, I felt like myself, like *a* self. Outside her office, I no longer knew who I was. Because I wasn't working, I didn't feel like myself, a neurosurgeon, a scientist—a young man, relatively speaking, with a bright future spread before him. Debilitated, at home, I feared I wasn't much of a husband for Lucy. I had passed from the subject to the direct object of every sentence in my life. (141)

Kalanithi is "debilitated" not only physically due to his illness, but also mentally from the stress of trying to make sense of who he is—or, perhaps, who he can be—as a terminal cancer patient. He demonstrates a dimension of suffering caused by his diminished role as a physician and a husband rather than by the physical effects of the illness.

Nevertheless, the illness causes its own separate kind of suffering by way of physical pain. To better understand how suffering arises from physical pain, whether created by illness or treatment, it is important to clarify the distinction between the two. Cassell states that "although pain and suffering are closely identified in the medical literature, they are phenomenologically distinct" (641). According to Cassell, pain affects a person's physical being; suffering, on the other hand "extends beyond the physical" and "can be defined as the state of severe distress associated with events that threaten the intactness of the person" (640). Cassell believes that "the difficulty of understanding pain and the problems of physicians in providing adequate relief of physical pain are well known" (641), but that physicians are untrained in recognizing the nonphysical dimension of suffering.

This experience with physical pain provides Kalanithi with yet another learning opportunity as a patient, though it is an agonizing one. Before his diagnosis, Kalanithi experiences "ferocious back pain" (4), "unexplained weight loss" (5), "bouts of severe

chest pain," and "a persistent cough" (7). He speaks to a physician about his symptoms, but together they agree to "[chalk] the symptoms up to hard work and an aging body," so Kalanithi deals with this physical suffering by medicating with "a healthy dose of ibuprofen" (6). This, however, is only a temporary fix, and the physical pain caused by his illness soon becomes very grave: "Over the past few months, I'd had back spasms of varying ferocity, from simple ignorable pain, to pain that made me forsake speech to grind my teeth, to pain so severe I curled up on the floor, screaming" (11). Kalanithi's pain diminishes his quality of life, forcing him to cut short a visit with friends and take time away from medicine to focus on his health, among other things. The consequences of his pain then add to his suffering.

As Kalanithi's cancer progresses, his physical pain worsens and his suffering deepens. He considers how the physicality of his being—cancer, pain, and all—interacts with the private mentality of his identity, writing, "My body was frail and weak—the person who could run half marathons was a distant memory—and that, too, shapes your identity. Racking back pain can mold an identity; fatigue and nausea can, as well" (140). The new limitations of his abilities and his powerlessness to return to his former physical identity increases Kalanithi's suffering. Cassell believes that "people in pain frequently report suffering from the pain when they feel out of control, when the pain is overwhelming, when the source of the pain is unknown, when the meaning of the pain is dire, or when the pain is chronic" (641). Similarly, Frank, who experiences pain and suffering through testicular cancer, believes that "pain is thus one of the first experiences an ill person has of being cast out" (31). As suffering can arise from this separation between the ill and the well, "the ill person has to find a way back in among those he has become separated from" (31). Before his diagnosis, Kalanithi endures pain from his

illness and endures suffering from his fear of cancer. After his diagnosis, he better understands the origin of his pain, which creates a different type of suffering: he knows what is happening to him, but he is powerless to control it alone.

Suffering from the illness itself, however, is not the only dimension of Kalanithi's physical affliction. Yet another dimension is that of suffering from the treatment, which can have negative effects, both physical and mental. This suffering can be caused by the prescribed treatment itself, where side effects impact quality of life, or by interaction with physicians. Each treatment practiced by a physician is of course influenced by the illness itself, but the treatment needs to then be tailored specifically to the patient, as illness differs from patient to patient. The patient is being treated, not the illness; when the illness is forefront, however, Cassell writes that "physicians may, in concentrating on the cure of bodily disease, do things that cause the patient as a person to suffer" (640). If a physician focuses on treating the illness rather than the patient, then the patient may suffer as collateral damage to the illness. Furthermore, each patient's ability to manage their illness and treatment differs, whether by their age, physical capabilities, personality, or attitude, so there is no one-size-fits-all approach to medicine. As Cassell writes, "It is not possible to treat sickness as something that happens solely to the body without thereby risking damage to the person" (640). Therefore, by dismissing the patient and focusing on treatment, it is possible that suffering that might otherwise be avoided will be unnecessarily inflicted.

Kalanithi experiences suffering through treatment due to both medical treatment and physician interaction. His first-line medication to treat the tumours, Tarceva, begins to fail, and he is forced to begin chemotherapy. On top of struggling with exhaustion and having difficulty eating, Kalanithi "shuffled in and out of the hospital with minor

complications, which were just enough to preclude any return to work" (184). Nonetheless, he meets the graduation requirements for his residency. Just when it seems that Kalanithi is finally able to achieve his dream and coalesce his identities, chemotherapy overtakes him, and he reluctantly admits, "I would not be going to graduation, after all" (184). Kalanithi is hospitalized for a week in critical condition:

> Over the course of the day I began to deteriorate, my diarrhea rapidly worsening. I was being rehydrated, but not quickly enough. My kidneys began to fail. My mouth became so dry I could not speak or swallow. At the next lab-check, my serum sodium had reached a near-fatal level. I was transferred to the ICU. Part of my soft palate and pharynx died from dehydration and peeled out of my mouth. I was in pain, floating through varying levels of consciousness…. (188-89).

Kalanithi's reaction to chemotherapy nearly kills him. This traumatic experience induces suffering for Kalanithi and, presumably, for his family. His wife Lucy, who is thirty-eight weeks pregnant, and Kalanithi's father are present, "[lending] their voices" and "discussing [his] condition with a team of doctors" (189), unable to detach themselves from Kalanithi's care when he is incoherent. And once he is lucid, Kalanithi is so affected by his suffering that he relinquishes power over his own medical care, asking Emma to "'be the doctor'" so he can "'just be the patient'" (190). When Emma initially offers to liberate Kalanithi from his own care, he is deeply confused, writing, "I hadn't ever considered that I could release myself from the responsibility of my own medical care. I'd just assumed all patients became experts at their own diseases" (182). However, Kalanithi changes his mind after suffering through this life-threatening ordeal caused by treatment.

It seems that the further his suffering progresses, the more powerless he is to control it; yet in becoming more aware of his ability to shed his professional identity, he gains a certain limited agency. Kalanithi's decision to take a backseat role in his own care is a demonstration of putting the patient before medicine—even if the patient is himself.

Kalanithi's relationship with Emma is in-sync from their first meeting. With a similar approach to medicine and patient care, Kalanithi "immediately [feels] a kinship" (129) with Emma, and throughout his illness, she remains a source of optimism and strength for Kalanithi. Despite this trusting patient-physician relationship, Kalanithi does experience suffering at the hands of a second-year medical resident, Brad, when he is first admitted for his week-long stay. Initially, Kalanithi and Brad "[chat] amicably" and "[discuss] advances in molecular therapies, especially Tarceva, which [Kalanithi] was still taking" (185). Later in the evening, Kalanithi studies his list of medications and notices that Brad neglects to include Tarceva, seemingly an oversight. But when Kalanithi questions Brad about the misunderstanding, Brad becomes impatient and unkind, stating that he made the decision to discontinue Kalanithi's medication because his "liver enzymes are too high" (185). Kalanithi shares that it is Emma's opinion he remain on Tarceva, despite the higher-than-usual enzyme count, yet Brad continues to resist, much to Kalanithi's shock: "Usually invoking the attending's orders ends the discussion" (186). When Kalanithi explains that "without that pill, [his] bone metastases become active and produce excruciating pain" (186), Brad ignores his patient's suffering, and instead coldly replies, "'Well, given the half-life of the drug, that probably won't happen for a day or so'" (187).

Brad is unwilling to hear and address his patient's concerns, even if his patient has much more experience as a physician than himself. He is caught up in numbers and

statistics, focusing solely on the illness and entirely overlooking his patient. Kalanithi writes, "I could see that in Brad's eyes I was not a patient, I was a problem: a box to be checked off" (187). Kalanithi admits that he had occasionally been impatient or hasty when dealing with patients in the past. During his medical residency, he too "was not yet 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). However, he is soon able to "meet [patients] in a space where [they were] a person, instead of a problem to be solved" (90). Brad, however, treats Kalanithi as just another illness, no more than his lab statistics. Nevertheless, Brad's error soon becomes about more than simply neglect of his patient. He admits to Kalanithi that "'Tarceva is a special drug, and it requires a fellow or attending to sign off on it'" (187). Brad says, "'Do you really want me to wake someone up for this? Can't it wait till morning?'" (187). Brad's reluctance to prescribe Tarceva "meant adding one more thing to his to-do list: an embarrassing phone call with his boss, revealing his error" (187-88). Brad displays a lack of consideration and care for his patient by putting his own interests ahead of Kalanithi's. By forcing his patient to suffer needlessly and wrongfully, Brad fails to fulfill the obligation of the Hippocratic Oath he had sworn.

Kalanithi's experience with Brad underscores how suffering can be exacerbated by illness and treatment. Kalanithi is admitted to the hospital as a consequence of his chemotherapy, but as if his physical symptoms aren't suffering enough, his distress is compounded at the hands of Brad's careless attitude and inconsiderate nature. Brad epitomizes the aloof physician. While it would be ideal to be treated by a personable and compassionate physician, it is obvious that, as Charon explains, "physicians sometimes lack the capacities to recognize the plights of their patients, to extend empathy toward

those who suffer, and to join honestly and courageously with patients in their illnesses" ("A Model for Empathy" 1897). Unfamiliar with medicine, the average patient may be too intimidated or too unacquainted with the medical profession to speak up for themselves; as if illness is not already scary enough, the added burden of an unkind physician does nothing to promote healing or comfort. Kalanithi is fortunate. As a physician himself, he is more familiar with Brad's role. Yet he too suffers at the hands of a physician who forgets that the end goal of medicine is not a defeat of illness—truly, it is patient care. His experience with Brad is both confusing and infuriating, especially during a time when Kalanithi is so unsure of how to be just a patient, separate from a physician. He confesses to the reader early on that his confidence within medicine differs on either side of the stethoscope: "Why was I so authoritative in a surgeon's coat but so meek in a patient's gown?" (5-6).

No matter the origin or method of suffering through chronic or terminal illness, the patient's identity can be profoundly affected. Whether they are enduring physical pain or mental anguish, patients can find themselves unable to operate as usual in their day-to-day lives. Cassell addresses this correlation between identity and function in noting that "patients decide that they are ill because they cannot perform as usual, and they may suffer the loss of their routine. If they cannot do the things that they identify with the fact of their being, they are not whole" (642). This proves true for Kalanithi, who, upon seeing his unfavourable CT scans for the first time, believes that "One chapter of my life seemed to have ended; perhaps the whole book was closing. Instead of being the pastoral figure aiding a life transition, I found myself the sheep, lost and confused" (120). His metaphor of life as a book is interesting, as it is literary awareness that helps him cope as the "book" of his life comes to a close. However, literature's role in Kalanithi's illness only

comes into play as his health worsens and recovery seems improbable. Instead, at the moment his cancer is confirmed, Kalanithi instantly considers how the diagnosis affects his life in medicine. He believes that he will be unable to continue working in neurosurgery; his identity is so closely connected to his life path as a neurosurgical resident that being diagnosed with a "severe illness wasn't life-altering; it was life shattering" (120). Nothing changes from one minute to the next, besides the fact that Kalanithi is now aware of his diagnosis—Emma even states at one point, "'You aren't any sicker than you were a week ago'" (180)—yet somehow everything changes for Kalanithi.

Even before he confronts the misery from treatment, Kalanithi experiences a final dimension of suffering in the form of an identity crisis—crucially bred from the loss of a future. He suffers "unremittingly from [his] perception of the future" (Cassell 639). Cassell believes that suffering "would not exist if the future were not a major concern" (641), because "in order for a situation to be a source of suffering, it must influence the person's perception of future events" (641). Kalanithi's life is abruptly disrupted with his diagnosis, most significantly his career endeavours of becoming a neurosurgeon and neuroscientist. As his illness becomes more severe and his life expectancy grows shorter, Kalanithi is forced to reconsider his plans for the short future he has left: "If I no longer sought to fly on the highest trajectory of neurosurgeon and neuroscientist, what did I want? To be a father? To be a neurosurgeon? To teach? I didn't know" (166). Eventually, Kalanithi is too sick to continue as a physician. It is in these moments that he struggles to self-identify as a physician: "Which is correct: 'I am a neurosurgeon,' 'I was a neurosurgeon,' or 'I had been a neurosurgeon before and will be again'?" (198). Along with Kalanithi's powerlessness as a physician comes his struggle with identity: "Whether

the patient is a doctor who cannot doctor or a mother who cannot mother, he or she is diminished by the loss of function" (Cassell 642). Kalanithi's dilemma with identity in illness is not unfounded. Not only do his current dimensions of identity hang on a tenuous thread; he also gains a new facet of identity as a patient. While his past remains, his present experience with cancer consumes him, and his future expires.

Kalanithi's perspective is unique, but his experience with serious illness is shared. Before him, many illness narratives share stories of suffering, pain, and loss, but they also carry a thread of hope and wonder. In particular, Anatole Broyard's experience with prostate cancer and Arthur Frank's experience with testicular cancer both succeed in shedding light on what it means to live with cancer and how to find purpose in it all. Illness narratives such as Kalanithi's, Broyard's, and Frank's, as Charon notes, "reveal how illness comes to one's body, one's loved ones, and one's self. These narratives, or pathographies as they are sometimes called, demonstrate how critical is the telling of pain and suffering, enabling patients to give voice to what they endure and to frame the illness so as to escape dominion by it" ("Honoring the Stories" 65-66). Illness narratives serve the reader, and especially the writer, as they are given an outlet to express themselves and possibly make peace with their experience. Charon writes, "Illness, no matter how minor, reminds one of one's mortality and frailty and ultimate end" (78), and it is through the act of crafting illness into a narrative that a person may be better able to understand the fragile balance between life and death.

Broyard's *Intoxicated by my Illness: And Other Writings on Life and Death* explores his illness experience with metastatic prostate cancer. He begins by noting, "When you learn that your life is threatened, you can turn toward this knowledge or away from it. I turned toward it" (3). Mirroring Kalanithi, Broyard too is concerned with the

thought of his future. He writes that "time had tapped [him] on the shoulder" and "had given [him] a real deadline at last," and though "it sounds trite," Broyard is most concerned with how illness "was going to interrupt [his] leisurely progress" (3). His suffering begins when he "[realizes] for the first time that I don't have forever" (4), paralleling Kalanithi's difficulty in coming to terms with his disrupted future. But further, the two also share common ground regarding their interest in their illness: Kalanithi, though devastated, finds solace in finally being able to observe mortality and death in the midst of illness; Broyard, too, seems pleased that at least his life has been put into perspective for him. He believes that "illness is primarily a drama, and it should be possible to enjoy it as well as to suffer it… In this phase I'm infatuated with my cancer. It stinks of revelation" (7). Though he celebrates the "revelation" that illness provides, the ironic use of the word "stink" to signify its presence demonstrates his bitterness at how illness puts life into perspective while simultaneously threatening to take it all away. Broyard's cancer diagnosis pushes him to explore through life-writing how illness affects his life trajectory.

Though he undoubtedly suffers through illness and treatment, Broyard's most noteworthy episode of suffering stems from his experience with an unsatisfactory physician, specifically his urologist. He writes, "From the beginning I had a negative feeling about this doctor. He was such an innocuous-looking man that he didn't seem intense enough or willful enough to prevail over something powerful and demonic like illness. He was bland, hearty, and vague, polite where politeness was irrelevant" (36). Though Broyard admits that his opinion of the physician may be "unjust" (36) and that "this man was in all likelihood an able, even a talented, doctor" (39), Broyard "simply couldn't warm up to him" (36), and so his distrust and discomfort with the physician

prevents a successful patient-physician relationship. Broyard believes, "To get to my body, my doctor has to get to my character. He has to go through my soul" (40). Broyard's lack of connection with his urologist, and the urologist's inability to exhibit a personable manner, inhibits Broyard's sense of trust in the care he is receiving: his suffering begins in the discomfort of his physician's medical care.

Broyard's experience with the urologist forces him to consider how a physician's role in patient care can affect a patient's suffering and satisfaction with their treatment. He succinctly captures the patient experience when he writes, "To the typical physician, my illness is a routine incident in his rounds, while for me it's the crisis of my life" (43). If a physician is unable to demonstrate consideration and empathy for their patients, they will be unable to build a patient-physician relationship on a foundation of trust; the patient may suffer as a result. "When a doctor refuses to acknowledge a patient," Broyard writes, "he is, in effect, abandoning him to his illness" (50). Broyard's urologist offers no ease or understanding to Broyard, leaving Broyard to suffer from insecurity in his medical treatment. He understands that "the doctor has the impossible job of trying to reconcile the patient to illness and dying" (66), and although "not every patient can be saved," Broyard believes that "[a patient's] illness may be eased by the way the doctor responds to him" (57). Broyard's unsatisfactory experience with his urologist allows him to explore how important the role of the patient-physician relationship can be to promote treatment and prevent suffering.

Both Kalanithi and Broyard succumb to their cancer, and so their illness narratives are truly the final piece of shared knowledge and experience they are able to offer. Frank, on the other hand, survives testicular cancer and captures his experience in *At the Will of the Body: Reflections on Illness*. He explains his decision to record his bout with serious

illness, writing, “Those who are ill find it valuable to know that others share their experience” (46). Similarly to how Broyard sees his illness as a revelation, Frank sees “opportunity” in illness, as it affects a person wholly:

> To seize the opportunities offered by illness, we must live illness actively: we must think about it and talk about it, and some, like me, must write about it. Through thinking, talking, and writing we can begin, as individuals and as a society, to accept illness fully. Only then can we learn that it is nothing special. Being ill is just another way of living, but by the time we have lived through illness we are living differently. Because illness can lead us to live differently, accepting it is neither easy nor self-evident… I want to enter into the experience of illness and witness its possibilities, but not so far as to become attached to being ill. Seizing the opportunity means experiencing it fully, then letting go and moving on. (3)

The illness experience for Frank is one that should be explored and appreciated, as many people in their lives will unwittingly share in the sentiment. Frank’s fear of “[becoming] attached to being ill” is not unfounded; Broyard, for example, is “energized, ‘intoxicated,’ by his illness, and determined to face it, to write about it, with all the strength he could” (Sacks xii). Broyard passes from his illness within fourteen months, and so while he succeeds in “seizing” his illness, he does not have the opportunity to let it go. For ill persons who survive their illness, Frank believes that by “accepting illness fully” and then “moving on,” a person will become better equipped to deal with illness in their own lives, whether as a patient or as a survivor, and will hopefully obtain a better perspective on how one lives with illness.

In Frank's memoir, he shares not only his sorrows and triumphs with illness, but also his experience of suffering, whether at the hands of physicians or simply from the illness. During a round of his chemotherapy treatment, Frank has the misfortune of experiencing poor patient care at the hands of a nurse, who in "speaking to Cathie, [Frank's wife], referred to [Frank] as 'the seminoma in 53' (my room number)" (52). The nurse "crowded out [his] name entirely" (52) and treats Frank as nothing more than his illness, completely disregarding not only his identity but also disregarding Cathie's identity as Frank's wife. Frank writes, "The hospital had created its own version of my identity. I became the disease, the passive object of investigation and late of treatment" (52). Not only does the classification of Frank as his illness create suffering for himself, but it also creates suffering for Cathie. As a patient or a caregiver, it is unnerving to be identified solely by illness. As Broyard writes, "The important thing is the patient, not the treatment" (68). However, in Frank's case, the nurse is unable to see past the illness and treatment, and so she completely fails to empathize with Frank, the patient. By ignoring Frank, the nurse demonstrates that medicine is deemed more important than patient care: as Frank sees it, "Medicine has no interest in what pain means in a life; it can see pain only as a symptom of a possible disease. Medicine cannot enter into the experience; it seeks only cure or management" (52). Frank is demeaned and lowered by this interaction with a medical professional who sees no interest or value in Frank besides his illness.

Frank's experience with suffering is also very similar to Kalanithi's when it comes to the influence of the future. Kalanithi's career goals and family plans are altered as a consequence of his illness, and even towards the end of his journey with metastatic lung cancer, he still ponders what the future may hold for him and his family. For Frank, a witness to testicular cancer, the thought of the future also causes him great suffering, as

he is unable to gauge how illness will impact his life in the long-term, stating, “My future was pervaded by uncertainty” (36). Further, Frank feels as though he “lost [his] sense of belonging” (36) with the diagnosis, as he can no longer place himself in the future, not knowing if he will be around to live it. His fear of death is incited by the thought of losing years forward with his family and friends, stating, “The pain of my death was in losing my future with those others,” and so, with illness, “[his] reasons for living have never been clearer” (37).

Unfortunately for Frank, he finds that “loss of the future is complemented by loss of the past” (37), specifically where physical function is concerned. Frank demonstrates a strong connection to his bodily identity, which can not only affect his “sense of belonging,” but is also tied to his perception of the future. He believes, “My body is the means and medium of my life; I live not only in my body but also through it” (10). With a sickly body, Frank lives a sickly life and is disconnected from his identity. He “[feels] like [he] was losing [his] body’s continuity with its youth” (37), even though “the changes, the deteriorations, had been gradual” (38). Not only does his illness cause these changes, but so too does his treatment. Frank accepts that the body he has known his whole life will suffer and change in illness: “Surgery and chemotherapy would irrevocably break my body’s continuity with its past. I did not dread what I would become, but I needed to mourn the end of what I had been… I had tried to take care of my body, and it had treated me well enough, but now treatments I did not yet understand would change it into something else” (38). Frank wrestles with how his illness and medical treatment will affect his physical identity, and he suffers as a consequence. Frank underscores the identity tied to one’s body and how physical changes through medicine can deeply impact a patient’s identity experience.

Frank, Broyard, and Kalanithi all experience different types of illness, and so their experience with suffering differs as well. However, all three experience similar types of suffering, whether it be by illness and medical treatment, by interacting with physicians, or by the loss of a future and its impact on identity. Cassell tells us that "if suffering occurs when there is a threat to one's integrity or a loss of a part of a person, then suffering will continue if the person cannot be made whole again" (644). In Kalanithi and Broyard's cases, they are not "made whole again," as they both die as a result of their illness. For Frank, however, the suffering decelerates when he is fortunate enough to be in remission, though his perspective on suffering is not lost: "I had seen too much suffering from a perspective that is often invisible to the young and the healthy. I wanted less to recover what I had been than to discover what else I might be" (2). Here, Frank signals a turn to what he calls a "quest narrative": "as the ill person gradually realizes a sense of purpose, the idea that illness has been a journey emerges," and so "the journey is taken in order to find out what sort of journey one has been taking" (*The Wounded Storyteller* 117). All three writers suffer, and all three writers struggle to find purpose in their illness. By developing their separate illness narratives, they each demonstrate strength in illness and use writing as an outlet to express the suffering they bore during their illness experiences.

Returning to Kalanithi, it is clear that suffering, no matter the origin, is often an overlooked aspect of the patient experience. Pain and suffering are often considered to be similar, although suffering is a much broader, more challenging, and more abstract concept that inflicts the mind as well as the body. The tragedy of a life-altering illness is that the pain of the disease can be less than that of the suffering that accompanies it; the spectre of death can pale in comparison to the agony of enduring. Cassell writes, "The

relief of suffering, it would appear, is considered one of the primary ends of medicine by patients and lay persons, but not by the medical profession. As in the care of the dying, patients and their friends and families do not make a distinction between physical and nonphysical sources of suffering in the same way that doctors do" (640). Kalanithi, however, understands and explores the concept of suffering separately from the idea of pain, both as a patient and a physician. He notes that "the physician's duty is not to stave off death or return patients to their old lives, but to take into our arms a patient and family whose lives have disintegrated and work until they can stand back up and face, and make sense of, their own existence" (166). For those suffering from serious illness and the loss of what was and might have been, illness narratives like Kalanithi's serve as a restorative by illuminating the darkness of diagnoses, treatment, and outcome. Words matter, and the words and thoughts of those who have faced a similar fate can be a more soothing balm than anything found in the well of a syringe. The realization of one's imminent mortality is somehow made more bearable through the words like those of Kalanithi, who went on before, lighting the path for others to follow.

Chapter Four: Discussion

Suffering as part of serious illness is a key element in shaping identity. Suffering plays its part not only in creating a person's illness identity, but also in disassociating them from their past. As Blaxter states, "Identity is a life story" (170), and so the act of creating an illness narrative can help a person come to terms with their new life and "articulate their situation in the social world" (170). For Kalanithi, the writing of his memoir provides an outlet for him to share his experience, identify his suffering, and chart his identity change throughout life, preceding and during his illness. Kalanithi writes, "The tricky part of illness is that, as you go through it, your values are constantly changing. You try to figure out what matters to you, and then you keep figuring it out" (160). His values shift from the moment he is diagnosed and continue to develop during each stage of his illness: diagnosis calls him back to literature, reignites his interest in mortality, and realigns his understanding of the patient-physician relationship. Kalanithi's evolution throughout his illness provides an exemplar of how illness identity is formed and what effects it has on a person living with terminal illness.

Kalanithi's memoir explores his life in its entirety, from early childhood to death, and highlights the many different aspects of his identity, both personal and professional. Kalanithi grows from a son into a friend, a husband, and a father; he changes course from a literature student to a medical student; he advances from a medical resident to a neurosurgeon; and he too soon finds himself in the role of a patient, an unfortunate circumstance that encourages him to become the writer he once aspired to be. These individual threads of identity all contribute to Kalanithi's complete self, and with each new dimension of identity, his life is greatly changed. The creation of his illness identity

is perhaps one of the most overwhelming transformations to his life journey: each new identity advances Kalanithi's future, but only this illness identity limits it.

Although each identity is distinctly its own, they are not always mutually exclusive. There are, of course, moments in Kalanithi's life where these different dimensions may seem separate in that his focus is primarily on one aspect of his identity rather than another. For example, Kalanithi is a student of literature and of medicine at different times in his life. However, even then, his identities are connected by a common thread: an interest in mortality and the meaning of life. Though he takes two distinctly different paths, each path allows him to seek a common understanding: he writes that he "studied literature and philosophy to understand what makes life meaningful" and "studied neuroscience and worked in an fMRI lab to understand how the brain could give rise to an organism capable of finding meaning in the world" (35). Even when Kalanithi is fueled by different ambitions, his interests intersect.

The overlap between his dimensions of self is certainly evident within *When Breath Becomes Air*, especially when it comes to his relationship with medicine. Lucy Kalanithi notes in the memoir's epilogue, "We all inhabit different selves in space and time" (220). Throughout his memoir, Kalanithi gracefully weaves between his different selves and inhabits different roles, depending on the situation. The primary selves to this story are Kalanithi as a physician and as a patient; at some times he is a physician, at other times he is a patient, and often he is both simultaneously. Kalanithi writes about how he interacts with the roles and how he bridges the gap between the two dimensions. He writes, "Once I had been diagnosed with a terminal illness, I began to view the world through two perspectives; I was starting to see death as both doctor and patient" (138). Illness does not make him any less of a doctor; rather, it creates for him a new perspective

as a patient through which he can view medicine and, more broadly, the human condition. From a physician's perspective, Kalanithi knows how important a patient's attitude is in diagnosis, and he is able to approach his diagnosis with this knowledge: "As a doctor, I knew not to declare 'Cancer is a battle I'm going to win!' or ask 'Why me?' (Answer: Why not me?)" (138). Kalanithi knows that illness can favour anyone, and his chances at survival lie in the hands of the medicine he so dearly believes in.

Coming to terms with a newly-formed illness identity is no easy feat, even for someone who is so familiar with illness, often little more than a scalpel blade away. Kalanithi perhaps best sums up his experience with stage IV cancer when he writes, "Death may be a one-time event, but living with terminal illness is a process" (161). Part of the process relates to how a patient views themselves both outside of and within their illness. Outside of illness, Kalanithi is no less the son, husband, and physician he was previously, before the diagnosis was articulated. He carries on with these roles, simply creating room in his life for the resolute role of a patient. Within illness, however, things change: he becomes a father just eight months before he passes; he becomes a dedicated writer to compose his book; and he becomes a witness to illness and the inevitability of mortality, of which he knew so much and yet so little. The process of living with terminal cancer for Kalanithi is not only about coming to terms with the limited time he has left, but it is also a learning experience in which he must adapt to his new illness identity. Coincidentally, with this new illness identity comes an opportunity for Kalanithi to better explore the complex nature of one's own mortality.

Kalanithi's interest in mortality becomes more important than ever in the midst of his illness, as suddenly the prospect of death becomes real and immediate. While he decides to study medicine "to bear witness to the twinned mysteries of death, its

experiential and biological manifestations," as a medical student, he finds medicine "at once deeply personal and utterly impersonal" (53). As a medical student and later a physician, Kalanithi often meets patients during the most challenging time of their lives. He becomes a part of their illness narrative, and his interaction with the patient can affect how they conceive of their illness, for better or worse. Kalanithi understands how personal illness is to a patient and their supporters, but he also finds medicine "utterly impersonal" due to his distance from illness. Only ever on one side of medicine, Kalanithi cannot fully empathize with the patient, and so regardless of his good intentions, a profound disconnect remains at the most personal level. With a high volume of patients and too little time to spend with them, medicine becomes impersonal. The importance of patient care is lost in favour of treating the greatest number of patients: quality is sacrificed for quantity. However, once he becomes a patient, Kalanithi bridges the gap between patient and physician, and suddenly, medicine becomes much more personal. Further, with the likelihood of death on his mind, Kalanithi is reminded of the foundation of mortality on which medicine is built. As he straddles the tenuous line between life and death, illness doubles Kalanithi's perspective on both patient care and mortality. To him, "coming in such close contact with [his] own mortality had changed both nothing and everything" (131): before and after his diagnosis, he was always going to die—death is inevitable for everybody—but suddenly, death becomes tangible. Mortality is no longer something he simply studies in texts and through medicine; it is something to which he is subjected constantly.

Being ill reveals to Kalanithi not only the proximity of mortality, but also the importance of patient care. Even before illness, Kalanithi demonstrates compassion and an empathetic understanding towards patients. Early in his medical career, he wonders if

he is making "moral slides" (84), as he begins to feel desensitized to the trauma of others, but when he is reminded of the patients' suffering, he "[resolves] to treat all my paperwork as patients, and not vice versa" (77). When he is weak from the progression of his illness and the aggression of his treatment, Kalanithi takes on a limited role as a physician: his efforts are mostly spent performing surgery, and he limits the time that he spends with the patients. This model of medicine, however, does not last long for Kalanithi. His superiors pressure him to take on a fuller schedule and a more well-rounded approach to medicine before graduation, despite knowing the extent of his illness. Medicine begins to lose its charm for Kalanithi when practicing excludes connecting with patients rather than simply treating an illness. Once Kalanithi "[reconnects] with patients," he is able to once again take delight in practicing medicine, as "the meaning of the work" returns (158). If illness does not radically transform Kalanithi's perspective on patient care, it at least gives him a stronger appreciation for it. A medical resident does not typically fulfill only partial responsibility for the patient; Kalanithi's "good excuse" (158) of having cancer subsequently provides him with the opportunity to experience medicine primarily from the surgical side. Returning to a full workload "[puts] the patients back in the centre of [his] mind at all times" (158). Kalanithi is able to experience the separation of surgery from the patient, and he finds that medicine without patient care is "joyless" (156).

Kalanithi's work in medicine, his interest in literature, and his philosophical contemplation on mortality all define him. Each of his interests plays a role in his identity, both before and during his illness. As a young man, his focus on literature was a means to understanding human nature and to finding meaning in life. He looked to literature to answer "why?". But Kalanithi soon believed that "the formal ethics of

analytic philosophy felt dry as a bone, missing the messiness and weight of real human life" (31), and so he embarked on a journey into medicine. He states that focusing on medicine "would allow me a chance to find answers that are not in books, to find a different sort of sublime, to forge relationships with the suffering, and to keep following the questions of what makes human life meaningful, even in the face of death and decay" (42). Medicine allows him to take an active role in human life and suffering, where he can work to challenge mortality on behalf of others, where he can try to influence medical outcomes. When he has his health, literature becomes less meaningful to Kalanithi than medicine: there is no driving imperative for him. But when Kalanithi is diagnosed with terminal cancer, everything changes. Despite his extensive medical knowledge and surgical expertise, he is powerless to influence his own medical outcome; his cancer is aggressive and death is on the horizon. He returns to literature with a renewed hunger to gain a personal understanding of life and mortality. Literature takes centre stage in this new identity and gives his life new meaning and a renewed purpose. Kalanithi reads for understanding and writes with purpose. Through his writing, he is able to express his hopes and fears with a clarity and elegance that would otherwise be denied him. His writing allows us to share his journey and know his truths. Kalanithi acknowledges, "Words have a longevity I do not" (199). In *When Breath Becomes Air*, the words of a dying man live on as his legacy, his literary immortality.

Kalanithi was a student of literature and of medicine, a husband and a father, a physician and a cancer patient. Throughout his memoir, Kalanithi records his transition from physician to physician and patient. He maintains this role for as long as he is able, but inevitably, illness soon triumphs. He must evolve once more: he is no longer a physician combatting disease, but tragically a patient in a life and death struggle to

survive. It is in this final stage that he is forced to abandon his influence as a physician; instead, he must make peace with possessing medical knowledge that allows him to know his illness while being powerless to control it. Kalanithi's literary expertise helps him to demonstrate this in ways that have spoken to countless readers. He effectively portrays the struggle of illness identity and highlights the effects that cancer and its treatments have on the mind and body. The illness narrative is completely his own, as each cancer patient experiences illness and treatment differently. However, Kalanithi's narrative transcends his illness. It notably offers a perspective on how his illness affects the many dimensions of his identity. With such a multi-faceted identity as his, Kalanithi's *When Breath Becomes Air* provides an exemplar of how illness and identity interact.

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