

From Scalpel to Struggle: Paul Kalanithi's Journey Through the Lens of Disability

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Abstract

Paul Kalanithi's memoir *When Breath Becomes Air* is a profound autopathography—a self-reflective narrative on his life, career, and battle with terminal lung cancer. This paper examines Kalanithi's journey through the **lens of disability studies**, exploring how his narrative challenges and enriches theoretical frameworks related to **identity**, embodiment, temporality, and **societal perceptions of disability**. Through his dual perspective as a neurosurgeon and a patient, Kalanithi provides invaluable insights into the intersections of illness, disability, and resilience. His **autopathography** underscores the need for a broader understanding of disability that transcends physical impairments and considers the lived experiences of **chronic illness and terminal conditions**. This paper investigates how Kalanithi's memoir aligns with and contributes to core disability studies principles, offering new perspectives on agency, interdependence, and the narratives of illness.

Keywords: Autopathography, Disability, Chronic illness and Identity

Introduction

Paul Kalanithi's *When Breath Becomes Air* is a remarkable narrative that bridges the realms of medicine, philosophy, and personal experience. As a neurosurgeon diagnosed with terminal lung cancer, Kalanithi's transition from doctor to patient reveals an intimate exploration of identity, purpose, and mortality. His work captures the nuances of living with a life-altering illness, making it an essential text for disability studies. Disability studies challenge the traditional medical model of disability which views it as a problem to be cured and instead focuses on the social, cultural, and political dimensions of disability. By examining how societal structures and attitudes shape the experiences of disabled individuals, disability studies redefine disability as a complex interplay of identity, embodiment, and systemic barriers. Kalanithi's narrative, grounded in the embodied realities of illness, serves as a powerful case study to examine the intersection of chronic illness, terminality, and disability.

This paper argues that *When Breath Becomes Air* provides a unique perspective on disability by highlighting the fluidity of identity, the impact of illness on temporality and agency, and the role of narrative in reclaiming autonomy. Through its critical application to disability studies, Kalanithi's memoir enriches discussions on resilience, interdependence, and the societal framing of illness and disability.

Autopathography

Autopathography refers to self-narratives of illness that explore the personal and existential impact of medical conditions. Kalanithi's memoir exemplifies this genre by capturing his transformation from a

high-achieving surgeon to a patient grappling with mortality. The key characteristics of autopathography is their emphasis on the lived experience of illness—the subjective realities of dealing with a diagnosis, treatment, and ultimately, the broader meaning these experiences bring to life. Autopathographies help bridge the gap between medical knowledge, clinical procedures, and the deeply human experience of confronting illness or mortality (Genette 56). In the case of Paul Kalanithi's memoir *When Breath Becomes Air*, he transitions from a skilled surgeon to a patient grappling with terminal cancer, making his experience a prime example of autopathography. His narrative explores not only the medical facts but also the emotional toll and existential questions raised by his diagnosis, enriching the larger discourse on mortality, identity, and the human condition. And Disability studies emphasize the fluidity of identity in the face of illness or impairment. Kalanithi's transition from caregiver to patient challenges normative distinctions between ability and disability, highlighting the shared vulnerability of human existence.

Disability Studies

Disability Studies originated in the late 20th century as a response to the medical and social treatment of disabled individuals, aiming to shift the narrative from a purely clinical understanding of disability to a more critical examination of its cultural, political, and social dimensions. Emerging from the intersection of fields such as sociology, anthropology, and political theory, disability studies is influenced by the disability rights movement, which challenged social stigmas and advocated for the inclusion of people with disabilities in society. One of its core features is the **social model of disability**, which asserts that disability is not just a consequence of an individual's impairment, but a product of societal barriers be they physical, attitudinal, or environmental that exclude disabled people. This model stands in contrast to the medical model, which frames disability as a condition to be fixed or cured.

Disability studies emphasize the **fluidity of identity**, recognizing that disability can be a shifting and dynamic experience, and it stresses **interdependence** over independence, advocating for the support and inclusion of disabled individuals. It also critiques the **normative frameworks of ability**, challenging societal standards that devalue those whose bodies or minds function differently. Ultimately, disability studies seek to reframe disability as part of the human experience, promoting equality, inclusion, and broader cultural change. Disability Studies, on the other hand, is an interdisciplinary field that examines the social, cultural, historical, and political aspects of disability (Davis 108). It challenges the traditional medical model of disability, which views it merely as a physical or psychological impairment needing correction or treatment. Instead, disability studies focus on the **social model**, which argues that disability is not simply the result of an individual's impairment but the outcome of social, environmental, and attitudinal barriers. It emphasizes the ways society marginalizes people with disabilities by framing them as “other” or less capable. Disability studies explore **identity fluidity** in relation to illness, impairment, and disability, recognizing that a person's sense of self is often dynamic and constantly reshaped by their experiences with their body and society's response to their condition.

Journey From Scalpel to Struggle

Paul Kalanithi's experience of transitioning from a high-functioning surgeon to a cancer patient resonates strongly within disability studies. His journey disrupts normative ideas about the **binary** between "ability" and "disability," showcasing how even individuals who are traditionally seen as highly capable—doctors, professionals, caregivers—can experience vulnerability and become “disabled” in the face of illness. Kalanithi's personal transformation challenges society's typical distinctions between able-bodied people and those with disabilities, highlighting a shared human vulnerability rather than creating division. His

reflections reveal how fragile the notion of health and vitality is, and how illness can transcend the boundaries between those who are sick and those who are deemed healthy or able-bodied, thus offering an example of the **fluidity of identity** that disability studies scholars emphasize.

Furthermore, Kalanithi's exploration of his transition from doctor to patient also aligns with disability studies' critique of societal perceptions and stereotypes about people with chronic illness or disability. It questions the normative view that defines a person's value solely by their physical or mental abilities and highlights the intrinsic value of human life, no matter the condition. Through this lens, Kalanithi's memoir not only enriches the broader understanding of illness but also contributes to the evolving cultural and academic conversations on disability, identity, and the lived experience of vulnerability.

Kalanithi's narrative resists reductive portrayals of disabled individuals as either "tragic" or "heroic," offering instead a nuanced reflection on the coexistence of strength and fragility. Kalanithi's detailed descriptions of physical decline such as the fatigue and weakness induced by cancer treatments underscore the importance of embodiment in disability studies. His narrative aligns with the phenomenological approach to understanding how illness reshapes one's relationship with the body. "I had never before experienced such profound weakness. The chemotherapy, which was both a lifeline and a burden, drained the energy from my body. I could hardly make it from the bed to the bathroom, much less to the hospital or the operating room." (Kalanithi 150). Despite his declining health, Kalanithi demonstrates agency through his writing, reclaiming purpose and meaning. Disability studies frame such acts as critical in challenging societal narratives that equate disability with passivity or helplessness. Terminal illness disrupts linear perceptions of time, forcing individuals to navigate a precarious balance between long-term goals and immediate needs. Kalanithi's reflections on temporality—from planning for his child's future to savoring everyday moments—highlight the altered temporal frameworks experienced by those living with illness. Disability studies engage with the existential implications of living with chronic or terminal conditions, emphasizing the ways individuals find meaning and purpose amidst uncertainty. Kalanithi's philosophical reflections contribute to this discourse.

Primarily, Kalanithi's medical training reflects the traditional medical model, which views disability as a condition to be "fixed." However, his lived experience reveals the limitations of this perspective, aligning more closely with the social model that examines systemic and environmental barriers. Kalanithi's privilege as a doctor with access to advanced medical resources contrasts with the systemic inequities faced by many disabled individuals, highlighting disparities in healthcare and support systems. Through storytelling, Kalanithi reclaims control over his narrative, countering the passive roles often imposed on patients. Disability studies recognize narrative as a powerful tool for advocacy, self-expression, and identity formation. *When Breath Becomes Air* serves as an educational resource for healthcare providers, offering insights into the emotional and psychological dimensions of patient care. Paul Kalanithi's memoir blurs the lines between illness and disability, highlighting how both profoundly shape a person's identity, sense of agency, and how they are seen by society. "Being a physician is a kind of existential stance, where one puts their whole self in service of other people. Being a patient is similar, but far more difficult... It's not easy to accept dependence after you have spent a life in the service of others" (142). His experience with terminal cancer gives disability studies a broader, more inclusive perspective, extending the conversation to include chronic and life-threatening conditions. By telling his story, Kalanithi helps to deepen our understanding of how illness and disability can redefine a person, not just physically, but emotionally and socially, while urging a reconsideration of how we approach those living with these experiences.

Championing Empathy and Patient-Centered Care in Medicine

Kalanithi's memoir calls for a shift in medical practice, advocating for an approach that emphasizes empathy and truly values the lived experiences of patients. Rather than focusing purely on the symptoms and the medical treatment of a disease, he argues for a holistic approach—one that sees the person as a whole and not just as their illness. This resonates with the principles of disability studies, which reject the idea that people must be fully independent to be whole. Instead, these studies highlight the importance of interdependence and mutual support in a meaningful life. Throughout his journey, Kalanithi celebrates the support of his wife, family, and colleagues, showing how vital communal care is, especially during times of severe illness. "Lucy was the one who kept things from falling apart. She stepped in where I had left off, managing the affairs of our family and the details of my care, but also, crucially, reminding me of what life had been like before cancer." (161) His own resilience, expressed through his writing, pushes against the stereotypes that society often holds about what those with disability or chronic illness can achieve. In doing so, he challenges the assumptions of limitation and opens a door to a broader cultural narrative—one that recognizes the complexity and diversity of living with disability or illness, and the richness it can bring to personal and social life.

Conclusion

In *When Breath Becomes Air*, Paul Kalanithi takes us on an intimate, powerful journey through his experience of facing terminal cancer. His memoir not only delves deeply into the emotional, physical, and existential challenges of illness but also invites us to reflect on how our identity is so closely tied to our bodies and abilities. By looking at his story through the lens of disability studies, Kalanithi's personal narrative becomes a tool that challenges conventional ideas about disability, expanding our understanding of the connection between the mind, body, and society. As Kalanithi transitions from being a doctor who treats others to a patient grappling with his own mortality, he underscores how much of our self-worth and identity is tied to our physical capabilities. His experience sheds light on the intense emotional toll that accompanies an illness like cancer and the profound changes it brings to how one views themselves and the world. His journey is a reminder of how the medical system often disconnects us from our humanity, treating illness and disability with a clinical detachment that overlooks the person.

Kalanithi reflects on resilience and interdependence, encouraging readers to rethink what strength truly means. He offers a more compassionate view of vulnerability, showing that we are all interconnected and that there is great strength in asking for and accepting help. His insights not only speak to the medical profession but also to disability studies, emphasizing the importance of seeing illness and disability as a part of the shared human experience rather than something to fear or stigmatize. And Kalanithi's story is a call for empathy, respect, and a shift in how we treat those who are living with disability or illness. It encourages a broader societal change that embraces human connection and deeply challenges preconceived notions about strength, independence, and the meaning of living with a disability.

Through Kalanithi's story, we can also reflect on the cultural perceptions surrounding death, illness, and disability. While modern Western society tends to view illness and disability through a negative lens as something to avoid, hide, or treat quickly Kalanithi used his writing to challenge this view. His exploration of meaning-making during his illness provides a broader perspective that could be considered in the context of disability studies, which often critiques society's stigmatization of illness or physical limitation. In conclusion, Kalanithi's journey as outlined in *When Breath Becomes Air* offers rich reflections that can be examined through the lens of disability studies, shedding light on how illness, professional identity,

and physicality intersect in complex ways. His ability to embrace his experience as a patient, despite his earlier role as a surgeon, invites readers to reimagine how we view disability and the human capacity for adaptation and meaning-making amidst life's most challenging moments.

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