

## Illness Narrative: Exploring Patient Experience through Literature

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### Abstract

This qualitative analysis explores patient's experience of chronic and terminal illness in the literary works *Five Feet Apart*, *The Cancer Journal*, *When Breath Becomes Air*. By studying the themes of these literary works, this article analyzes patient's suffering, patient's struggle to maintain identity during adversity, resilience revealed in storytelling and patient's expression of pain through art and literature. Taking into account the theoretical frameworks such as medical humanities and biopsychosocio-cultural model and identifying how they are applied in the literary works mentioned, the research reveals the importance of patient-centered care, the relationship between patient and health care providers, the biological, psychological, socio-cultural factors that affect the patient's ongoing life. The findings of this study emphasize patient-centered care, provides a nuanced approach in perceiving suffering and illness, fosters empathy and compassion towards patient's journey of illness, highlights the importance of story-telling in enabling the patients to give voice to their suffering which also helps them in coping up with their illness and finding comfort. Though the interpretations may be subjective, illness as narrative provides deep understanding of the patient's agony, amplifies and gives power to patient's voice through literature.

**Keywords:** *Illness, identity, resilience, patient experience, storytelling.*

### Introduction

"Words may fall short to express my pain, but the ache in my heart could be sensed through my words" (Esther Joy). Illness narrative attempts to bring out the patient's experience of pain by looking through various lenses in order to interpret their journey of struggle. John Donne, in the poem "No man is an island unto himself," shared human beings' dependency on the other person, stating how badly mankind would go if they were being isolated. It was written in less than a month when he was diagnosed with stomach cancer. The book was inspired by his illness, which served as an illness narrative in the 17<sup>th</sup> century. The emergence of illness narrative gave way to a change in perspective and literary movements

from modernism that dealt patients as a tool of doctors to postmodernism that gave voices for patients to express themselves rather than being an idol in their stories. This study explores biopsychosocio-cultural understanding of illness, patients' experience of illness characterized by their strife in maintaining their identities during adversity, and patients' resilience revealed through storytelling. The significance of this research is to analyze how patients give voice to their suffering and how illness as narrative gives the sufferer a voice for expatiating illness that knits the split ends of time. Apart from how illness is illustrated by biomedicine, illness as narrative gives way to understanding the relationships between patient and the doctor, patient and illness, patient and society. The scope of this article is to investigate patients' experiences of suffering, the power of storytelling in patients' coping mechanisms, and a shift in perspective that fosters a patient-centered approach. By applying theoretical frameworks such as biopsychosocio-cultural models and medical humanities, this study provides a deeper understanding of patients' suffering, disruption of patients' ongoing lives, and patients' tenacity through illness narratives.

### Literature-Review

An Illness narrative can be defined as a story that explores patients' experiences of illness, how illness affects a person's life, and what consequences it will impart in the person's life even after recovery. It is mostly written in first-person narrative. Either the patient shares his/her story of illness or the caregiver, the person who witnesses the suffering of the patient, writes the story. Hence, they are autobiographical in the form of pathography that describes personal experience of illness, treatment, and sometimes death. The Illness narrative serves as a key to getting connected with the patients' emotions, to understand and feel their pain through the voice that has been given to their suffering. They can be fictional and non-fictional and can take the form of poetry, novels and drama.

Literary works like *Five Feet Apart* by Rachael Lippincott, Mikki Daughtry, and Tobias Laconis is narrated by the characters Stella Grant and Will Newman about their experiences of suffering from cystic fibrosis and the moments of joy that cystic fibrosis has taken away from their lives. The novel begins and ends with Stella's perspective. The alternating perspectives of Stella and Will in narrating about their illness, and how they cope with, it is the significant technique handled in this novel as it examines how they are different and how they are the same in sharing their pain. The protagonist Stella had always been confident, a girl who takes decisions for herself, emphasizing her autonomy, a perfectionist, but after being affected by cystic fibrosis, though she remains to be holding her identity as a

strong woman, in one instance she talks about her body, how she feels insecure about it, how her body turned unlikeable to her because of scars. Being a person who takes decisions for herself, she changes herself after meeting Will, shows concern for Will, and breaks the rule of six feet apart, which contradicts her perfectionist character. Stella and Will gain resilience through their relationship; Stella connects with others through internet, and Will expresses his voice of suffering through art. The novel takes the framework of the medical humanities, reflecting Rita Charon's concept of "narrative medicine," in which health care agents interact and engage with patients' narration of their stories, nurturing empathy and comfort. In this novel, the character Barb, a nurse at Saint Grace Hospital, helps in building up resilience in Stella during her tough times. She acts as a mother for Stella as she has been taking care of Stella since she was 6 years old. The novel also emphasizes patient-centered care, portraying Will and Stella as having some freedom in their choices and to express themselves through art and by posting blogs, which differs from the traditional health care method in which the doctor decides the decisions and actions of the patient.

Another notable work, *The Cancer Journal* by Audre Lorde, is a nonfiction memoir of her own suffering due to breast cancer. In this nonfiction and memoir, the author, Audre Lorde, expresses her mental thoughts, emotions, depression, and stress that cancer has caused, which also briefs her identity as a lesbian, as a postmastectomy woman, and as an Afro-American feminist who advocates for civil rights. During the face of adversity, she builds her resilience by embracing her changed body, affirming herself as a black lesbian feminist, and uses storytelling in her narration of *The Cancer Journal*, which serves as a therapy for her pain. By sharing her fears and emotions in her work, she finds comfort and relief that slowly enabled her to cope with her condition. This work of Lorde, implicitly implies a biopsychosocio-cultural model, highlighting the biological factors, the implications of breast cancer in her body, her treatments of chemotherapy and hormone therapy and her experiences with mastectomy; psychological and emotional struggles that she had as a black lesbian and as a feminist; social and cultural factors that forced her to comply with beauty standards and questioned her identity, after she had her breast amputated. All these factors are interconnected and impact or influence one another. Though her life has been disrupted by cancer, leaving her with one breast and exposing her identity as a lesbian, which is not acceptable according to social norms, she rises above her pain, fostering her emotional strength by expressing herself through writing.

*When Breath Becomes Air* by Paul Kalanithi, a neurosurgeon, is a memoir of the author, who has been diagnosed with terminal lung cancer in his mid-thirties. The book was

started to be narrated by Paul, but his wife Lucy completes the narration as Paul left the world without being able to complete the book. Through his narration, Paul wanted to convey to humanity how they can create a stable identity for themselves when faced with terminal illness, but at the same time he points on the acceptance of death and facing mortality. As a neurosurgeon, and spending his day mostly at the hospital and in the operation theater, Paul witnesses other patients who suffer from various illnesses and who struggle for life. He can resonate his suffering with them, which helps him to share his identity as a patient striving for life. Paul fortifies himself, finding strength and optimism to live with the help of his family, his relationship with his wife Lucy, and his desire to spend time with his newly born daughter. He also finds solace and comfort by recording his experiences and sharing his thoughts in the book that he has been writing. By narrating his story, his painful journey, he reflects on his past experiences, evaluates his identity, and envisions a possible future for himself. Applying the biopsychosocio-cultural model to his memoir, the biological factor that is lung cancer and the treatments that he takes make him question his identity as a doctor who turned into a patient. It disturbs his ongoing life as a neurosurgeon, driving him to have emotional conflict in overcoming his illness, pushing him to strive to live for his family. The socio-cultural factors that put Paul in tight corners-if he should be having a child when he is dying-and the concern for his wife Lucy and his daughter's future after his death are all intertwined, conveying the distress that Paul as a terminal illness patient undergoes. Yet Paul asserts his willpower through his narration in his memoir by accepting that his death is near.

### Methodology

This study takes a qualitative approach to understanding the underlying themes, such as maintaining identity during adversity, resilience revealed through storytelling, and expression of pain through art and literature. Through narrative research, these themes can be analyzed with the narration of the characters in fiction and non-fiction as they convey their stories of their suffering as patients, or they can be narrated by someone who witnesses the agony of the patient. The method used for the collection of data for this study is by analyzing biographies of patients who themselves are the authors, memoirs, and fictional books that transmitted the essence of the patient's suffering through first-person narration. By employing this research design, it enables the readers to gain insights into a patient's experience of illness, to relate to their lives, to feel their emotion and personal struggle, and to develop empathy and understanding. This study also has challenges in interpretation biases and subjectivity, as the conceptual understanding, feelings evoked, and interpretation may vary



from person to person, yet by close reading of the texts, the main themes and the patient's personal experience with illness could be understood, and it would reach out to the readers through their narration that carries their emotions.

### **Maintaining identity during adversity**

Disruption in a patient's ongoing life due to illness will impact the patient in several ways. One such major impact that the patient experiences is the struggle to maintain identity. The miserable and unfortunate events that happened to them will trigger patients to doubt if they are worthy to be a part of this universe. In the novel *Five Feet Apart*, the protagonist, Stella, is traumatized by her sister's death and also grieves for her parents' divorce. She feels that her parents' marriage died; her sister Abby died, but she is alive fighting with cystic fibrosis. She also feels insecure about her body, as she sees her body as nothing but full of scars. Amidst these circumstances that challenge her identity for living, she identifies herself as a strong woman who has a list of goals to be accomplished in life. She lists her goals in a notepad and maintains a checklist as she completes each goal. On the other hand, Will, who has the passion to go around and explore the world, does not give up his identity. He feels that his illness cannot stop him from his interest towards traveling. He maintains his identity by acting according to his will and travels around the world after he leaves the hospital. As narrated in *The Cancer Journal*, Audre Lorde asserts her identity as a postmastectomy woman. She accepts her body that has only one breast and refuses to have an artificial breast as recommended by her nurse. "I am a post-mastectomy woman who believes our feelings need voice in order to be recognized, respected, and of use" (Audre Lorde 9). In this line, it is understandable that Lorde is not ashamed of her body and her condition as a post-mastectomy woman who lost a major part of her body. Though breast cancer has questioned her womanhood, she accepts the identity that she is being left with and believes that her feelings as a cancer patient will be voiced out. Identity crises may also occur due to confusion in roles. In Kalanithi's memoir *When Breath Becomes Air*, Kalanithi finds himself as a doctor and as a patient, which makes him question his role. In one moment, he sees himself as a doctor who operates and treats his patients and the next minute, he is turned into a patient being examined by another doctor. Delving between two roles creates identity crisis, but Kalanithi accepts his roles as a patient and as a doctor as he prepares himself to face mortality. Here, Paul, who once had only one identity as a neurosurgeon, acquired another identity as a terminal illness patient who suffers from lung cancer. But his new identity as a patient does not stop him from maintaining his identity as a doctor, as he performed surgeries until his body supported him.

### Resilience revealed in storytelling

Analyzing the texts through the lens of illness narrative, the patient's resilience and optimistic approach towards coping with their illness are revealed. The patient's builds resilience to overcome his/her illness in order to achieve their ultimate aim. In *Five Feet Apart*, Stella's willpower is revealed in the line, "I want to be fearless and free. It's just life, Will. It will be over before we know it" (Rachael Lippincott, *Five Feet Apart*). By Stella's statement, it is clear that her aim is to be fearless and free. Hence, in order to fulfill that wish, she stays optimistic, she is not afraid of her condition, she follows a strict regimen, and she believes that she would get her lungs transplanted and she would live for some more years. In *The Cancer Journal*, though Lorde has been suffering from breast cancer, struggling to live in a judgmental society that does not accept a woman who does not confine to beauty standards, who is a lesbian and an Afro-American civil rights activist and a feminist, she gives no space for grief to take over her life. She says, "There is no time for despair, no place for self-pity, no need for silence, no room for fear; we speak, we write, we do express through language" (Audre Lorde, *The Cancer Journal*). Her aim is to give voice to her suffering, and advocate for the rights of Afro-American women, and she considers it the most important duty in her life and builds resilience to face her shortcomings rather than staying behind and sobbing for her condition of being a cancer patient. Her strength is revealed through her voice in her narration. In *When Breath Becomes Air*, Kalanithi knowing that he is nearer to death, builds his resilience by accepting his fate. "Like my own patients, I had to face my mortality and try to understand what made my life worth living" (Paul Kalanithi, *When Breath Becomes Air*). Kalanithi, accepting his fate does not mean that he has gone tired in his faith, but he is resilient to face his death, which is evident when he removes the oxygen supply as he does not want to extend his days with its help.

### Expression of pain through art and literature

The pain that cannot be spoken can be conveyed through art and literature. Patients who suffer from terminal illness and chronic disease find a way to give voice to their suffering. In the novel *Five Feet Apart*, Stella posts blogs, sharing with the world her pain of taking treatments for cystic fibrosis since she was six years old. By engaging with the world, and connecting with others through the internet, she gives voice to her suffering, motivates and encourages others who suffer like her, and comforts herself by reading their comments. Though she cannot stay close to her loved ones in real life, she manages to interact with them virtually. The secondary protagonist, Will, expresses himself through art. He draws his

desires, the ones he cannot achieve because of his chronic illness. Though he carries the pain in his heart that he cannot stay close to Stella, he draws several portraits of hers and manifests his suffering by sending letters, conveying his emotions through art to Stella. This novel was inspired by the real-life story of Clare Wineland, a YouTuber who would post videos of her condition as a cystic fibrotic patient. Similarly, Lorde, in her work *The Cancer Journal*, writes her painful journey, and her battle with breast cancer in a way that motivates others who suffer and fight for their lives. “May these words serve as encouragement for other women to speak and to act on our experiences with cancer and with other threats of death, for silence has never brought us anything of worth”(Audre Lorde 10). Though she is considered powerless as an Afro-American woman, she voices out her experience, and her trauma through writing. The author Kalanithi, in his autobiography *When Breath Becomes Air*, has mentioned that writing about his experience has helped him to find peace and comfort. He left literature and moved to the medical field, as he thought medicine would offer him the opportunity to feel patients’ experience of suffering and would provide a deeper understanding of the humanities. But towards the end, he returns to literature that he left many years ago in order to pursue medicine. After becoming a patient, he understands the power of art and literature that would empower someone, give solace to the afflicted, and enable a patient to give voice to suffering, and serve as a mode of expression of the patient’s pain through writing. Kalanithi shares his agony in his memoir which he cannot verbally speak to anyone. His life journey is captured in his memoir, through which he conveys a message to humanity to accept the truth that everyone faces mortality one day.

## Conclusion

This study has analyzed the experience of patients’ suffering, and their resilience through a qualitative analysis of literary texts such as *Five Feet Apart*, *The Cancer Journal*, and *When Breath Becomes Air*. By exploring themes such as maintaining identity during adversity, resilience revealed in story-telling, and expression of pain through art and literature, this study has brought out a nuanced approach for understanding patient-centered care, and developing empathy and compassion towards those who suffer. By applying the frameworks of medical humanities and biopsychosocio-cultural models in the literary texts, this study helps to view the stories of patients from different perspectives and understand their lives in a more humanistic way than that which biomedicine perceives. Illness is similar to setting foot into a new country, or new place where the language, culture, customs, and beliefs seem to be unfamiliar. Hence, the illness narrative acts as a platform to tell the world

about patients suffering, and their feelings and emotions, providing new perspectives that underscore the importance of patient-centered care and conveys the relationship between doctor and patient. It is one way of retrieving the voice of the patients that illness has taken away from them. Narrating their experiences as stories will help them to find comfort in the midst of adversity. When there is no one to share their agony, literature aids the patients in voicing out their agony and acts as a medium to convey the message that the patients want to tell the world.

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