Journey Towards Acceptance: Analyzing the Impact of Acquired Disability in L. Subramani's Memoir, Lights Out

Kowsalya G[1], Dr. Dhanabal C[2]

[1]Research Scholar, Department of English, Bishop Heber College, Affiliated to Bharathidasan University, Tiruchirappalli, Tamil Nadu, India.
[2]Associate Professor and UG Head, Department of English, Bishop Heber College, Affiliated to Bharathidasan University, Tiruchirappalli, Tamil Nadu, India.

Abstract
Disability, across cultures was perceived in various ways. From being considered as the punishment of Gods, undergoing involuntary euthanasia by Nazis, being denied of the basic rights and equal opportunities in all walks of life, the history of disabled people was filled with struggles and discrimination. With the wake of Disability Rights Movement, the twentieth century witnessed numerous protests and strikes by the advocates of disability rights. This resulted in the enactment of policies that could improve the disabled people's quality of life. Disability Studies, an academic outcome of Disability Rights Movement pointed out the socio-political and cultural aspects of disability and integrated other fields of knowledge with disability. Impairment as a bodily condition can either be congenital or acquired in later period of life. While the congenitally disabled experience a singular yet challenging reality, individuals who acquired disability later in their life undergo a painful transition. The memoir taken for the study is Lights Out by L. Subramani where the author was diagnosed with a medical condition called Retinitis Pigmentosa. This disorder results in the gradual loss of his vision and leads to an eventual blindness. This paper discusses the psychological impacts of acquired disability. It also employs the Five stages of grief proposed by Elisabeth Kubler-Ross to effectively scrutinize the phases of Subramani in acquiring blindness.

Keywords: Acquired disability, Congenital disability, Acceptance, Memoir

INTRODUCTION

Throughout ages, disability as a condition has been perceived through various lenses across different cultures. The ancient Greeks, believed the body and the soul to be a single entity, thus a defect in the body reflected a flawed soul. They despised disability for religious, economic, and eugenic reasons thus children with congenital disabilities were routinely killed or abandoned. The Songye people in Africa viewed disability as the consequence when a mother violates the taboos during her pregnancy thus blaming the parents for the child's defects. In India, according to the Hindu notion of 'karma', disability is believed to be the result of being sinned in the previous birth and one needs to accept and internalize the pain as atonement. In England, a gradual development in the medical field in the wake of renaissance, ensued the establishment of asylums where patients were studied and treated by the physicians. The industrial revolution in nineteenth century demanded able-bodied workers who could withstand harsh working environment for long hours, thus leaving the disabled jobless. Thus, the disabled were relegated to the margins – socially and economically. Only after the World War II, when many war veterans returned injured and impaired, does the voice of the disabled reached the government and policy makers.

The 1900's witnessed some radical changes in the perception and treatment of the disabled. The disability rights movement was steadily gaining momentum and various organizations in the West were challenging the government. However, in India, the voices of the disabled were largely scattered and the lack of leadership made it even more difficult. Though there were several non-governmental organizations that fought for the cause of the disabled, they were working on a particular disability, lacking the consolidated demands of the disabled overall. Inspired by the western counterparts, the Disability Rights Movement in India emerged in 1980's and it focused on the welfare of the disabled demanding education, equal rights, job opportunities, barrier-free access through organized protests, massive rallies, hunger strikes and publishing books of the same cause. The announcement of 1982-1983 as The Decade of Disabled Persons by the United Nations opened the discussion about rehabilitation in India. Finally, Persons with Disabilities Act was enacted by the Indian parliament in the year 1995, providing opportunities and reservations that uplift the status of the disabled. An amendment was passed on 2016 and the PWD Act was replaced by RPwD (The Rights of Persons with Disabilities) Act that focuses more on the socio-cultural and attitudinal barriers that hinders the disabled thus paving way to active participation of the disabled on an equal basis.

Disability Studies

Disability Studies is an interdisciplinary domain where disability is studied through the socio-political lens rather being confined to the field of medicine. It challenges the notions of dependence – independence, normality – abnormality, strength – weakness, and ability – disability. Simi Linton defines this emerging discipline as

Disability Studies takes for its subject matter not simply the variations that exist in human behavior, appearance, functioning, sensory acuity, and cognitive processing but more crucially, the meaning we make of those variations. (2)

This area of scholarship does not consider disability as a problem but offers perspectives that alter the stereotypes and stigma associated with disability. Disability Studies question the 'norms' that dictates the society and positions disability in the center. It highlights the prejudice, discrimination, pain, and stigmatization faced by the disabled. As Addlakha points out, "Disability Studies, at the core, involves an engagement with the experiential reality of disability" (8).

The different understandings of disability emanate multiple approaches that in turn categorized as models of disability. In the Medical Model, disability is a bodily impairment that needs cure. Here, the physicians take the central role and the disabled were advised to follow the medical instructions. In this model, it is assumed that something is 'wrong' with the disabled body and offers no solution to the everyday needs of the disabled. In contrast, the Social Model argues that disability is the result of disabling environment. This model propagates that the way to an inclusive society lies in removing the barriers that are physical, social, political, and psychological. The moral model believes that disability is an act of punishment by God and this results in the stigma and shame linked with disability. The Charity Model view disability as a tragedy. This brings about a dehumanizing attitude and creates hierarchy in people's minds. While a radical shift from medical to social model is observed in the west, in India, Addlakha observes the "the strange and uneasy coexistence of the medical and social models" (9). She further records "a social context in which the charity and human rights discourses on disability uneasily sit side by side points to the urgent need to inaugurate a serious discussion on disability" (9).

Emergence of Autobiographies

Disabled people are often marginalized even in literature. They are sidelined in fiction and are portrayed as negative characters. Classic novels such as Moby Dick, Jane eyre and Treasure Island have portrayed the negative roles sporting a disability. Writing autobiographies paved way for their self-representation. In the essay, "Body Solitaire: The Singular Subject of Disability Autobiography", David Mitchell addresses the contrast between disability in literature and disability in autobiography. "In literature disability functions largely as a metaphor of social collapse, while in autobiography disability represents the coordinates of a singular subjectivity" (311). The disabled population have been represented by non-disabled authors for years. The twentieth century, influenced by war and illness narratives, witnessed the emergence of disability life writings. In the West, autobiographies like Sight Unseen by Geogina Kleege, Stigma: Notes on the Management of Spoiled Identity by Erving Goffman and Autobiography of a Face by Lucy Grealy voiced out the reality of living with a disability in an ableist society. These autobiographies highly augmented the public awareness and governmental policies.

For years, the disabled in India were spoken about, spoken for, and spoken of. They were constantly misrepresented, stereotyped and negatively picturized in the movies and fiction. With the emergence of disability autobiography, the disabled voiced out their lived experience, their personal autonomy and encountered the narratives created by the society. Some of the notable disability autobiographies are Ved Mehta's Face to Face, Malini Chib's One Little Finger, and Preeti Monga's The Other Senses. Thomas G. Couser in his essay, "Disability autobiography" opines, "Autobiography is a particularly valuable and liberatory medium for the representation of disability because by definition it involves self-representation" (3). This paper has taken the memoir of L.Subramani, who is the Chief Copy Editor at Deccan Herald, holds about twenty-five years of experience in journalism and works as an online content creator. This book is a recollection of events when he was affected by Retinitis Pigmentosa, a medical condition that resulted in his gradual loss of vision. Subramani himself clearly states the cause of this disorder in his work. It is caused by consanguinity, "a kind of genetic similarity usually found between a closely related male and female. The weaker gene in them could possibly express itself as a disability in the offspring" (72). Subramani was fifteen when he was diagnosed with the disorder and in this work, he vividly narrates the shock and the feeling of helplessness of his family when encountered with a condition that has no cure. He also records the psychological impact of a sudden disability, the ensued rituals and his coping strategies that aided him towards accepting his new reality.

Acquired Disability and Its Challenges

Disability can be either congenital (inborn) or acquired because of illness, accident, or environmental factors. "Unlike congenital disabilities which are present at birth, acquired disabilities develop later in life, altering individual's abilities and necessitating adaptation to new circumstances". (Peer Support Network). The severity of the condition often determines the disability that affects the major aspects of patients' lifestyle. In order to adapt, individuals with acquired disabilities had to make use of the rehabilitation services. This process teaches the necessary information about that disability and helps with the strategies to cope. Individuals with acquired disability usually experiences stress, depression, and isolation. These people often struggle to adapt and undergo various stages of emotions in the process of accepting their new self. Elisabeth Kubler Ross, in her book, On Death and Dying, lists out five stages of grief one experience when faced with terminal illness. Some scholars of disability studies applied them to the process of acquiring disability since the emotional journey of losing oneself is similar to losing one's past self. Kubler Ross has laid out he five stages as Denial and Isolation, Anger, Bargaining, Depression and Acceptance. This article applies Kubler-Ross's five stages of grief to Subramani's memoir and examines his journey of acceptance.

First Stage: Denial and Isolation

The memoir begins with Subramani's first day at school in his higher secondary. He has taken up the commerce stream and shares how his classmates nicknamed him ‘four eyes’ as he wears spectacles. He further expounds the difficulties of wearing glasses at a young age as it might hinder one from playing sports. The fear of breaking them prevented his presence from the sporting arena. Subramani also shares about his yearly eye check- up at Dr. Rakesh’s clinic. That day, once he got over with the examination, he was asked to step outside for a moment and Dr. Rakesh informed his mom about the medical condition, Retinitis Pigmentosa. When he was informed that he could go blind, he could not believe how a person could go blind all of a sudden. He writes the horror he felt thus: “To me, blindness or vision impairment is no different than coming across a three-eyed monster on our street corner” (19). Only when his uncle, Dr. Raman confirmed that his condition is real, did Subramani realize the gravity of his situation. Kubler-Ross in her seminal work, writes about a patient who isolated herself in order to come terms with her illness. Here Subramani does the same. Even when he felt like sharing his disorder with his friend Balu, he hesitates. He writes thus: “At this moment, it feels right to pour out my heart and let Balu know of the diagnosis and its devastating impact. But I hold back, fearing that I might sound like a cry-baby before a friend and risk losing his respect and friendship” (29) and “Moreover, I wouldn’t like to become the object of sympathy among my peers” (30). The other symptom of the first stage is denial that lasts longer than isolation. Subramani exhibited denial until he was almost blind but he half-heartedly accepted his condition. “Denial is usually a temporary defense and will soon be replaced by partial acceptance” (40). He started believing in rituals and quips, “Belief in rituals is not such a danger when compared to the denial of the condition itself” (32).

Second Stage: Anger

Kubler-Ross explains how the terminally ill patients get angry by the fact that they could not enjoy the activities they used to cherish. This happens with individuals with acquired disabilities too and they get angered by their incapacity. This state of anger could be observed in Subramani’s narrative too. He describes an incident when his vision suddenly fails him in a movie theatre. He was unable to find his seats in dark and had to dragged down in his seat by his friend. He couldn’t walk to school as the sun’s harsh glare would make it difficult for him to navigate the Indian roads. Kubler-Ross notes that, “When the first stage of denial cannot be maintained any longer, it is replaced by feelings of anger, rage, envy and resentment. The logical next question becomes: ‘Why me?’” (50). This mentality could be seen in Subramani’s memoir. He writes thus:

‘What have I done to deserve this?’ this question echoes in my mind, and I have only that helpless trembling for an answer because none of them makes sense. If everyone really thinks that this is the result of some unknown sin, as many godmen and people seem to suggest, I’d like to know how serious a sin is that. Had I known I would have probably bartered an arm or a leg to retain my eyes because I do realize their importance…..What loving God would let one of his creations struggle like this? (68).

This anger and frustration found in Subramani’s writings proves that it is a phase in the journey towards accepting disability.

Third Stage: Bargaining

Kubler-Ross defines this state as “If we have been unable to face the sad facts in the first period and have been angry at people and God in the second phase, maybe we can succeed in entering into some sort of an agreement which may postpone the inevitable happening” (82). Born in a Tamil Brahmin family that believed any problem could be solved by prayers, Subramani observes how, “all worldly remedies naturally take a backseat” (20) in his household. He recounts the numerous bargains his mother did with God, middlemen and alternative medicine. She consulted so many astrologers, many of them suggesting that his blindness is the result of his karma. He went on pilgrimage to Nattarasankottai, Samayapuram and other shrines. In one of the temples, he was "instructed to perform the 'roll-on' prayer. I had to lie down on my stomach, wearing nothing but a white wet cloth around my waist, and roll over the entire length of the long granite passage around the sanctum sanctorium….this ritual would enable me to absorb the divine energy stored in every inch of the temple's floor" (51). Subramani asks whether they would do anything about his defective genes, the real cause of Retinitis Pigmentosa.

Fourth Stage: Depression

Subramani recalls an encounter with blind schoolmate. When he saw him for the first time, he had numerous questions in his mind about blindness. Slowly depression kept in when he could no longer study, play cricket or even ride a bicycle. Because of this condition he lost his school years and failed exams. His future became uncertain. The stares and questions of people demotivated him. He lost the positive outlook of life and couldn't believe his own eyes anymore. He shares a vivid dream that reflects his depressed state and fear. In that dream he sees a man wearing a pair of dark glasses, walking with a stick. He realized the man in the dream was himself. He writes thus:

Terrified, I sit up. My heart is pounding and sweat is trickling down my temples. I am breathing heavily staring wildly at the darkness surrounding me. The boy I saw in the dream was me! 'Is that real? Will I really…?' I take a few breaths to get a grip over myself. 'It's just a dream. It's alright. I'm not blind…I won't be…'(112).

Fifth Stage: Acceptance

Kubler-Ross states, "Acceptance should not be mistaken for a happy state" (113). Subramani when he got the opportunity of sight seeing in and around Kerala and Karnataka, he was hesitant at first. Later with his mother's insistence, he went to tour the great temples and beautiful landscapes. He wonders, "Would I be seeing more of these mesmerizing images or was this some kind of finale before the lights went out forever?" (136). His words at this stage were void of any anger or depression, revealing that he is on his way to acceptance. Subramani, at the end of this book was still few steps away from accepting his disability but his vision was completely deteriorated. His steps became doubtful and his posture has stooped. He ends his work thus: "If someone had told me that he'd welcome blindness and accept it more in relief, I would have laughed at him, but now anything seems better than this hell" (156).

Conclusion

A study on the difference between congenital and acquired disability shows that the psychological impact is greater in acquired disability since there is pressure in adapting to an altered reality. Disabled people who encountered impairment later in their life struggles to accept and adapt. This loss of identity and self-esteem is clearly portrayed in Subramani's Lights Out. While grappling with blindness himself, the author had to face social stigma as well. Many of his neighbors pitied that he would be useless. This stigma of assuming a blind man useless angers Subramani. His work candidly records the confusion and helplessness of a teenager who gradually loses his sight. His journey towards acceptance has thus traversed all the stages proposed by Elisabeth Kubler-Ross. Topics for further research includes Blindness and its stereotypes, Disability Culture in India and Inclusive Education.

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