

Life-writing and the Disabled Self in the Works of Oliver W. Sacks

Sandeep R. Singh

The term life-writing is not easy to define as it encompasses varied modes of self-narratives and it does not follow any one particular style, structure, theme, trope or literary genre. Several critics have attempted to define this form of writing by extending their horizons to all possible forms of self—confessional, experiential, recollective. Life-writing, as Zachary Leader defines it, ‘is a generic term used to describe a range of writings about lives or parts of lives, or which provide materials out of which lives or parts of lives are composed.’ (2015, 1). Life-writing as a form therefore encompasses sketches, memoirs, vignettes, anecdotes, musings, confessions, biography, autobiography, memoir, testimony, letters, oral narratives, fictional and non-fictional interventions into narratives of everyday, (psycho)pathologically marked discourses, trauma narratives, confessional narratives (ranging from religious to online blogs), and narratives of illness or disability. However, the list of such writings is ever expanding, especially now, with the advent of different forms of cyber technology and social media. As Leader states in the “Introduction” to his edited anthology *On Life-Writing*

Some writers on life-writing distinguish between shorter forms, conceived of as source material, and ‘life-writing proper’ or ‘extended life narratives’ or ‘formal biography and autobiography’; others distinguish between life-writing that is exemplary or formulaic, often associated with older periods, and the sort that seems or seeks to express more modern qualities: authenticity, sincerity, interiority, individuality (2015, 1)

The “modern qualities” of life-writing that lend itself to the affective, has—as suggested by Leader—facilitated a premise for an engagement with the interiority of experience in the pursuit of an authentic subjectivity. The reiteration of an authentic subjectivity becomes crucial within the domain of hegemonic, violent and oppressive structures that enable the discourse of normativity. Therefore, life-writing as a form, since its inception, has engaged with the narratives of the afflicted and marginalised and this resonance of voices speaking from marginal and liminal spaces characterises life-writing even today. Experiential accounts of battered and raped women, victims of the holocaust, homosexuals, slave narratives, and people who suffered from the traumas of caste atrocities, racism, war, and social exclusion have found voice in this form. Similarly, it is only after 1980s that the narratives of the disabled—who have been “For centuries.... oppressed and repressed...isolated, incarcerated, observed, written about, operated on, instructed, implanted, regulated, treated, institutionalized, and controlled to a degree probably unequal to that experienced by any other minority group” (Davis 2013, xv)—began to emerge in the form of life-writing. Some examples of this are Hellen Keller’s *The Story of My Life* (1903), Irving Zola’s *Missing Pieces: A Chronicle of Living With Disability* (1982), Fern Kupfer’s *Before and After Zachariah* (1982), Lucy Grealy’s *Autobiography of a Face* (1994) and Lennard J. Davis’ *My Sense of Silence* (2000).

In her essay "Coming to terms: Life writing – from Genre to Critical Practice" Marlene Kadar argues that:

Life writing as a critical practice....encourages (a) the reader to develop and foster his/her own self-consciousness in order to (b) humanise and make less abstract (which is not to say less mysterious) the self-in-the-writing. Thus, there are many forms, or genres, in which a reader may glean this written self, but we usually think immediately of autobiography, letters, diaries, and anthropological life narratives, genres in which the conventional expectation is that the author does not want to pretend he/she is absent from the text. Add to these original life-writing genres the fictionalised equivalents, including self-reflexive metafiction, and life writing becomes both the 'original genre' and critical comment on it, and therefore the self-in-the-writing. At its most radical, the critical practice of life writing enhances reading as a means of emancipating an overdetermined 'subject,' or various subject-locations (1992, 12).

While life-writing need not necessarily locate itself in the first-person experience, it does tend to adopt the first-person narrative. By attempting to perceive itself from a third-person perspective, it also tries to understand the 'other' from a first-person perspective. While engaging in each of these activities the narrator 'transgresses' the boundary between the 'self' and the 'other'. Thus, the engagement of life-writing as a genre would be to make the realm of the unexperienced real to the reader, and also conceive of the 'other' as a complete being in the world. In as much as this is concerned, Bakhtin's notions of self and other dynamics as articulated in *The Problems of Dostoevsky's Poetics* are relevant:

The consciousnesses of other people cannot be perceived, analyzed, defined as objects or as things—one can only *relate to them dialogically*. To think about them means to *talk with them*-, otherwise they immediately turn to us their objectivized side: they fall silent, close up, and congeal into finished, objectivized images (1972, 68).

The experiential mode of discourse embodied in life-writing allow for the 'reader to glean' identities and communities beyond the familiar but also more significantly those that operate from the margins or spaces of liminality. As apparent in the Bakhtin quote, relating to the other prevents the other from becoming a mere objectivised persona. In as much as this is concerned, while one is addressing concerns of subjects who were sufferers of historical victimisation—slaves, victims of the holocaust, untouchables, women, homosexuals and the disabled—who have been operating from the periphery of social normativity, life-writing accords them a mode of subjectivisation. Further, life-writing allows for the self-consciousness of the subject who is also the other for the reader to permeate the self of the reader. In doing so life-writing also enables for a potential engagement and counteraction of dominant discourse.

The recounting of life stories whether in the form of oral narratives or biographies is influenced by both experience as well as peculiarities of genre. For instance the American slave narratives of the early nineteenth century that were initially recovered in oral form and were documented towards the late nineteenth and the early twentieth century provide a historiography of violence and pain through experiential narratives. However, the very genre of oral history lends itself to '...the search for a connection between biography and history, between individual experience and the transformations of

society....' (Portelli 1998, 25) Thus, genre also plays a vital role in the realm of life-writing owing to the way it enables the representation of the self.

Derrida in 'The Law of Genre' argues 'Every text participates in one of several genres, there is no genreless text...yet such participation never amounts to belonging'(1980, 212). A text while operating within a genre is seemingly determined by it or more specifically the genre might at a certain level effect the narrative but because for Derrida the law of the genre is transgressive, i.e. the text operates within a genre through participation and transgression, the text also moves beyond genre confines. Life-writing like memoir, testimony, biography, oral narratives are therefore marked by genre 'demarcations', however, narratives of self-consciousness allow for the articulation of subjectivities that move beyond the confines of genre. Derrida's position in the essay is also about what constitutes the 'inside' or the 'outside' of a text. This position is vital when, specially within the purview of life-writing, one is looking at experiential narratives articulating positions of the self inside the text being negotiated by the other outside the text. In connection with this idea, the chapter seeks to navigate the terrain of life-writing and disability discourse to question the means of subjectivisation offered in the dialectics between abled-bodied others and the disabled self. This premise will be examined through the works of neurologist and writer Oliver W. Sacks (1933-2015). However, before such an examination it would be helpful to trace an epistemology of Disability Studies.

It is in the early 1960s that Disability Studies began to emerge as a field of inquiry, the primary focus of which was to provide a position that came from a medical approach wherein matters related to cure and rehabilitation were given impetus. It was a discourse largely emerging from the perspective of an "ableist" position which to a great extent undermined the voice of disabled individuals. In the late 1960s and 70s, however, there was a slight shift in the existing discourse. During this period, Disability Studies departments were established in a few Western universities to study and challenge the existing medical model of disability. A critical framework was also being built to create a social model whereby an inclusion of persons with disability in the society could be made possible through a criticism of the social barriers that perpetuate disability. This was largely attempted by the disabled thinkers and activists themselves, who began to question the very notions of "normalcy" and began to raise questions about who belonged where and how one had come to belong where one did. While the battle for survival and the demand for inclusion continued in this period, not many writings of the disabled self emerged.

Though Disability Studies emerged as both an academic field of inquiry and an area of political activism, it was only in the next decade that Disability Studies as a new discourse could 'claim space in a contested area, trace its continuities and discontinuities, argue for its existence, and justify its assertions.' (Davis 2013, xv). Thus, Disability Studies encountered another major shift wherein experiential narratives began to find a position of reckoning. Some of these narratives were written by disabled writers themselves, while most of them still remained to be the narratives written by the abled-bodied others, who recorded the extracts of the lives of the disabled self through their engagement as care-givers, therapists and friends and family members; who had direct access to the trauma faced by disabled persons and the coping mechanisms they developed to survive in this world. It is only in the last decade and a half that the proliferation of the experiential narratives of the self by the disabled

themselves has gained momentum. The emergence of this self-narrative has facilitated disability discourse to enter into other disciplines like Literature and Cultural Studies, Psychology, Gender Studies, Sociology, Economics, Political Science and so on. On the one hand, Disability Studies engages with questions of the body, identity, sexuality, normativity, poverty, accessibility, issues related to exclusion, rights and policies, and so on through an epistemology of disability, and on the other through activism, self-representation, community and groups of disabled individuals under the rubric of call to action to achieve what has so far been denied for persons with disability.

Within Disability Studies, experiential narrative has created a special moment of consonance and dissonance which allows the able-bodied other to move away from the sympathetic moment of association to the empathetic moment of belonging. This specific relationship can only be established through continuous involvement with the disabled self and observing the challenges faced by them in adapting to a world which so far the 'other' has not been able to delve into. This form of involvement can be realised in the form of a parent, partner, care-giver, therapist, neurologist, or councillor. It could also be a friend, a well-wisher or a teacher who observes one's life from close quarters. John Lehrer in his article "The Listener" suggests about Oliver Sacks that a neurologist has to be in constant connection with his patient to observe the slightest of changes that the patient experiences to mark her/his alternative ways of being. By which he means that a therapist or a neurologist cannot afford to disconnect with their patients at any time, lest they may miss out on the biggest leap that the patient may have taken in her/his recovery. Especially, when a therapist or a neurologist is converting a case study into a life narrative, these small but yet important details may represent a greater reality of the patient who otherwise cannot represent herself/ himself. At this juncture, I would like to illustrate this point by providing what Hans Render has to say about a life writer, in comparison to an autobiographer:

...the Life Writer adopts the stance of a therapist. The subject is declared a sacred and infallible source. Every bit of information that the Life Writer obtains from the subject is considered exciting and worthwhile. The critical contextual analysis of research materials, so important for academic biography, is omitted. This cultural-historical confirmation of solidified victimization at its best is not only a fundamental watershed between biography and Life Writing, but also between scholarship and well-meant therapy. (2014, 174-5)

It is in this milieu that I wish to explore the inter-relationship of life-writing and the narratives of illness and disability. As Renders points out life-writing's primary preoccupation is not a deconstructive critique but the articulation of a narrative imbued with a potential sense of catharsis. This has to be read as a movement away from the restraint of normative discourse to alternate modes of articulation available outside of a conformity to definitive identities like victim or survivor. Therefore, life-writing of the disabled self enables a movement away from the patronising tokenism that either extends sympathy or valorises the disabled identity to allowing for a disability discourse to undercut the normative. For instance, Sara Newman in her essay 'Disability and Life Writing Reports from the Nineteenth-century Asylum' notes, historically, especially before the twentieth century, issues of access to accommodation and education have constrained all individuals with disabilities, preventing most from acquiring the means to self-express and thus to present a public voice. Nonetheless, individuals with disabilities in past centuries have found ways to present their own perspectives on creativity, difference, identity,

politics, and other issues. The forms these earlier statements have taken, the individuals who succeeded in speaking, and the stories thereby told offer significant insights into lives otherwise lost.

In his essay, 'Disability, Life Narrative, and Representation', G. Thomas Couser argues that 'one of the most significant developments in life writing', within an American context (this is also largely applicable to most of the western world), since the 1970s has been the 'proliferation of book length narratives' from both first and the third-person point of view of living with illness and disability.' (2013, 456) Life writings engaging with disability can be traced from the Second World War. As Couser remarks that 'war both produces and valorizes certain forms of disability; not surprisingly, then, disabled veterans produced a substantial number of narratives after the war' (2013, 457). Couser goes on to examine how 'the post- World War II cultural phenomenon was the generation of large numbers of narratives about a small number of conditions', in contrast, he argues that a 'complementary phenomenon has been the production of small numbers of narratives about a large number of conditions...' (2013, 457). Couser very quotably puts it: 'As the twentieth century drew to a close.... many disabilities came out of the closet into the living room of life writing' (2013, 457).

It is in the interstice between the varied critical positions stated that I wish to locate the genre of life-writing through the works of Oliver W. Sacks, a neurologist and writer who gives experiential accounts of several diseases and disabilities through narrating the lives of his patients. Sacks' work reflects that he is concerned above all with the way in which individuals survive and adapt to different neurological diseases and conditions, and what this experience can tell us about the human brain and mind. Sacks' stories are based on neurological cases such as Tourette's syndrome, Autism, Parkinsonism, Musical Hallucination, Phantom Limb Syndrome, Schizophrenia, Retardation, Alzheimer's disease, and other disabilities encountered by him as a physician. His association with his patients has led him to study the medical history of some of these cases which he uses as a reference in order to present the case in consideration. In representing their neuro-pathological conditions, Sacks in his preface to *The Man Who Mistook His Wife for a Hat* affirms that a neurologist cannot study any case without looking at the subjective experience of the diseased. *It is this basic connection that Sacks as a physician establishes with his patients that allows him to heal his patients, letting them recover their 'sense of self'.*

Thus, this chapter will now examine how the narratives of non-personal accounts of disability can be studied from the perspective of the able-bodied other through Bakhtin's analysis of the dynamics of the relationship between the self and the other. Bakhtin in his *Dialogic Imagination: Four Essays* (1975) argues on the lines of how the self discovers itself from the experience of the other and how dialogicity between the two precipitates this action. It is through this interdependency of self and the other which is enabled by the dialogicity that exists between them that aids the constitution of the self from the perspective of the other. It is within these circumstances that Sacks' experiences with his patients creates a moment of 'empathetic epiphany' in his writings. Hence Sacks' narrative is marked by his uncanny ear for the consonances and dissonances of being. He believes 'we underestimate the power of listening,' he goes on to say that: 'it is by listening to our patients that we can discover their humanity. It is the only way to grasp what they are going through'. (Lehrer web)

It is through a close association of Sacks with his patients that the narrative of the self from the perspective of the other vis-à-vis the voice of the narrator emerges. Sacks in his *Preface* to the original edition of the book *Awakenings* (1973), claims,

My aim is not to make a system, or to see patients as systems, but to picture a world, a variety of worlds - the landscapes of being in which these patients reside. And the picturing of worlds requires not a static and systematic formulation, but an active exploration of images and views, a continual jumping-about and imaginative movement.
(1973, xviii)

Sacks utilises the narratives of his patients to create an arena where the disabled experience gets expressed. He explores an active image of an imaginative movement in describing their 'thoughtscape'. The term 'thoughtscape' is taken from Wittgenstein's *Preface* to his *Philosophical Investigations* (1953) wherein he talks about the necessity of depicting the landscape of the mind or thoughtscape by images and remarks to denote the most complex sufferings and the thoughts which are most difficult to grasp or express.

While Sacks focuses on the aspect of disability, he also gives us some of the other idiosyncrasies and positive approach that his patients have with which they continue to live life and accept their disability. Sacks in most of his stories changes the names of his patients, the name and the location of the hospital where they live due to his professional constraints, but he does try to preserve the feeling of their lives, their characters, their illnesses, their responses and the essential qualities of their strange situation creating a landscape of their being. He also narrates the changes that disability brings in to the lives of his patients and how they apply themselves to a new mode of living. In appreciating the lives of his patients with imaginative lyricism, Oliver Sacks convincingly ushers his writings into the domain of life writing.

The imaginative element in Sacks' narratives enhances the aesthetics of 'life cases' of the patients and assists in moving the 'cases' over the threshold of medico-pathological discourse into the realm of creative rendition. The imaginative element situates his writing in the purview of a semifictional mode that is however largely marked by the narratives focusing on the human spirit, 'preservation' of the 'self', and studying the identity of the patients to reflect upon the inner worlds that they create during their illness.

Sacks in *Awakenings* (1973, Rev Ed. 1990), narrates the medical history of a group of patients who had contracted sleeping sickness (*encephalitic lethargica*) after the First World War. Sacks administered them with an experimental drug L-Dopa as part of the cure. This drug had an astonishing and immediate effect of 'awakening' these patients from their decades long sleep. Sacks' chronicles the changes in the lives of his patients brought about by L-Dopa. The book also looks into the basic care and question of health. Sacks' states,

...when I came to Mount Carmel I did not just encounter 'eighty cases of post-encephalitic disease,' but eighty individuals, whose inner lives and total being was (to a considerable extent) known to the staff, known in the vivid, concrete knowing of relationship, not the pallid, abstract knowing of medical knowledge. Coming to this community - a community of patients, but also of patients and staff - I found myself encountering the patients as individuals, whom I could less and less reduce to statistics or lists of symptoms. (1973, xxvii)

Sacks here seems allied to the notions of a Bakhtinian dialogic engagement between the patients and staff, this terrain of the self and other dynamics mediated through the genre of life-writing moved beyond the sterility of medical discourse and engaged with the human subjects participating (rather than 'objectivised') in them. 'So what one studied, was not just disease or physiology, but people, struggling to adapt and survive'.(Sacks 1973, xxvii)

Sacks' third book, *A Leg to Stand On* (1984) is an autobiographical testimony of his experience after sustaining an injury in his leg. Sacks was gored by a bull in the mountains of Norway and had to face a period of recuperation during which he experienced what it felt like to be a patient—Sacks claims that his injured limb felt like an alien appendage to his body. This book offers a unique perspective of a neurologist who has become the patient and simultaneously analyses one's identification with the body. Hence it suggests that though Sacks' writings are based on his case studies, they do take up concerns which are not narrowed to the confines of illness and its cure. Sacks' writings address the emotional experiences of his subjects and their ways and means of adapting themselves in their socio- cultural milieu.

Sacks' narrativising the case studies of his patients has been criticised by critics like *The Nation's* columnist, Alexander Cockburn and disabled British academic Tom Shakespeare for depathologising his subjects, by presenting their obscure neurological conditions in nonclinical language. Couser in a lecture titled 'The Case of Oliver Sacks: The Ethics of Neuroanthropology' presented by him at Indiana University on 24 October 2001 evaluates Cockburn and Shakespeare's arguments against Sacks. He addresses the questions of the ethics of representing the disabled experience in Sacks' writings about his cases. Couser in the first half of his lecture explores how some of the reviewers of Sacks' writings have been critical in their responses. He quotes Cockburn, according to whom Sacks' works are a high-brow freak show that invites his readers to gape at human oddities. Couser also highlights that reviewers of Sacks claim that he functions, '...as a genteel contemporary Barnum who displays his cases with often devastating (and generally irremediable) conditions that place them at the border of humanity as cautionary examples of calamities that might beset his audience.'(Couser 2001, web)

Couser's lecture also illustrates how Sacks' in studying people with 'neurological anomalies' makes an argument for the emergence of a community of the neurologically affected. This community identity diminishes the divide between the affected and the non-affected, between the patient and the physician thereby enabling a levelling of the power hierarchy that makes the physician dominant and the patient subservient. In spite of these criticisms that are labelled on Sacks' work I wish to locate his writings within the interstice of medico- humanistic concerns. By this I imply that even though there is a divide between the physician and his patients that excludes the physician from the community that he engages with, he is nonetheless able to adequately bring out their subjective experiences and in doing

so accords them with a space that counteracts the normative order by attempting to present the neurological disorders in the form of ethnography rather than pathology, creating what Margaret Rose Torrell claims as 'emancipatory disability community'. I believe Sacks' writing is also contributing to this group identity of the disabled community by providing representation to those who have been isolated from this 'emancipatory disability community.' Thus, in conclusion, I would like to put forth the point that Sacks in creating an ethnographic mode of generating a disability discourse manages to resuscitate disability discourse from the margins of scholarship and creates a space for it that challenges the normative. Simultaneously, he also succeeds in subversively normativising discourses on disability by deliberately using the mode of the narrative to investigate his case studies. He removes his patients from the isolation of being othered by becoming the other voice that can articulate their disabled self. By narrativising the case studies of his patients, he does not merely look at them as objects of medical study but also as subjects of an alternate experience. Sacks familiarises his reader to the disabled experience through the narratives of life-writing that mediate an elimination of the divide between the able-other and the disabled self.

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