

Disability and Life Writing: A Memoir of Wheel Chair User Fulbrighter to America

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Abstract

The present article is a nobody narrative related to physical disability, which is more important since it is related to my odd body. The nobody narrative becomes significant and coincided with physical and mental disabilities in life writing. A part of the culture, memoir is the most visible genre of life writing because it is the most literary one and part of daily life. In this way, it will reflect a part of the life of an Indian mobility disability person who goes to America. The present memoir has unique democratic potential because it not only discusses the pains of the disabled in the community but also in an alien society. In the age of memoir, it will be among the few disability life writings to show the status and respect of disability changes according to the development of the society and the country.

Keywords: Disability, Memoir, America, Pain, Fulbright, Wheelchair, Autism, Disability Life Writing

Disability refers to the physical, social, cultural, legal and architectural obstacles. Disability is an essential part of our culture for centuries but now it has generated a large body of self-representation in the form of personal writings. Life writing is becoming popular in disability studies in the twenty-first century. It is a kind of first-hand source for the existing disability and its social perception. Probably it is the reason behind its wider acceptance in the academic world and sometimes adapted into films, documentaries and books. We can classify disability-related narratives into two categories based on their author i.e. the somebody narrative and the nobody narrative. Somebody's narrative's author is known before its publication and the nobody's narrative's author is known only through its publication. There is a significant increase in nobody's testimony in the last several decades with the rise of self-awareness among the disabled. Several persons are writing about the personal experiences of their disability relating to childhood, physical, mental and catastrophic memories. If we keep the traditional born or childhood disabilities aside, persons mention life-changing events, suffering, and pains in their life writing such as childhood abuse, childhood alcohol, violence, quadriplegia, amputation, disease, death, madness, addiction, brain damage etc.

The rise of disability life writing shows two interesting distinct patterns. First, very few conditions have produced a large number of narratives such as autism, Alzheimer, breast cancer, blindness, deafness and paralysis. Second, a large number of conditions ranging from anorexia to stroke have generated small numbers of narratives. Here the question arises that why the narrative of hitherto overlooked disabilities is popular. What makes these narratives such valuable literary and cultural properties? Disability life writings emerge from personal, social and institutional practices; probably that's why common or dominant disabilities produce a large number of narratives. Disability-related memoirs are widely shared and practised which in turn become the prime source for the representation and study of disability today. Nearly everyone has a story and tells personal stories related to daily life. Most of us write, produce and consume life narratives in our memoirs. In disability narrative form, memoir is a highly developed human activity because it is the narration of our actual lives, as we live them. Also, disability life writing describes social and cultural constraints, politics of disability, self-awareness about disability rights and the value of a particular body. Sometimes these narratives acknowledge medical discourses of disability. Life writing of achieved impairment is not the same as a disability. A person with sudden, early or late acquired impairment generally focuses on the formation of a disabled identity in life writing referring to social, cultural, legal and architectural obstacles.

It is probably not possible to give a complete catalogue of the forms of representation comprising life narratives. Certainly, the daily and the journal, private forms of life writing are important. Life writing is applied to existing modes of visual representation like portraiture, photos, internet, YouTube, social media, television and films. The oldest form of visual expression of anyone's life is the portrait, which testifies the human creativity to capture distinctive personal qualities. In ancient times, portraits were devoted to prominent people like philosophers, emperors, monarchs and nobles and gods. The invention of photography in the 19th century, the development of cameras in the 20th century and the growth of the internet in the 21st century led to the visual representation of life widely accessible to common people. Most of us are now busy recording, arranging and disseminating our life's moments with the help of new technologies. Low-cost home movies and documentary films with the help of modern cameras are quite popular today, which also come under the umbrella of life narrative. In this series, the relatively expensive biographical feature films come next with a paid actor. Today many good feature films are either documentaries or biopics, which visualise distinct genres of life writing. Biopics focus on characters defined by some disability such as Howard Hughes (*The Aviator*), Ray Charles (*Ray*) and Amelia Earhart (*Amelia*) nominated for awards. *A Brilliant Mind* (2001) was based on Sylvia Nasar's 1998 biography of John Forbes Nash, a Nobel Prize-winning economist who also had schizophrenia; *Ray* (2004) followed the life and career of the blind musician Ray Charles and the HBO documentary *Temple Grandin* (2010) depicted the life of the famous animal behaviourist and autism spokesperson. Perhaps more significant-because the subject is not a celebrity-a made-for-television movie, *Riding the Bus with My Sister* (2005, based on the book of the same title), depicted the everyday life of a woman with a developmental disability. Life writing can also take dramatic form on the

stage which is sometimes equivalent to the biopic insofar as the characters are impersonated by professional actors.

Memoir of Physically Disabled Fulbrighter to America Polio

Life narratives grasp all sorts of records of our lives. Many people do life writing regularly. In addition to the oral forms, ordinary people like me records life-changing events like the first day at school, leaving home for higher studies, marriage, etc. sometimes our friends, doctors, family or doctors also write our lives.

Life writing especially sharing a special event of our life is increasing in India today, which is a good source of effective self-representation. We can trace the start of disability life writing to the work of Helen Keller. The bulk of disability and life writing including my focuses on the very recent past. Self-publishing became cheaper and more respectable in the modern era.

My brief memoir is related to my life-changing event i.e. the award of Fulbright Nehru Postdoctoral Research Fellowship. Before I start sharing my life narrative, I would like to mention that I have physical disability since I am one year old. I acquired a mobility disability due to Polio disease. Unfortunately, I acquired this disability due to the impure vaccination of Polio. Once I came to my senses, I started experiencing the pain of physical impairment due to the limited access to the surroundings compared to a normal child. I still remember my limited access to social, cultural, family, and physical spaces that used to cause lots of pain. Often it is hard for a normal person to know or feel this pain. Unfortunately, contemporary disability studies also neglect this suffering which is inherently connected to all forms of disability. Naturally, pain is difficult to communicate. Sometimes personal memoir serves this purpose and becomes a reliable source to express the experienced pain.

In October 2015, I travelled to the University of Virginia (UVa), Charlottesville, Virginia, in the United States of America as a Fulbright-Nehru Postdoctoral Research Fellow with my wife. I was supposed to travel out in August 2015, but I became late due to the non-availability of papers and the wheelchair required. After lots of fear, anxiety, paperwork, and restlessness for almost more than one year since I applied for Fulbright-Nehru postdoc, I came to know in April 2015 about my affiliation confirmation i.e. my final selection. It was not the end instead of a beginning of a series of new complex documentation and vaccination. Being the first orthopedically handicapped awardee, I did more documentation than an ordinary awardee being a disabled person, especially the submission of medical reports and clarifications twice or thrice. I became connected with almost all members of the United States and India Education Foundation with my endless queries, and I am indebted to them for ultimately a pleasant stay in America.

The award of the Fulbright-Nehru Postdoc fellowship was a reaction of a mixture of happiness and uneasiness for me. I was happy that my dream came true of living and researching in the United States of America, the topmost country in the world. I was worried that I am going to live and study abroad for the first time and how will I survive in another part of the world. Notably, these suspicions became double being an orthopedically

handicapped person. The USIEF's marvellous three days pre-departure orientation almost solved more than half of the doubts of common awardee but that was of little use for a disabled. The exchange of information and ideas between the current Fulbrighters and the Fulbright alumnus provided peace of mind to all. Still, I was worried about my mobility and transportation in America. I was unable to bring my modified bike to America, and I did not have a wheelchair. I was unable to buy a costly electric wheelchair for personal mobility. The USIEF agreed to half-finance my electric wheelchair after a series of emails and the intervention of my US Fulbright program officer Meaghan Wallace. It shows that once you are a Fulbright, the organization will take care of every aspect of your safe living and sound research.

The Demand and Response Transportation (DART) Program solved my transportation within the university and sometimes outside, which is a federal government-funded university program of free rides for all persons having trouble walking either permanently or temporarily. The coordinator at UVA Mrs Oliver Melissa enrolled me on this program. Being an everyday user of DART, I became friends with many yellow cab drivers such as Kenny, Ngandu, Wayne, Mark, Ali, Rob, Mike, etc. and dispatchers such as Candy, Mandy, David, Bill, Brown, etc. a service provider of DART. Altogether, on-ground housing, USIEF, CIES, my faculty host Professor John Nemecek, DART, staff of the Department of Religious Studies and libraries of UVA, neighbours of University Gardens, my wife, and electric wheelchair created a support system and made my stay at Charlottesville comfortable, memorable, and mesmerizing. I was able to enjoy my stay in the beautiful but costly small city of Charlottesville, home of American Presidents Thomas Jefferson and James Monroe with pleasant weather, greeneries, vineyards, and apple gardens. I have been asked by several Americans if it is one of the best locations in America to live, which seems accurate.

I used to hear from Fulbright alumni that it changes the life of a scholar. Now, I can say while participating in this exchange program at the University of Virginia, Charlottesville as a Fulbright-Nehru Postdoctoral Fellow that it changes the perspective of a scholar's life in reality. Altogether, it turned a disabled person into a more productive unit for both academia and society. The first-hand experience of the American environment is encouraging me to think from a global perspective. Now, an Indian scholar became an international student in the literal sense. It is a matter of pride for me to be a Fulbright scholar when I witnessed real respect and recognition for Fulbright scholars in the contemporary academic and social world. After becoming a Fulbright scholar, I can access international academia with prestige. I got a unique new identity, which separates me from other millions of non-Fulbrighters but connects me to the world of Fulbright alumina.

The biggest change I felt was when I was moving through my electric wheelchair on the streets of America. A crawling person from India reached America and became self-independent both physically and mentally. My selection in this exchange program provided me with an opportunity to represent one of the weakest sections of Indian society on an international level. I am leading the physically challenged Indian community in America by probably setting the first example in the history of Indian Fulbrighters. It was a life-changing event for me to

come to America for further study after completing my Graduate degree, which is also a story of my endless struggle. It was a big reward for me when a yellow cab driver at UVA told me that I do not suppose you are a handicapped person and you are doing more than an average person. I am amazed to say that I never felt my disability during my residency in America both morally and physically with the dynamic behaviour of fellows and the available high-class facilities. The positive attitudes, devotion to my work, and punctuality of Americans will always prompt me to think of ways to be a better person and think of a better Indian society.

Sustainable partnerships like the Fulbright fellowship connected me with American communities, which positively shaped my personality. It was a time not only for research but also for learning and participating in American culture. While I was researching, I was also focused on learning as much about American culture to be able to teach students and teachers back home about the U.S.A. After coming to the U.S.A. and settling down in the climate and the university, I started investigating many aspects of American culture to be able to live, study and research respectfully. I learned many things such as greeting ways and patterns, wishing a good day, meeting with somebody by appointment, emailing, etc. Interestingly, opposite to India, here in America everything works with email, and it is stronger than meeting someone face to face. Emailing has become a formal, authoritative, and accepted means of cultural, professional, and social interactions. With the knowledge gained from these investigations, I started feeling a part of American culture and began my participation.

My family and I almost did not miss any cultural and social events organized by Lorna Sundberg International Center, the On-ground UVa housing society, and International Students Inc. in Charlottesville, with the social activities of the University and American families. I felt welcome at these American cultural events. I had been looking forward to the big Halloween celebration on the lawn of UVa. After working in the office until the afternoon, I went to attend the Halloween party that evening and got fascinated by the Halloween spirit. Hundreds of people from UVa particular and Charlottesville, in general, crowded into the lawn in different costumes and disguises. There were decorations everywhere, games, singing, dancing and lighting. Especially, my wife and son in monkey dresses had lots of fun while collecting chocolates from every dormitory based on the lawn. I was surprised to hear that this is the largest Halloween party in Charlottesville distributing chocolates worth 10000\$, even bigger than the celebrations in Europe. I also cannot forget the Thanksgiving meal with the extended family and friends of Professor John Campbell. Professor Campbell has a unique place during my stay by providing help in settling down and marketing by offering food and bed on the first tired night. I never forget Campbell's help in my life. We were glad enough to accept his invitation for Thanksgiving and learn more about the tradition. The family picnic with American Sheila and Amber and after sightseeing in Charlottesville also allowed me to connect with the locals. I gave many dinners in my home to American families, friends, and professors and utilized this occasion to share Indian culture, religion, society, politics, and food. The sense of community celebrations and positive outlook is something I hope to bring back to my work in India. Taking time to support colleagues and friends is one of the biggest lessons I will take home with me. I learned a lot about American culture and made many contacts, which will help me to continue to make connections between Indians

and Americans in the future.

I can recall my participation in another important seminar "Global Leadership Forum 2016: Empowering Changemakers," organized by the Presidential Precinct and the UVA in partnership with the U.S. State Department at the UVA. I was very much satisfied when I got the opportunity to share my struggle, life, and career with leaders from different sections of society as an afternoon panellist in the seminar. Here, I met the leaders of under-developed countries especially Africans who brought a change in their particular communities and made contacts with them. Interestingly, I met a similar disabled American Garrett Brumfield and became friends instantly, who enjoys motivating persons with disabilities and folks who lost hope in life. I was fortunate to attend and present my research at the annual conference of the European Association for the Study of Religion at the University of Helsinki, Finland in the mid of 2016 with the help of the UVA New Horizon Travel Grant of 1000\$ and my Fulbright program officer Meaghan Wallace. It turned into a little break from my current research project and hectic schedule while exploring a new research theme. I now have contacts with scholars of religious studies based in Europe.

Conclusion

Life writing is all around us; we live and breathe it. We disabled people sometimes write a memoir to describe our life-changing events. In the past, one of the drawbacks of the memoir was its focus on disability self-representation or on the self, which sometimes limits its social and community relevance. Here, the memoir tried to transcend the limitation of community mobility and transcend national boundaries. I tried to show in this memoir that the suffering of the disabled decreases as per the available resources and community attitude as I felt in India and America. The established identity and negotiating identity in the existing society accordingly work for the status in the particular society.

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