LIFE OF BARANI DARAN S: AN INDIAN AFFECTED BY ESSENTIAL TREMORS IN BOTH HANDS

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Abstract

There is lack of qualitative research articles both in India and abroad where a person with special needs has documented his own life. This autobiographical qualitative research article would bring out the varied aspects pertaining to life of the researcher as an Indian affected by neurological disability termed as Essential Tremors in both hands. More number of research as well as research articles should be documented on life of persons with special needs. It would enlighten common man about life of differently abled persons, their problems, perspectives, family conditions, etc. This research article is very much relevant to India as there is lack of awareness on life of differently abled persons among people of our country. This research article is a step towards bringing out acceptance for uniquely talented persons in our country, which in turn would contribute to social inclusion in true spirit. This research article would bring out suggestions for bringing out realities of life pertaining to differently abled individuals in India.

Background of the research article

It is revealed from the Census of India 2011 that there are 2.68 million people with disabilities in India who constitute 2.21 percent of the total population. People in both rural as well as urban areas of our country may lack awareness on life of differently abled persons among people of our country. Awareness about life of differently abled souls in society is essential in India for their acceptance, survival, empowerment and contributes to social inclusion of them (as cited by Barani Daran, 2020).
Critical analysis of literature pertaining to disability studies in both foreign countries and India reveals that there is lack of comprehensive research work or qualitative research article in both India and abroad documenting life of differently abled persons among people in society.

**Statement of the research problem**

This autobiographical research article would enlighten on various facets of life pertaining to the researcher as an Indian affected by neurological disability termed as Essential Tremors in both hands since birth. It would bring out suggestions for bringing out realities pertaining to life of uniquely talented persons in India.

**Significance of the research article**

**Disability studies discipline**

There is lack of research articles documenting the life of person with special needs in both India and abroad. Hence, this research article would add to the body of knowledge and existing literature in the discipline of Disability Studies in specific.

**Interdisciplinary significance**

It also has interdisciplinary significance as it adds to the existing literature in Social Work and Sociology as life of persons with special needs are relevant to the above mentioned disciplines.

**India**

It is relevant to India as there is still lack of research work on life of differently abled persons among people of our country.

**Indians**

This research article draws attention on various aspects of life pertaining to the researcher. It is needed for their social inclusion in true spirit, sustenance, growth and empowerment of persons with special needs.
Researchers

This research article would draw attention to researchers into the emerging areas of research in the life of uniquely talented persons, which in turn would contribute to inclusion in true spirit.

Differently abled persons

This research article would draw attention to the life of researcher as an Indian having disability, which in turn would contribute to inclusion in true spirit.

Scope of the research article

This research article would enlighten on life of the researcher as an Indian having neurological disability termed as Essential Tremors in both hands. It would provide suggestions for bringing out realities pertaining to life of persons with disabilities in India.

Review of Literature

Disability

“The Convention on the Rights of Persons with Disabilities (CRPD) (2006) is the first legally binding disability specific human rights convention, adopted by the United Nations gives two descriptions of disability. The Preamble to the Convention states that “Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others”. It emphasizes that, “Persons with disabilities include those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (as cited in Malvika, 2016)”.

According to Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act (PWD) (1995), “Person with disability” means a person suffering from not less than forty percent of any disability as certified by a medical authority (any hospital or institution, specified for the purposes of this Act by notification by the appropriate Government). As per the act “Disability” means - (i) Blindness; (ii) Low vision; (iii) Leprosy-cured; (iv) Hearing impairment; (v) Loco motor disability; (vi) Mental retardation; (vii) Mental illness.
According to Census of India 2011, the types of disabilities were expanded from five to eight namely: (i) Seeing, (ii) Hearing, (iii) Speech, (iv) Movement, (v) Mental retardation, (vi) Mental Illness, (vii) Any other, and (viii) Multiple disability.

Essential Tremor

“Essential tremor is a neurological condition coming under the broad category of Locomotor disability that involves shaking of fingers in hands. Person affected by Essential Tremor may not be able to perform activities involving fine motor skills like writing, drawing, painting, holding a cup of hot milk, lifting weights, riding bike, etc (Barani Daran, 2020).”

Life of Barani Daran S: An Indian affected by Essential Tremors in both hands

Family details

“My family consists of my mother, father and younger brother. My mother is a homemaker. My father has retired as a Finance Manager from a reputed organization on 2016. My younger brother has completed Bachelor of Mechanical Engineering and is currently looking for job in information technology sector.”

Birth

“I was born on 25th March, 1986 in 8 months as a person affected by neurological disability termed as Essential tremors from birth. My birth weight was very less. I was kept in incubator for 60 days.

My maternal grandparents got my mother married at an young age after completing 10th standard to her maternal uncle. Age difference between my parents is more. The above factors could have resulted in my neurological disability.”

Milestone developments

“There was delay in all my milestone developments.”
Constrictions as a result of Essential Tremors in both hands

“I have difficulties in performing fine motor skills like writing, drawing, painting, holding hot cup of tea or milk, lifting weights, etc. I cannot ride bike. My personality has been very tender since birth. I perceive that there is relationship between my disability and personality of mine. Past life events show that I had been emotional and sensitive towards harsh situations or events in life.”

School days

“My school days were the most innocent days of life. I did my schooling in Odisha (Significantly) and in Karnataka state of India as my father was working in a transferrable job. I had few close friends in my school days who are still in contact with me through Facebook. I spent majority of my school life in Nalco Nagar, Angul district in Odisha. I was blessed to visit Odisha in the month of March, 2020 for national seminar in School of Management at Kalinga Institute of Industrial Technology, Bhubaneswar, Odisha. I was blessed to visit Nalco Nagar and Angul, see my school, meet my school friends and visit important places of spiritual importance in Odisha state after 17 years of completing my school education in 2003.”

College and University days

“I pursued all my education as a full time student or full time research scholar. I did my Bachelor of Commerce degree from Bishop Heber College during 2003 to 2006 in Tiruchirappalli District, Tamil Nadu, India. I did my Master in Social Work specializing in Clinical Social Work from Jamal Mohamed College during 2006 to 2008 in Tiruchirappalli district, Tamil Nadu, India. I did my Master of Philosophy degree in Social Work from Madras School of Social Work during 2009 to 2011 in Chennai, Tamil Nadu, India. I did my doctoral degree in Social Work – Management Studies from department of Management Studies in University of Madras at Chennai, Tamil Nadu, India during 2012 to 2014. I had few close friends in colleges as well as in University where I studied. I am still in contact with all my college as well as university friends through Facebook.”
Professional experience

“I have worked as Young Professional of CAPART (An organization coming under the aegis of Ministry of Rural development, Government of India) at Tamil Nadu Corporation for Development of Women limited, Trichirappalli district from August 2008 to February 2009. I resigned the job as I got selected for full time Master of Philosophy Degree in Social Work in Madras School of Social Work, Egmore, Chennai. I have worked as University Grants Commission Major Research Project Fellow under the supervision of Dr. Thenmozhi R madam, Professor in department of Management Studies at University of Madras cum Principal Investigator (University Grants Commission Major Research Project) for the period 20.05.2011 to 31.01.2013. I have also worked as a full time doctoral research scholar under the guidance of Dr. Thenmozhi R madam during 2012 to 2014. I have also worked as Guest Faculty in Social Work department of Pondicherry University during academic year 2016 to 2017 at Puducherry, India.”

Current work profile

“I am currently an independent researcher carrying out research in the area of disability and differently abled persons. I am writing research articles in the above mentioned area and in the process of writing a book connected with differently abled persons. I am currently financially dependent on my parents. I don’t currently have full time job profile of my own. I would be joining teaching profession in Social Work discipline or research profession soon in upcoming academic year.”

Impact of disability on my life

“My neurological disability has impacted my personal, academic and professional life. I had secured mediocre marks in my school days despite of my passion towards academics as I was enrolled as a normal student despite of having Essential tremors that has an evident impact on speed of writing as well as on my handwriting. My parents and younger brother lacked knowledge about my Essential Tremors as disability until I completed my school education. I had to persuade my parents to get medical certificate for the mentioned medical condition for my welfare during my B.Com. My entire family lacked knowledge of my disability
as well as on the knowledge of laws as well as Government schemes meant for persons with special needs. My parents and my brother even lacked the knowledge of impact of my neurological disability on my personality. Entire family had suffered as a result of lack of knowledge on my disability and my personality as well.

My relatives were initially reluctant to accept me as a uniquely talented soul. They lacked knowledge on my disability, my personality and were unable to help me.

I based on my life experiences feel that school teachers, college teachers, university teachers, employers, employees, friends and common man may lack knowledge on impact of my neurological disability on my personality, health, family circumstances, aspirations and my life experiences.

I have faced a lot of harsh situations in my life, criticism and pains in life. My mental health became affected in the past as a result of adverse circumstances that I faced in my life. My life experiences have developed patience, resilience, empathy, kindness, mental strength and have sculptured me as a good human being.”

My aspirations

“I wish to settle soon in my academic profession. I wish to be a Social Work educator or researcher working in the area of differently abled persons. I feel that it is my morale responsibility as a son to make my parents happy and take care of them. I wish to get married to a life partner based on the consent of my family members after settling down in academic profession.”

Spiritual belief

“I am Hindu by religion. I firmly that there is a supreme power and his grace is necessary for every human being. I go to Hindu temples, celebrate religious festivals and worship God at home regularly. I workshop both Shiva and Vishnu. I perceive that religious practices are merely an aspect of spirituality. I firmly believe that an individual who is truly spiritual should practice it in true spirit in his or her own life.”
Personality, hobbies and Habits

“My personality is tender from my birth. I am a simple person who believes in human relationship. I am unconditionally affectionate with every person. I am an extrovert. I am emotional as well as sensitive person. I am kind, sincere, honest, straight forward, perfectionist and a person who follows integrity to his best. I strongly believe in ethics. I liking listening to Hindi as well as Tamil music, travelling, developing friendship and meeting new people. I have no bad habits like smoking, drinking, etc.”

Words of gratitude

“I remain ever grateful to God almighty for giving me an opportunity to be born in this world and for all his blessings on me. I would like to acknowledge my due regards to my parents for giving me a biological identity and for all their unconditional affection, morale and financial support till date. I would like to emphasis on affection of my younger brother towards me till date. I also would like to recognize the morale support extended by my relatives, friends, neighbours, colleagues, employers and every individual who has helped me in the smallest way possible.

I place on record my sincere gratitude to my doctoral research supervisor Dr. Thenmozhi R madam, Professor in department of Management Studies at University of Madras, Chennai for all her patience, genuine academic support, benevolent help and concern towards me as a doctoral scholar having special needs and for giving me an opportunity to work as a Project Fellow in University Grants Major Research Project on the area of work family conflict. I ever remain indebted to you madam. Your research inputs have honed my research skills mam. My passion for doing doctoral research work would not have come true without your support and motivation. I express my hearty thanks to my doctoral committee members Dr. P.T. Srinivasan sir and Dr. V.D. Swaminathan sir for all their suggestions to improve the quality of doctoral research work. I would like to express my appreciations to Dr. Khaja Sheriff sir, Dr. Satyanarayanan sir, Dr. Manjula madam, teaching staffs and non-academic staffs in department of Management Studies at University of Madras for all their morale support to me during my doctoral program. I am ever grateful to authorities in University of Madras for all their genuine academic support to me as a doctoral research scholar. I would always remember
my alma mater University of Madras with pride as an institution that has helped me in enhancing my academic as well as research proficiency.

I place on record my sincere gratitude to the Principal, Management and teachers in Social Work department at Madras School of Social Work, Chennai for their entire genuine academic as well as morale support to me during my M.Phil. program that laid strong foundation stone and ignited my passion for academic research in my discipline. I am ever grateful to the Principal, Management, Head in charge and teachers in Social Work department of Jamal Mohamed College in Tiruchirappalli for laying down strong foundation in above mentioned academic discipline during my post-graduation. I would like to express my hearty appreciation to Principal, Management, Head as well as teachers in Bachelor of Commerce department for laying down strong foundation in my under graduation. I am thankful to Principal, Management and teachers in School for all their academic help, morale support and for laying down strong foundation in academics.

I remain indebted to CAPART and Tamil Nadu Corporation for Development of Women Limited in Trichirappalli where I worked as Young professional. I am ever grateful to authorities, dean of Social Sciences, head and teachers in Social Work department of Pondicherry University where I worked as Guest Faculty. I am not able to mention name of every person as the list is long. But I wholeheartedly remember and remain grateful to everyone.”

Open Confession

“I openly accept and repent for all my mistakes, sins and misdeeds in my life. I also accept all negative facts about me. I firmly believe that life is a gift of God and is an experience. I have seen lots of downfalls and pains in my life. I am into the path of enlightenment. I respect every human being and every creation of God. I wish to end my misunderstanding with every person in my life. It comprises of both elderly people and young people as well. I am not consciously responsible for my mistakes. Past events in my life show that both my physical as well as mental health was affected as a result of harsh events or circumstances. I feel sorry and repent for my mistakes or misdeeds or sins. I firmly believe that both elderly and young people who misunderstand me would be able to forgive myself as a differently abled individual in society considering my disability, birth background, personality and genuineness in me as a
human being. I request people in society to continue their acceptance, help and support to me. Blessings of every human being in society are essential for my life and career. My best wishes and prayers are there for every person in this world.”

Suggestions

“My suggestions to bring out realities pertaining to differently abled persons in India are as follows:

Researchers and academicians

Researchers and academicians working in the area of differently abled person in India should undertake qualitative research studies on the following:

(a) Life experiences of persons with special needs.

(b) Problems in family domain, academic domain, professional domain, marital domain and social domain affecting uniquely talented persons.

(c) Employability challenges of differently abled persons.

(d) Any other contemporary research area pertinent to differently abled persons.

Non-Government organizations

Non-government organizations in India should undertake above qualitative research studies pertinent to life of differently abled persons in India after getting financial support from Government, local, national as well as international organizations.

Social workers in non-government organizations as part of their community organization program can create awareness about life experiences of differently abled persons by inviting them and their family members to give a talk to people in rural and urban community. This would enable common man in society to know about their life, their problems and challenges. It is a step towards bringing out social inclusion in true spirit in our country.
Clinical Social Workers and Psychologists

- Clinical social workers and psychologists in our country can conduct awareness among their differently abled clients and their families during individual counselling sessions about life experiences of such persons with whom they have contacts or based on their professional experience.

- They can invite differently abled persons and their family members to share their life experiences as a part of awareness program for the inpatients as well as caregivers in hospitals.

- They can create awareness among people in society as part of their community work about their life experiences by inviting differently abled persons and their family members.

Colleges and University teachers

- College as well as University teachers in India should undertake qualitative research studies on life experiences of uniquely talented persons.

- They can create awareness among people in society as part of their community work about their life experiences by inviting differently abled persons and their family members.

Government

- Government of India as well as State Governments should provide financial assistance to researchers who are interested to undertake qualitative research studies on life of persons with special needs.
Media

- More number of Indian films needs to be released based on the real life of persons with special needs.
- Newspaper journalists and book authors should documenting life of differently abled persons in India.
- More number of television serials in India should be made on life of persons with disabilities.

Parents and family members of differently abled persons

- Parents and family members of differently abled persons should join association or group specifically meant for such persons in their area or state or at national level.
- They can present their life experiences in meeting of association meant for differently abled persons. This could be a platform for persons with special needs to know about life of varied people having different disability.
- Associations meant for differently abled persons can create awareness in society about life of such persons by inviting them and their family members.

University Grants Commission

- University Grants Commission after getting approval of Ministry of Human Resource Development in Government of India should provide financial support to research scholars and academicians who are willing to undertake qualitative research studies pertaining to life of differently abled persons.”

Conclusion

This autobiographical qualitative research article has brought out varied aspects pertaining to the life of researcher. It also has provided suggestions to bring out realities of life pertaining to uniquely talented persons in India. This is essential for making the life journey of differently abled individuals smooth as well as cherishable.
Bibliography


