

Living the Exclusion While Growing Up with Physical Disability: A Case Study Using Life Story Approach

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Abstract

The article culls out the exclusionary experiences in immediate contexts of an individual growing up with a physical disability. This is the personal story of Iqbal aged 33 years, diagnosed with polio and scoliosis within three months of birth. At the time of writing the paper, Iqbal works as a supply officer in the government sector. This life story is part of a research study conducted to explore the lived experiences of adults with physical disability in Delhi. The study employs the life story approach to gain an insight into the experiences of disability, giving primacy to participants' voices. It is pertinent to hear these silenced and marginalized voices to gain an insight into their lived experiences. Besides, the interest was to understand how the context shaped the lived experiences of these individuals in becoming what they have become. The research deploys the life history method, wherein a story is constructed by an individual living the phenomenon in question while sharing the retrospective life events and narratives.

Keywords: *Life story approach, disability, experiences of exclusion,*

Life story approach and people with disabilities

People with disabilities traditionally have been facing ostracism and discrimination as they live amidst the stereotypical standards of society. They are viewed as incapable, flawed (Rioux, 2001). Over time such attitudes have inflicted prejudice and discrimination on the disabled. Gerber (2006) asserted that people with disabilities historically were seen as objects of pity, and as passive beings with their voices reproduced in lawless and powerless ways. He stressed on the greater importance of including voice of people with disabilities thus, "So powerful is the voice of disabled people becoming, and so powerful are the intellectual and ideological forces that seek to give that voice centrality in shaping the discussion of disability, that it may soon become difficult to recall that a short time ago, people with disabilities were little more than the objects of study." (Gerber, p. 245). Research methodologies deployed by several studies missed the element of inclusivity and saw disability as a duality consisting of physical or

social barriers with fewer narratives of the disabled person's personal experiences.

The life story approach includes not only internalized oppression but also opportunities for empowerment. Life stories act as eye opener for experiences and diverse realities of marginalized groups (Goodley, 2000). While sharing their stories people with disabilities spell out their needs and these unheard, suppressed voices for long, make space for new altogether different narrations of life experiences (Chataika, 2005; Chandler-Smith et al., 2014). This approach employs dialogical, interactive connections being made between the interviewer and the storyteller to collaborate and produce the story together (Ghorashi, 2008). Thus it provides the space for individuals who are ill-treated by society to have another person who gives substance to their feelings (Walmsley & Johnson, 2003).

Through storytelling in our research study, we uphold the belief that these people have rights to express and their voices need to be heard. Atkinson (2005) pointed that in sharing experiences of struggle against exclusion and

stigma and exhibiting resilience, life story approach can lead to an understanding of difficult phases of life, thus motivating an individual's enhanced sense of self and identity. The biographical method, the life-story allows the interviewer to make note of the participant's life-world in full complexity and it is a way by which the teller builds a self or an identity (Yow, 1994, p. 173) and the processes by which an individual becomes the 'whole' person (Chamberlayne et al, 2000).

Stories are the basic element of an event and reality. Through stories individuals portray who they are and what have become and the story lays the ground for having knowledge of what to do next (Somers, 1994, p. 618). The narratives enable us to comprehend the macro picture i.e. placing the individual's experiences alongside the contextual factors (Chataika, 2005). This approach depicts the personal and emic perspective of the individuals living the phenomenon in question. The story isn't just a neat order of events but how the teller makes sense of each life event and how these events stand for the teller. Life story has its significance in enabling people to make sense of their lives in a chronological fashion.

Method

Objectives: The research is based on the premise that humans are storytelling organisms who, individually and collectively, lead storied lives. People with disabilities too have past events, a history of their lives. This paper is drawn from a study that aims to examine the lived experiences of adults with physical disability. It helps understand what it means to live with a physical disability and how the self of a person evolves living with a disability and what all are the factors that shape that transition.

The *specific objectives* of the study are:

- To explore the daily experiences of living with a disability.
- To find out the experiences of adults with physical disability with respect to participation in social life, employment, relationships.
- To understand the exclusion that adults with disability face
- To understand the challenges faced at different stages of life and the emergence of self.

Sample: This paper focuses on the experiences of growing up of a single individual who was diagnosed with polio and scoliosis at the age of three months. In the larger study, for recruitment of the participants, the organizations working for people with disabilities were contacted through email and later in-person meetings were conducted. The initial participants of the study were identified from the organizations and later on referrals were taken from these already identified participants through snowballing.

Data Collection: During the recruitment process, consent form was shared with the participants and consent to participate was obtained from them. The participants were assured of the confidentiality and anonymity of the research. Rapport formation involved talking to them on neutral topics such as discussion on day to day happenings or their likes and dislikes etc. Besides this, meetings were planned around conversations or attending events such as Holi organized by the associated organization. Each session began with a casual chat on any topic and allowing them to ask any question from me as it helped in developing trust. This was followed by asking an open ended question, "Could you please share your story of life, living with a physical disability?" This allowed the participant to share his/her story from wherever he/she intended to begin and how he/she wanted to shape it. Followed by sharing of story, the participant was probed for areas that required further clarification. This process continued till redundancy, or till no new findings emerged and saturation was achieved. Between the two sessions, enough time was given to the participant to reflect, and also by then the researcher went over the interview in order to probe in for more details. All the interviews were audiotaped for the transcription process and these were transcribed verbatim.

Traditionally, disability was viewed with a medical lens. But over the past 2 decades, a shift gradually happened with disability being regarded as being exacerbated by discriminatory and exclusionary practices followed by the 'normal' mainstream, which oppressed and marginalised the persons with disability. This study brings to you insights on how living with a disability impacts the person's life, what discrimination the person faces at different stages of life, how the attitudes and comments of people affect him emotionally and what events

can help develop a disability identity, to which he came to terms with. It's a story the subject narrates in his voice, primarily aimed for you to understand what it means to live with a disability. It's Iqbal's story.

Iqbal's story of growing up with physical disability

Accepting the impairment: distress

At the time of interviewing, Iqbal was a thirty three year old supply officer working in the public works department. He had been married for a year and was active at many platforms that work for people with disabilities and other marginalized groups. Iqbal was born in a middle income group family and his father owned a small garment factory in the pockets of North Delhi. He was born without disability. At the age of three months, his mother noticed that one of his shoulders was raised and his neck was dropping to one side. She 'sensed something was unusual' and he was taken to the nearby government hospital. Here he was diagnosed with polio and scoliosis, though the initial reaction of the family was of dismay. Later, they directed their efforts for his treatment. His journeys to the hospitals began in early childhood and he underwent a number of medical procedures till he attained early adulthood. One of the procedures which involved using body brace brought in light the visibility of impairment and also it created physical, emotional and social issues.

Living the impairment:

The body brace caused physical discomfort to him as it covered his body from shoulders till lower back. Wearing this on a prolonged basis restricted his mobility and also resulted in body heat. Being encaged in body brace impacted his participation at school and as a child he missed that. In addition to this repeated medical procedures caused pain and malaise at the bodily level. Iqbal talks about his physical discomfort:

I was prescribed a body brace which covered from shoulder to hips, so that's not easy. The plastic of the brace was hard and I was somewhere bound, isolated. The brace used to pierce the neck and hip, I had physical discomfort.

Assistive device as an object of gaze

The body brace intensified the visibility of impairment and created a 'visible' difference

between him and others. The assistive device acted as a symbol of disability and he was repeatedly stared at with 'weird' eyes and he was also taunted for his physical deformity as he was labeled as, "kubda", "langda". The curiosity driven stares of the people and labeling were an inescapable part of everyday life, as Iqbal explained:

I wore this body brace even in school and children used to copy me and stare at me. I used to feel weird. I used to feel normal within myself but the way the children stared at me I used to feel weird. People used to call me, "tedha", "kubda", "kubda" word was very common.

The visibility of the impairment puts the individual with disabilities vulnerable to public stare, to examine the bodily differences and this diagnostic staring is based on discernment of the differences (Lourens & Swartz, 2016; Garland-Thompson, 2009). Such stares reproduced the notion of the body of a particular kind. The diagnostic gaze invalidates the impaired bodies that do not fit in the norm of the society (Loja et al., 2013). Disability, compounded with how 'others see the person with disability' comes to be seen as the master identity thus masking the other aspects of personhood (Shakespeare, 1996).

School as site of exclusion: bullying, social isolation, denial of participation

Seeking admission to schools was not an issue. However, social connect was missing throughout his schooling experience. Seeing no one around with similar condition what he had, he felt different and the feeling intensified because of the body brace. In school his peers maintained a distance from him, and often labeled him as, 'kubda', 'langda' etc. They didn't involve him in activities and this widened the gap between his peers and him. This gap didn't let him establish friendly connections with peers, and he felt isolated. Despite his willingness to be a part of the sports activities he wasn't asked by the teachers to participate and he felt excluded. In this regard, he further added that as a child he wished to be part of the activities and often in order to be included he avoided wearing the body brace. The social isolation seeped in due to incidents of bullying by children, and denial of participation by teachers as he spoke about his plight:

In class, I noticed that children were imitating my moves and began taunting. When children used to stare at me, I felt weird. Many times in school, sports activities are organized and you want to play but you are made to sit separately, so that thing creates a difference because of your disability. What really made me sad that no teacher asked me whether I wanted to take part or not.

Stigma attached to disability leads to social isolation of people with disabilities. The discriminatory attitudes and expectancies of other children in schools lead to stigmatization and marginalization in the school social context. Lightfoot, Wright, and Sloper (1999) found that adolescents with chronic health conditions also encountered social isolation, barring from peer activities, and felt 'different' in the classroom. In a similar vein to this, studies have shown that students living with disabilities were at risk of being ignored, bullied, and isolated at school and encounter difficulties finding friends and developing personal relationships with their peers (Davis & Watson, 2001; Edwards & Imrie, 2003; Koster et al., 2009; MacArthur & Gaffney, 2001). Establishing and sustaining friendship is necessary for the social development of children in order to promote their resiliency to life's challenges. The stigma attached to disability is deep seated and results in social isolation. Iqbal's experience affirms this. He was denied participation which thwarted the opportunities for him to build friendly ties and to be included like everyone else (Matheson, 2007). This social isolation at school had a toll on his social development. His narrative of school experiences indicate his intense desire to feel accepted, valued, feel belonged and included in the school system.

Physical infrastructure as barrier

At school, Iqbal also faced accessibility issues which worsened his physical state as most of the classes were on the top floors and climbing stairs led to breathlessness. This continued throughout the academic journey and no mechanism was put in place to address this concern. This clearly outlines how environmental barriers put pressure on the person with impairment to accommodate his surroundings. In most of the cases this is one of the reasons that puts an end to a child's education. And those who continue, negotiate as Iqbal did by stressing his limbs and bearing the pain. What becomes more relevant

here is the personal tragedy viewpoint that sees that the onus is on the individual as the system didn't seem to be bothered to bring changes to welcome this child or plan reasonable accommodations given his impairment. Inaccessible structure forced him to climb stairs which caused bodily issues as he shared:

In school classes were on the top floors so climbing stairs causes difficulty such as breathing issues, fatigue etc.

Emotional issues

Growing up in the atmosphere that reproduced the feeling of difference through dehumanizing ways of negative comments and medical gazes filled Iqbal with anxiety. He began to question himself why only he had such an issue and not others. He experienced emotional heaviness due to the daily experiences of stigma and exclusion. He once asked his father to take him to the hospital to get him cured as he shared his anxious state:

I wasn't able to accept that disease; society people say such things that you feel psychologically bad. Since childhood the word 'Kubda' was common and everyone said this, even my father's friends and this created anxiety in me that why people are saying like this. I began to ask myself why am I like this? I used to feel bad and one day I went to my father and asked him to get me treated.

The emotional responses of the children clearly convey a feeling of being stigmatized (Goffman, 1963, 1997). People with disabilities struggle with a body status that is largely governed by a medical model that brings it down to a flaw, and thus underscores the need for correction (Zitzelsberger, 2005). The societal concept of a disabled body as a deviant and a flawed one stresses on the individual to normalize the body. In Iqbal's case, the desire for a non-disabled body, led him to make repeated requests to his father to be 'treated'.

Impact of societal discrimination: negative associations with the 'self'

Regarding his sense of self, Iqbal was in a fix as he saw himself as normal, but the reactions of other children at school made him feel awkward. So he couldn't comprehend or come to terms with why they called him with names, or imitated his moves. The visibility of impairment was in the spotlight more due to the body brace

and this had an impact on his sense of self and also how his peers identified him. Having such experiences on a routine basis, he became negative and was incessantly saddled with the question 'why me' He said,

I used to feel negative and awkward due to the stares of children. I was feeling, "why me"?

The negative self-imagery became obvious due to the societal discrimination in form of negative comments and labeling, denial of participation and family experiences. With regard to developing self-perception, it is commonly observed that people with disabilities yield to societal construction of disability (Williams, 1994). Finkelstein and French (1993) assert that as a consequence of societal discrimination, people with disabilities incorporate the negative attitudes of society and thus view themselves in a negative light. Iqbal viewed himself as normal as everyone else. But the attitudes of peers made him feel 'conscious' about his bodily-self and this reinforced the 'difference' and the 'deviance from the norm' (Becker, 1963).

Family responses: concern vs. lack of emotional connect

Iqbal mentioned the supportive role of his parents in his life journey as they stayed put by his side and made all efforts for betterment of his condition. They were keen to get a cure for his condition and in this regard they tried both allopathic and traditional modes of medicine. While his father managed his education, mother catered to hospital trips. The parents were concerned and encouraging but as parents of any child with a disability they lacked the requisite skills to deal with his emotional issues as whenever he came back home from school with a dull face no one gave ears to his emotional heaviness. On the emotional front, he missed the moral support from the parents which he believed if provided could have helped him in dealing the inner conflict caused due to societal discrimination. The parental support was acknowledged by Iqbal, but what was disturbing for him was their lack of sensitivity to deal his emotional issues as he talked about their role:

Parental support was there, my mother was taking me to the hospitals and my father was managing my education. So yes they supported me, and they also tried "desi nuskas" such as applying oil or "desi dawai" in addition to going to hospitals. So they tried every effort but

they didn't know how to deal with a child like me as in, they didn't listen to my emotional issues, already I was facing comments from people and at home....no support, I felt isolated.

Relatives' remarks: prejudice

In addition to lack of moral support what was more disappointing were the snide remarks and comments of relatives who took him as incapable and wanted his family to focus more on his healthy siblings. Also they were pessimistic about his education, and wanted him to open a shop once he grows up.

My relatives were like, "what he will do by going to school? He won't be able to do anything, when he grows up, get him a shop and let him sit over there.

The remarks of relatives corroborated the societal perception of people with disabilities as passive beings, with complete lack of agency in accomplishing anything or making decisions about their life. All this added up to the anxiety that Iqbal encountered.

Relationship with siblings: ambivalence

Talking of his siblings he cited a mixed role as sometimes they were friendly towards him but whenever any disagreement happened they used to bully or tease him. So the transient tension occurred between the siblings, and otherwise the siblings were no different as like other siblings as he shared sibling interactions:

It was all normal except that at times when we have disagreements then they might push or taunt me.

Conclusion

Life story as a methodological approach has unraveled the emic perspective of the participants when they shared their stories. In narration of the stories they were the experts and they pointed at the stark reality of their inner life-worlds which was in contrast to what connotations society holds of people with disabilities. Their life stories were a journey where they depicted their agency in resisting the societal discriminatory attitudes. In narrating their life-stories they discussed the past events and how their lived experiences shaped up of who they were now and without the life story approach it wouldn't be possible to trace the events that shaped up their lived experiences and led to the change in their self-concepts. Thus, it

enabled me as a researcher to see the holistic view of the participants' lives through their stories.

Tracing the life story of Iqbal, from the time he was diagnosed with polio and scoliosis and his growing up experiences as a child with disability, it is evident that his gains across developmental domains were jeopardized. At the bodily level, he encountered the pain due to the condition and as well as the ongoing medical procedures too inflicted pain. His free movement was restricted and thus physical development wasn't a smooth one. Besides this restrictive movement, what tormented him was that his body was scrutinized in every context through the stigmatized and oppressive actions of the society. This in turn impacted his social-emotional development. Such as, in school contexts the experiences of exclusion or stares, or negative comments of relatives made Iqbal anxious. Schools are the contexts where opportunities for social development of children thrive as avenues of participation are more i.e. children participate in activities with peers and learn but in Iqbal's story such opportunities were denied. It was obvious that as a child his choice of participation was barred by denial of opportunities, and thus he experienced social exclusion. It is suggested from his story that the school hadn't imbibed the principle of inclusion and thus continued to suppress Iqbal's need to be included through its exclusionary way of being. He had emotional outbursts due to the exclusionary events as he became anxious and he began to internalize the negative views of society in his sense of self. Living with impairment comes with challenges that take into account both the corporeal ones and society related. What added more to his woes was the inability on parents' part to deal with his anxiety. Dealing with daily interactions of negative social attitudes with no emotional relief from parents, he felt isolated. He did encounter accessibility issues but that he somehow negotiated; what

took toll on his life was social apathy towards him.

Talking of the macro picture, Iqbal's experiences of exclusion, stigma and negative self-concept underlie the ableist construction of the society that sets difference between a person with disability and non-disabled based on the bodily features. These ableist images permeated every context and he found himself trapped in the disability as master identity and his personhood seemed to be lost. Living such experiences in isolation further worsened his sense of self. However, it doesn't imply that impairment effects are to be disregarded, but more than impairment effects, what broke him was the ableist discourses of the society that perpetuated the sense of difference through their disabling actions. Family is the immediate context that needs to be aware of a child's needs but in this case that connect was missing.

The complexity of contexts need to be catered before planning interventions and the research studies planned should locate the voices of children with disabilities so as to have their agency and say in what they need for optimum participation. In the present study, although the experiences were personal but they were situated and influenced by the social patterns. As Iqbal's story highlighted the underlying prejudice held by society for people with disabilities. The findings of Iqbal's story are crucial as they illuminate what events he faced that shaped up his sense of self and how life story as an approach details the holistic view of an individual's life and thus bringing to the policy makers the overall picture so that policies are planned consciously. Listening to the voices of person with disability, what one could recommend is a comprehensive approach to deal with their concerns, which could be school-parents' partnership, additionally having social policies to create empathy and awareness about disability and their rights, and concerted efforts to reduce attitudinal & physical barriers and barriers in participation.

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