

Evolution from Negative Identity to Affirmation of 'Disability Identity': Life story of a Woman with Spina Bifida in India

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ABSTRACT

Purpose: *This paper is part of a research study that explored the lived experiences of adults with physical disability in Delhi, India. It traces the evolution of a positive outlook towards disability in a young woman living with spina bifida.*

Method: *This paper is part of a larger study, and is one of the twelve narrative accounts of adults with physical disability, who had been selected to be part of the study using purposive sampling. The study adopted a life story approach wherein the participant talked about their life events in a chronological order. It is believed that stories constitute the psychological realities, including identity, and identity is expressed in sociocultural relations through talk. This paper is the life story of one woman with spina bifida and it recounts her journey depicting the dynamic nature of identity construction. Her life story gives rich insights in terms of personal and social experiences that enabled the researcher to explore the complexities in identity construction. A pseudonym, Ashima, has been used to maintain confidentiality.*

Results: *By describing her childhood experiences, medical journey, relationships, and marriage, the participant was able to make sense of the events leading up to the emergence of a positive disability identity. The daily lived realities of exclusion had instilled a sense of negativity in her but she began to affirm the disability identity after contact with disability groups. The positive role of the family was an additional factor in the participant's acceptance of her disability identity.*

Conclusion: *The paper presents the emergence of a positive identity by challenging the traditional approaches and oppressive social constructions of disability. It underscores the importance of voice, agency and the celebration*

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of disability identity, and paves the way for future researchers to listen to the insider's perspective in order to create a culture of valuing differences.

Key words: *disability, disability identity, life story, lived experiences*

INTRODUCTION

"This chair is not my wheelchair, it's my will chair, means full of will power and I feel good. This helps me in moving so I take it positively"- Ashima (2018).

Ashima's life story depicts the journey of her evolution from negativity, due to societal ascriptions to her impairment, to the proud affirmation of her disability identity. It reveals how she navigated a path through the experiences of living with a physical disability, and finally embraced her identity in a collective context of people with disabilities. Her life story clearly demonstrates that coming to terms with a disability identity was not smooth sailing but a process in itself.

Disability Identity Development and the Life Story Approach

Historically, disability has been seen as a medical tragedy that situates the problem within the individuals considering negative self-identity as an outcome of physical impairment, and the onus lies with them to correct or normalise their problem (Shakespeare, 1996). For a long time, people with disabilities have struggled with a bodily identity that was boxed in a medical model and thus reduced it to an abnormality (Zitzelsberger, 2005). This model has invalidated the bodies that do not conform to the norm, and such impaired bodies were seen as deviant, flawed and inferior (Campbell, 2008).

With the emergence of disability activism, the social model was proposed which espouses the role of disabling barriers in the environment as a root cause of oppression and disability (Swain & French, 2000). The two approaches can be understood by viewing identity as a narrative where focus is on the stories that people tell about themselves. As Giddens (1991) said, 'Self-identity is not a distinctive trait, or even a collection of traits possessed by the individual. It is the self as reflexively understood by the person in terms of her or his biography'.

To support what Giddens has asserted, it is relevant to mention the significance of the life story approach as a method in exploring identity. McAdams (1990) pointed out that identity should be seen as an autobiography project which situates a person in the world, integrates a life in time, and provides meaning

and purpose. Furthermore, stories constitute the psychological reality including identity (McGannon & Smith, 2015). For researchers adopting the narrative research tradition, identity is not something inside the individuals but it is performed through the stories that they share (Frank, 2010). Here, the participant's life story portrays the emergence of a positive identity and empowering outlook. This further emphasises that recounting the life story is empowering, which Meininger (2006) also found in research on people with intellectual disabilities. Besides, when people share their stories of struggle and resilience against experiences of discrimination and exclusion, the life story approach contributes to a better understanding of their journey, thus adding up to a profound sense of self and identity (Atkinson, 2005). The life story method offers the story teller an opportunity to recall her/his life and trace the events that occurred at various periods. The method examines "the insider's perspective of the individuals; how they understand, interpret, and define meaning of the world around them" (Faraday & Plummer, 1979). In a similar vein, Cole (2001) expressed that by giving importance on the subjective meanings and perspectives that individuals ascribe to their experiences, the life story approach gives voice to the experiences of those people whose voices remain suppressed or unheard. Given the advantages that the life story approach offers, it qualifies as a suitable method for the study.

Identity construction task is a composite one that does not take place in isolation; instead, it is expressed in the influence of socio-cultural interactions (Bruner, 1990). Disability as a negative identity emerges out of social processes that view impairment as the sole criterion of analysis (Olkin, 1999). People with disabilities may stoically accept such negative identities and take it as an individual loss. These individuals take the blame on self, and experience grief and loss personally (Shakespeare, 1996). However, research claims that there are ways in which individuals from stigmatised groups tend to manage stigma and thus try to improve their self-concept (Tajfel & Turner, 1979). There may be instances where these individuals manage disability by passing off as normal or by hiding their disability identity (Goffman, 1963). Shakespeare (1996) termed all these processes of identity management as psychologically and socially unhealthy. According to him, all these processes involve a component of denial or failure to accept disability identity; and doing this could result in a temporary identity that might affect an individual psychologically. The emergence of disability as a positive identity is a process where individuals living with impairment resist the negative ascriptions that society has attached to them, thus asserting that the problem resides in the social barriers. This also means that they reject subjection and move

into positive self-identification. This can be a self-awakening process or can take place in a collective context (Shakespeare, 1996). For people with disabilities, disability identity entails growing up with a positive sense of self, and a feeling of connection to, and affinity or solidarity with, other members of the disability community (Scotch, 1988; Gill, 1997; Olkin & Pledger, 2003).

The advent of the disability movement has led to a slow cultural shift towards a social construction of disability that identifies the prevalent nature and extent of disability oppression and offers a new lens of viewing disability as diversity to be affirmed and celebrated (Mackelprang & Salsgiver, 1999). From the disability studies perspective, identity and self tend to be viewed through an interpretation of oppressive social relations with the emphasis on changing society and empowering people with disability; for example, Barnes' analysis (1990) of the socialisation and identity formation of young people with disability. The disability studies proponents contribute to a new approach that is focused on the person's agency to counteract the challenges of oppression.

RATIONALE OF THE STUDY

Historically people with disabilities have been subjected to oppression, exclusion and discrimination amidst the stereotypical attitudes of the societies that view them as flawed and undesirable beings (Rioux, 2001; Chandler & Swart, 2014). Much of the documented research on people with disabilities focused on the quantitative aspects, thus making their experiential accounts invisible and eventually furthering the perpetuation of stereotypical attitudes of society towards them. In this regard Oliver (2006) maintained that a change in research process is a must in order to alter the prevalence of such stereotypical attitudes towards people with disabilities. This calls for listening to the perspectives of individuals with disabilities. Here it is pertinent to mention Gerber (2006) who asserted that the voices of people with disabilities are critical in defining the discussions around disability.

Thus the present study is premised on listening to the voices of people with disabilities as it is believed that their voices are crucial in sharing their experiential accounts of life with a disability. By having their experiential insights of living with disability the study attempts to fill the gap i.e. seeing the people with disabilities as passive beings with no voices of their own.

METHOD

Study Design

Gaining perspectives and experiences of those whose voices have been suppressed for long and are not heard through traditional academic discourse, lies at the heart of qualitative research (Booth, 1996). The life story approach not only caters to internalised oppression but also provides space for empowerment by bringing the diverse realities of the marginalised to the light (Goodley, 2000). Life story is a form of narrative research where lives of individuals are studied by conducting interviews with them in order to gain a detailed insight of their lives (Creswell, 2002). By hearing their stories, the study believes in the philosophy that these individuals have the right to express themselves, and their voices need to be heard. Life story method allows the researcher to see the person's life in all its complexity and all the processes that have gone into making the individual who he or she is now (Chamberlayne et al, 2000). Keeping in mind the above belief, the life story method serves as the best choice in examining the experiences of adults with physical disability who are hardly represented in Indian research. In this paper, the life story of Ashima depicts the experience of living with a physical disability in India and illustrates how she developed as an individual capable of affirming her disability identity with pride.

Sampling

Twelve participants were selected through a purposive sampling strategy meant to select "information rich cases" so as to get detailed insights about the phenomenon in question (Merriam, 2009). Ashima's story was selected from among the twelve participants' stories, as her story captured the essence of personal and social experiences that explored the complexities involved in identity construction. Ashima's life story depicted the dynamic nature of identity construction. From being trapped in a negative identity due to the experiences of living with disability, she developed as a positive individual embracing her disability identity in the present context.

She takes pride in who she is and has found the experience of living with disability as a positive one and she takes it as her strength. This positive aspect wasn't observed in the life stories of the other eleven participants as they were ambivalent when it comes to accepting disability identity, hence her story of resilience and positivity is presented through this paper.

Study Participant

Ashima, a 30-year-old income tax clerk, is a married woman. The researcher met her at one of the events of the organization (X) working for persons with disabilities, where people with all kinds of disabilities socialise and seek support. Ashima had been associated with this organisation for more than a year.

Data Collection

The sessions began by giving the participant an information sheet that contained details regarding the study, procedures, associated risks and benefits, and a consent form. Her consent was obtained after she had read the information sheet and agreed to participate. She was assured of anonymity, i.e., nowhere in the study would she be identified, and a pseudonym was used. She was also informed that her participation in the study was voluntary and she could withdraw from the study whenever she chose. Her approval was also sought for audio-recording of the sessions.

After obtaining the participant's consent, the focus was on building and strengthening rapport with her by conducting meetings in cafes, or seeing her at the events organised by the disability organisation. This process helped in fostering familiarity so that she could begin sharing her life story without any apprehensions. Once a relationship of trust was established, the interview sessions began. These were conducted either at her home or workplace, depending on her convenience. Light conversation on day-to-day happenings would be followed by the recounting of her life story. The participant was asked to begin her story of living with a physical disability from her childhood days and continue up to the present.

An interview guide, consisting of areas to be covered, was used to facilitate the discussion. The areas included, "Experiences related to daily life activities", "Describing experiences of social life", "Sharing experiences at the workplace", "Sharing the way you see yourself", etc. The sessions usually began with the participant talking about her life uninterruptedly, and at the end of the sessions the researcher would probe the areas that had not been covered. In this way additional details and clarifications were obtained. Follow-up sessions that were conducted involved clarification, elaboration and the use of probes to gather richer insights (Sparkes & Smith, 2014). This technique validated the narratives collected so far and helped in establishing the rigour of the research. The sessions were audio-recorded and transcribed verbatim for thematic analysis (Patton, 2002).

Ethical Considerations

The ethics clearance for the study was granted under the project code number 1811 by the Institutional Ethics Committee, Institute of Home Economics, University of Delhi.

RESULTS

Life Story of Ashima

Ashima (name changed) is a 30-year-old married and independent woman who works as a clerk in the Income Tax department. She comes across as a lively lady with a sparkle in her eyes, defying the image that society holds of disability. Her positive demeanour took years to evolve. Ashima has now emerged as an optimistic person who affirms and celebrates her identity. Her journey is presented in different phases, recounting the major challenges she faced and her emotions at the time.

Medical Journey: an Anxious Phase

Ashima was diagnosed with spina bifida when she was born. Spina bifida, one of the most common birth defects, occurs when the spinal column is split due to failed closure of the embryonic neural tube during the fourth week post-fertilisation (Fletcher & Brei, 2010; Copp et al, 2016). Individuals living with spina bifida present motor and sensory neurological deficits below the level of lesion, which hamper or reduce walking. Lack of sensation and urinary and faecal incontinence are other physical issues that happen frequently (Copp et al, 2016). Owing to the complex nature of spina bifida, the diagnosis and treatment begins at birth and through adulthood involving multiple disciplines (Fletcher & Brei, 2010).

As the impairment caused physical issues, a corrective surgery was conducted on Ashima when she was two years old. However, a few years later impairment related issues such as difficulty in walking and irregular bowel-bladder movements arose, to the distress of her parents. Despite unfavourable circumstances they persevered in trying to locate doctors wherever they were assured of better treatment. Consecutive surgeries were conducted which did not yield positive results and this worried the parents further. The medical journey continued till Ashima turned seventeen. It was a nightmare as, with each corrective treatment, her condition deteriorated instead of getting better. With no fruitful outcome and

lack of guidance by the doctors on post-operative care, the medical phase was a nerve-wracking experience according to Ashima.

"I wasn't told about post-surgery issues... that I was supposed to do physiotherapy or do these, do that as in like what to do after surgery. When during follow-up doctor was asked, then he said, 'What I have to do I did; now it's your duty how you would manage'. There was nobody to tell me. Because of medical line I had always faced difficulties."

Frustration at Home

The growing number of physical issues and poor treatment outcomes created emotional turmoil for Ashima. She would often get infuriated with her family members for paying extra attention to her. The frequent hospital visits that accompanied treatment procedures were physically and emotionally taxing. She began to question, "why me?", and was gradually slipping into depression.

"My nature was becoming weird on each new day... was getting frustrated. I was not willing to talk to anybody and when my parents took extra care of me I used to feel bad that why are they taking care of me. Why my mumma always say to me, 'you take care like this, do exercise 3-4 times, do physio...all this'. I was getting irritated, that every morning when I wake up there is new problem that comes up."

Feeling "different" at School

Being at school was not easy, as Ashima had to face bullying when other children commented about her physical condition or imitated her movements. There was a feeling of 'being different' when she was not involved in scholastic activities like the other children were. She described one incident where she was willing to be part of an event, but was denied participation due to her physical condition. Such episodes made her feel different from the rest of the children at school.

"Like I used to limp a bit, then children used to copy that, then I used to feel bad. Sometimes it used to happen that everyone was going to prayer ground but I wasn't, then I used to feel tormented. So all this was there. I was willing to do everything and they used to say that 'you can't do, you leave it, you sit down... you can't do it'. Like this, so this thing was more..... small- small things were more harrowing."

Facing Rude Stares and Curious Comments

Ashima's physical condition was eye-catching. Everywhere she went, people used to stare and pass belittling remarks. This made her acutely aware of her physical impairment. While growing up she was constantly being asked awkward questions. This was so irksome that she wanted to avoid people and usually locked herself away at home or kept her outings to the minimum. These societal attitudes engulfed her identity in negativity and she lost the confidence to face people.

"You don't get acceptance in society, and whenever I used to go out people used to ask me what has happened. I wanted to forget my problems and people just poke me to remind all this things, all that things. I couldn't face people that why they keep on asking me? Why are they irritating me? Most of the times they used to give weird gestures like no one was more helpless than us, such expressions they used to give, then after all this it became most difficult and I decided not to go anywhere and just be at home."

Losing Hope

Weakness due to her impairment and associated physical issues had increased by the time Ashima reached standard 11 in school. This led to further hospital visits where doctors advised another surgery albeit with minimal chances of improvement. Losing all hope, Ashima was in a state of shock and depression. This had a debilitating effect on her.

"Gradual weakness was imminent and when doctor was asked about the same and sought suggestion he said, 'okay, fine, will do surgery of spine where 50-50 percent chances will be there, either she will be alright or she will be bedridden.' That time such things like getting bedridden used to affect badly, so much that I used to cry-cry-cry.... troubling everyone..... I went into depression."

Phase of Emotional Stress: Questioning Self

Oppressive attitudes were weighing Ashima down. She began to view herself in a negative light. Loss of confidence and vexation at constantly being asked about her impairment led her to question, "why me?" The harsh attitudes of society caused her agony.

"That time people, too many of them used to ask... who all to answer, face their reactions, and gestures. My confidence was almost gone to face others, to prove myself to achieve something in life; I wasn't able to face anyone."

Assistive Devices as a Source of Shame

When walking seemed no longer feasible, Ashima resorted to using a stick. She was hesitant to do so because the visibility of her impairment invited questioning and stares from people. These made her feel ashamed to rely on assistive devices. However, her discomfort while walking increased to the extent that she finally had to use a wheelchair.

“When I started using a wheelchair, I felt that I shouldn’t look at anyone else, I shouldn’t face anyone; people were surprised all of a sudden that till few days back she managed to walk and what has happened now that she’s on wheelchair....questioning by people...”

Curtailing Social Participation

Stigmatising attitudes towards her impairment led to emotional trauma. Objectionable stares and questions by people were hurtful and Ashima cut back on attending social gatherings and avoided visits.

“I wasn’t able to face people... I was getting annoyed...frustration was there. I used to avoid going to marriages as there people will gather to ask what happened... what happened... what happened....and again I have to repeat the story.”

Visibility of Impairment: Impediment to building Love Relationships

Ashima’s visible physical impairment was a deterrent in attracting the opposite sex. She noticed a change in the behaviour of the opposite sex once they spotted her disability. This gave her a clue that nobody wanted to be in a relationship with her.

“When I keep on sitting, the person stares or look, like treated me like a normal person and when I started walking the behaviour actually changes. I didn’t like this though I wanted to be in a relationship, but nobody was willing to, just because of my impairment.”

Hiding of Disability: Discomfort at being Noticed

Ashima found it harrowing to be stared at and felt the need to hide her disability. She did not want people to be aware of her impairment as she wanted to be treated like everyone else.

"I wanted to hide my disability. I wasn't able to show anybody, I was anxious regarding this thing. I wanted to live a normal life from within. I used to feel that people should treat me like everyone else but it wasn't happening."

With Disability and Without Disability: a pronounced "difference"

At the time when Ashima was studying for the competitive examinations, she happened to meet a person without disability who grew close to her and they were soon in a relationship. The bubble burst when doubts crept in because of his hesitation in acknowledging her as his partner, disability and all, in front of his friends or at social gatherings. This deepened the gulf that is established by society between a person with disability and one without disability. A person with a disability is not regarded as a suitable choice for love relationships, as Ashima found.

"I was in a relationship with the able-bodied person. His friends knew where I live, what job I do, how I look.....means everything.....that where my father's shop is... everything...but they didn't know that I am disabled. Then sometimes I felt like why didn't you disclose it, then he said, 'I don't want to take opinion of others, like if they say anything negative to me or something like that then I don't want to listen that.' I felt that he had problem sharing my disability."

Getting married as a turning point

Ashima faced difficulty in love relationships and marriage prospects as nobody saw her as a potential partner. This made her feel that marriage wasn't meant for her until one day when she happened to meet Rohit (changed name), an independent man living with spine disorder, through one of the disability organizations. Meeting Rohit made her believe that she could also be loved, and there she decided to give marriage a chance. She described her marriage as one of the turning points in life as it made her strong in terms of love as she spoke about it:

The kind of negative reactions I was receiving from boys and later on relationship with the able bodied man which was heartbreaking... I began to feel that marriage wasn't happening...marriage wasn't meant for me. But when I met Rohit, the kind of confidence he gave, I thought let's give it a chance and I can say it was the best decision. It made me strong and when you have partner who is psychologically supporting so that matters... and I have one such.

Family as a Buffer against the Odds

Although Ashima was plagued by impairment-related issues and baffled by societal attitudes, it was the constant efforts of her family and siblings that kept her going. Her family urged her to participate in the wider context and feel independent. She highlighted the catalytic role of family in fostering positivity in her.

“Family was the greatest pillar, my foundation, my base was strong, that is my family. They stood by me as in to date I never felt that in family anyone has any problem in going out with me. My family supports me a lot, a lot. Then gradually I started moving out. Sister also said move out and then family members also made me understand regarding the same. They never compelled me for anything, always kept in comfort zone, and also supported my education.”

Meeting with an Accident: a Rebirth of Self

Till her first year of college, although walking with a stick, Ashima felt independent as she could drive. However the following year she met with an accident. She was lucky to escape with minor injuries but her parents were alarmed and subsequently stopped her from driving a car. This incident filled Ashima with the fear of losing her independence. Living in a society where daily social interactions had already made her feel negative, the accident increased feelings of dependence. Then one day she happened to read an article which featured a person with disability who had successfully managed to drive a car with the necessary modifications. She decided to see him and as per his suggestion was back to driving after modifications were made to her vehicle. From here began her new journey of reading about people with disabilities and, thereafter, socialising with them.

Coming in Contact with People with Disabilities: an Awakening of Self

Meeting and mingling with people with disabilities gave Ashima a feeling of solidarity. She was able to empathise with them. She realised that she was not the only person living with disability and there were others whose impairments were more severe than hers. She grew attached to the group and decided to work both for and with people with disabilities.

“The biggest thing is when I met with my disability group, then I saw that there are people whose hands don’t work, or many people can’t even get up from

bed so there was so much of problem. When I am with those people I feel that I don't have any problem, still I am cribbing so much about my problems. I have family support, financial support, I have good job and everything and I am independent and still I am crying. Then I felt that dear no, now no crying, in fact do something for others so that you feel life isn't that difficult."

Accepting Self: Route to a Positive Outlook towards Disability

Knowing about the situation of other people with disabilities helped Ashima learn to accept herself as she was. From this point onwards she began to appreciate her disability identity and took pride in celebrating the disability. She now believed that what mattered more than physicality was the attitude towards disability. So, having a positive mindset that embraces oneself the way one is, according to her was a way of negotiation while living with disability, for then the effects of disability will not matter much.

"When I met people with disabilities in a group then I felt that the more we crib about anything, the more problem will worsen. So, learn to accept, more than societal acceptance, one's own acceptance matters, that accept oneself. And in today's time I can face anybody, I don't have any problem in facing anyone. I don't have any problem with my disability. If you have won over your mind and heart, then body will remain like what it is. There will be no change but yes you will get comfortable living with problem."

At present Ashima is in a position of strength as she accepts a life with impairment in a sanguine way.

"I take disability as my strength as it has made me strong. This chair is not my wheelchair, it's my will chair means full of will power then I feel good. This helps me in moving so I take it positively."

DISCUSSION

The current paper depicts the experiences of a young woman living with a physical disability and shows how her sense of self evolved from being negative to celebrating the disability identity.

The study adopts the life story approach. As a research method this was deemed appropriate. While sharing their stories, people with disabilities bring up their needs, and these unheard voices, long suppressed, are an avenue for totally

different narrations of life experiences. It is believed that by listening to their voices the principles of inclusivity and empowerment can be imbibed, and can counter the societal notions that people with disabilities are inferior and voiceless beings.

The life story approach also gives the macro picture about how the teller's life is impacted by various events of life (Chataika, 2005). From Ashima's experiences of life with a disability, it is quite evident that disability is an outcome of both the impairment effects and the disabling barriers present in the environment. This finding is in congruence with what the International Classification Model of Functioning, Disability and Health (ICF) proposes, namely that an individual's health experience is the interaction between the health condition (biological dysfunction) and social, personal and environmental factors (Wade & Halligan, 2003). Ashima's medical journey was an ongoing affair from the onset of impairment until the day she realised she had no chance of being normal. This medical journey entailed both physical pain and psychological issues which, in combination with societal discrimination, added to Ashima's woes and thus exacerbated her experience of disability.

Research shows that disability is seen as a stigmatised identity (Goffman, 1963). For years people with disabilities have been living in a culture where charitable and medical views have invalidated their bodies. Such societal perceptions have led people with disabilities to regard themselves as inferior beings. Ashima's life story illustrates clearly that she was tormented by frequent questioning, labelling and the stares of people, on a daily basis. These encounters made her feel different, and eventually she began to define herself negatively because of the messages society was sending out towards her impairment. This is similar to the assertion of Guthrie (1999) that within a society that values perfectionist ideals of bodily beauty, gender and impairment converge to make the identity process more complex, and thus it becomes more difficult to maintain a positive identity as meeting the normative body standards appears to be a distant concept. This self-devaluation deepened further when Ashima did not see others who were living with a similar condition. She began to question, "why me?" The exclusionary practices of the society negatively impacted her sense of self. This is similar to what Morris (1991) stated with regard to the dominant ideology of subjection and how such messages of perfection and personal deficit are intensified. 'The messages we receive are very strong and clear and we have little access to different values which may place a more positive value on our bodies, ourselves and our

lives. Our self-image is thus dominated by the non-disabled world's reaction to us' (Morris, 1991).

The daily interactions rooted in discriminatory patterns took a toll on Ashima's well-being. In order to avoid these incidents she tried to conceal her disability by not using a stick or wheelchair, or remaining seated whenever people were around. The hiding of disability is one of the ways of managing spoiled identity, as mentioned by Goffman (1963) in his book, "Stigma: Notes on the management of spoiled identity". As Shakespeare (1996) said, coming out is not that easy, but definitely a difficult process full of obstacles. Ashima, while growing up, was devaluing herself based on societal perceptions, but her situation took a turn for the better when she came to know about other people with disabilities who were excelling in their domains despite their physical conditions. From these encounters she regained her sense of confidence. As she said, by being with other people with disabilities she realised that she was not the only one, which further boosted her sense of self. This exactly underpins what Morris (1991) called one of the salient features of the experience of prejudice faced by people, i.e., they suffer this as isolated beings. In other contexts where they interact, such as families, school, work or wider society, they encounter individuals without disability who fill their minds with their judgements, and people with disabilities live by and define their lives based on those perceptions. In contrast to this, when Ashima got acquainted with other people with disabilities she happened to encounter collective power (Shakespeare, 1996). This is in accord with the opinion of Weeks (1998) about shared identity, such that 'Identity is about belonging, about what you have in common with some other people and what differentiates you from others. At its most basic, it gives you a sense of personal location, the stable core to your individuality'.

By associating with other people with disabilities, Ashima interacted and participated in activities organised by disability groups. She felt connected with them and her sense of self was strengthened. She could now resist the labels or attitudes that society had targeted at her, and from this emerged her positive identification with the disability identity. Ashima's solidarity and alignment with other people with disabilities was a strategy to boost her self-esteem (Fernández et al, 2012; Darling, 2013; Dunn & Burcaw, 2013). This also confirms what Dunn and Burcaw (2013) mentioned, i.e., communal attachment, a recurring theme observed in the formation of disability identity. It involves not only having the feeling of connection with a disability group but also taking pride in disability

and finding this experience meaningful, as was observed in the life story of Ashima (Swain & French, 2000; Darling, 2013; Dunn & Burcaw, 2013; Nario-Redmond et al, 2013). This implies the significance of community, where people with disabilities actively engage with peers due to similar experience. There is research evidence that mentions community integration as “coming home” for people with disabilities (Dunn & Burcaw, 2013). In a similar vein, Johnstone (2004) highlighted the role of organisations for people with disabilities that aim at empowering and lending voice for people with disabilities. Barnes and Mercer (2001) mentioned this as common identity, where members of oppressed groups celebrate their virtues and thus support the concept of a disability culture which is an important factor in the formation of a disability identity.

Besides, having supportive and encouraging family members was the impetus for the positive affirmation of Ashima’s disability identity. Her family always stood by her and never hesitated to take her out or introduce her to others. This finding is in congruence with research that suggests that positive parental support and warm and loving behaviour act as contributing factors in managing life with disability and thus lead to enhanced self-concept (Wood, 1973; Bellin et al, 2007; Shah, 2010).

CONCLUSION

This paper underscores the importance of voice, agency and the celebration of disability identity thus challenging the stigmatised notions attached to disability. The paper reflects what Shakespeare(1996) said, that disability identity is all about having stories, giving the individuals a platform to share and recognising the differences, and all this starts by having a voice.

The story of Ashima is a testament of resilience and grit, as she emerges as a stronger individual who values her differences and takes pride in her disability identity. The research paves the way for future researchers to listen to the insider’s perspective in order to create a culture of valuing differences or, as Powel (1995) said, the emergence of a disability culture which is based on the insider’s perspective where people with disabilities share experiences that highlight their inner feelings, and not on how the condition is viewed by outsiders.

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