

Qualitative Study

Experiences of a visually-challenged student: a qualitative study

Ms. Zarnab Zahoor^{1*}

ABSTRACT

The present study is a qualitative research that aims to investigate the lived experiences of a girl with visual impairment and the mechanisms to combat her notions of disability. For this purpose, a 19 year old female college-student was interviewed using a semi-structured interview. The data thus gathered was analysed using thematic analysis and the emergent themes were discussed. Results indicated that the visually impaired girl has a stronger focus on achievements but at the same time, tends to be distressed by her disability. Because of this, she seems to have developed an induced sense of inferiority complex. However, she seems to persist through her disability with self-reliance and also seems to take a broader notion of life in general. The study provides useful insights into dynamics of upbringing and essential provision of services to the blind.

Keywords: *Visual Impairment, Semi-Structured Interview, Thematic Analysis, Achievements, Inferiority Complex, Self-Reliance*

As per “The Rights of Persons with Disabilities Bill” (2016) disability is an evolving and a dynamic concept. It is an umbrella term covering impairments related to intellect, psychiatry, cognition, neurology, sensation, or physical body and sometimes even a combination of more than two of all of these. It categorizes all in all 21 types of disabilities: Blindness, Low-vision, Leprosy Cured persons, Hearing Impairment (deaf and hard of hearing), Loco motor Disability, Dwarfism, Intellectual Disability, Mental Illness, Autism Spectrum Disorder, Cerebral Palsy, Muscular Dystrophy, Chronic Neurological conditions, Specific Learning Disabilities, Multiple Sclerosis, Speech and Language disability, Thalassaemia, Haemophilia, Sickle Cell disease, Multiple Disabilities including deaf blindness, Acid Attack victim, Parkinson's disease. Therefore, the person requires continual support services that may aid him/her to overcome the problems experienced by them as a result of their disabilities.

Speaking strictly, blindness can be defined as a state where a person is fully sightless in both eyes. He/she is unable to see at all. The word blindness usually connotes visual impairment or low vision, thus indicating a person cannot see even if he uses eyeglasses, contact lenses or even goes for a medical surgery. An individual can experience mild to severe kind of visual impairment, owing to causes like diabetes, traumatic injuries, glaucoma, macular degeneration, infection of the cornea or retina, inflammatory disease, primary or secondary malignancies of the eye, congenital abnormalities, hereditary diseases of the eye, chemical

¹Student, Indraprastha College for Women, University of Delhi, India

*[Responding Author](#)

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poisoning from toxic agents like menthol and deficiency of Vitamin A. The treatment as well as prognosis of it is dependent mainly on its cause. Approximately, the visual disability is estimated to be between 300 million-400 million people worldwide. Amongst these, around 50 million people fall in the category of being 'totally blind', with no vision in either eye. However, 80% of the blind people are over 50% years of age. Additionally, India shoulders the world's largest burden of blindness with as many as 15 million people blind, with an additional 52 million visually impaired. (Huurre, 2004)

It has been claimed that visually-impaired individuals have more developmental difficulties that may tamper with their concept of self. Meighan (1971) analysed a sample of adolescents with visual incapacity. Some were completely blind while others were partially. The results showed significant differences between the self-concept of the blind and that of the people who were not blind. However, no significant differences were observed between the subgroups of adolescents with visual impairments.

Additionally, Tarannum & Khatoon (2009) attempted to study certain demographic variables as determinants of self-esteem and emotional stability of visually challenged students. The data collected indicated that out of the demographic variables of gender, age, class, family system and area of living, only gender emerged as the significant predictor of emotional stability of visually challenged students and none of the demographic variables emerged as predictors of self-esteem of these students.

Petrucci (1953) studied adjustment of sighted and non-sighted students and found that 78% of her subjects had greater need for sociability; 73% were less self-sufficient; 71% were not confident; 67% were more introverted and 22% were more submissive than sighted individuals. However, a comparatively older research by Hastings (1947) found no differences between visually handicapped and sighted students from class one till twelve.

Greenberg & Jordon (1957) found that totally blind participants of their research were less authoritative than partially blind participants. Jervis (1959) found that blind children seemed to worry more about their future than sighted and also tended to endorse more extreme positions.

Especially, in case of visually-handicapped girls, they may particularly face a disadvantage and may be isolated from the peer group (Scholl, 1986). Thus, they usually spend more time in passive activities and those all who have friendships have to work harder to maintain them. However, they see their disability as one of their physical characteristics, so being impaired is a normal condition for them. People with low vision seem to face more hardships in psychosocial development than the complete blind. Parents, teachers, peers, etc. ought to expect more of them, thereby placing more pressure on them to perform as sighted individuals. However, most visually challenged individuals have claimed to have close relationships with their parents and rest of the family members and that they derive much of their social support from them (Kent, 1983). Research findings indicate that the extra attention that the individuals with disabilities need from their parents lead to a very intimate parent-adolescent relationship (Andrew, 1978). Hence, visually challenged people have been found to list a smaller number of extended family members, neighbours, and friends (Kef, 1999).

Research on social functioning of visually-handicapped people is replete with contradictions and inconsistencies. However, two important issues that have emerged from all these studies are that visually-challenged individuals have fewer and poorer social experiences than their

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sighted peers and receive less and sometimes hostile feedback from their peer member. Thus these findings suggest that visually-challenged people may face a larger risk of interpersonal dysfunction (Ammerman, 1986)

The present study is a qualitative study involving the study of experiential realities of a visually-challenged female who is studying in a Delhi University college. The rationale of the present study is to comprehend and analyse the lived experiences of this young lady from early childhood to the present in the light of complete absence of visual sensation. The research questions that guide the study are:

1. To understand the nature of her experiences and agency to combat disability as evolved through her interaction with school, college, family and peer groups.
2. To examine her social networks and social support systems.
3. To investigate her core beliefs and concepts of friendship, beauty, etc.

METHODOLOGY

Participants

The study sample was collected using non-probability sampling technique. Since the study involved studying the subjective experiences of an individual participant and therefore doesn't aim to generalize results, the participant was selected using purposive and convenient sampling. The participant is a college-going 19 year old girl who is hostelling in a Delhi University college. She is visually-challenged with no other handicapping condition at present. She hails from district Kanauj of UP where she lives with her family who belong to the middle-class strata of the society.

Tool

For the present study, a qualitative method of research was adopted in order to explore the complexity and meaning of social phenomena and also to portray the subjectivity of the individual. Specifically, a semi-structured interview was used to study the formulation of the experiential realities of the participant. It proved to be an effective tool to capture the nature of her ideas as evolved through her interaction with the environment as well as her support systems such as parental acceptance.

Procedure

Before beginning with the actual conduction of the interview, a proper literature review was done around the topic to find the domains to be tapped in the interview schedule. The questions were framed accordingly and a mock interview with a colleague was conducted. Few of the questions were revised and a proper semi-structured interview schedule was prepared. Thereby the data was gathered by approaching the participant in the hostel, asking for her consent and willingness to be a part of this research. It was only after she readily agreed to be a part of the study that she was selected for the study. The interview was conducted in two sessions of around 20 minutes each in the hostel library. First of all, she was asked to sign the consent form that also included the clause to record the conversation. She was assured confidentiality of her responses and to use her data for strict research purposes only. After this, a light conversation was started to make the participant comfortable and establish rapport. Then the proper interview was begun to collect all the details that could be elicited from the participant for the present study. The interview surprisingly went on smoothly. She was excited to be a participant of a psychological research. After recording all the responses for all the scheduled questions, the participant was thanked and again assured of the confidentiality of her responses. After this another interview was scheduled to ask for clarifications. The data gathered from the interview was analysed using thematic analysis.

RESULTS

Thematic Analysis is a method for the identification, analysis and reporting of patterns and themes in the data. It is a widely used qualitative analytic method in psychology as it provides a theoretically flexible approach to the analysis of qualitative data. Thematic analysis involves six steps: 1) familiarising oneself with the data 2) generating codes 3) searching for themes 4) reviewing themes 5) defining and naming themes 6) producing the report. Thus it minimally organizes and describes data set in (rich) details.

The results were generated using the technique of thematic analysis. A total of 8 themes were extracted from the data gathered. These themes have been summed up in Table 1 as under:

Table1. *Table showing Themes, Codes and Verbatim after Thematic Analysis*

Themes	Codes	Verbatim
Focus on achievements	Fulfilled her dream. Elated to be in a prestigious college Study-practices as leisure activity	“ye mera ek sapna tha ki mai kisi bade institute se apni padhai complete karu” “mujhe boht khushi hai ki mai yaha apni padhai complete kar rahi hu” “mai acha perform karti hu, exams bhi ache se hojate hai mere aur results bhi ache aate hai” “mai aisehi free time mei kch naya padhne ya seekhne ka try karti hu kyuki wo kabhi toh kaam aahi jaata hai”
Perception about social support	Pet child Good bond with siblings/friends Emotional about parents	“mai apne parents ki ek hi beti hu.wo mujhse boht pyaar kaarte hai” “mere gharwale boht ache hai. mere siblings bhi boht ache hai” “mere parents ne mujhe kabhi burden nahi samjha” “lekin mere parents zyada ache hai. wo mera support karte hai” “wo har cheez provide karte hai jo mujhe chaiye ho”
	Seeks friendship	“aur bhi friends banana chahti hu”

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<p>Idea of friendship</p>	<p>But none out of sympathy</p> <p>Understanding of friendship and its sensitivities</p> <p>Selflessness in friendship</p> <p>Trust in friendship</p> <p>Care in friendship</p> <p>Helping behaviour</p>	<p>“koi aake mje meri disability ki wajah se importance de, befriend karei, wo chaiye ni mje”</p> <p>“help ke bina bhi toh friendship ho sakti hai”</p> <p>“I think friendship boht important hai”</p> <p>“ye ek sensitive bond hota hai”</p> <p>“ye selfish nahi hota”</p> <p>“do log ek dusre pe bharosa karei aur wo bharosa na tode”</p> <p>“friendship wo hai jab do log ek dusre ki care karte hai”</p> <p>“kehte hai na ‘a friend in need is a friend indeed’...woi”</p>
<p>Distress of disability</p>	<p>Hesitant to talk about blindness</p> <p>Normalizing her condition</p> <p>Wishes to be cured</p> <p>Functional restrictions</p>	<p>“meri aankho ki condition?”</p> <p>“waise toh ye normally jo log 60 ya 70 ya bhudde hote hai, unke sath hota hai...lekin mere sath ye tab hua jab mai mai boht choti thi”</p> <p>“tab se hi mai apni donu eyes se dekh nahi sakti”</p> <p>“kabhi kabhi mai sochti hue k din achanak se uth k agar meri eyes cure hogyi ho”</p> <p>Mujhe group mei friends k sath jana padhta hai, cane use karni padhti hai, mess mei bhi khana wo mess workers hi serve karte hai”</p>
	<p>Bullied upon</p>	<p>“shayad mai blind hu toh unke liye easy target thi”</p>

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<p>Induced sense of Inferiority complex</p>	<p>Perception of disability as an obstacle</p> <p>-</p> <p>Wishful identification</p> <p>Uncomfortable with unknown people</p>	<p>“lekin mere liye wo school mei padhna difficult tha”</p> <p>“sab log mere around apni classes mei jaa rahe thai. Mujhe kch bhi samaj nahi aarha tha”</p> <p>“mai dusru ki tarah aisehi uth ke kahi bhi nahi jaa sakti.</p> <p>“strangers se baat karna acha nahi lagta”</p>
<p>Endurance and persistence as critical forces to combat disability</p>	<p>Strong-willed & determined</p> <p>Avid learner</p> <p>Seeking motivation</p> <p>Seeks parallelism with the sighted</p>	<p>“lekin kehte hai na hardships se hi aap strong bante ho”</p> <p>“mujhe sab kch naye se start karna padha. Jaise dusre bache kar rahe thai , maine bhi unko dekh ke kar liya”</p> <p>“lekin Ira Sehgal meri inspiration hai. Jaise wo disability k sath IAS kar paayi, waise mai bhi karu”</p> <p>“toh mam ki baatu se mai boht encouragement feel hui”</p> <p>“mujhe unke sath padhna acha lagta hai kyuki wo teacher ko questions karte hai”</p> <p>“yaha meri classes alag se blind bachu k sath nahi ho rahi thi. Mai sab baaki sighted bachu k sath meri classes hoti hai. Mujhe unke sath padhna acha lagta hai”</p>
	<p>Philosophical</p>	<p>“agar hum deeply sincerely soche toh beauty ek aisa concept hai jo logu ne khud hi ‘construct’ kia hai”</p>

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<p style="text-align: center;">A broader outlook of life in general</p>	<p style="text-align: center;">Perceives an inner meaning of things</p> <p style="text-align: center;">Broader notions of beauty, health</p> <p style="text-align: center;">Self-Confident</p> <p style="text-align: center;">Wants to break stereotypes</p>	<p style="text-align: center;">“I think kisi bhi insaan k thoughts, uska nature, uske intentions beautiful hone chaiye”</p> <p style="text-align: center;">“bahar se lipstick makeup laga diya toh ye sab toh superficial cheez hai”</p> <p style="text-align: center;">“lekin aisa kabhi mujhe nahi laga mai ugly hu ya uncomfortable feel nahi kia hai apni disability se bhi”</p> <p style="text-align: center;">“humare samaj mei kahei ki rule hai ya custom hai Kinjo disabled hai...blind hai, uski shaadi ussi jaise se kar do. Lekin mai ye change karna chahti hu ye norm”</p>
<p style="text-align: center;">Need for Self-reliance as an important driver of the art of living</p>	<p style="text-align: center;">Focus on independence</p> <p style="text-align: center;">Seeks self-dependence</p> <p style="text-align: center;">Abhorrent about help from sympathy</p> <p style="text-align: center;">Importance to stand on her own-feet</p>	<p style="text-align: center;">“warna toh mai usually apna kaam khud hi karti hu”</p> <p style="text-align: center;">“kisi pe depend hona achi baat nahi”</p> <p style="text-align: center;">“sab ko apna kaam khud hi karna chaiye”</p> <p style="text-align: center;">“usually log aajate hai help karne ko kyuki mai dekh nahi sakti. Lekin mujhe uski need nahi hai. Mai apna kaam khud kar leti hu”</p> <p style="text-align: center;">“mai job karna chahti hut toh isliye sath sath UPSC ki coaching kar lugi”</p>

DISCUSSION

The broad purpose of this research was to study and explicate the understanding of lived experiences of a visually-challenged girl. Therefore, a qualitative interview was carried out to assess and tap the reality and nature of the world through the lens of a visually-challenged girl. The gathering of the data was followed by extracting themes from it, congruous to the research questions. Thus the themes that came up from the analysis of the data are summarized as under:

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The first theme that arose from the data was the participant's focus on achievements. The core of her life seems to be converged to be able to accomplish tasks, reach a goal and bring successful conclusion thereof. When she is saying that, "*ye mera ek sapna tha ki mai kisi bade institute se apni padhai complete karu*", she seems to have fulfilled her dream of being able to achieve what she's wanted to and seems to be ecstatic to study in a prestigious Delhi University college. According to Uttermohlen (1997), visually-impaired people have the need to regard themselves as competent; therefore they believe that for this need to be satisfied, the only avenue is education. Thus the participant's focus on achievements is realized through education. The participant also mentioned her leisure activities to be passive and comprised of study related practices only. For instance, she commented, "*mai aisehi free time mei kch naya padhne ya seekhne ka try karti hu kyuki wo kabhi toh kaam aahi jaata hai.*" According to Suokas (1992), the scope of experiences of visually challenged persons is generally narrower and they have a fewer hobbies than the other sighted. Since she's got a few or no hobbies, therefore she even utilizes the time that she would have spent on her recreational practices on learning something new that may prove to be useful to her sometime later to achieve or accomplish something.

The next theme that emerged was the participants' perception about her social support. She acknowledged support from her family, especially her parents. As for example, she remarked, "*lekin mere parents zyada ache hai. wo mera support karte hai.*" Researches have claimed that the extra attention which persons with disabilities need from their parents may lead to a very close parent-child relationship (McAndrew, 1979). The participant also acknowledged assistance from her peer members and seemed to share a good bond with them. According to Kef (1999), social networks of visually challenged have been reported to consist mostly of family members, close relatives and friends. Kef also reports that girls with visual impairment report more support from peers than boys.

Additionally, the next theme that emerged was her idea of friendship; she seemed to understand its intricacies and sensitivities and quickly added that, "*aur bhi friends banana chahti hu.*" She also mentioned it to be a bond of trust, help and careful behaviour between two people that needs to be selfless. Hartup (1983) mentions that blind young adults form a basis and sense of friendship with an increased involvement, intimacy and shared thoughts and feelings with their peers. However, it is pertinent to mention that her idea of friendship doesn't arise from any kind of sympathy. In other words, she doesn't want other people to help her out of pity for her disability. She remarked, "*Koi aake mje meri disability ki wajah se importance de, befriend karei, wo chaiye ni mje.*" Uttermohlen (1997) says that visually-challenged people don't see their impairment as a disability but instead want to feel able and competent with the sighted. Thus they don't want other people to sympathise with them. They just seek social acceptance from others.

Next up, the distress of her disability emerged as one more critical theme. Initially, she seemed to be hesitant to talk about her blindness as she remarked, "*meri aankho ki condition?*" but simultaneously seemed to normalize it as she further remarked "*waise toh ye normally jo log 60 ya 70 ya bhudde hote hai, unke sath hota hai...lekin mere sath ye tab hua jab mai mai boht choti thi.*" It seems that her distress about disability stems from her functional restrictions as she said, "*Mujhe group mei friends k sath jana padhta hai, cane use karni padhti hai, mess mei bhi khana wo mess workers hi serve karte hai.*" Support to this finding is lent by numerous studies. For instance, Huurree (2000) contends that visual impairment can cause functional restrictions, especially relating to mobility and orientation. Therefore, visually-handicapped persons may find it more difficult to participate in social

events and maintain relationships with other people which ultimately, may cause them to feel distressed about their disability.

The next theme that came up was her induced sense of inferiority complex. She remembered to be bullied by her peers and acquaintances when she was quite young as she remarked, *“shayad mai blind hu toh unke liye easy target thi.”* There seems to be a kind of wishful identification within her too as she further remarked, *“mai dusru ki tarah aisehi uth ke kahi bhi nahi jaa sakti.”* Current research supports this finding. For example, Meighan (1971) found in her study that visual impairment may cause people to feel inadequate and inferior to others. These feelings may reflect their lack of social acceptance, physical incapability and social maladjustment. Thus, they wish to be like their other sighted peers.

Despite all this, the next theme that emerged was her endurance and persistence as critical forces to combat her perception of disability. She seemed to seek motivation from her sighted peers as she acknowledged, *“mujhe sab kuch naye se start karna padha. Jaise dusre bache kar rahe tha , maine bhi unko dekh ke kar liya.”* She is also an avid learner and seemed to seek parallelism with the sighted as she remarked, *“yaha meri classes alag se blind bachu k sath nahi ho rahi thi. Mai sab baaki sighted bachu k sath meri classes’ hoti hai. Mujhe unke sath padhna acha lagta hai.”* Thus, she appeared quite strong-willed and determined and quickly mentioned, *“lekin kehte hai na hardships se hi aap strong bante ho.”* This is consistent with the present findings as Das (2015) also found in her study that blind students were confident, capable of shouldering responsibilities, adaptable and determined. She attributes this to the role of parents, especially the support they lend in shaping their child’s behaviour.

Additionally, a broader outlook of life in general emerged as a central theme in our data. She seemed a bit philosophical and also appeared to perceive an inner meaning of things as she remarked, *“I think kisi bhi insaan k thoughts, uska nature, uske intentions beautiful hone chahiye.”* She also seemed to wish to break stereotypes as she remarked that, *“humare samaj mei kahe ki rule hai ya custom hai Kinjo disabled hai...blind hai, uski shaadi ussi jaise se kar do. Lekin mai ye change karna chahti hu ye norm.”* According to Warren (1989), the general outlook and development of a visually-impaired person is shaped by the environmental circumstances and education. Thus the participants’ broader perspective about things and her attitudes towards impairment-stereotypes may be a result of her sensory and learning environment (the participant studies in a prestigious Delhi University college) or it may also be fashioned by the patterns of her family interactions, especially the support that she derives from it. It may also be the case that she is unconsciously trying to break off from her label of disability by trying to consider herself above stereotypes and hence using the same as a coping strategy.

Finally, the need for self-reliance as an important driver of the art of living emerged as one more important theme. She seemed quite self-dependent when she remarked, *“mai apna kaam khud karti hu, kisi pe depend hona achi baat nahi.”* She also acknowledged the importance of standing on her own feet by saying that, *“mai job karna chahti hut toh isliye sath sath UPSC ki coaching kar lugi.”* However this is contrary to existing body of research. For example, McAnarney (1985) found that many disabled persons especially women find it difficult to become independent of their families because of their physical incapacity or psychological dependence. Others are not allowed by their families to develop distance. But in this study, the participant reported a stronger need for independence as her family had allowed her to study outside her hometown. Studying with the sighted might be the reason for

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her to feel this way as it may have induced a need in her to feel as competent as her sighted peers.

Put in a nutshell, the discussion broadens and explicates the crux of the research questions. For example, participants' endurance and persistence as critical forces to combat disability corresponds to the first research question that seeks to explore her agency to contest against disability. Further, the examination of social support system as demanded by the second research question is illustrated in the second theme of the research whereby the participant acknowledges support from her family and peers. Contrary to our expectations, her parents are extremely supportive to the extent of sending their visually challenged child to a new place, far from her hometown. Thus her inherent need for support coupled with the fact that she actually receives it from her parent aids her negotiation with her disability. With regard to the third research question, other themes focus on her core ideas for instance about friendship and her outlook about life in general.

CONCLUSION

Thus the current study examined the nature of experiences of a visually challenged girl and her notions about life in general and ideological beliefs in particular. The results indicated that her life revolved around focussing on achievements and her distress with her disability. Nevertheless, she seemed to be strong-willed and determined and tries to persist through her disability with self-reliance.

Implications, Limitations and Directions for future research

The findings of this research may have implications for the upbringing of children with visual impairment as well as the provision of services to them. Also, in order to achieve a happy and a healthy life, it is important for persons with visual impairment to have more experiences of cooperation, independence in mobility and more opportunities to attend activities with their peers. Furthermore, there is a need for a better understanding of the experiences of social reality of persons with visual impairment in order to enhance their psychological well-being.

Though this study offers support for most of the research questions, there are limitations to be mentioned. First, the sample utilized in this survey was made up of a convenience sample of an undergraduate student only. Though this sample is easy to capture, the overall generalizability is not optimal. Thus others should use caution when generalizing these results. With this, the lack of diversity within the sample can also be considered a limitation. The cultural level of the participant is also homogenous; additionally, the absence of a comparison group with/without visual impairment or male versus female in similar conditions can be considered a limitation too.

It is suggested that longitudinal studies with large sample can also be undertaken to look into the interactions between lived experiences and its impact, for instance on self-esteem, etc. Comparative studies can also be undertaken to find out differences in the lived reality and adjustment difficulties between blind and individuals having other kinds of disability. Besides these studies can also be undertaken to find out the same kind of differences among individuals with various categories of visual impairment, i.e. blind, partially sighted, low-vision, and also among congenitally and adventitiously blind individuals.

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Conflict of Interest

The author declared no conflict of interests.

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