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A Study of Quality of Life and Problems Faced by People Living With Blindness in Organizations Working For the Welfare and /Or Rehabilitation for the Blind in Delhi

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A B S T R A C T

Introduction*:**According to the World Health Organization blindness is defined as "visual acuity of less than 3/60, or a corresponding visual field loss to less than 10 degree, in the better eye with the best possible correction" [1]. The National Program for Control of Blindness (NPCB) was renamed as National Program for Control of Blindness and Visual Impairment in 2017 also the definition of blindness was adopted in accordance with the definition that is used by the World Health Organization which is" presenting distance visual acuity less than 3/60 (20/400) in the better eye and limitation of field of vision to be less than 10 degree from centre of fixation" [3, 4]. WHO defines Quality of Life as "an individual's perception of their position of life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." [4] From the patient's own perspective the impact of the disease or disability on their life helps give a holistic view of assessment of QoL. QoL can also provide decision-making in health care at the micro and macro [5]. Understanding the challenges faced by blind people on a regular basis in their lives from their own perspective and their own experiences is important to help orient and improverehabilitation services, health care services and governmentschemesthat are more responsive to the needs of the blindpersons in the community. ***Methodology: The present study was a cross-sectional, descriptive study conducted in non-governmental organizations that were working for the welfare and /or rehabilitation for the blind in Delhi. The study population consisted of blind residents, people with blindness who were employed at organizations and blind people receiving vocational training at organizations working for the welfare and /or rehabilitation for the blind. **Findings**: Out of total 215 participants, most of the participants were male. Majority of them were in the age group 18 - 25 years. Most of the participants were unmarried or single (79.1%) and (20.9%) of the participants were married. Most of the participants had received secondary education and very few them had received higher education. Most of them (79.1%) were unemployed and were receiving vocational training in order to get employed. Only 20.9% of the participants were employed /working. Most of the participants had below average income (52.6%), 3.2% had average income and the remaining (44.2%) had well below average income. The mean overall quality of life of the participants was 3.30 ±0.935. The quality of life of the male participants was significantly higher than the female participants. The quality of life of the participants who had congenital blindness was significantly higher than those participants who had acquired blindness. The quality of life was also higher among participants that had received higher education, and were employed /working. ***Conclusion*:**Low education, unemployment/not working and being unmarried was associated with poor quality of life. The quality of life was positive in the social domain, spiritual domain and the psychological domain. The physical domain score was low. The domain with low scores were level of independence and environment. Transport was a major obstacle in their view and most of them them felt that public transport was not friendly and needed to be improved. Therefore there is a need to focus on making public transport more user friendly and creating more job opportunities for the blind. ***Recommendations***: Planning for providing services to blind should focus primarily on

transport, improvement in the range and quality of vocational training and skills provided for securing employment and creating more job opportunities as these were the areas which the blind people felt posed maximum hurdles in their lives. There is a need for more information, education and communication campaigns to provide more awareness and sensitization to the public regarding blindness so that there is ideally no or minimum possible stigma and more acceptance of blind persons. In the workplace, they should be sensitization so that there is more acceptance of people with disability like the blind.
Keywords: Blindness, Quality of Life, visual acuity.

INTRODUCTION

'Blindness 'is defined as visual acuity of less than 3/60, or a corresponding visual field loss to less than 10°, in the better eye with the best possible correction. 'Visual impairment 'includes both low vision and blindness [3].

The definition of blindness according to the National Program for Control of Blindness and Visual Impairment also adopted the definition of blindness in line with the definition used by WHO which is 'Presenting distance visually acuity less then 3/60(20/400) in the better eye and limitation of field of vision to be less than 10 degrees from center of fixation" [2].

According to NPCB & VI [4].

- Social blindness: Manifest blindness: Absolute blindness: Curable blindness:
- Preventable blindness:
- Avoidable blindness:
- Vision 3/60 or diminution of field of vision to 10°
- Vision 1/60 to just perception of light
- No perception of light
- That stage of blindness where the damage is reversible by prompt management e.g. cataract
- The loss of blindness that could have been completely prevented by institution of effective preventive or prophylactic measures e.g. xerophthalmia, trachoma, and glaucoma
- The sum total of preventable or curable blindness is often referred to as avoidable blindness.
- According to "The Global Economic Cost of Visual Impairment" report 2010 the total health care expenditure that is associated with VI was forecasted to increase from $2.30 trillion in 2010 to $2.77 trillion in 2020 [5].
- IMPACT OF VISION LOSS: Quality of Life

In most studies it was concluded that Visual impairment has a poor impact on the quality of life. On every dimension of the EQ-5D. Visually impaired patients reported more problems than the general population [6].

Risk of falls and fractures

Many studies have concluded that impaired balance caused by poor vision increases the risk of falls and fractures especially in older people [7]. Elderly Respondents who reported severe vision impairment also reported a fall during the previous year more often compared to those elderly that did not report vision impairment [8].

Quality of life (QOL)

Quality of life (QOL) is a broad multidimensional concept that mostly includes subjective evaluations of both positive and negative aspects of life [9]. It is difficult to measure QoL, the reason being that even though the term "quality of life" has meaning for almost everyone and every academic discipline, it can be defined differently individuals and groups. Overall quality of life has health as one of its important domain however it also includes many other domains like jobs, housing, schools, the neighborhood. Other aspects in overall quality of life that add to the complexity of its measurement include culture, values, and spirituality [10].

WHO defines Quality of Life as "an individual's perception of their position of life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." It has a wide spectrum that includes a person's physical health, their psychological state, their personal beliefs, social relationships and their relationship to their environment [11]. From the patient's own perspective the impact of the disease or disability on their life helps give a holistic view of assessment of QoL. QoL can also provide decision-making in health care at the micro and macro [12].

WHO-QOL:

In WHOQOL-100 there are six broad domains of quality of life, and within these six domains twenty-four facets are covered. Each facet includes four items, also there are four general items that cover overall subjective QOL and health, together all of these produce 100 items in the assessment. All items are rated on a five point scale (1-5).

Domains and facets incorporated within domains Overall Quality of Life and General Health.

Physical Health

- Energy and fatigue
- Pain and discomfort
- Sleep and rest

Psychological

- Bodily image and appearance
- Negative feelings
- Positive feelings
- Self-esteem
- Thinking, learning, memory and concentration

Level of Independence

- Mobility
- Activities of daily living
- Dependence on medicinal substances and medical aids
- Work capacity

Social Relations

- Personal relationships
- Social support
- Sexual activity

Environment

- Financial resources
- Freedom, physical safety and security
- Health and social care: accessibility and quality
- Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation/leisure
- Physical environment (pollution/noise/traffic/climate) Transport Spirituality/Religion/Personal beliefs
- Religion /Spirituality/Personal Beliefs (Single facet) [13].

The WHOQOL-BREF is a shorter 26-item version of the WHOQOL-100 assessment. From a survey of adults carried out in 23 countries (n = 11,830), cross- sectional data obtained which was used for analysing its psychometric properties. Along with socio-demographic and health status questions, the WHOQOL-BREFself-assessment was completed. WHOQOL-BREF performs well in preliminary tests of validityand has good to excellent psychometric properties of reliability , which was shown after analyses of internal consistency, item-total correlations, discriminant validity and construct validity through confirmatory factor analysis. WHOQOL-BREF is a sound, cross-culturally valid assessment of QOL was proved by the results.

RATIONALE FOR STUDY

The blind people face many difficulties in their daily lives in relation to their physical, social, environmental, psychological and independent life skills. Understanding the challenges faced by blind people on a regular basis in their lives from their own perspective and their own experiences is important. The study will try to understand their challenges in order to determine the ways and means by which they may be improved.

A large part of our country's infrastructure is inaccessible and unfriendly to India’s differently-abled population which includes people with blindness. Many public places like movie theaters, parks, restaurants are difficult to access for the blind because the buildings or public spaces are not equipped according to their needs. . By getting a better insight into the challenges and issues faced by the blind it may be possible to orient and improve rehabilitation services, health care services and government schemes that are more responsive to the needs of the blind persons in the community.

Materials and Methods

The present study was a cross-sectional, descriptive study conducted in non- governmental organizations that were working for the welfare and /or rehabilitation for the blind in Delhi.

Sampling technique

Study Population

1. Blind residents of organizations working for the welfare and /or rehabilitation for the blind.
2. People with blindness who are employed at organizations working for the welfare and /or rehabilitation for the blind.
3. Blind people receiving vocational training at organizations working for the welfare and /or rehabilitation for the blind.

InclusionCriteria:

1)People who fell into the definition of blindness according to NPCB &VI.
2)Blind people that were 18 years and above.
3)People that were born with congenital blindness or had acquired blindness.
4)Blind People with no other disability.
5)People who gave their consent.

ExclusionCriteria:

Blind people below 18 years of age.Blind people with any other disability like deafness etc.Blind people that did not give their consent.

Sample Size

The data regarding prevalence of quality of life with blindness was not known even from previous studies therefore in order to calculate sample size, prevalence was assumed to be 50%.

Sample size — $n=z^2pq/d^2$Where z is 95% confidence interval p is prevalence q is (1-p) d is precision.

Sample size — $n=z^2pq/d^2$ where z=1.96 and d= 7 % level of significance, p=0.5 and q=(1-p) =0.5 the sample size comes out to be 196.

Taking non response as 10% the sample size was taken as 215.

Data collection

Both primary was collected. Interview schedules for blind participants above the age of 18 years after taking their consent. The interview was a semi- structured interview.

Data Analysis

The data collected from close ended questions was analyzed using quantitative analytical techniques with the help of SPSS/Excel software. Descriptive statistical techniques like mean and standard deviation were used where applicable. Descriptive statistical techniques like frequency tables, percentages, cross tables and chi - square test were used for calculating various measures as per the objectives. The various issues of blind people were analyzed. The data that was collected from open ended questions were analyzed by qualitative and quantitative methods as applicable. A p value of <0.05 was considered as statistically significant.

RESULTS

The mean age of the participants was 32 ±11.10 years, with the predominant age group being 18 to 25 years. Out of the total 215 participants majority of the participants i.e, 136 (63.3%) were male and 79 (36.7%) were female participants. The quality of life of the male participants was significantly higher ($p< 0.05$) than their female counterparts.

The majority of the participants had received secondary education (36.7%). Most of the participants were not working (79.1%) and were receiving vocational skills training in order to get employment.

The quality of life of participants with acquired blindness was significantly lower (P value=0.01) i.e. ($p < 0.05$) than the quality of life of participants with congenital blindness.

The domain with high scores were the social relations domain, the psychological domain and spiritual domain. The participants had high self confidence. The physical domain score was low.

Annexure:

Table 1: Socio demographic profile of participants

ClassintervalAgein years	Frequency	Percent%
15-25	81	37.7
26-35	65	30.2
36-45	42	19.5
46-55	15	7.0
56-65	12	5.6
Total	215	100.0
Meanage	32.04	
Std.Deviation	11.100	
Range	47	
Minimum	18	
Maximum	65	

The age of the participants ranged from minimum 18 years to maximum 65 years. Themean age of the participants was 32 ± 11.10years.

Table 2:DistributionofparticipantsaccordingtoGender

Gender	Frequency	Percent%
Male	136	63.3
Female	79	36.7
Total	215	100.0

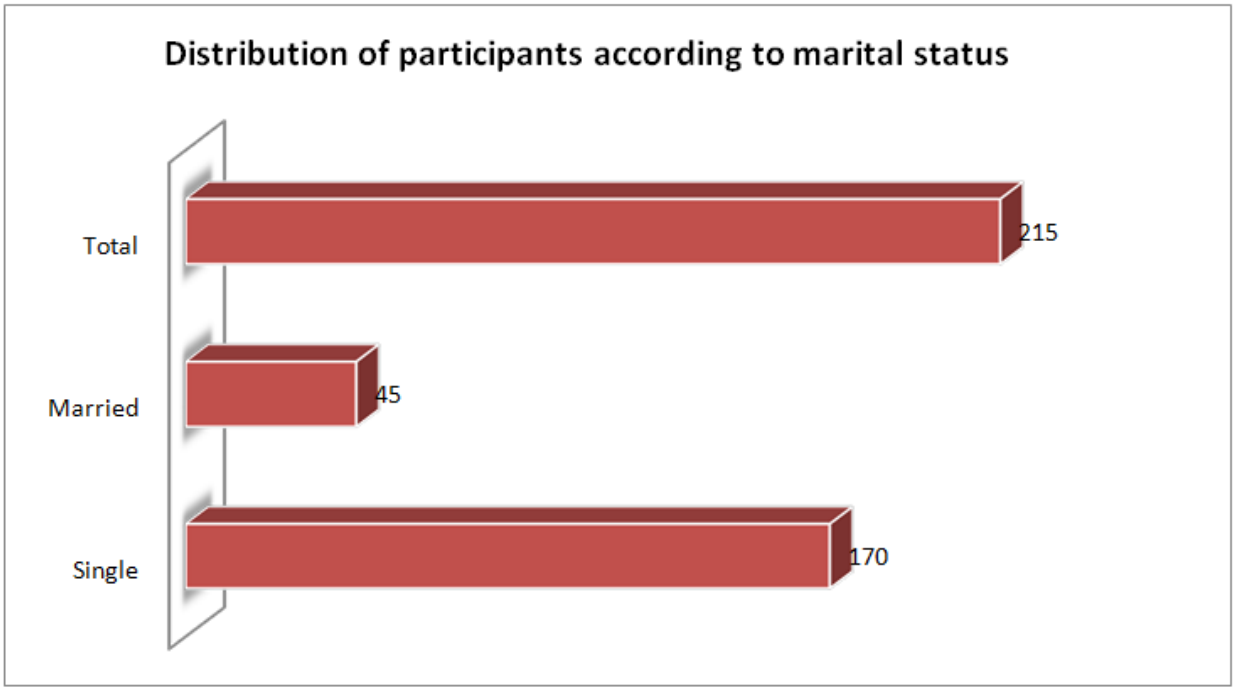

Fig 1: Distributionof participantsaccordingtoMaritalStatus

Table 3:DistributionofparticipantsaccordingtoEducation

Education	Frequency	Percent%
Illiterate	15	7.0
Primary	33	15.3
Secondary	79	36.7
Graduate	73	34.0
Postgraduate	15	7.0
Total	215	100.0

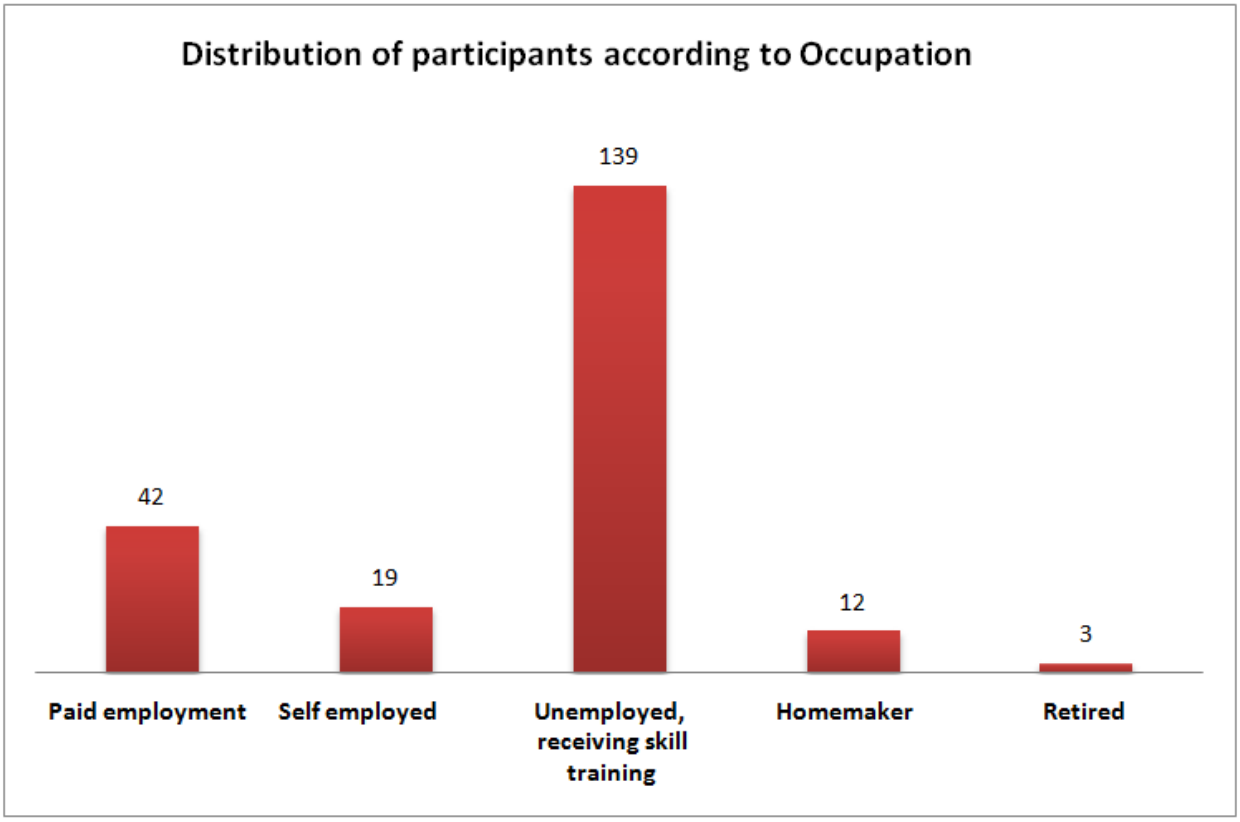

Fig 2: DistributionofparticipantsaccordingtoOccupation

Table 4:Mean qualityof life

Quality ofLife	
Mean	3.30
Std.Deviation	.935

Table 5: MeanScores(±SD)ofWHO domains

Domains	**Mean±Standarddeviation**
Physical	41.8± 12.35
Psychological	61.72± 10.92
LevelofIndependence	35.92 ±11.23
SocialRelations	64.84 ± 12.07
Environment	46.34±12.18
Spiritual	53.72±3.94

Ethical Considerations

The study protocol was presented before the Ethical Committee of the NIHFW on 26thOct 2018. The Ethical Committee cleared the protocol for further research and issued the ethical clearance letter (Scanned Copy attached in Annexure I). Permission for pilot study and data collection was also taken from the respective in charge of the selected non-government organizations that were working for the welfare and /or rehabilitation for the blind.

DISCUSSION

The quality of life of the male participants was significantly higher ($p< 0.05$) than their female counterparts. The study found that majority of the participants were single .The quality of life of the married participants was significantly higher ($p < 0.05$) than the single or unmarried participants. The finding shows that people with blindness often tend to be single.

The quality of life of the participants who were working was significantly higher ($p= 0.021$) i.e, ($p < 0.05$) compared to the participants who were not working.

Many participants complained of fatigue and low energy, a possible reason could be that they were suffering from anaemia or that they were not consuming nutritious foods. It could also be possible that food provided at the

welfare organizations were not very nutrient dense .The domain with very low scores were the level of independence domain and the environment domain.

CONCLUSION

Out of total 215 participants, most of the participants were male and were in the age group 18 - 25 years. The quality of life of participants with acquired blindness was significantly lower than the participants with cogenital blindness.

Most of them were unmarried or single (79.1%) and most of them (79.1%) were not working and were receiving vocational training in order to get employement.

Low education, unemployment/not working and being unmarried was associated with poor quality of life.

Most of the participants (75.3%) were not satisfied with the vocational training opportunities that were provided for the blind. Nearly 78% of the participants said that they had experienced difficulty in receiving vocational training. Sincenot- working/unemployment was associated with poor quality of life there needs to be an improvement in the range and quality of vocational training and skills provided in the facilities that cater to the blind.

The quality of life was positive in the social domain, spiritual domain and psychological domain. The physical domain score was low. The domain with low scores were level of independence and environment. Transport was a major obstacle in their view and most of them them felt that public transport was not friendly and needed to be improved. Therefore there is a need to focus on making public transport more user friendly and creating more job opportunities for the blind.

RECOMMENDATIONS

Planning for providing services to blind should focus primarily on transport, improvement in the range and quality of vocational training and skills provided for securing employment and creating more job opportunities as these were the areas which the blind people felt posed maximum hurdles in their lives.

There is a need for more information, education and communication campaigns to provide more awareness and sensitization to the public regarding blindness so that there is ideally no or minimum possible stigma and more acceptance of blind persons. In the workplace, they should be sensitization so that there is more acceptance of people with disability like the blind.

Most of the blind participants felt that transport was one of the major factors contributing to hindrance in their lives. Therefore in order to improve their lives public transport should be made more user-friendly to their condition.

REFERENCES

1. WHO. VISION 2020 THE RIGHT TO SIGHT. Global Initiative for the Elimination of Avoidable Blindness Action Plan 2006-2011 [Internet] France WHO 2007. available from http://www.who.int/blindness/vision 2020/report
2. PIB. Revision in the definition of blindness National Programme for control of blindness. [Internet] 2017. Press Information Bureau, Government of India, Ministry of Health and Family Welfare 18 July 2017 [14.57 IST], Available from http://pib.nic.in/newsite/PrintRelease aspx
3. Leat, S. J., Legge, G. E., &Bullimore, M. A. (1999). What is low vision? A re-evaluation of definitions. *Optometry and Vision Science*, *76*(4), 198-211.
4. World Health Organization. Expert Committee on Health Statistics. Third Report of a Meeting Held in Geneva from 21 to 26 November 1951. WHO. 1952. [Last cited on 2017 Jan 18]. Available from: http://www.who.int/iris/handle/10665/40190.
5. Prevention of Blindness: Report by the Director-General. Geneva: WHO; 1972. World Health Assembly 25.
6. WHO. VISION 2020 THE RIGHT TO SIGHT. Global Initiative for the Elimination of Avoidable Blindness Action Plan 2006-2011 [Internet] France WHO 2007.available from http://www.who.int/blindness/vision 2020/report pdf.
7. Lamoureux, E. L., Hassell, J. B., &Keeffe, J. E. (2004). The determinants of participation in activities of daily living in people with impaired vision. *American journal of ophthalmology*, *137*(2), 265-270. doi:10.1016/j.ajo.2003.08.003
8. Gore, W. (1972). The relationship between sex roles, mental illness and marital status. *Social Forces*, *51*, 34-44.doi: 10.1093/sf/51.1.34.
9. Umberson, D. (1987). Family status and health behaviors: social control as a dimension of social integration. *J Health SocBehav*, *28*(3), 306-319.
10. Wexler, D. J., Grant, R. W., Wittenberg, E., Bosch, J. L., Cagliero, E., Delahanty, L., ... &Meigs, J. B. (2006). Correlates of health-related quality of life in type 2 diabetes. *Diabetologia*, *49*(7), 1489-1497.

11. Wrzesińska, M., Binder, K., Tabała, K., Lipert, A., Miller, E. (2019). Burnout and Quality of Life Among Massage Therapists with Visual Impairment. *J OccupRehabil, 29*(2), 384-394. doi:10.1007/s10926-018-9793-7
12. Kranciukaite, D., Rastenyte, D, &Jureniene, K. (2007). Evaluation of the quality of life in the population of Kaunas city using the SF-12 questionnaire. *Medicina (Kaunas), 43*(6), 501-507. PMID: 17637523
13. Yun, Y. H., Kim, S. H., Lee, K. M., Park, S. M., & Kim, Y. M. (2007). Age, sex, and comorbidities were considered in comparing reference data for health-related quality of life in the general and cancer populations. *J ClinEpidemiol, 60*(11), 1164-1175.