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TRENDS OF VISUAL DISABILITY CERTIFICATION AT A TERTIARY CARE CENTER OF GUJARAT: A RETROSPECTIVE STUDY.

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Abstract

Background

Visual disability is a major public health issue in India, significantly impacting individuals' quality of life and imposing a substantial economic burden. The government has introduced the Unique Disability ID (UDID) system to provide certification and benefits for persons with disabilities, including those with visual impairments. This study aims to analyse the UDID-certified visual disability certificates issued at a tertiary care centre in Rajkot, Gujarat, to evaluate the degree, causes of visual disability, and identify any gaps in the current certification system.

Methods

This was a retrospective cross-sectional observational study conducted at P.D.U. Government Medical College, Rajkot, from January 2017 to December 2022. Data from 500 UDID-certified visual disability certificates, including demographic details, degree of disability, and underlying causes, were collected and analyzed. Inclusion criteria included individuals with a visual disability of 30% or higher. Statistical analysis was performed using SPSS software, and results were summarized using mean, median, and range.

Results

A total of 500 UDID-certified certificates were analyzed. The majority (31%) of certificates were issued in the 20–40 years age group, with a male preponderance (69.6%). The most common categories of visual disability were blindness (82%) followed by one-eyed (9.2%) and low vision (8.8%). Retinal diseases (41%), particularly retinitis pigmentosa (15.2%), were the leading causes of disability. Optic atrophy (17.8%) was the second most common cause. The study identified the under-representation of older adults and females in the certification process.

Conclusions

Retinal diseases, particularly retinitis pigmentosa, and optic atrophy were the most common causes of visual disability. The 20–40 years age group predominantly sought UDID certification, primarily for availing government benefits. The study highlights the need to revise the certification criteria to include individuals with less than 40% disability.

Recommendation

Expanding UDID certification at sub-district levels or through outreach camps to ensure broader access and inclusion.

Keywords: *Visual disability, UDID, blindness, retinitis pigmentosa, optic atrophy.*
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Background

Blindness is the most devastating reality for visually impaired people as it significantly affects their emotional, social, physical, educational, and financial well-being [1]. Visual impairment and disability pose an enormous global financial burden with the annual global cost of productivity losses associated with vision impairment estimated to be US$ 411 billion. The economic burden of blindness and vision impairment in India is estimated to be US dollar 38.4 billion. Currently, there are 4.95 million blind persons and 70 million visually impaired persons in India, among which 0.24 million are blind children [2]. Support services for visually impaired and disabled persons are given worldwide

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by providing certification for blindness or partial sight which entitles them to education, employment, health care, and other social benefits [3]. In India, it is voluntary to register as blind or partially sighted and the Ministry of Social Justice and Empowerment is responsible for laying the guidelines to evaluate various disabilities including visual disability, and procedure for certification. The minimum degree of disability should be 40% to be eligible for any concessions/benefits. The visual disability certificate is issued by the medical board constituted by the central/state government having, at least 3 members out of which at least one member shall be an ophthalmologist [3,4]. The medical board decides whether the status of disability is temporary or permanent. Disability certificate is issued only in case of permanent disability. The benefits like reservation in employment, education, etc are restricted to permanently disabled persons only and often fail to accommodate the expectations of those with temporary disability [5]. Blindness registers are widely used to keep records, especially in developed worlds, and are very frequently used as an important tool in public eye health programs to assess various causes of blindness. In India, limited studies are available that analyze the blindness certificate and registers due to poor reporting and lack of proper record keeping [4]. Department of Empowerment of Persons with Disabilities (DEPwD), under the Rights of Persons with Disabilities Rules, 2017 under the RPwD Act in 2016 made it mandatory to issue a certificate of disability through online mode by providing a Unique Disability ID (UDID) and a disability card which would be applicable pan India. This was done with the view of creating a national database for persons with disability (PwDs) and creating a holistic end-to-end integrated system for issuance of disability certificates for persons with disabilities with their identification and disability details which can be accessed anywhere in India with help of card reader thus eliminating the need for carrying multiple documents [4-7].

Present study aims at analysis of UDID- certified visual disability certificates from database issued by constituted medical board a Tertiary care centre at Rajkot district Gujarat and determine degree of and cause of visual disability as well as identify loopholes if any, in current certification system.

Methodology

Study Design, settings, and duration

This was a retrospective cross-sectional observational study that was done at a tertiary care centre at Rajkot district Gujarat. This study included patients from rural as well as urban Rajkot voluntarily coming for UDID visual disability certification. The UDID- certified visual disability certificate issued by medical board of hospital from January 2017 to December 2022 were collected and analyzed.

Inclusion and exclusion criteria

Inclusion criteria

All the patients from rural as well as urban areas in Rajkot district to whom UDID- a certified visual disability certificate was issued with visual disabilities of 30% or above at the Department of Ophthalmology, P.D.U Government Medical College, Rajkot during the study period were included in the study. The percentage of disability was based on guidelines from the Gazette of India notification published in 2018, by the Ministry of Social Justice and Empowerment, India, based on best-corrected visual acuity.

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Better eye Best Corrected	Worse eye Best Corrected	Per cent Impairment	Disability category
Visual acuity: 6/6 to 6/18	6/6 to 6/18	0%	0
	6/24 to 6/60	10%	0
	Less than 6/60 to 3/60	20%	I
	Less than 3/60 No Light Perception	30%	II (One eyed person)
Visual acuity: 6/24 to6/60 Or Visual field less than 40 degrees upto 20 degrees around center of fixation or hemianopia involving macula	6/24 to6/60	40%	III a (low vision)
	Less than 6/60 to 3/60	50%	III b (low vision)
	Less than 3/60 to No Light Perception	60%	III c (low vision)
Visual acuity: Less than 6/60 to 3/60 Or Visual field less than20 degrees upto10 degrees around centre of fixation	Lessthan6/60to3/60	70%	III d (low vision)
	Lessthan3/60toNoLightPerception	80%	III e (low vision)
Visual acuity: Less than 3/60 to 1/60 Or Visual field less than10-degree around centre of fixation	Less than 3/60 to No Light Perception	90%	IVa (Blindness)
Visual acuity: Only HMCF Only Light Perception, No Light Perception	Only HMCF Only Light Perception, No Light Perception	100%	IV b (Blindness)

Figure 1: Percentage of disability based on guidelines from the Gazette of India notification published in 2018, by the Ministry of Social Justice and Empowerment, India, based on best-corrected visual acuity

Exclusion criteria

All patients with rejected UDID certificates and preventable blindness were excluded from the study.

Data Collection

All UDID-certified visual disability certificates were downloaded from the medical records department of the hospital via the UDID portal ((http://www.swavlambancard.gov.in/) from January 2017 to December 2022. Various demographic data of patients, such as age, gender, and residence, were documented. The degree of visual disability and the cause of visual disability were also recorded from the certificate.

Statistical Analysis

The data were entered in a Microsoft Excel 2010 spreadsheet and analyzed using IBM Statistical Package for Social Sciences (SPSS) software (IBM Corp., version 26.0, released in 2019; Armonk, NY: IBM Corp.). Age, Gender, percentage of visual disability, and cause of disability were our main variables. Results were summarised in terms of mean, median, and range.

Ethical consideration

This study was approved from the institutional ethical committee of P.D.U government Medical college (approval number PDUMCR/IEC/37/2023). The ethics committee did not seek patient approval to study their medical records, but patient identity and data confidentiality was maintained.

Results

A total of 500 visual disability certificates were analyzed in the present study. The age range was 5-85 years with the majority of certificates issued in the working age group i.e. 20-40 years age group (n=155,31%). Overall, the mean age was 40.12±19.8 years and the median age was 40 years. Furthermore, 92 (18.4%) certificates, 149 (29.8%) certificates, and 104 (20.8%) certificates were issued at less than 20 years of age, 40-60 years of age group, and more than 60 years of age respectively. Out of the total 500 disability certificates, 348 (69.6%) belonged to males and 152 (30.4%) belonged to females with male to female ratio of 2.3:1 showing male preponderance (Table 1).

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Table 1:- Age-wise distribution of UDID-registered visually disabled patients

Age groups(in years)	Total (n=500)	Male	Female
<20	92(18.4%)	53	39
20-40	155 (31%)	100	55
40-60	149(29.8%)	104	45
>60	104 (20.8%)	82	22

Table 2:- Distribution of UDID registered visual disabled patients based on category of visual disability as per Gazattee notification of India

Category of visual disability		Number of certificates	Percentage
One Eyed	II (30%)	46	9.2%
Low Vision	IIIa (40%)	10	2%
	IIIb (50%)	01	0.2%
	IIIc (60%)	07	1.4%
	IIId (70%)	10	2%
	IIIe (80%)	16	3.2%
Blindness	IVa (90%)	22	4.4%
	IVb (100%)	388	77.6%

Out of 500 certificates, 46 (9.2%) were one-eyed certificates (i.e. Category II), 44 (8.8%) were low vision certificates (Category IIIa to IIIe) and 410 (82%) were blindness certificates (category IVa and IVb). The mean age in the eyed category was 40.08±17.87 years and the median age was 40 years, while in the low vision category mean age was 38.97±12.89 years and the median age was 39 years and in the blindness category mean age was 40.22±17.65 years with median age of 40 years.

Retinal diseases were the most common cause of visual disability and blindness (n=205, 41%). Among retinal diseases, the most common cause was retinitis pigmentosa (n=76, 15.2%) followed by macular degeneration (n=45, 9%). Causes for macular degeneration included both hereditary macular degeneration and acquired age-related macular degeneration. Other retinal causes included old retinal detachment (n=36, 7.2%), degenerative pathological myopia (n=21, 4.2%), advanced diabetic eye disease (n=12, 2.4%), ocular albinism (n=10, 2%) and retinopathy of prematurity (n=5, 1%). Optic atrophy was the second most common cause following retinal diseases (n=89, 17.8%). The causes for optic atrophy included various causes for primary and secondary optic atrophy such as Leber's hereditary optic neuropathy, toxic optic neuropathy, etc., and consecutive optic atrophy due to severe retinal degeneration.

Corneal causes mainly included leucomatous corneal opacity (n=48, 9.6%). The causes for glaucomatous corneal opacity included healed corneal ulcer, trauma to the eye, interstitial keratitis, congenital glaucoma, etc. Other corneal causes were anterior staphyloma (n=4, 0.8%) and failed keratoplasty (n=2, 0.4%). Phthisis bulbi accounted for 15%(n=75) of visual disability. Causes of phthisis bulbi included healed perforated corneal ulcer, chronic iridocyclitis, trauma to the eye, etc.

Congenital malformation comprised of retinochoroidal colobomas (n=12, 2.4%), anophthalmos (n=6, 1.2%), and microphthalmos (n=6, 1.2%). Other causes of visual disability included glaucomatous optic atrophy (n=28, 5.6%), eviscerated eye (n=11, 2.2%), amblyopia (n=9, 1.8%), and chronic iridocyclitis (n=5, 1%).

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Table 3:- Distribution of UDID registered visually disabled patients according to causes of visual disability

Cause of disability	Total number of certificates	Percentage(%)
Optic atrophy	89	17.8
Retinitis pigmentosa	76	15.2
Phthisis bulbi	75	15
Macular Degeneration	45	9
Leucomatous corneal opacity	48	9.6
Old Retinal Detachment	36	7.2
Glaucomatous optic atrophy	28	5.6
Degenerative Pathological Myopia	21	4.2
Advanced Diabetic eye disease	12	2.4
Retinochoroidal coloboma	12	2.4
Eviscerated	11	2.2
Ocular Albinsm	10	2
Amblyopia	09	1.8
Anophthalmos	06	1.2
Microphthalmos	06	1.2
Retinopathy of prematurity	05	1
Chronic iridocyclitis	05	1
Anterior Staphyloma	04	0.8
Failed Keratoplasty	02	0.4

The most common cause of visual disability in less than 20 years was glaucomatous corneal opacity (n=17/92, 18.5%)) followed by Macular degeneration (n=15/92, 16.3%)) due to hereditary macular dystrophy (p=0.04). Retinitis pigmentosa (n=52/155, 33.5%) was the most common cause of visual disability in the working age group i.e. between 20 to 40 years of age (p=0.15). Optic atrophy (n=65/149, 43.6%)) due to various optic nerve diseases and macular degeneration (n=29/104, 27.9%) from diseases such as age-related macular degeneration (ARMD), choroidal neovascularization, etc. were most common cause for visual disability between 40 years to 60 years age and more than 60 years ago, respectively.

Table 4:- Age-wise distribution of various causes of visual disability among UDID-registered visually disabled patients.

Cause of disability	<20 years (n=92)	20-40 years (n=155)	40-60 years (n=149)	>60 years (n=104)	Total number of certificates (n=500)
Optic atrophy	3	6	65	15	89 (17.8%)
Retinitis pigmentosa	12	52	12	0	76 (15.2%)
Phthisis bulbi	7	28	16	24	75 (15%)
Macular Degeneration	15	0	1	29	45 (9%)
Leucomatous corneal opacity	17	09	14	08	48 (9.6%)
Old Retinal Detachment	02	15	16	03	36 (7.2%)
Glaucomatous optic atrophy	03	04	07	14	28 (5.6%)
Degenerative Pathological Myopia	04	14	03	0	21 (4.2%)
Advanced Diabetic eye disease	0	02	06	04	12 (2.4%)

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Retinochoroidal coloboma	02	10	0	0	12 (2.4%)
Eviscerated	0	01	08	02	11 (2.2%)
Ocular Albinsm	08	02	0	0	10 (2%)
Amblyopia	03	06	0	0	09 (1.8%)
Anophthalmos	05	01	0	0	06 (1.2%)
Microphthalmos	06	0	0	0	06 (1.2%)
Retinopathy of prematurity	03	02	0	0	05 (1%)
Chronic iridocyclitis	0	03	1	1	05 (1%)
Anterior Staphyloma	02	0	0	2	04 (0.8%)
Failed Keratoplasty	0	0	0	2	02 (0.4%)
p-value	0.04	0.15	0.02	0.01	

Discussion

Present study compares findings of 500 UDID certified visual disability certificates collected from UDID portal with the other population-based studies and studies of blind certifications.

In our study, a maximum number of disability certificates were issued in the age group 20-40 years age (n=155,31%) which was a major working and earning group. Similar findings were recorded in studies by Ghosh et al., Dharbarde et al., Khan et al., and Farooq et al. [1,3,8,9]. The reason for the younger population to get registered for disability certificates might be the benefits in education, jobs, tax benefits, etc., and concession in various fields which are of greater need to young individuals compared to the older population. In contrast to the study by Dharbarde et al. and Brunce et al. where the total percentage of certifications in < 20 years of age and > 70 years of age were very low, in the current study it was somewhat closer to 20-40 years age group [1,10]. The reason behind this finding could be increased education and awareness among all age groups people regarding the UDID registration portal increased number of outreach camps and increased transportation availability helping elderly people from remote rural and urban areas to access disability certification easily.

In the present study, 348 (69.6%) belonged to males and 152 (30.4%) belonged to females with male to female ratio of 2.3:1 showing male preponderance. Other studies by Dharbarde et al., Ghosh et al., Khan et al., and Ambastha A et al. in India reported similar male preponderance in disability certification [1,3,6,9]. It might be due to the greater responsibility of male members of the family to earn and support the rest of the family. Also, males have greater mobility outside the house and access to various health services whereas, females face restrictions due to social norms, and low levels of education leading to limited access to health services.

In the present study, blindness (categories IVa and IVb) was the most common visual disability category. Studies by Dharbarde et al., Ghosh et al., Ambastha A et al., and Sadananda et al. [1,3,6,11] also reported partial/total blindness as the most common disability category. Only 46 certificates (9.2%) were one-eyed. It may be because only individuals with 40% or above are eligible for various government benefits and concessions. Contrary to this, in a study by Khan et al. one-eyed certificates (30% visual disability) were the maximum in number(60.3%) because a maximum number of enrolled disabled persons belonged to less than 40 years of age to whom temporary disability certificates for visual impairment were issued [8].

The most common overall cause for visual disability in the present study was retinal diseases (n= 205, 41%) with retinitis pigmentosa (n=76, 15.2%) being the most common retinal cause that was similar to findings in a study by Dharbarde et al. [1] In a study by Ambastha et al., the macular scar was a most common cause of visual disability followed by optic atrophy [6]. However, in a study by Khan et al. and Ghost et al., phthisis bulbi followed by microphthalmos was the most common cause of visual disability [3,8]. The reason for this finding was that the majority of the population who registered for visual disability in their study were of younger age group (< 20 years of age).

In the present study, leucomatous corneal opacity (18.5%) followed by hereditary macular dystrophy (16.3%) were the most common causes of visual disability in the less than 20-year-old age group. Similarly in the study by Ambastha et al., Hornby et al., and Titiyal et al. hereditary and congenital disorders such as hereditary macular dystrophy, microphthalmos, retinol-choroidal coloboma, etc. were reported as the most common cause of visual disability registration in < 20 years age [6,12,13]. In a study done in blind schools by Dandona et al., and Bhalerao SA et al., amblyopia after cataract surgery and complicated pseudophakia were found to be the most common cause of childhood blindness and disability certification [14,15]. Both of the causes were preventable/avoidable blindness and an explanation for their high number was

given as due to a lack of dedicated pediatric units with trained surgeons and poor follow-ups due to illiteracy.

Retinitis pigmentosa was the most common cause of disability certification in the 20-40 years age group in the present study. Similar findings were found in a study by Dharbadhe et al. [1] Study by Ambastha et al. reported macular scar due to hereditary macular dystrophy to be the most common cause for certification in this age group [6]. Another survey by Malhotra et al. done in the young population 15-49 years in Haryana, reported amblyopia due to uncorrected refractive error as the most common cause for visual disability [16]. The differences in the study might be attributed to variations in geographic location, sample size, study methodology, timing, availability, and utilization of eye care services.

In the present study, the most common cause for visual disability in the 40-60 years age group and > 60 years age group was optic atrophy and acquired macular degeneration respectively. In the study by Ambastha et al., glaucoma and diabetic retinopathy were the most common cause of visual disability in the 46-65 years and > 65 years age group respectively [6]. In developed countries like the United Kingdom, age-related macular degeneration and posterior pole degeneration were recorded as the most common cause for disability certifications in older age groups [10].

In our institute, even patients with < 40 percent visual disability (one-eyed and low vision patients) are issued UDID disability certificates all though they don't fit in criteria of getting any benefits and concession as per the Gazette of India notification which states that < 40 % disability are not eligible for any concession/benefits [17]. As a result, one-eyed patient fall face great difficulty in getting government jobs or benefits. In contrast to this, in a study by Dhabharde et al., patients with < 30 percent visual disability were not issued UDID visual disability certificate as it provided no benefits/concession to the patients thus highlighting the need for changes in the present certification system to benefit one-eyed and low vision patients. [1]. Similarly, a retrospective review by Monga PK et al. addressed a similar issue and proposed a new classification as per NPCB definitions of low vision and blindness which included all possible combinations of BCVA in two eyes and provided a wider range of disability categorization that could help patients having less than 40 percent visual disability to avail benefits and concessions [18].

A study by Dhabharde et al. and Ghosh et al. also reported an underrepresentation of older patients > 65 years of age and females for visual disability certification causing an underestimation of visual disability burden. There is a need to establish a UDID certification system at the district level, or more outreach camps for disability certification should be arranged. This might overcome barriers faced by females and older age patients thereby allowing more visually handicapped to get benefits/concessions.

Conclusions:-

Optic atrophy followed by retinal disease mainly retinitis pigmentosa was the most common cause for issuing visual disability certificates. Mostly 20-40 years age group patients enrolled for the certificate to avail benefits/ concessions as they form a major working and earning group of society with male patients significantly higher than females. The study highlighted the need for changes in the current certification system to benefit one-eyed and low-vision patients having less than 40 percent visual disability. It is recommended to establish the UDID certification system at the sub-district level or arrange more outreach camps for disability certification to overcome barriers faced by females and older patients, thus enabling registration of more visually handicapped individuals to access benefits and concessions.

Limitations:

The first limitation of our study was that we used hospital data in our study, without a specific population denominator therefore we could not calculate specific rates. The second limitation was that our study involved only patients from one district who voluntarily registered for UDID certification, so we could not extrapolate this data to get the true prevalence of low vision and blindness in the overall population. Another limitation was that we could not study certain details like the occupation of patients, educational status, and reasons for seeking blindness certificates as this study involved only analysis of UDID certificates from hospital databases in which this information was not available.

Recommendation: Expanding UDID certification at sub-district levels or through outreach camps to ensure broader access and inclusion.

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Data Availability

Data is available upon request.

Author contributions

All authors contributed to the design of the research. N and SD collected and analyzed the data. VJV and AP wrote the manuscript. RP and N edited the paper. All authors read and approved the paper.

List of abbreviations:

UDID- Unique Disability ID
DEPwD- Department of empowerment of persons with disabilities
RPwD- Rights of Persons with Disabilities Rules
Pwd- persons with disability

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Conflict of interest

The authors have no conflicting interests to declare.

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