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Low-vision rehabilitation in Italy: Cross-sectional data from the Device and Aids Registry (D.A.Re)

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Abstract

Objectives: We are reporting on the characteristics of low-vision adults attending large rehabilitation services which provide data to D.A.Re (Devices & Aids REgister) in Italy. D.A.Re aims to gather information about low-vision aids owned by Italian patients with visual impairment.

Methods: We included consecutive patients attending low-vision rehabilitation centres providing data to D.A.Re from 2019 to July 2021. Demographic features, self-reported use of technology and aids, vision performance, and the Instrumental Activity of Daily Living (IADL) score were collected.

Results: 720 patients were included in the D.A.Re. About half of the patients were affected by Age-related Macular Degeneration (389, 54.9%). Patients reported a long interval between onset of vision disability and access to low-vision rehabilitation, which was over two years in almost 30% of cases. Blindness registration status was almost complete when reported, but almost 40% were unable to report on this. IADL scores were higher for younger people and those with better visual acuity and critical print size (CPS), and lower for visual field restriction ($p < 0.01$ for all predictors). Of interest, better IADL scores were recorded for those with computer knowledge who used optical aids and software in univariate analyses and multivariate analyses, adjusting for level of visual disability and employment status ($p < 0.01$ for all predictors).

Conclusions: We report on the profile of low-vision patients using rehabilitation services in Italy. Longitudinal data during and after vision rehabilitation were collected. Our results support the validity of the D.A.Re to monitor the use of low-vision devices in Italy.

Keywords

Retina, age-related macular degeneration, glaucoma, retina, retinal pathology/research, genetics, optics/refraction/instruments

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Background

The World Health Organization (WHO) reported that globally 2.2 billion people are suffering from blindness or low vision (LV).[1] The International Classification of Diseases 11[2] classified vision impairment in two groups, that are distance and near conditions. In distance condition, mild vision impairment is defined as a best-corrected visual acuity between 6/12 and 6/18, moderate vision impairment is between 6/18 and 6/60 best-corrected visual acuity and severe visual impairment is defined as best-corrected visual acuity between 6/60 and 3/60. The definition of blindness is visual acuity level worse than 3/60 with the best possible correction. The term visual impairment includes both LV and blindness conditions.

In general, LV and blindness are visual impairment conditions that interfere with daily living tasks: they affect work activities, relationships, and independence.[3] Obtaining a better reading speed is the most necessary activity for people affected, then physical comfort, weight, cosmesis, and cost are also important secondary elements. Low vision aids (LVAs) can increase the residual functional sight ability, improving independence in daily activities.[3–5] A systematic review has shown that low-vision aids may improve quality of life in adults with LV by enhancing residual visual function and patients' autonomy.[6]

In Italy, the D.A.Re (Devices & Aids REgister) was developed by the National Institute for Device and Technology Assessment (Istituto Nazionale Valutazione Ausili e Tecnologie, INVAT) to gather information about the type of LVAs owned by Italian patients with visual impairment, the use of these devices, their efficacy and patients' visual function features. The D.A.Re was created in 2019 and collects data from several low-vision rehabilitation centres which are part of the Italian Union for the Blind and Visually Impaired (Unione Italiana Ciechi, UIC).

Using D.A.Re, we conducted a cross-sectional study and reported on the characteristics of patients in the registry, including demographic features, experience with devices and aids, reading performance, and activities of daily living.

Methods

We included 720 consecutive patients attending low-vision rehabilitation centres providing data to the D.A.Re from 2019 to July 7th, 2021. Of these, 358 were assessed at the Cavazza Institute for the Blind in Bologna, 149 at the Centre for Vision Rehabilitation and Education in Florence, 111 at the Regional Centre for Low Vision Rehabilitation (Padua), and the others in different low-vision services (located in Vicenza, Catania, Rome, Ascoli Piceno).

The following data were collected in an anonymous standardised fashion in the D.A.Re: demographics, occupational status, blind registration status (including registered level of better eye visual acuity and visual field), concurrent disabilities, ocular diseases causing low-vision, visual symptoms, visual acuity, reading performance using MNREAD charts, general knowledge and use of computers and software, knowledge of Braille, low-vision devices used (optical, electronic, others), including type, brand, and scope of use. Moreover, we adopted the validated Italian version of the Instrumental Activity of Daily Living (IADL) scale.[7]

The protocol for this study using the D.A.Re registry was approved by the Ethics Committee of the Area Vasta Centro-Careggi, Florence in May 2019.

We used descriptive statistics to report on the cohort characteristics. We fitted univariable and multivariable regression models to explore the association of relevant collected variables with the IADL score. All analyses were carried out using Stata 17.0 software (StataCorp, College Station, TX).

Results

Demographics and access to low vision services

Seven hundred and twenty patients were included in the D.A.Re, of whom 338 (46.9%) in 2021. Out of 721 subjects, 122 (16.9%) were aged 18–50, 276 (38.3%) were 50–79, and 320 (44.4%) were 80 yrs or more. There were 439 females (60.9%).

About half of the patients were affected by AMD (389, 54.9%), whereas primary diagnoses other than AMD were retinal dystrophies (94, 13.3%), glaucoma (39, 5.5%), and pathologic myopia (84, 11.9%). All other diagnoses were each 5% less frequent, including optic nerve atrophy, diabetic retinopathy, albinism, and neuro-ophthalmological conditions.

Four-hundred and thirty patients (59.6%) were able to report, or could be classified, in terms of visual disability according to the law nr. 138/2001. Of these, 71 patients (16.7%) had mild to moderate LV, 149 (34.7%) had severe LV, 156 (36.3%) partial blindness, and 53 (12.3%) total blindness.

Our study reports time from visual disability onset to access to LV services for 655 patients (91.0%); a period of 6 months or less was reported for 224 patients (3.2%), between 6 and 24 months for 239 (35.2%), and more than 24 months for 192 (28.9%), with 67 patients reporting over 6 years between their disability onset and access to LV service.

Table 1 presents the legal classification of visual impairment at the time of presentation to LV services, with respect to categories of better-eye visual acuity. Only 6 patients were unaware of their legal rights, as they positively stated not to have any legally recognised disability, but 283 patients were unable to report their status, 92 of whom (32.5%) had better-eye visual acuity of 1 logMAR

Table 1. The legal classification of visual impairment at the time of presentation to LV services, with respect to categories of better-eye visual acuity.

	VI and blindness status registration						
VA level	Mild	Moderate	Severe	Partial blindness	Complete blindness	Unknown	Total
Driving	1	1	11	0	0	10	23
Mild	4	3	6	1	0	20	34
Moderate	22	34	36	16	1	161	270
<20/200	1	4	72	14	2	51	144
<20/400	0	0	19	108	6	37	170
blind	0	1	2	8	43	4	58
Total	28	43	146	147	52	283	699

or worse. Moreover, 6 patients out of 79 with VF restriction of 10° or less had no legally recognised disability.

Knowledge of devices and assistive technology

At the time of examination, no low-vision aids were used by 286 (39.7%) patients, 1 device was used by 278 (38.6%) patients, and 2 to 4 by the remaining patients. Optical devices were used by 321 (44.5%) patients, electronic devices by 160 (22.2%), and software by 119 (16.5%).

Basic knowledge of computer use was reported by 328/701 (46.8%) patients. Knowledge of Braille was reported by 55/640 (8.6%), use of Braille software by 31/692 (4.5%) patients, and no knowledge of assistive technology was reported by 136/697 (19.5%) patients.

Of interest, there were significantly different computer skills ($p < 0.001$) depending on working status, with better skills in those employed (94.9%), followed by those looking for a job (75.7%) and finally by those unable to find a job due to their disability (57.1%); however, this figure is not adjusted for disability level, which may have influenced both their ability to use the computer and to find a job.

Performance in activities of daily living (IADL) and visual ability

Figure 1 presents boxplots of visual acuity by age, better-eye visual acuity, Critical Print Size (CPS), and primary diagnosis. Data are consistent with worse IADL score with increasing age, worse better-eye VA, and worse CPS, whereas no clear pattern is seen for primary diagnosis. The IADL score seemed to decline and was very variable at normal or near-normal acuity, which may be due to the co-occurrence of VF reduction as a cause of visual disability in these patients.

In a regression model in which IADL was the response variable, better-eye logMAR VA (0.42 IADL units per 1 logMAR), age (0.11 IADL units per 10 years), CPS (0.30 IADL units per 10 cp), and known visual-field related disability (VF < 10°: 1.05 IADL units), were all predictors of the IADL score ($p < 0.01$ for each predictor). However, only 25% of IADL variance was explained by these predictors, as is common with QOL questionnaires.

Determinants of IADL performance

We explored whether other patient characteristics were associated with the IADL score.

Self-report of good computer knowledge was recorded in 48.6% of patients and was significantly associated with the IADL score in univariate analyses (−1.0, $p < 0.001$). This finding persisted (−0.84, $p < 0.001$) even after adjusting for age, severity of VA, and employment status; on the other hand, in the multivariate model, people looking for employment accounted for 1.36 IADL units, worse ($p = 0.008$) due to disability, with respect to people retired, and being unable to work accounted for 2.37 IADL units ($p < 0.001$).

Similarly, the use of at least 1 low-vision device was recorded in 64.1% of patients and accounted for −0.38 IADL units ($p = 0.004$), a figure that did not change with multivariate adjustment.

Use of devices and IADL performance

We investigated whether the use of different device types was associated with IADL. In univariate regressions, we found that optical aids (−0.34, $p = 0.007$) and software (−0.82, $p < 0.001$), but not electronic (−0.06, $p = 0.681$) and mobility aids (−0.31, $p = 0.327$), were associated with better IADL. These results were confirmed when all devices were included in the multivariate analyses. Moreover, optical aids (−0.28, $p = 0.019$) and software (−0.50, $p = 0.005$) were still associated with better IADL when adjusted for level of visual disability and employment status.

Discussion

We have reported on the characteristics of a large sample of people with VA attending low-vision clinics in Italy.

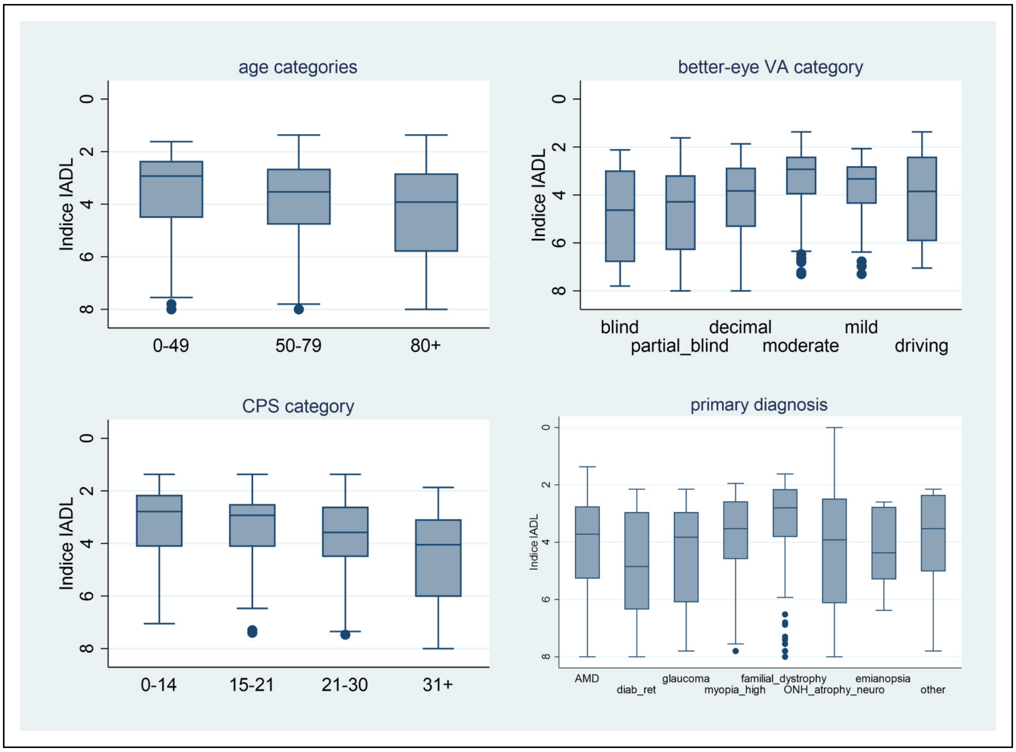

Figure 1. Presents boxplots of visual acuity by age, better-eye visual acuity, critical print size (CPS), and primary diagnosis. Data are consistent with worse IADL score with increasing age, worse better-eye VA, and worse CPS, whereas no clear pattern is seen for primary diagnosis. The IADL score seemed to decline and was very variable at normal or near-normal acuity, which may be due to the co-occurrence of VF reduction as a cause of visual disability in these patients.

AMD was the primary cause of visual loss, but hereditary retinal dystrophies were also prevalent in this series, possibly due to the referral modalities and the major data collection at the Cavazza Institute in Bologna. Noticeably, patients reported a long interval between onset of vision disability and access to low-vision rehabilitation, which was over 2 years in almost 30% of cases. Blindness registration status was almost complete when reported, but almost 40% were unable to report on this, of whom one fourth met the criteria for registration.

Regarding skills in using technology, about half of the patients had basic computer knowledge and one fifth used assistive technology. These skills were widespread among patients with jobs compared to those who were unable to find a job.

As expected, IADL scores were higher for younger people and those with better VA and CPS. Visual field restriction also independently affected IADL. Better IADL scores were recorded for those with computer knowledge who used optical aids and software in univariate analyses and multivariate analyses, adjusting for level of visual disability and employment status.

The major influence of tech-IADL may be linked to daily activities with technology options. Being able to manage money using home banking, shopping online, or smartphone use with vocal control, allows patients to perform daily living tasks independently. However, using technology implies good computer knowledge.

Another cause of better use of tech-IADL could be related to the current transition to virtual and online services and interaction, which has been increased by the COVID-19 pandemic. This has improved the possibility of accessing many services that were unavailable online before. This is important for vision-impaired patients who need to manage life issues/matters independently. However, this opportunity is possible only for people who know how to use technology: performing targeted training courses and creating infrastructure is necessary at present to enhance peoples' digital competence, which would result in a reduction of social exclusion and an increase in independence for low-vision and blind people. Furthermore, Braille and technology knowledge will increase the possibility of work, regardless of visual impairment.

Magnifying glasses are the first aids bought by patients because they are easily available and there is no need for rehabilitation training or a medical prescription. Optical aids seem to be associated with fewer benefits compared to high-tech devices, which may be due to the fact that they rarely meet daily life activity needs.

Another important issue is the long time gap between visual impairment onset and access to visual rehabilitation, which may have a negative impact on independence in daily activities. Reasons for this delay might be the lack of services and accurate guidelines for referral to rehabilitation.

Our study is difficult to compare with others due to context and design issues. Golubova et al.[8] collected data on patients' experience of device use and provided suggestions for their design. They found that handheld magnifiers were preferred over desktop magnifiers, and they also recorded the users' favour regarding PC accessibility software and portable electronic devices. Finally, they presented a list of desirable and undesirable device features, also concluding that preferences varied across participants. Starke et al.[3] conducted a mixed-methods study that mapped tasks and activities of interest for low-vision individuals and suggested that modern aids should accommodate quickly-changing focus planes and object distances, allow for visual scan and ideally facilitate walking. They also identified that acceptability in public spaces was a concern for many people. Dai et al.[9] used artificial intelligence to identify which device can be predicted to suit each patient's needs in 629 Chinese low-vision individuals, including young adults and children and mostly from rural areas. They found that aids improving tasks at intermediate distance and listening aids were preferred and suggested that age, education, and the economic level should also be considered for prescription. Engesser et al.[10] conducted a retrospective study of 1203 patients' charts and found that individual and personal examination is the basis for magnification prescriptions. Moreover, Lorenzini and Wittich[11] considered poor motivations a predictor of aids non-use. Although not directly related to our study, this information is relevant to understand and plan research on how to tailor low-vision aids to each person's need.

The main limitation of this study is that its cross-sectional design can detect associations, but cannot prove causation, especially regarding predictors of IADL scores. Nonetheless, the association between device and software use and IADL persisted after adjusting for important confounders, including employment and disability levels. We collected but did not analyse data on device use and experience, since these were obtained retrospectively from the D.A.Re. The registry could be improved with a standardised, prospective collection of these data, specifically in its longitudinal perspective.

In conclusion, we have reported on the profile of low-vision patients using major rehabilitation services in Italy. Although our data collection is cross-sectional, results suggest that the use of low-vision aids improves patients' independence and quality of life. This result supports the use of the D.A.Re to monitor the use of low-vision devices and patients' experience with low-vision services, as well as a multi-dimensional evaluation of all daily activities and all device types available for patients. We are at present collecting longitudinal data during and after vision rehabilitation in the D.A.Re, which will provide more robust information on the use of low-vision devices in Italy.

Declaration of conflicting interests

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