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Characterizing Functional Complaints in Patients Seeking Outpatient Low-Vision Services in the United States

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Abstract

Purpose—To characterize functional complaints of new low-vision rehabilitation patients.

Design—Prospective observational study.

Participants—The Low Vision Rehabilitation Outcomes Study recruited 819 patients between 2008 and 2011 from 28 clinical centers in the United States.

Methods—New patients referred for low-vision rehabilitation were asked, “What are your chief complaints about your vision?” before their appointment. Full patient statements were transcribed as free text. Two methods assessed whether statements indicated difficulty in each of 13 functional categories: (1) assessment by 2 masked clinicians reading the statement, and (2) a computerized search of the text for specific words or word fragments. Logistic regression models were used to predict the influence of age, gender, and visual acuity on the likelihood of reporting a complaint in each functional category.

Main Outcome Measures—Prevalence and risk factors for patient concerns within various functional categories.

Results—Reading was the most common functional complaint (66.4% of patients). Other functional difficulties expressed by at least 10% of patients included driving (27.8%), using visual assistive equipment (17.5%), mobility (16.3%), performing in-home activities (15.1%), lighting and glare (11.7%), and facial recognition and social interactions (10.3%). Good agreement was noted between the masked clinician graders and the computerized algorithm for categorization of functional complaints (median κ of 0.84 across the 13 categories). Multivariate logistic regression models demonstrated that the likelihood of reading difficulties increased mildly with age (odds ratio, 1.4 per 10-year increment in age; 95% confidence interval, 1.3–1.6), but did not differ with

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visual acuity ($P=0.09$). Additionally, men were more likely to report driving difficulties and difficulties related to lighting, whereas women were more likely to report difficulty with either in-home activities or facial recognition or social interaction ($P<0.05$ for all). Mobility concerns, defined as walking difficulty and out-of-home activities, showed no relationship to gender, age, or visual acuity.

Conclusions—Reading was the most commonly reported difficulty, regardless of the patient’s diagnosis. Neither visual acuity nor gender were predictive of reading concerns, although, age showed a small effect. Addressing reading rehabilitation should be a cornerstone of low-vision therapy.

Patients seeking low-vision rehabilitation (LVR) have chronic visual impairments that limit their ability to participate in daily activities. These patients have a broad range of vision-mediated functional limitations, lower quality of life, and decreased independence.^{1–8} Depending on the visual acuity (VA) criteria used ($\geq 20/70$ or $<20/40$), studies estimate that 1.5 or 3.5 million Americans older than 40 years of age, respectively, have low vision.^{9,10} The prevalence of vision impairment is even greater in patients older than 65 years of age. Given the predicted growth of this age group, LVR will become an even more essential part of routine ophthalmic care.¹¹

Low-vision rehabilitation is individualized for each patient’s functional goals¹²; yet to date, there is little detail on the prevalence of different functional concerns in patients seeking outpatient low-vision services. Recognition of common rehabilitative needs will provide researchers and clinicians direction in the development and planning of LVR outcome measurements and rehabilitation strategies necessary to address the growing demand of the visually impaired population. Targeted and effective rehabilitation therapies can enable patients with chronic visual impairment to improve activities of daily living and overall quality of life.¹³

The Low Vision Rehabilitation Outcomes Study¹⁴ was designed to characterize typical patients seeking LVR in the United States and offers a unique opportunity to identify the rehabilitation priorities in these patients. In this prospective observational study, new low-vision patients seeking treatment at 1 of 28 clinical centers in the United States provided a complaint statement regarding their reason for seeking low-vision services. We categorized the difficulties voiced in these complaint statements, thus defining the primary functional categories in which patients seeking LVR services expected improvement in their daily function.

Methods

The study protocol was approved by The Johns Hopkins Institutional Review Board and adhered to the Declaration of Helsinki. When required, each study site obtained separate institutional review board approval. All participants signed a contact authorization and were contacted by the coordinating center at The Johns Hopkins University. Research assistants described the study and obtained oral consent on the telephone.

Subjects

Low Vision Rehabilitation Outcomes Study participants were recruited into this prospective, observational study from 1 of 28 clinical centers across the United States. Eight hundred nineteen participants were identified from new patients scheduling a low-vision appointment between April 25, 2008, and May 2, 2011. Eligible patients were older than 18 years of age, able to communicate in English over the telephone, and had not received low-vision services in the previous 3 years. Complaint statements were transcribed by research assistants from 535 women (66.4%) and 271 men (33.6%). Median participant age was 77 years, ranging from 18 to 110 years (standard deviation, 16.1 years). The mean VA in this sample was 0.68 logarithm of the minimum angle of resolution (logMAR) units (Snellen equivalent, 20/96), with a standard deviation of 0.50 logMAR. Median VA was 0.60 logMAR (Snellen equivalent, 20/80), with the interquartile range extending from 0.4 to 1.0 logMAR (95% confidence interval [CI], 0.64–0.72). The primary ocular diagnosis was commensurate with macular disease in the eye with the better habitual VA in 55% of the patients. No VA, visual field, or diagnosis exclusions were used because the goal was to capture a typical distribution of patients seeking LVR services.¹⁴

Categorization of Functional Complaints

Patients completed a phone interview before their initial low-vision assessment appointment and were administered several questionnaires, including an intake survey. This intake survey comprised 1 open-ended question about functional concerns followed by standardized check-box questions detailing ocular, medical, physical, psychological, and social history.¹⁴ For the open-ended question, patients were asked, “What are your chief complaints about your vision?” Interviewers transcribed patients’ statements as free text. Patients were encouraged to describe functional difficulties resulting from their vision.

Free-text complaint statements were categorized by 2 methods. First, 2 clinicians (J.G. and T.C.) specializing in LVR reviewed each participant’s statement independently and coded each complaint statement using any number of the 13 functional categories characterized in Table 1. All disagreements in categorization between the 2 reviewers were discussed, and a final decision was determined for each patient’s complaint statement by consensus. Second, a computerized algorithm was used to search participants’ transcribed statements using a set of standardized query terms created by a third clinician (P.R.) independent from the other graders (Table 1). This computerized coding by search terms was conducted to corroborate objectively the coding dictated by the 2 low-vision specialists. Finally, the functional codes were analyzed against patients’ primary ocular diseases as defined by the ninth edition of the International Classification of Diseases (ICD-9).

Statistical Analysis

Complaint frequencies for each functional category from the clinician and automated search-generated results were calculated and κ statistic was used to test the concordance in the categorization of these results. Chi-square analyses were used to compare results across genders. Multivariate logistic regression models were used to assess the relevance of age, gender, and VA with regard to the likelihood of expressing complaints in each functional

category (using the adjudicated grader analysis). Analyses were conducted in Stata software version 12 (Stata Corp, College Station, TX).

Results

The agreement between clinician graders regarding whether or not a complaint was present within each functional category was high, and κ values were greater than 0.75 for all functional categories except out-of-home activities ($\kappa = 0.45$). For most functional categories, the consensus opinion of the 2 low vision specialists and the computerized search algorithm demonstrated high agreement regarding whether a complaint within the category was present ($\kappa > 0.7$ for 10 of 13 functional categories). Slightly lower agreement was found between the grader consensus and computerized search when assessing the presence or absence of lighting complaints ($\kappa = 0.56$), difficulty with outside activities ($\kappa = 0.59$), and difficulty with in-home activities ($\kappa = 0.63$; Table 2).

Participant statements could have complaints in 0, 1, or more than 1 functional category, and 11.2% (92/819) of patient statements did not describe a functional complaint. One functional complaint was identified in 27.4% of statements, 2 functional complaints were identified in 28.7% statements, 3 functional complaints were identified in 20% of statements, and 4 or more complaints were identified in 12.7% of patient statements (Fig 1). Overall, reading was the most frequent complaint and was reported by 544 (66.4%) of 819 patients (Fig 2). Driving concerns (228 patients; 27.8%) and the use of assistive devices (143 patients; 17.5%) were the next most commonly reported complaints. Other complaints reported by at least 10% of patients included difficulty with in-home activities (124 patients; 15.1%), lighting-related activities (96 patients; 11.7%), and recognizing faces or interacting socially (84 patients; 10.3%). Categories with less than 10% of patients included difficulties with walking, performing hobbies, using technology, watching television, doing out-of-home activities, and working- or school-related activities. Mobility-related complaints, defined as a complaint with either walking or out-of-home activities, were voiced by 133 patients (16.3%).

Disorder diagnoses were available in 586 of 819 patients and showed the most common primary diagnosis to be atrophic macular degeneration (ICD-9-CM code 362.51). This diagnosis was found in 25% (149/573) of patients, and 77% of these patients had reading complaints. Driving (26%) and use of assistive devices (20%) were the next most common complaints in atrophic age-related macular degeneration patients, whereas all other complaints were reported less than 20% of the time in this patient group. Similarly, in all other diagnosis categories, reading and driving were overwhelmingly the most common patient complaints (Fig 3).

In univariate analyses, women were more likely to report difficulty using assistive devices (19.3% vs. 13.6%; $P = 0.04$), performing in-home activities (18.1% vs. 9.2%; $P < 0.001$), engaging in social activities (12.2% vs. 6.3%; $P = 0.007$), and walking (11.2% vs. 6.6%; $P = 0.03$). Men were more likely to report driving difficulty (36.2% vs. 23.6%; $P < 0.001$) and light-related problems (14.0% vs. 10.1%; $P = 0.01$; Table 3). The prevalence of reading or

other functional complaints was not significantly different between men and women (all $P>0.06$).

In multivariate analyses, older age was associated with a greater odds of reading complaints (odds ratio [OR], 1.4 for 10-year increment in age; 95% CI, 1.3–1.6). No significant association was found between VA or gender and the presence of a reading complaint. Men had a 1.9 times greater odds of reporting a driving complaint when compared with women (95% CI, 1.3–2.8), and younger subjects also were more likely to report driving concerns than older subjects (OR, 0.87 per 10-year increment in age; 95% CI, 0.8–1.0). Assistive device complaints were more likely in older subjects as compared with younger subjects (OR, 1.3; 95% CI, 1.1–1.5), whereas complaints about using technology (OR, 0.70 per 10-year increment in age; 95% CI, 0.6–0.9) and functioning at work or school (OR, 0.74 per 10-year increment in age; 95% CI, 0.6–0.9) were less frequent with increasing age. Men were less likely to report difficulty with facial recognition and social interactions as compared with women (OR, 0.44; 95% CI, 0.2–0.8) and also were less likely to report difficulty with in-home activities compared with women (OR, 0.39; 95% CI, 0.2–0.7). Worse VA was associated with a greater likelihood of reporting difficulty with in-home activities (OR, 1.9; 95% CI, 1.3–2.9) and television watching (OR, 1.8; 95% CI, 1.0–3.2) and a lower likelihood of light-related complaints (OR, 0.5; 95% CI, 0.3–0.9). The frequency of complaints within other functional categories did not vary significantly across age, gender, or VA (Table 4).

Discussion

Reading

The current study was the first to assess systematically the chief complaints of a large group of patients seeking outpatient LVR across the United States. We found that reading difficulty was by far the most common presenting concern, characterized in the complaint statements of two-thirds of new LVR patients. This frequency was significantly greater than the frequency observed for other categories of complaints including driving, assistive devices, and in-home activities (frequency less than 30% for all). The overwhelming prevalence of reading-related concerns found in our study supports the idea that improving reading function should be the cornerstone of LVR.

Despite the extensive literature describing a strong relationship between reading ability and VA,^{2,15–17} we did not find an association between VA and the presence of reading complaints in this study sample. One possible explanation for this finding is that patients have deficits other than VA loss that affect their reading ability and initiate seeking low-vision services independent of VA. For example, paracentral scotomas resulting from macular disease, visual field loss resulting from glaucoma,¹⁸ or reduced contrast sensitivity or glare with discomfort resulting from corneal disease may contribute to reading difficulty even with good VA.^{19,20} Thus, our study corroborates previous work suggesting that VA measurements should not be the only determining factor when identifying reading concerns or referring for low-vision services.^{14,21,22}

A second possible explanation for the lack of association between VA and the presence of a reading complaint is that the specific reading tasks that the patients desired to perform varied

across the spectrum of VA. Indeed, the term *reading* covers a broad range of activities with significant variability in difficulty, including sustained continuous reading of a book, magazine, or computer versus spot reading of medicine bottles, bills, or food labels.^{16,19,23–26} Furthermore, previous research suggests that sustained reading tasks may be significantly more affected than spot reading tasks with certain types of visual impairment.^{20,27} Finally, advances in technology have increased the number of formats in which reading takes place. Today, reading takes place on computer screens, tablets, e-readers, and smart phones in addition to traditional reading sources such as hard-copy magazines, newspapers, and standard large-print books; hence, reading difficulty may vary significantly across these media. Understanding the importance of reading tasks for patients' specific needs and the required ability to achieve these diverse tasks is essential for generating evaluative measures to address all spectrums of reading tasks and for development of customized LVR protocols aimed at rehabilitating task-specific reading activities.

We did find that reading complaints became slightly more significant with older age (Table 4). Additionally, complaints regarding visual assistive equipment also increased slightly with age, although the small magnitude of these findings suggests they have limited clinical significance. Similar to previous reports,²⁸ we did not find any associations between gender and the likelihood of reporting reading concerns, nor did we find that ocular diagnosis significantly impacted the chief complaint of patients. Rather, our findings show that reading is consistently the most common complaint among all patients seeking LVR services.

Driving

Driving difficulty was the second most common complaint and was reported in more than one quarter (28%) of low-vision patients. The severity of VA loss was not predictive of having a driving complaint, which may reflect the increased prevalence of driving cessation with worse VA.^{29–31} As VA declines and cessation of driving occurs, adjustment to becoming a nondriver may reduce the importance of driving as a concern, explaining our observed findings. Additionally, the relationship between VA and driving complaints may be minimized because of effective changes in driving practices that occur in low vision populations. It is estimated that one quarter to one third of patients seeking low-vision services drive and that most of these patients self-restrict their driving practices.^{14,31,32} Driving in familiar environments and fewer miles per week limit the need to perform more difficult behind-the-wheel tasks that require better VA, such as reading road signs, maps, and GPS devices.³¹ As a result of more limited driving demands and modifications in driving behavior, many patients may feel that their driving activities are manageable and not a concern that needs to be addressed.

Our findings showed that younger individuals seeking LVR were more likely to report driving complaints. This is consistent with the everyday demands of family, work, or school responsibilities requiring transportation. The median age of our sample was 77 years, and with increasing age comes the associated physical, cognitive, and psychological comorbidities that can contribute to driving cessation regardless of vision loss.³³ Gender also was found to be a strong predictor of driving complaints. This effect may occur because men continue to drive despite having visual concerns, and women discontinue driving

earlier.^{33–37} Based on these findings, it is important to query younger male patients with any level of visual impairment about their driving concerns and practices to limit risks to public safety.

Mobility

Mobility-related complaints, described as walking and out-of-home activities, were a concern in 16.3% of the sample. The concern was more evident in females; however, after adjusting for age and VA, gender was not predictive of having a mobility-related complaint. The prevalence of mobility concerns may be even greater in patients with visual impairment because other activity categories (i.e., in-home activities, hobbies) also may involve walking. Mild visual impairment and reduced physical ability notably increase the risk of falls both in and out of the home, decrease independence, and reduced quality of life.^{14,33,38} Considering that the prevalence of mobility-related concerns in people with peripheral vision loss is greater than those with central loss^{8,38,39} and that most patients in our sample had macular disease with central visual impairment,¹⁴ our potential undersampling of diseases causing peripheral visual field loss may underestimate the impact of mobility concerns in LVR patients. It is noteworthy that the prevalence of complaints related to walking was greatest when the primary diagnosis was categorized as glaucoma, diabetic retinopathy, or optic neuritis—all of which are commonly associated with peripheral visual field loss.

The classifications of patient complaints into functional categories show good agreement between the 2 clinicians and between the clinicians and key word searches. The ability to classify functional complaints of low-vision patients consistently is essential because LVR evaluation and treatment is guided by key domains (e.g., reading, mobility) of valued activities. Complaint categorization typically is guided by clinician interview, visual function questionnaires,⁴⁰ or the use of item banks.⁴¹ The changes in functional ability within these domains often are used as the primary outcome measures in LVR, and our study showed that clinical categorization of complaints voiced by patients is consistent with objective computerized methods to categorize complaints.

Our assessments of reading and other functional complaints were free form, so we could not report detailed information about patients' functional ability. Additionally, complaint statements do not specify particular subtasks, for example, reading books versus computer reading versus reading medicine bottles. Different reading tasks may be affected at different stages of vision loss, perhaps explaining the lack of relationship between VA and reading complaints in the current study, whereas an extensive literature describes a strong association between visual acuity and reading ability.^{16,19,33,42} Our large sample size with geographic diversity provided generalizability to our characterization of the typical patient seeking low-vision services in the United States, although different findings may be found in other countries.

The predominance of reading complaints in low-vision patients and high reading demands as part of everyday activities in the United States necessitate careful consideration in attending to patient concerns regardless of their level of VA or gender. Patients seeking outpatient LVR may have multiple concerns that require discussion and evaluation because of the potential health (e.g., falls) and public safety consequences (e.g., driving). Development of new

technology and approaches to reading rehabilitation should remain a directive in ongoing research to address the reading demands of patients with vision loss.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations and Acronyms

CI	confidence interval
logMAR	logarithm of the minimum angle of resolution
LVR	low-vision rehabilitation
OR	odds ratio
VA	visual acuity

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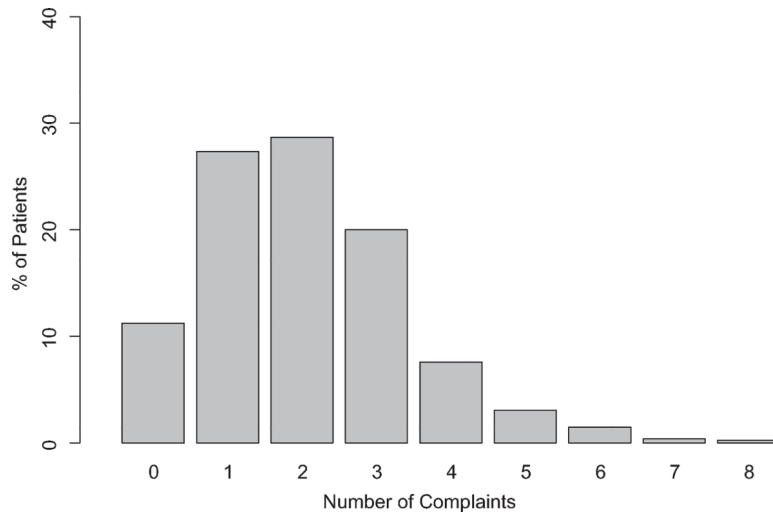


Figure 1. Bar graph showing the number of functional complaints per individual in a national sample of patients seeking low-vision treatment. Data taken from 819 new low-vision patients seeking treatment at 1 of 28 clinical centers.

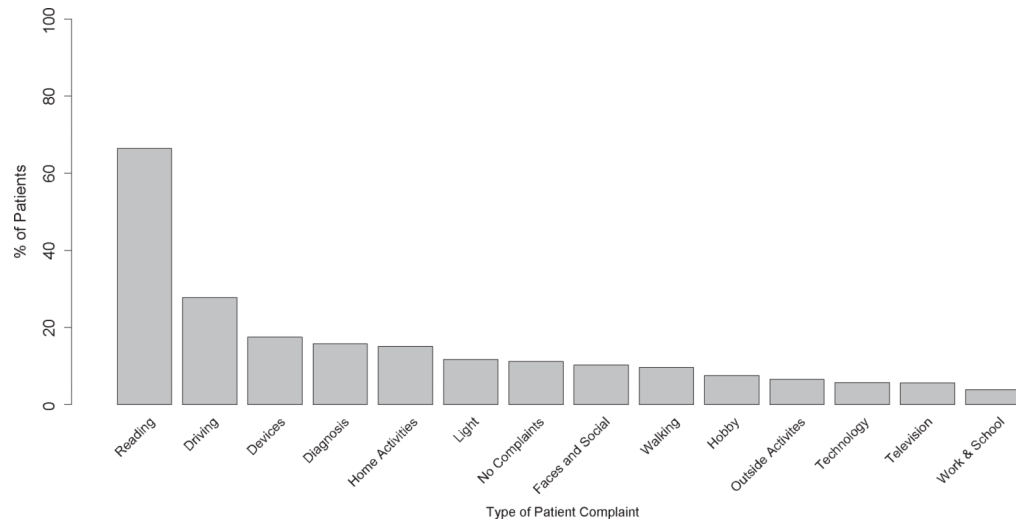


Figure 2. Bar graph showing the frequency of various functional complaints among a national sample of patients seeking low-vision treatment. Data taken from 819 new low-vision patients seeking treatment at 1 of 28 clinical centers.

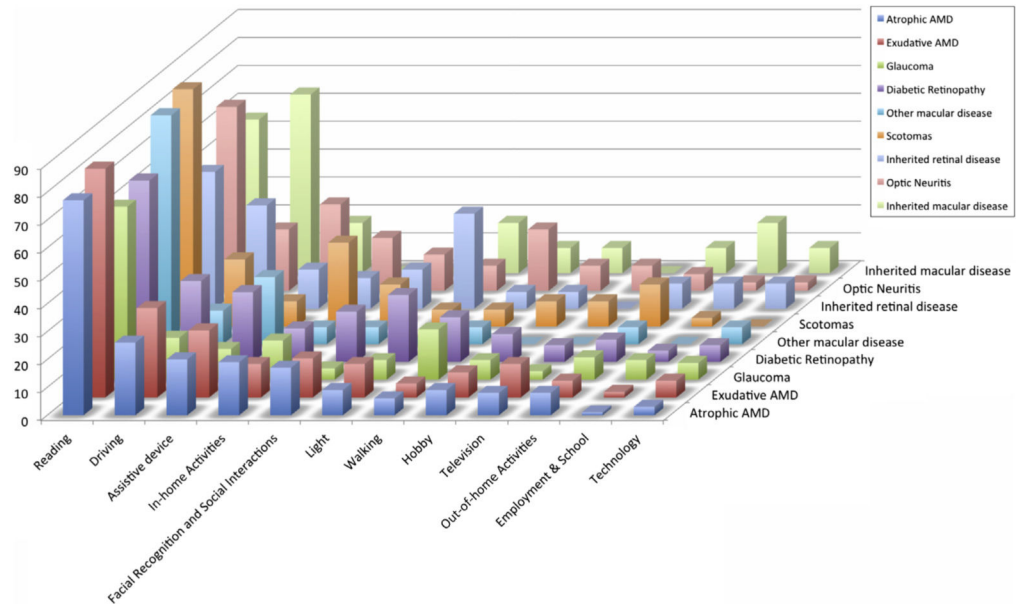


Figure 3. Bar graph showing the frequency of functional complaints by ocular disease diagnosis in a national sample of patients seeking low-vision treatment. Diagnosis defined by International Classification of Disease, Ninth Edition, coding. AMD = age-related macular degeneration.

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Table 1.

Categorization of Functional Complaints of a Low-Vision Population

Complaint	Definition	Automated Search Keywords
Diagnosis	The patient restates their diagnosis or medical condition, or referenced their disease	glauc,* macula,* hemianopsia, amd, retin,* stargardt, choroid,* cataract*
Reading	Difficulty reading any type of material	read, print
Television	Difficulty viewing television	television, tv
Driving	Complains driving difficulty or cessation, or if family or doctor concern present	driv,* road, drove
Facial recognition and social interactions	Complains identifying faces and expressions, especially if inhibitory to social interactions	face, kids, people, son, daughter, facial, church
Hobby	Discretionary activities that are nonessential for independence or daily function	golf, music, sew,* art, bold (shot pool), piano, stitch, baseball, crossword, bowling, tennis, hobb,* bingo, boat, hunt, paint, garden, craft, needle, crochet, puzzle
Light	Difficulty with lighting (glare, sensitivity, or night blindness) that restricts function	glare, dim, dark, night, light, photosen*
Employment and school	Visual complaints that impact patient's ability to work or function in school	school, blackboard, job, courses, employ, occupation, work
Assistive device	Complaints regarding visual assistive equipment, excluding eyeglasses	polarize, sunglass, magnif,* cctv (closed-circuit television), binocular
Technology	Complaints about difficulty using technology	computer, type and typing, mouse, palm pilot, kindle
In-home activities	Difficulty with daily activities inside the home	writ,* cook, mail,* phone, ingredients, recipes, clothes, packag,* clean, paperwork, bill,* check, yard, microwave, bath, label, oven, eat
Out-of-home activities	Difficulty with daily activities requiring the patients to leave their home	getting around, getting places, shop, transportation, go out, going out, travel, leave* home, store, grocery, supermarket
Walking	Complaints regarding trouble walking	bump, curb, run into, step, walk, navigat,* balance, trip, fall, fell, stair, ground, moving around, o&n(orientation and mobility), terrain, maneuvering

* Indicates wildcard letters for the key word search; allows multiple permutations of the word.

Table 2.

Frequency of Complaints in Low-Vision Patients by Automated Search versus Manual Grading*

Type of Complaints [†]	Manual (%)	Keyword (%)	κ Value [‡] (95% Confidence Interval)
Reading	66.4	66.7	0.94 (0.91–0.97)
Driving	27.8	28.8	0.95 (0.92–0.97)
Assistive device	17.5	15.4	0.91 (0.87–0.95)
Diagnosis	15.8	8.3	0.63 (0.55–0.71)
In-home activities	15.1	16.7	0.63 (0.56–0.70)
Light related	11.7	16.4	0.75 (0.68–0.81)
No complaints categorized	11.2	12.5	0.80 (0.74–0.87)
Facial recognition and social interactions	10.3	12.7	0.86 (0.80–0.91)
Walking	9.7	9.4	0.84 (0.78–0.91)
Hobby	7.6	8.8	0.71 (0.62–0.8)
Out-of-home activities	6.6	7.2	0.59 (0.48–0.70)
Technology	5.7	5.7	0.97 (0.95–1.0)
Television	5.6	7.3	0.86 (0.79–0.93)
Employment and school	3.9	6.2	0.56 (0.43–0.69)

*The automated search was conducted by using keyword search terms created by a clinician independent of the 2 low-vision rehabilitation clinicians who performed manual categorization.

[†]Each patient's statement may be categorized under multiple complaint categories.

[‡]Reflects agreement between for the categorization determined by the computerized key word search versus the adjudicated patient statements.

Table 3.

Types of Complaints * in Low-Vision Patients by Gender

Type of Complaint	Women (%)	Men (%)	P Value
Reading	68.6	62.7	0.097
Driving	23.6	36.2	<0.001
Assistive device	19.3	13.6	0.043
In-home activities	18.1	9.23	<0.001
Diagnosis	15.9	14.8	0.68
Facial recognition and social interactions	12.2	6.27	0.007
Walking	11.2	6.6	0.03
Out-of-home activities	7.9	4.4	0.06
Light	10.1	14.0	0.10
Hobby	8.6	5.5	0.11
Technology	6.2	5.2	0.56
Television	5.8	5.2	0.71
Employment and school	3.7	3.2	0.76

Boldface indicates $P < 0.05$.

* Each patient's statement may be categorized under multiple complaint codes.

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Associations in Low-Vision Patient Complaints after Adjusting for Gender, Age, and Visual Acuity

Table 4.

Type of Complaint	Independent Variables: Odds Ratio (95% Confidence Interval)		
	Male Gender	Age (per 10 yrs)	VA (0.1 LogMAR Worse)
Reading	0.78 (0.5–1.1)	1.4 (1.3–1.6)	1.3 (1.0–2.0)
Driving	1.9 (1.3–2.8)	0.87 (0.8–1.0)	0.94 (0.7–1.4)
Assistive device	0.74 (0.5–1.2)	1.3 (1.1–1.5)	1.2 (0.8–1.8)
In-home activities	0.39 (0.2–0.7)	1.2 (1.0–1.4)	1.2 (1.3–2.9)
Diagnosis	0.93 (0.6–1.4)	0.99 (0.9–1.1)	0.49 (0.3–0.9)
Facial recognition and social interactions	0.44 (0.2–0.8)	1.1 (0.9–1.3)	1.4 (0.9–2.3)
Walking	0.51 (0.3–1.0)	0.9 (0.8–1.1)	1.6 (1.0–2.6)
Out-of-home activities	0.50 (0.23–1.1)	1.1 (0.9–1.3)	0.62 (0.3–1.3)
Light	1.9 (1.2–3.2)	0.82 (0.7–1.0)	0.5 (0.3–0.9)
Hobby	0.64 (0.3–1.3)	1.2 (0.9–1.4)	0.90 (0.5–1.7)
Technology	0.86 (0.4–1.9)	0.70 (0.6–0.9)	0.61 (0.3–1.4)
Television	0.99 (0.48–2.0)	1.2 (0.9–1.6)	1.8 (1.0–3.2)
Employment and school	0.34 (0.1–1.2)	0.74 (0.6–0.9)	1.4 (0.6–3.2)

logMAR = logarithm of the minimum angle of resolution; VA = visual acuity.

Boldface indicates $P < 0.05$.