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Leveraging Electronic Health Records to Identify and Characterize Patients with Low Vision

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Abstract

Purpose: To use electronic health record (EHR) data to estimate the prevalence and characteristics of low-vision (LV) patients.

Methods: EHR data were obtained for all patients at the nine clinical locations of the Wilmer Eye Institute in 2014. LV status at each visit was defined as visual acuity (VA) worse than 20/40 in the better-seeing eye. Prevalence and incidence estimates were determined over a 12-month period. Demographic and clinical data were used to compare the characteristics of patients with and without LV. Logistic regression analyses were used to determine prevalence and incidence estimates adjusted for age, sex, race, and ethnicity.

Results: A total of 100,755 patients were included in the analysis. There were 7752 (7.7%) prevalent and 1962 (2.1%) incident cases of LV. Among patients with LV, 55% had VA between 20/40 and 20/60. Outside of LV clinics, retina and glaucoma clinics had the highest prevalence (18% and 14%, respectively) and incidence (5% and 4%, respectively) of LV. The urban hospital center had twice the prevalence of LV than suburban clinics (11.5% vs. 5.6%). The odds of prevalent LV was greatest among patients 80 years and older (odds ratio = 6.18; 95% confidence interval: 5.62–6.80) as compared to those 20–39 years old.

Conclusions: EHR can be used to estimate the prevalence and describe the characteristics of patients with LV seeking ophthalmic care. The highest prevalence rates of LV are observed in the urban setting and among patients obtaining retina and glaucoma care.

Keywords

Low Vision; Prevalence; Electronic Health Records

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Disclosure Statement

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Introduction

Previous research indicates that the utilization of low-vision rehabilitation (LVR) services is low,^{1,2} and interventions intended to increase service uptake are mixed.^{3–6} An important limitation of these efforts is the difficulty in identifying the source population for these interventions, which are patients with low-vision (LV) in ophthalmic care settings. Since the majority of patients who access LVR services are already under ophthalmic care, estimating the magnitude and characteristics of these patients is essential for tailoring interventions aimed at increasing LVR services utilization. Although definitions and categorizations of LV vary,^{7–9} the American Academy of Ophthalmology (AAO) emphasizes the importance of early identification and intervention, and therefore recommends ophthalmologists consider referral of patients when visual acuity (VA) is less than 20/40 in the better-seeing eye.¹⁰

Currently, there is no information on the incidence and prevalence of patients with LV in the outpatient ophthalmic care settings in the United States. Nearly all estimates of LV are from population-based studies, which may not reflect the characteristics of individuals accessing ophthalmic care.^{11–13} Prior to the widespread use of electronic health records (EHR), estimating the number of patients with LV in ophthalmic care settings would require significant manpower and organization, as one would have to review a representative sample of hand-written records across multiple practices of varying subspecialties (e.g., retina, glaucoma, cornea). This has not been done given the difficulty in coordinating such an effort, and therefore population-based surveys have been the primary approach to creating estimates. With the extensive deployment of EHRs, we now have the opportunity to examine the prevalence and incidence of LV as defined by VA, as well as determine the characteristics of patients with LV among those seeking ophthalmic care.

In this study, we aim to estimate the prevalence and incidence of LV among patients seeking ophthalmic care in a university hospital center and satellite suburban clinics, to compare the prevalence of LV by ophthalmology subspecialties and service locations, and to compare the demographic and clinical characteristics of patients with and without LV in these settings. Additionally, this research establishes a method to characterize the total population of patients with LV by leveraging EHR data that can be applied in any ophthalmic setting.

Materials and methods

Study design

The Johns Hopkins University School of Medicine Institutional Review Board approved this study's protocol. This study uses data abstracted from EpicCare Ambulatory (version 2014, Epic Systems, Verona WI), Johns Hopkins Medicine's single EHR system. All patients with at least one appointment at the Wilmer Eye Institute urban hospital center (East Baltimore) and eight suburban satellite clinics between January 1, 2014 and December 31, 2014 were eligible for this study, which included 104,711 patients who had 223,811 ophthalmic and optometric clinical encounters (Figure 1).

From this population, the following exclusions were made: (1) patients under 5 years old; (2) clinical visits with allied health personnel (e.g., nonoptometrists or

nonophthalmologists); (3) encounters without valid VA measure recorded; and (4) patients without a follow-up visit postcataract surgery in 2014 who had a VA measure of worse than 20/40 prior to that surgery (see “Cataract Patients” section below for more information) (Figure 1).

Low visions status

VA data were obtained from the EHR for each encounter. These measures included: (1) habitual VA; (2) pinhole VA (if available); and (3) manifest refraction VA (if available). LV status was identified at each clinical encounter, and defined as the best available distance VA (the best of habitual, pinhole, or manifest VA) worse than 20/40 in the better-seeing eye. The best VA from either binocular or monocular VA was used. There were 15,221 encounters from 7667 patients where VA was only recorded for one eye, but VA data were documented in both eyes in other encounters, indicating the patient had VA information available in two eyes. Therefore, data from the chronologically previous encounter was used to fill in the missing eye’s VA, and LV status was subsequently determined for that encounter.

LV status for 2014 was defined as having at least one appointment where the above LV criteria were met. Best VA in the better-seeing eye was further categorized as: (1) no visual impairment (VI) (VA at least 20/40), (2) mild VI (VA worse than 20/40 and at least 20/60), (3) moderate VI (VA worse than 20/60 and better than 20/200), (4) severe VI (VA 20/200 or worse and better than 20/500), and (5) profound VI (VA 20/500 or worse, including count fingers, hand motion, light perception, and no light perception). These categorizations are based on prior work identifying and characterizing patients with LV.^{14–16}

Cataract patients

When determining LV status based on VA alone in an ophthalmic setting, patients with cataracts and no other pathology may be misclassified as having LV, when in fact vision should be restorable with surgery. To account for this, we obtained data from surgical visits to identify all patients who had cataract surgery in 2014 ($N = 5486$). For these patients, VA used to define LV status was based on visit data at least 60 days after surgery. Therefore, VA data obtained prior to the cataract surgery and within 60 days post-surgery were not used to define LV status for patients undergoing cataract surgery in 2014. If cataract surgery occurred at the end of 2014 (in November or December) and the 60-day postcataract surgery time-frame spanned into 2015, VA data obtained from day 61 to day 121 after surgery were used to define VI status ($N = 887$). Additionally, any patient undergoing cataract surgery in 2014 who had VA worse than 20/40 prior to this surgery, but did not have a follow up visit after the 60-day period were excluded from all analyses ($N = 479$).

Demographic and clinical data

All demographic and clinical data were obtained from the EHR for the study population described above. Demographic data included: (1) date of birth, (2) sex (male or female), (3) race (Caucasian, African American, Asian, American Indian/Alaskan native, or other) and (4) ethnic group (Hispanic or not Hispanic). Age (in years) was calculated as of January 1, 2014 and further categorized as: (1) 5–19; (2) 20–39; (3) 40–64; (4) 65–79; and (5) 80 or older.

Data for each clinical encounter included: (1) date of service; (2) provider subspecialty or division; and (3) location of service. Provider specialty/division included: anterior segment; (2) comprehensive; (3) glaucoma; (4) neuro-ophthalmology; (5) oculoplastics; (6) residency service and general eye service; (7) retina; (8) strabismus and pediatrics; (9) uveitis; and (10) low-vision rehabilitation. Service locations were categorized as: (1) The Johns Hopkins Wilmer Eye Institute East Baltimore hospital center, and (2) any of the 8 satellite suburban clinics.

EHR data integrity

A sample of 100 records was randomly selected for manual abstraction from the EHR by a trained researcher, and entered directly into a research data-base. The objective was to ensure that the data were complete and accurate. Our review included all of the demographic and VA variables described above. This manual abstraction of EHR data found no omissions or errors in the electronic download of the EHR data.

Low vision prevalence and incidence

LV prevalence was calculated as the number of patients classified as having LV at one or more appointments in 2014 divided by the total number of patients in our study population seen during 2014. The first appointment that a patient was classified as having LV in 2014 was classified as the “LV index appointment” and used to determine incident LV status. For patients classified as having LV at their first appointment in 2014, data from visits between August 1, 2013 and December 31, 2013 were used to determine incident LV cases. For these individuals, only patients who were not classified as having LV at any visit in this 2013 time period were defined as an incident case. However, patients classified as having LV at their first appointment in 2014 who did not have a visit between August 1, 2013 and December 31, 2013 were not defined as incident cases, but rather prevalent cases.

Statistical analyses

Prevalence estimates, as well as the associated 95% confidence intervals (CI), were determined over a 12-month period (January 1, 2014 to December 31, 2014 as described above). In order to assess if our observed prevalence estimates were robust to our definition of LV based on a single ophthalmic visit, we performed two sensitivity analyses, which estimated the prevalence in patients with at least 2 visits in 2014 and defined LV as: (1) patients having LV at any two separate appointment dates, and (2) patients having LV at two consecutive appointment dates. Chi-square tests were used to compare categorical demographic and clinical characteristics between patients with and without prevalent LV.

Recognizing that VA measurements may fluctuate and measures may also change over time, the distribution of VA among patients with LV was determined using two methods (worst and best VA). For both methods, better-seeing eye VA was determined at an encounter-level, so that each patient had one VA measure (the better-seeing eye VA) defining each encounter. From this information the distribution of VA among patient with LV was determined based on: (1) the worst VA measure in 2014 (“worst-visit” VA), and (2) the best VA measure in 2014 (“best-visit” VA).

Incidence was calculated as the number of incident cases of LV in 2014 divided by the number of persons at risk for LV over this time period. Similar calculations were used to determine the incidence of LV by age group, sex, race, and ethnicity.

To determine the percentage of patients with LV within each subspecialty/division at Wilmer, we divided the number of patients defined as having LV at one or more division-specific appointments by the total number of patients seen by that division in 2014. For example, for retina, we divided the number of patients who had LV based on VA obtained at a retina appointment and divided by the total number of patients seen by the retina division in 2014. Similar analyses were completed to determine the number and percentage of LV patients at the East Baltimore hospital center and for all eight suburban satellite locations combined.

Logistic regression analyses were used to determine the odds ratio (OR) of being either a prevalent or incident LV case and the associated 95% CI, after adjusting for age, sex, race, and ethnicity.

All analyses were performed using STATA 14 (Stata Corp., College Station, TX, USA).

Results

Our study population included 100,755 patients and 212,227 ophthalmology encounters in 2014 (Figure 1). A total of 7,752 (7.7%) had prevalent LV in 2014 (Table 1). Patients with LV were older, more likely to be male, and more likely to be African American than patients who were not classified as having LV (Table 1). Among patients with LV, more than half (55%) had “best-visit” VA worse than 20/40 and at least 20/60 (mild VI); and just over a quarter (27%) had “best-visit” VA worse than 20/60 and better than 20/200 (moderate VI). However, these percentages changed to 42% and 33%, respectively, for the distribution based on “worst-visit” VA (Table 2). In our sensitivity analyses restricted to participants with two or more encounters in 2014, prevalence of LV was 9.5% in patients who had LV during any 2 encounters, and 9.1% in those who had LV during 2 consecutive encounters.

The incidence of LV was 2.1% ($n = 1,962$) in 2014 (Table 3). In this population, the incidence was greatest among patients 80 years and older (7.5%), similar between males and females (2.1% for both groups), greatest in African Americans (2.6%), and not Hispanic patients (2.2%).

The prevalence and incidence of LV differed by division/subspecialty, and the location of ophthalmic clinical service. Low-vision rehabilitation, retina, and glaucoma divisions had the highest prevalence (58%, 18%, and 14%, respectively) and incidence (9%, 5%, and 4%, respectively) of LV in 2014 (Figure 2, 3). Additionally, the prevalence of LV was greater at the East Baltimore hospital center location (12% prevalence and 3% incidence) than at the 8 satellite suburban clinic locations (6% prevalence and 2% incidence) (Figure 2).

Multivariable logistic regression analyses were used to examine the odds of prevalent and incident LV after adjusting for demographic covariates (Table 4). After adjusting for sex, race, and ethnicity, patients 5–19 years were 1.5 times more likely to have prevalent LV (OR

= 1.47; 95% CI: 1.31–1.66), but were not more likely to have incident LV than adults 20–39 years old. Patients 40–64 years old were 1.4 times more likely to have incident LV than those 20–39 years old (OR = 1.38; 95% CI: 1.12–1.70), but the odds of having prevalent LV did not differ between these two groups (OR = 0.93; 95% CI: 0.84–1.02). However, those 65–79 years old and 80 years and older were significantly more likely to have prevalent (OR = 1.42; 95% CI: 1.29–1.56; OR = 6.18; 95% CI: 5.62–6.80, respectively) and incident LV (OR = 2.58; 95% CI: 2.10–3.17; OR = 9.39; 95% CI: 7.63–11.55, respectively) as compared to those 20–39 years old. Males were 1.12 times more likely to have prevalent LV than females (95% CI: 1.07–1.18), but there was no difference in the incidence by sex (OR = 1.03; 95% CI: 0.94–1.13). As compared to Caucasians, African Americans and patients reporting “other” race were more likely to have prevalent (OR = 1.85; 95% CI: 1.75–1.96; OR = 1.70; 95% CI: 1.51–1.90, respectively) and incident (OR = 1.65; 95% CI: 1.48–1.84; OR = 1.63; 95% CI: 1.31–2.04, respectively) LV. However, these odds did not differ between Caucasians and Asians or American Indians/Alaskan Native patients, or between Hispanic and not Hispanic patients.

Discussion

This study highlights how EHR data can be used to enumerate and describe patients with LV in an ophthalmic setting. Using EHR data from a university medical center, our study exhibits slightly greater prevalence of LV compared to population-based estimates of LV, which range from 2.0% to 6.6%.^{13,14,16} Our findings showed that the oldest old (over 80 years) are most likely to have and develop LV. Consistent with prior population study estimates, a higher prevalence of LV is observed in younger patients (< 20 years old), and is likely due to uncorrected refractive error.^{14,17}

EHR data confirmed that the majority of patients with LV in this setting had mild to moderate VA loss. When based on the “best-visit” VA, 55% had VA worse than 20/40 and at least 20/60. This percentage declined slightly to 42% based on “worst-visit” VA (Table 2). This result highlights the variability in VA measures within patient, and the related importance when calculating and stratifying the prevalence of LV using VA data from EHR. Additionally, consistent with prior work, findings show that the majority of patients in ophthalmic care settings with LV do not have severe loss of VA.¹⁸

Retina and glaucoma clinics had the highest prevalence and incidence of LV (Table 4) among non-LVR clinics. This is consistent with age-related macular degeneration, diabetic retinopathy, and glaucoma being the most common causes of VI in the United States.^{11,19} Compatible with the AAO Preferred Practice Patterns, we defined LV as VA worse than 20/40, but were unable to extract LV defined as the presence of scotomas, field loss or contrast sensitivity loss.¹⁰ Our results indicate that over half (58%) of patients accessing LVR clinics meet LV VA criteria, however just under half (42%) have VA at least 20/40 and are likely utilizing LVR services because their visual demands require VA better than 20/50, or for reasons related to loss in contrast sensitivity or visual field. This is an important finding, as it highlights the need to not rely on VA alone when considering LVR. Lastly, the prevalence of LV was approximately two times greater at the urban hospital center location as compared to the eight suburban locations. This difference is likely a reflection of the

variation in case severity at an urban hospital location, which in part operates as a tertiary care setting. Of note, routine optometric and ophthalmologic care is provided at all 9 locations.

Results from the multivariable regression analyses indicate that patients with LV in this setting are more likely to be male, African Americans, and either 65 years of age and older, or 5–19 years old. Understanding the demographics of this population may be important for identifying health and health care disparities among these patients, and may be informative for tailoring interventions targeting this group of individuals. It is important to note that we did not adjust for service location or division because these variables are not mutually exclusive, and patients can access care at more than one location and more than one division.

This study is strengthened by the inclusion of the entire Johns Hopkins Wilmer Eye Institute patient population in 2014 who were 5 years of age and older. The use of EHR data allowed us to analyze the VA information for every patient, at every encounter at every location during this period. Therefore, the results are representative of our entire patient population and reflect the categorization of patients with LV using a pragmatic approach (e.g., patients are not always refracted and VA does fluctuate between encounters). Secondly, this analysis offers new insight into the magnitude (5%) of patients potentially identified with LV by EHR, who subsequently have cataract extraction and vision is restored to normal levels. Thirdly, the similarity between our primary prevalence estimates, and those derived from our sensitivity analyses, which used more stringent criteria of LV (7.7% vs. 9.1%, respectively) suggest that our results are robust to the criteria used to define LV. The prevalence estimates were higher in the sensitivity analysis because only patients with at least two visits were included, and these patients were therefore more likely to have vision conditions that required more frequent care and visits than those with only a single visit. Fourthly, the inclusion of suburban clinical center data extends the generalizability of our results, as these satellite locations more closely resemble community ophthalmic care settings. Lastly, understanding the prevalence of LV by ophthalmic subspecialty informs us of the need and guidance for LVR service provision. Further work is needed to determine if institutional or geographic differences affect the prevalence and incidence of LV.

Despite the amount of data obtained, EHR are not without limitations. VA was recorded using an unrestricted field in the EHR system, and we found over 9000 permutations of how VA was recorded (i.e., 20/20 vs. 20.20 vs. 20). This finding is consistent with the fact that VA data recorded in the EHR are primarily obtained for clinical rather than research purposes, and habitual and pinhole VA were most often recorded. Given that manifest refraction did not occur for every patient at every encounter, LV status could not consistently be determined by “best-corrected” VA, and therefore we are unable to determine in certain cases if LV was due to refractive error or due to eye disease. However, we relied on the best VA across all methods recorded at each encounter, and the findings are reflective of usual ophthalmic care (e.g., how VA is assessed in most clinical settings).

This study is among the first to use EHR to estimate the prevalence and incidence of LV and describe the characteristics of these patients in a large, multispecialty ophthalmic care setting. Although these estimates may not be generalizable to other settings, these data

provide initial insight on the population of patients in ophthalmic care with LV and provide an EHR methodology that can be applied across ophthalmic settings. The results from this novel use of ophthalmic EHR data may help inform health care delivery and tailor efforts aimed at increasing utilization of LVR services.

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Figure 1.

Inclusion and exclusion of the study population.

*Patients no less than 5 years old and with at least 1 encounter in the Wilmer clinics were identified as eligible patients, encounters of office visit with optometrists or ophthalmologists, and with valid visual acuity were considered as valid. Total numbers of patients and encounters excluded under each eligibility criterion did not reflect the difference between the study population and the analytic population due to overlapping of patients/encounters under different criterion. #Number of cataract procedures did not reflect the total number of cataract surgeries of the institute. †Patients retained low vision after cataract surgery were defined as visual acuity < 20/40 in the better-seeing eye for at least one visit after postoperative day 60; patients did not retain low vision after cataract surgery were defined as visual acuity ≥ 20/40 in the better-seeing eye at all visits after postoperative day 60.

Figure 2.
Prevalence of low vision by ophthalmology subspecialty and service location.

Figure 3.
Incidence of low vision by ophthalmology subspecialty and service location.

Table 1.

Demographics for patients with and without low vision in Wilmer Eye Institute in 2014.

	Total N	Low Vision N = 7,752 (7.7%)		Not Low Vision N = 93,003 (92.3%)		Age-adjusted P value
		n	%	n	%	
Age Group (years)						< 0.001
5, < 20	8,060	626	8.1	7,434	8.0	
20, < 40	12,970	692	8.9	12,278	13.2	
40, < 65	40,102	1,976	25.5	38,126	41.0	
65, < 80	29,221	2,001	25.8	27,220	29.3	
80	10,402	2,457	31.7	7,945	8.5	
Gender						< 0.001
Female	59,473	4,464	57.6	55,011	59.2	
Male	41,282	3,290	42.4	37,991	40.9	
Race						< 0.001
White/Caucasian	68,676	4,821	63.3	63,855	70.0	
Black/African	20,232	2,052	26.9	18,180	19.9	
American Asian	4,070	236	3.1	3,834	4.2	
American Indian/Alaskan Native	241	16	0.2	225	0.3	
Other	5,579	496	6.5	5,083	5.6	
Ethnicity						< 0.001
Not Hispanic/Latino	89,583	7,022	97.4	82,561	97.2	
Hispanic/Latino	2,573	190	2.6	2,383	2.8	

Table 2.

Visual acuity distribution for all Wilmer Eye Institute patients with low vision in 2014.

	<u>Best-visit Visual Acuity[*]</u>		<u>Worst-visit Visual Acuity[*]</u>	
	<i>n</i>	%	<i>n</i>	%
< 20/40, 20/60	4,286	55.3	3,229	41.7
< 20/60, > 20/200	2,063	26.6	2,567	33.1
20/200, > 20/500	723	9.3	948	12.2
20/500	683	8.8	1,008	13.0

* Best-visit/worst-visit visual acuity were defined as the best/worst visual acuity measured among all valid encounters with visual acuity < 20/40 in the better eye for each person

Table 3.

Incidence of patients with low vision at the Wilmer Eye Institute in 2014.

	No. at Risk	Incident Low Vision	Incidence	
			%	95% CI
Study Population	94,817	1,962	2.1	2.0–2.2
Age Group (years)				
5, < 20	7,514	83	1.1	0.9–1.4
20, < 40	12,394	118	1.0	0.8–1.1
40, < 65	38,573	490	1.3	1.2–1.4
65, < 80	27,776	625	2.3	2.1–2.4
80	8,560	646	7.5	7.0–8.1
Gender				
Female	38,748	809	2.1	1.9–2.2
Male	56,069	1,153	2.1	2.0–2.2
Race				
White/Caucasian	65,035	1,273	2.0	1.9–2.1
Black/African American	18,615	477	2.6	2.3–2.8
Asian	3,895	65	1.7	1.3–2.1
American Indian/Alaskan Native	229	4	1.7	0.7–4.6
Other	5,198	121	2.3	2.0–2.8
Ethnicity				
Not Hispanic/Latino	84,232	1,811	2.2	2.1–2.3
Hispanic/Latino	2,425	45	1.9	1.4–2.5

CI = confidence interval

Table 4.

Association between demographic variables and prevalent and incident low vision patients of the Wilmer Eye Institute in 2014 ^{*}.

	<u>Prevalent Low Vision</u>		<u>Incident Low Vision</u>	
	OR	95% CI	OR	95% CI
Age Group (years)				
5, < 20	1.47	1.31–1.66	1.13	0.84–1.52
20, < 40	Reference	–	Reference	–
40, < 65	0.93	0.84–1.02	1.38	1.12–1.70
65, < 80	1.42	1.29–1.56	2.58	2.10–3.17
80	6.18	5.62–6.80	9.39	7.63–11.55
Gender				
Female	Reference	–	Reference	–
Male	1.12	1.07–1.18	1.03	0.94–1.13
Race				
White/Caucasian	Reference	–	Reference	–
Black/African	1.85	1.75–1.96	1.65	1.48–1.84
American Asian	1.05	0.91–1.21	1.21	0.93–1.57
American Indian/Alaskan Native	1.14	0.67–1.95	0.91	0.29–2.86
Other	1.70	1.51–1.90	1.63	1.31–2.04
Ethnicity				
Not Hispanic/Latino	Reference	–	Reference	–
Hispanic/Latino	1.01	0.85–1.19	1.09	0.78–1.52

^{*}Regression model adjusted for age, gender, race, and ethnicity; statistically significant values are indicated in boldface font