Diabetic Retinopathy Disease Severity Missingness in Electronic Health Records

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- Observational studies of diabetic retinopathy (DR) using electronic health
 record data often leverage ICD codes to determine disease severity
- Encounters with unspecified disease severity are often excluded from analyses
- The purpose of this study was to understand the mechanism of missingness for DR severity within the American Academy of Ophthalmology IRIS® Registry

Methods

Results

- Patient encounters in the IRIS Registry with an ICD-9/10 code for DR from 1/1/2019 to 12/31/2021 were included
- Demographic, clinical, practice and provider level characteristics were compared between clinical encounters with specified and unspecified disease severity
- Practices were divided into quartiles based on the proportion of encounters with unspecified disease severity and compared based on DR patient volume

Conclusion

- The results of this study suggest that DR disease severity is missing not at random (MNAR) given the significant differences between specified and unspecified disease severity clinical encounters
- The differences between specified and unspecified clinical encounters, including visual acuity, procedures performed, and timing of clinical encounters, suggest that unspecified disease severity is likely associated with less severe DR
- Several factors could explain this including a need to associate a specific disease severity with procedures performed for more severe stages of DR

Table 1. Baseline demographics and clincial characteristics of IRIS encounters with Unspecified and Specified DR Disease Severity for ICD-10 Encounters

	DR Encounters With Unspecified Disease Severity		DR Encounters with Specified Disease Severity		p-values
	N (or mean)	% (or SD)	N (or mean)	% (or SD)	
N, % of total DR encounters	1,052,344	4.61%	23,025,391	95.39%	
Age in years					<0.005
Mean, SD	67.97	12.02	64.74	12.42	
Sex, n (%)					<0.005
Female	536,817	51.01%	11,209,471	48.68%	
Male	510,573	48.52%	11,700,680	50.82%	
Provider specialty, n (%)					<0.005
Retina Specialist	347,563	33.03%	15,574,829	67.64%	
General ophthalmologist	298,012	28.32%	3,461,274	15.03%	
Non-Retina Subspecialist	260,704	24.77%	2,353,070	10.22%	
Optometrist	83,619	7.95%	992,864	4.31%	
Unknown	62,446	5.93%	643,354	2.79%	
Visual acuity at time of encounter					<0.005
Mean, SD	63.78	20.82	61.01	21.51	
Laterality at time of encounter, n (%)					<0.005
Known laterality	396,761	37.70%	20,116,195	87.37%	
Unknown laterality	655,583	62.30%	2,909,196	12.63%	
Procedures at time of encounter, n (%)					
Anti-VEGF injections	251,636	23.91%	12,789,566	55.55%	<0.005
Panretinal photocoagulation	69,535	6.61%	5,530,963	24.02%	<0.005
Pars plana vitrectomy	19,598	1.86%	1,524,677	6.62%	<0.005
Optical coherence tomography	626,718	59.55%	18,831,674	81.79%	<0.005
B scan ultrasonography	1,291	0.12%	29,142	0.13%	<0.005
Fluorescein angiography	235,618	22.39%	10,661,885	46.30%	<0.005
Comorbidities at time of encounter, n (%)					
Diabetic Macular Edema	460,805	43.79%	16,278,357	70.70%	<0.005
Encounter history					
Time since last encounter in months (mean, SD)	4.09	6.65	3.11	5.38	<0.005
Disease severity known at prior encounter (n, %)	113,333	10.77%	19,942,578	86.61%	<0.005
First encounter (n, %)	308,577	29.32%	2,841,244	12.34%	<0.005
lote: Analysis is at the patient encounter lev	vel				

- P-values were calculated using chi-square tests (categorical variables) and t-tests (continuous variables)
- Analyses were performed using PySpark version 2.4.7 (Apache Spark[™]) and RStudio version 1.4.1717
- Of the 10,456,243 ICD-9 and 24,077,735 ICD-10 DR encounters, 18.65% and 4.37%, respectively, had unspecified DR disease severity
 Patients with unspecified encounters were significantly older, had better visual acuity and lower utilization of ophthalmic procedures
 - High volume and retina specialist practices had lower proportions of clinical encounters with unspecified disease severity

Figure 1. Total Number of DR Patients between 2016-2021 by Quartiles



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