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A Service Coverage Analysis of Primary Congenital Glaucoma Care Across the United States

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Abstract

Purpose: To assess the number of infants at risk of delayed primary congenital glaucoma (PCG) evaluation due to long travel times to specialists.

Design: Cross-sectional geospatial service coverage analysis.

Methods: All American Glaucoma Society (AGS) and American Association for Pediatric Ophthalmology and Strabismus (AAPOS) provider locations were geocoded using each organization's member directory. Sixty-minute drive time regions to providers were generated using ArcGIS Pro (Esri, Redlands, CA). The geographic intersection of AGS and AAPOS service areas was computed because patients typically require visits to both types of specialists. American Community Survey data was then overlaid to estimate the number of infants within and beyond the AGS/AAPOS service areas.

Results: One thousand twenty-nine AGS and 1,040 AAPOS provider locations were geocoded. The analysis yielded 944,047 infants age 0-1 year (23.6%) who live beyond the AGS/AAPOS service areas. Therefore, approximately 14 to 94 new PCG cases/year may be at risk of delayed diagnosis due to living in a potential service desert. Compared to children living within the AGS/AAPOS service areas, children under age 6 years in these potential service deserts were more likely to live in households earning below the US federal poverty level, lack health insurance, and live in a single parent home. These communities are disproportionately likely to experience other rural health disparities, and are more prevalent across the Great Plains.

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Conclusion: Service coverage analysis is a useful tool for identifying underserved regions for PCG referrals and evaluation. These data may assist in targeting screening programs in low access areas for pediatric glaucoma care.

Introduction

Primary congenital glaucoma (PCG) care is associated with high levels of caretaker burden and economic costs per capita.[1,2] Increased familial stress and financial hardship may result in poor follow-up and disease outcome.[3-5] Besides caretaker burden, PCG care access may be limited by the proximity of nearby pediatric ophthalmology and glaucoma providers given the urgency and rarity of the condition. In contrast to other glaucoma subtypes, PCG often requires surgery as first line treatment and may require multiple surgeries for disease control.[6-9] However, prompt surgical treatment and meticulous visual development monitoring has demonstrated great surgical success rates and visual outcomes.[6-9] Nevertheless, there is limited data regarding access to pediatric glaucoma care worldwide.[10] The estimated prevalence rate of PCG is 1:10,000 to 1:68,000 in Western countries across various studies.[11-14] Furthermore, this disease accounts for 5% of childhood blindness.[15]

Travel time is one measure that is used to assess patient healthcare access. Prior ophthalmic studies have identified travel time as a barrier to general ophthalmology care in the Medicare population.[16,17] Service coverage analysis is a tool for analyzing geographic regions using travel time regions computed from health provider data and analyzed using publicly-available population characteristics. Our group previously determined that 11.6% of the population aged 65 years or older residing in Florida live over 60 minutes away from their nearest glaucoma specialist, but were less likely to live below the federal poverty level than those living within a 60-minute drive.[18] Identifying potential service disparities may enable more targeted care and be useful for urban planning and healthcare funding.

Given the complexity and urgency of PCG care, a referral to a pediatric- or glaucoma-trained ophthalmologist remains a crucial step in the prompt diagnosis of PCG.[19] Late-recognized PCG and poor vision at diagnosis have been associated with poor long-term visual acuity.[6,20] To date, no studies have evaluated travel time between the United States (US) population at risk for PCG and the nearest geographically accessible pediatric- and glaucoma-trained ophthalmologists. The US is a diverse country with various geographic regions and population densities. We sought to estimate the proportion of children at risk for PCG who live beyond a 60-minute drive of both an American Glaucoma Society (AGS) and American Association for Pediatric Ophthalmology and Strabismus (AAPOS) affiliated specialist, as well as analyze differences in select social determinants of health for populations living within and beyond the service coverage areas.

Methods

A cross-sectional geospatial service coverage analysis of PCG care was performed by geocoding all AGS and AAPOS provider locations, computing drive-time areas, and overlaying these zones with demographic data from the 2018 American Community Survey

(ACS). We analyzed travel time as a marker or proxy for other social health disparities. Institutional Review Board approval was not required for this study because all of the data used in this study was publicly available and did not include any protected health information.

A list of AGS and AAPOS office addresses was obtained from each society's member directory (https://secure.americanglaucomasociety.net/AGS/Find-An-AGS-Doctor and https://secure.aapos.org/aapos/Find-a-Doctor) between July 31, 2019 through September 19, 2019. If a member had more than one listed office, each office was listed as a separate entry for the analysis. Next, all office addresses were geocoded using ArcGIS Pro 2.4 (Esri, Redlands, CA). Regions representing 15-, 30-, 60-, and 120-minute drive times to each provider were created using average traffic conditions for 12:00 PM on Wednesdays as an average of traffic conditions over a typical business week. Driving times were generated using ArcGIS Pro's service area tool, which uses Esri's cloud-based road network layer. The intersection of the AGS and AAPOS 60-minute drive time regions was converted into the combined AGS/AAPOS service areas. The 60-minute window is consistent with the US Health Resources and Services Administration's (HRSA) peak threshold used to score primary care health professional shortage area (HPSA) travel times.[21,22]

Next, 2018 American Community Survey data were overlaid at the census tract scale to estimate the number and proportion of infants age 0-1 year within and beyond the intersection of the AGS and AAPOS 60-minute drive time regions. ACS population data were linked to census tract boundary files in ArcGIS Pro using Esri's Living Atlas of the World data service. We calculated the number of infants living inside and outside the 60-minute service areas by selecting all census tracts with their centroid located within (or beyond) the service area. We repeated this process to characterize the regions within and beyond the service areas for the following measures. To understand the role of social determinants of health, we extracted and overlaid select ACS population measures, relevant to infants and young children, that are theorized to generally limit healthcare access and utilization. We assessed the number of children under 6 years old who were living below the federal poverty line, lacking health insurance, living in a single parent household, and living in a single parent household with a foreign-born parent. We also assessed the number of households without internet access, and whether a family was of White Non-Hispanic origin. All of these measures can limit healthcare access through lack of financial resources, higher opportunity costs for single-parents missing work for medical appointments, barriers to health information due to language differences or limited internet access, or racial/ethnic marginalization from implicit bias.[23,24] Comparison between categories were analyzed using chi-squared tests.

HRSA HPSA and medically underserved area (MUA) data from the 2018 American Community Survey were also used to calculate differences in HPSA and MUA shortage designations within and beyond the AGS/AAPOS service areas. HPSA regions have been designated by the HRSA as having healthcare provider shortages. An HPSA score is measured between 0-25 with higher values indicating greater health professional shortage and thus greater need. This score is based on four factors: population-to-provider ratios, percentage living below the federal poverty level, infant mortality rates, and travel times to the nearest source of care.[22] Several federal and state assistance programs including Medicare provide incentive payments for primary care and mental health services provided in HPSAs.[25] Similarly, MUAs are HRSA-designated regions containing primary care provider shortages. This scoring system uses population-to-provider ratios, percentage living below the federal poverty level, infant mortality rates, and percentage of elderly living in the population.[22] In contrast to the HPSA scoring system, MUA scores do not have a discrete category for travel time. A region with a MUA score of 62 or below (0-100) is considered medically underserved.

Results

In total, 1,029 AGS (Figure 1a) and 1,040 AAPOS (Figure 1b) provider addresses were identified during the data acquisition period. The intersection of AGS and AAPOS provider 60-minute drive time regions are presented in Figure 2, and generally corresponded to the nation's largest metropolitan areas. Using 2018 American Community Survey population estimates of the US population between ages 0-4 years, 15,248,212 individuals (76.4%) lived within an hour's drive of an AGS and AAPOS provider, and 4,720,233 individuals (23.6%) lived beyond the service area. Assuming children were equally distributed across the five years in the age 0-4 years cohort and ignoring child mortality, then the estimated number of individuals age 0-1 year was 944,047 living beyond the service area. Using previously published estimates of PCG prevalence rates in Western countries (1:10,000 to 1:68,000),[11-14] we estimate that there could be approximately 14 to 94 new PCG cases per year in regions that are beyond a 60-minute drive to an AGS and AAPOS provider office.

An analysis of HPSA and MUA scores were compared for populations living within and beyond the AGS/AAPOS service areas. There were 3,017 HPSAs with HPSA scores ranging from 2-25 (mean HPSA score 13.9) in the entire US 50 states and Puerto Rico. Nine hundred three HPSAs (29.9%) had their centroid (i.e. geographic center) within the AGS/AAPOS service regions (mean HPSA score 13.9) and 2,114 HPSAs (70.1%) fell outside the AGS/AAPOS service area (mean HPSA score 13.9). Therefore, there were more HPSAs outside the AGS/AAPOS service areas, but we detected no differences in HPSA scores between regions within or beyond the AGS/AAPOS service areas, $p > 0.9999$. There were 4173 MUAs in the US in total, and 273 were excluded from the analysis due to an MUA score of 0, which was presumed as "no data". Of the remaining 3,900 MUAs, the MUA score ranged from 18.1 to 91.9 (mean 55.15, SD 7.31). The 60-minute AGS/AAPOS service areas intersected with 1478 MUAs with a mean score of 55.70 (SD 6.59), while 2,422 MUAs (62.1%) fell outside the AGS/AAPOS service areas with mean MUA score 54.81 (SD 7.69), unpaired t-test: $t = 3.70$; $df = 3898$; $SE = 0.241$; $p = 0.0002$. Therefore, there was a higher proportion of MUAs that were beyond the AGS/AAPOS service areas, and these areas had a statistically significantly lower (i.e. more underserved) mean MUA score than the MUAs within the AGS/AAPOS service areas (Table), though this was a substantively tiny difference (less than 1 point).

Lastly, six other social determinants of health were analyzed for differences within and beyond the service coverage areas using 2018 American Community Survey tract-level analysis, all of which yielded significant associations. Children under age 6 years living beyond the AGS/AAPOS service areas were more likely to be living in households with income below the federal poverty level, lack health insurance, lack internet access, and live in a single parent household (Table). Outside of the AGS/AAPOS service areas, 26.9% of children under age 6 years lived in a household whose income was below the federal poverty level compared with just 20.1% of households in these areas, X^2 (1, N = 23,555,304) = 112,305.2, $p < 0.00001$. Beyond the AGS/AAPOS service areas, 6.0% of children under age 6 years lacked insurance, compared with 4.5% in these areas, X^2 (1, N = 23,902,532) = 21846.6, $p < 0.00001$. Outside of the AGS/AAPOS service areas, 37.7% of children under age 6 years lived in single-parent households, compared with 34.3% in these areas, X^2 (1, N = 23,042,428) = 21262.9, $p < 0.00001$. Households beyond the AGS/AAPOS service areas were also more likely to lack internet access (21.6% beyond, vs. 14.2% within), X^2 (1, N = 120,935,191) = 899,728.8, $p < 0.00001$.

However, children under age 6 years living beyond the AGS/AAPOS service areas were less likely to be living with a single parent who was foreign-born, and more likely to be White Non-Hispanic (Table). Outside of the AGS/AAPOS service areas, 3.0% of children under age 6 years lived in single-parent households where the parent was foreign-born, compared with 6.7% in these areas, X^2 (1, N = 23,042,428) = 102794.7, $p < 0.00001$. Beyond the AGS/AAPOS service areas, 71.5% of the population was White Non-Hispanic, compared with 57.0% within these areas, X^2 (1, N = 326,289,904) = 5,250,065.2, $p < 0.00001$. Despite experiencing material deprivation and information barriers over a vast geographic area, the rural target population for pediatric glaucoma resources that lives outside of the AGS/AAPOS service areas is more homogenous than their urban counterparts, which can be an advantage for outreach.

Discussion

PCG infants who live far from a pediatric- and glaucoma-trained ophthalmologist face an additional burden to receiving prompt diagnoses, surgical management, and visual development monitoring. From our study, we estimate that 23.6% of children between 0-4 years of age live outside the AGS and AAPOS 60-minute service coverage areas, which corresponds with 4,720,233 children using American Community Survey demographic data. Using published prevalence rates,[11-14] we estimate that approximately 14 to 94 new PCG cases per year occur in communities where there is elevated risk of delayed screening and care. These communities are disproportionately rural, with especially low service coverage areas across the Great Plains. Beyond the AGS/AAPOS service areas, children under 6 years were more likely to be living in households earning below the US federal poverty level, lack health insurance, lack internet access, and live in a single parent home. All of these factors are social determinants that limit utilization of health services through material resource or time constraints, or through less general access to beneficial health-related information, and are generally proxies for other healthcare disparities.[23]

Diagnostic delay in recognizing PCG can result in potentially irreversible vision loss due to corneal scarring, optic neuropathy, and amblyopia. Walton et al. reported on the visual outcomes of late-recognized PCG cases sent to a referral practice.[20] At a mean age of 4.7 years, 84% of the cohort (26 of 31 patients) required a surgical intervention and 31% (15 of 49 eyes) had a final visual acuity of 20/200 or worse. From a cohort study (133 eyes) of all childhood glaucoma subtypes including PCG, Khitri et al. found that poor vision at diagnosis was associated with poor final visual acuity.[6] Reasons for diagnostic delay include unfamiliarity of the disease among family members and non-specialists, which affect referral speeds.[19,26] Our geospatial analysis examining travel time to the nearest specialists provides an outlook into other diagnostic barriers. Our estimate that 14-94 new PCG cases per year are at risk of delayed screening due to long travel times is wide because prevalence rates for this rare disease varied across our literature search.[11-14] Nonetheless, this estimate is descriptive in conjunction with 23.6% of infants living in potential service deserts, which are mostly in rural areas. Furthermore, our estimate does not include other childhood glaucoma diagnoses for which prevalence rates are less available and attention is also needed. In a study from our institution, PCG comprised 32% of all childhood glaucoma cases at our large referral practice, while the remaining 68% had other childhood glaucoma subtypes.[27]

The prevalence rate of PCG has been estimated to be between 1:10,000 to 1:68,000 in Western countries using various methodologies.[11-14] However, the rate also varies widely across different countries and within countries with large racial diversity. In the British Infantile and Childhood Glaucoma Eye Study, the incidence of PCG was 1:18,500 in Great Britain and 1:30,200 in Ireland.[13] The authors noted that Pakistani children had a nine times higher rate of PCG than in Caucasians. In contrast, the prevalence of PCG in countries with high consanguinity were 1:3000 in Saudi Arabia[28] and 1:1250 among Slovakian Gypsies.[29] In the Rochester Epidemiology Project, the prevalence of PCG was 1:68,000 for Olmstead County, Minnesota, where over 95% of residents were Caucasian.[12] Although much of rural America currently exhibits less demographic heterogeneity than urban places, rural communities are steadily increasing in diversity and will require more complex health messaging as the US slowly becomes a majority-minority country over the coming decades.[30,31]

The types of rural-urban disparities revealed here are typical of most health care services and are not unique to glaucoma care.[32-34] Using Medicare claims data, Lee and colleagues similarly found lower than expected numbers of patients seeking cataract surgery in the Great Plains and Rocky Mountains regions due to longer travel time.[35] In a separate study from our group, we showed that the largest areas where Floridians older than age 65 years had the lowest access to glaucoma specialists were in rural Northern and Central Florida.[18] However, we found in that study that 11.6% of elderly patients lived outside a 60-minute driving range from a glaucoma specialist, whereas the current study shows that 23.6% of children age 0-4 years live further than 60 minutes from both a pediatric- and glaucoma-trained ophthalmologist for the entire United States. This may reflect differences in the range of population densities between various states and/or in the geographic distribution of where people reside at different decades of life.

The lack of both an AGS and AAPOS provider within a 60-minute drive is just one social determinant that can prevent proper PCG diagnosis and treatment. But the reality is that US regions lacking these services already experience health professional shortages or are medically underserved, and generally have fewer household resources.[34] Long drive times thus compound existing social determinants and resource constraints, and thus pose significant challenges for timely diagnosis. In our study, we found that children under age 6 years living beyond the AGS/AAPOS service areas were also more likely to experience several social determinants of health that serve as barriers to healthcare relative to those within the service areas, except for those pertaining to race and ethnicity. This contrasts with our other study that examined elderly Floridians, in which those that lived further than a 60-minute drive from a glaucoma specialist were less likely to be living in poverty or receiving public assistance than those living closer to care, despite also being more likely to be White Non-Hispanic.[18] This may indicate that heterogeneous disparities in healthcare access for different age cohorts exist in different parts of the country.

In ophthalmology, research groups have attempted to address the shortage of eye care providers in rural areas through screening and teleophthalmology.[36,37] Service coverage analysis may aid in determining optimal locations for new glaucoma screening programs and services. Our study found more HPSAs and MUAs outside the AGS/AAPOS service areas than inside, though with relatively similar scores. HPSAs and MUAs have been associated with poorer health outcomes and access in primary care and other specialties.[25,33,38] Teleophthalmology using captured retinal images has been validated in pediatric retinal diseases.[39] Similar screening programs for pediatric eye diseases in targeted rural areas may provide a bridge to prompt referral and diagnosis.[40] However, remote PCG screening may be challenged by its less automated steps including intraocular pressure and axial length readings. Also, our finding that, beyond the AGS/AAPOS service areas children were more likely to be White Non-Hispanic and less than half as likely to be living in a single-parent household with a parent who is foreign-born, may simplify health communication in some rural areas, but must take care to adapt to, and not further marginalize, increasingly diverse minority communities who are among the fastest-growing rural demographics.[30,31]

There are several limitations for this study. Not all AGS and AAPOS members have consistent experience with managing PCG infants. Also, there is limited PCG prevalence data available for the United States in various regions with greater racial diversity than places such as Olmstead County. Thus, we estimate that our calculation of PCG patients at risk for delayed screening and care is a conservative appraisal. Also, the total number of referrals for patients with possible PCG is greater than the actual number of PCG patients that providers must evaluate. This analysis only includes the population that participated in the US Census. Thus, undocumented immigrants and international referral patients who are referred for PCG evaluation may not be completely reflected in this analysis. After the diagnosis of PCG is made by a pediatric- or glaucoma-trained ophthalmologist, PCG patients will often follow up care at an academic center for co-management. Our study does not examine the relationship between long travel times and clinical outcomes. Lastly, our study geocoded provider locations using their self-identified office addresses on the AGS and AAPOS member directory websites. Thus, information from providers who changed office locations or retired and did not update the directory may not be reflected in our analysis.

Long travel time is a risk factor that reflects a geographic barrier to PCG care and other markers of poor social determinants of health. Thus, inquiring about travel time, especially for families living in rural areas, may be a simple in-office screening tool to identify PCG patients who may need closer monitoring or more social services. The current study shows that almost a quarter of children age 0-4 years live in locations at risk of delayed screening for PCG. Service coverage analysis may help policymakers and physician organizations target underserved areas that need more providers, screening, or teleophthalmology. Future studies may consider investigating whether targeting regions with limited pediatric glaucoma care access using mobile or teleophthalmology screening interventions would improve clinical outcomes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Long travel times represent a barrier to appropriate subspecialty care. A cross-sectional geospatial service coverage analysis was performed to estimate the number of infants at risk of delayed primary congenital glaucoma evaluation based on travel time to the nearest pediatric ophthalmologist and glaucoma specialist in the United States. American Community Survey population data and both American Glaucoma Society and American Association for Pediatric Ophthalmology and Strabismus members' office locations were extracted for the analysis.

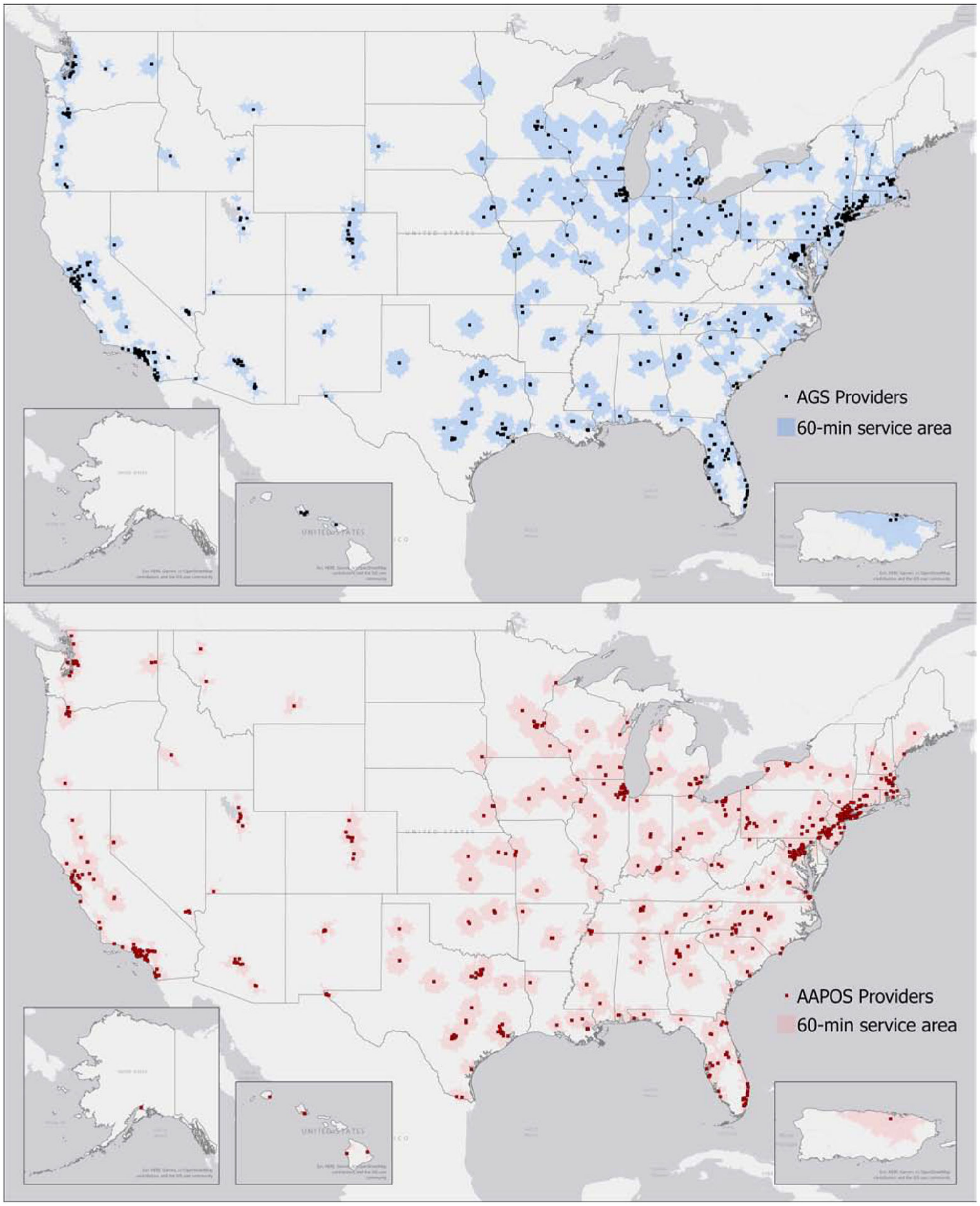

Figure 1:

AGS and AAPOS provider locations and their 60-minute drive time regions (a) 1,029 AGS providers (dark blue squares) and corresponding 60-minute drive time regions (light blue area fill). (b) 1,040 AAPOS providers (dark red squares) and corresponding 60-minute drive time regions (light red area fill). AGS = American Glaucoma Society; AAPOS = American Association for Pediatric Ophthalmology and Strabismus; min = minute

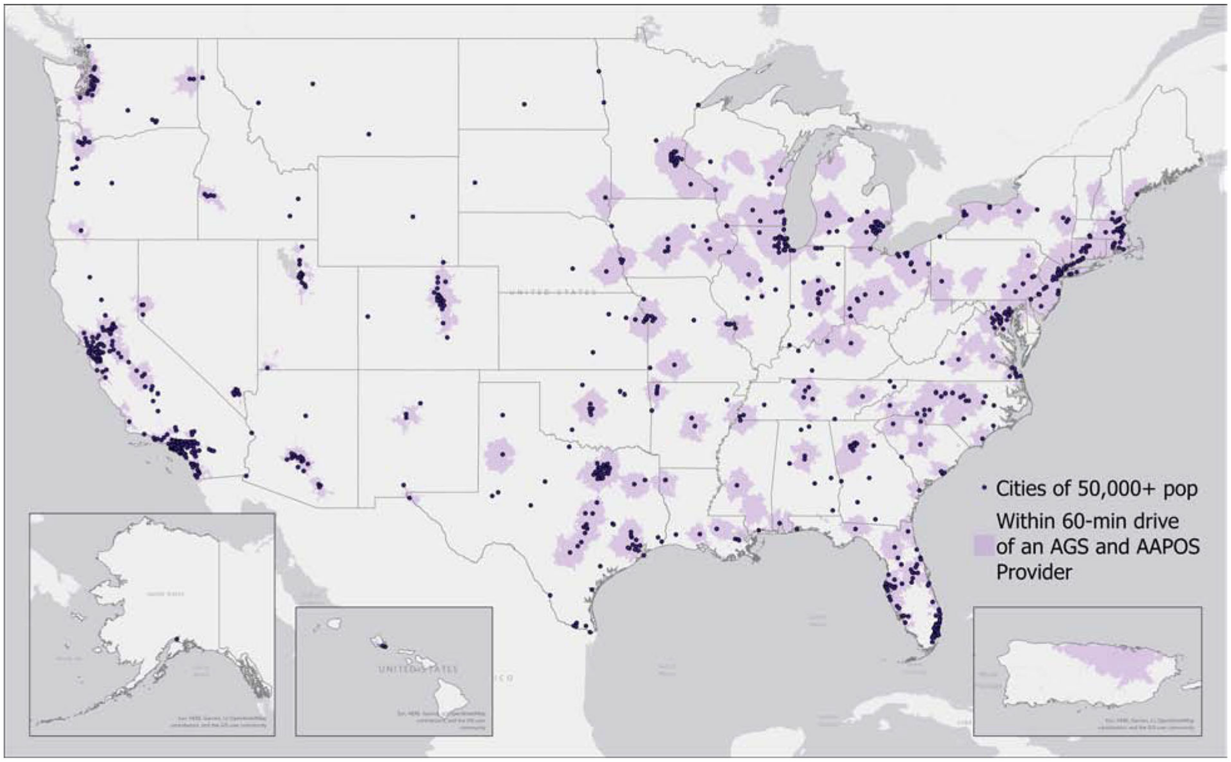

Figure 2:
Combined 60-minute service coverage areas for AGS and AAPOS providers Regions that are within a 60-minute drive of both an AGS and AAPOS provider (light purple area fill), shown with all US cities with population ≥ 50,000 (dark purple circles). AGS = American Glaucoma Society; AAPOS = American Association for Pediatric Ophthalmology and Strabismus; min = minute; pop = population

Table:

Comparison of select social determinants of health for the population within and beyond the AGS/AAPOS service areas (source: 2018 American Community Survey, US Census Bureau).

Characteristic	Within Service Region	%	Beyond Service Region	%	p-value
HPSA Score	mean = 13.9, SD = 3.6		mean 13.9, SD = 3.6		>0.9999
MUA Score	mean = 55.7, SD = 6.6		mean 54.8, SD = 7.7		0.0002
Children < 6 y.o. Living Below Federal Poverty Level	3,635,653	20.1	1,480,750	26.9	<0.00001
Children < 6 y.o. without Insurance	827,540	4.5	324,969	6.0	<0.00001
Children < 6 y.o. Living in a Single Parent Household	6,060,685	34.3	2,021,447	37.7	<0.00001
Children < 6 y.o. Living in a Single, Foreign-Born Parent Household	1,181,467	6.7	159,791	3.0	<0.00001
Households without Internet Access	12,955,147	14.2	6,413,009	21.6	<0.00001
White Non-Hispanic Origin	141,261,742	57.0	55,947,450	71.5	<0.00001

AGS = American Glaucoma Society; AAPOS = American Association for Pediatric Ophthalmology and Strabismus; US = United States; HPSA = Health Professional Shortage Area; MUA = Medically Underserved Area; y.o. = years old