

Understanding Healthcare Utilization Patterns among Neurological Disease Patients: Insights from the All of Us Research Program

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OBJECTIVE

To evaluate healthcare utilization (HCU) patterns among patients with major neurological disorders, using data from the All of Us Research Program.


CONCLUSIONS

➤ Over 93% of patients with major neurological disorders reported visiting a doctor in the previous 6 months, highlighting the significant healthcare needs and frequent engagement with the healthcare system among these populations.


➤ Younger patients (<60 years) and females were more likely to delay healthcare visits, with younger individuals also more frequently requiring emergency care. Nervousness about seeing a doctor was a key reason for care delays, particularly among patients with epilepsy and migraine.

➤ A substantial portion of patients, especially those with Alzheimer’s disease and migraine, reported difficulties with medication affordability, with 18.2% to 29.2% requesting lower-cost medications, indicating financial barriers to accessing necessary treatments.

ACKNOWLEDGMENT



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INTRODUCTION

- Neurological disorders are the leading cause of disease burden worldwide. Patients often require specialized care, leading to frequent outpatient visits, hospitalizations, diagnostic testing, long-term treatment and monitoring.
- We aimed to evaluate HCU patterns among patients with major neurological disorders.

METHODS

- The All of Us Research Program is an NIH sponsored program aiming to collect health data, including surveys, electronic health records, and biospecimens, from one million or more Americans.
- Eligible participants for this study included individuals with self-reported and electronically confirmed diagnoses of a single major neurological disorders (Total N=9649), including Alzheimer's disease (AD, N=33), Parkinson's disease (PD, N=305), cerebrovascular disease (CVD, N=467), epilepsy (N=701), multiple sclerosis (MS, N=588) and migraine (N=7555).
- Participants also completed the "Health Care Access & Utilization" survey, which assessed their HCU patterns over the past 12 months.
- Logistic regression was used to evaluate and compare barriers for each disease group
- Given the age and sex differences between patients in different disease categories, we evaluated differences in HCU patterns stratified by age (<60 vs ≥60) and sex.

RESULTS

- Participants had an average age of 54.8 years (SD=15.3), with 6.2% identifying as Black. There was a higher proportion of females in migraine (87.0%), MS (78%), epilepsy (59.9%), and CVD (53.6%), while males were more predominant in AD (53.1%) and PD (64.1%).
- Over 93% of individuals in each neurological disease category reported doctors visit over the previous 6 months.
- Females delayed healthcare visits more than males (48.8% vs 31.8%, p= <0.001).
- Individuals aged under 60, compared to those aged 60 and above, were more likely to delay healthcare visits (56.7% vs. 28.1%, p < 0.001) and were more likely to require emergency care (7.4% vs. 3.7%, p < 0.001).
- Among patients aged 60 and above, patients with AD (41.7%) and migraine (33.4%) reported higher rates of medication affordability issues than those with PD (29.1%), CVD (24.9%), epilepsy (29.1%) and MS (27.8%).
- Patients with epilepsy (30.0%) and migraine (29.9%) were more likely to delay their medical care than other groups (MS=25.2%, CVD=23.2%, AD=21.7%, PD = 17.9%, p<0.001 for all group-comparisons) with nervousness about seeing their doctor as the major cause of delay of care.

Table 1. Demographic overview of Sex and Age group (60-/+) for whole cohort

Variables	Female	Male	Total	P value	< 60 y/o	≥ 60 y/o	Total	P value
	7829	1820	9649		5413	4236	9649	
Female	100	0			4717 (87.1%)	3112 (73.5%)	7829 (81.1%)	< 0.001
Age	54.3 (14.9)	62.3 (15.2)	55.8 (15.3)	< 0.001	44.4 (9.3)	70.3 (7.0)	55.8 (15.3)	< 0.001
Race Ethnicity				< 0.001				< 0.001
- Black	515 (6.6%)	87 (4.8%)	602 (6.2%)		398 (7.4%)	204 (4.8%)	602 (6.2%)	
- Non-Hispanic White	6247 (79.8%)	1525 (83.8%)	7772 (80.5%)		4098 (75.7%)	3674 (86.7%)	7772 (80.5%)	
- Others	1067 (13.6%)	208 (11.4%)	1275 (13.2%)		917 (16.9%)	358 (8.5%)	1275 (13.2%)	
Income				< 0.001				< 0.001
- <35K	2113 (27.0%)	375 (20.6%)	2488 (25.8%)		1540 (28.5%)	948 (22.4%)	2488 (25.8%)	
- 35K-75K	2132 (27.2%)	444 (24.4%)	2576 (26.7%)		1390 (25.7%)	1186 (28.0%)	2576 (26.7%)	
- 75K-150K	2341 (29.9%)	595 (32.7%)	2936 (30.4%)		1602 (29.6%)	1334 (31.5%)	2936 (30.4%)	
- 150K<	1243 (15.9%)	406 (22.3%)	1649 (17.1%)		881 (16.3%)	768 (18.1%)	1649 (17.1%)	
Education, years				< 0.001				< 0.001
- High School	880 (11.2%)	192 (10.5%)	1072 (11.1%)		626 (11.6%)	446 (10.5%)	1072 (11.1%)	
- College	4604 (58.8%)	954 (52.4%)	5558 (57.6%)		3285 (60.7%)	2273 (53.7%)	5558 (57.6%)	
- Grad	2345 (30.0%)	674 (37.0%)	3019 (31.3%)		1502 (27.7%)	1517 (35.8%)	3019 (31.3%)	
Married	4099 (52.4%)	1199 (65.9%)	5298 (54.9%)	< 0.001	2725 (50.3%)	2573 (60.7%)	5298 (54.9%)	< 0.001
Disease				< 0.001				< 0.001
- Alzheimer's Disease	15 (0.2%)	18 (1.0%)	33 (0.3%)		1 (0.0%)	32 (0.8%)	33 (0.3%)	
- CVD	252 (3.2%)	215 (11.8%)	467 (4.8%)		65 (1.2%)	402 (9.5%)	467 (4.8%)	
- Epilepsy	420 (5.4%)	281 (15.4%)	701 (7.3%)		375 (6.9%)	326 (7.7%)	701 (7.3%)	
- Migraine	6573 (84.0%)	982 (54.0%)	7555 (78.3%)		4652 (85.9%)	2903 (68.5%)	7555 (78.3%)	
- MS	459 (5.9%)	129 (7.1%)	588 (6.1%)		303 (5.6%)	285 (6.7%)	588 (6.1%)	
- Parkinson Disease	110 (1.4%)	195 (10.7%)	305 (3.2%)		17 (0.3%)	288 (6.8%)	305 (3.2%)	

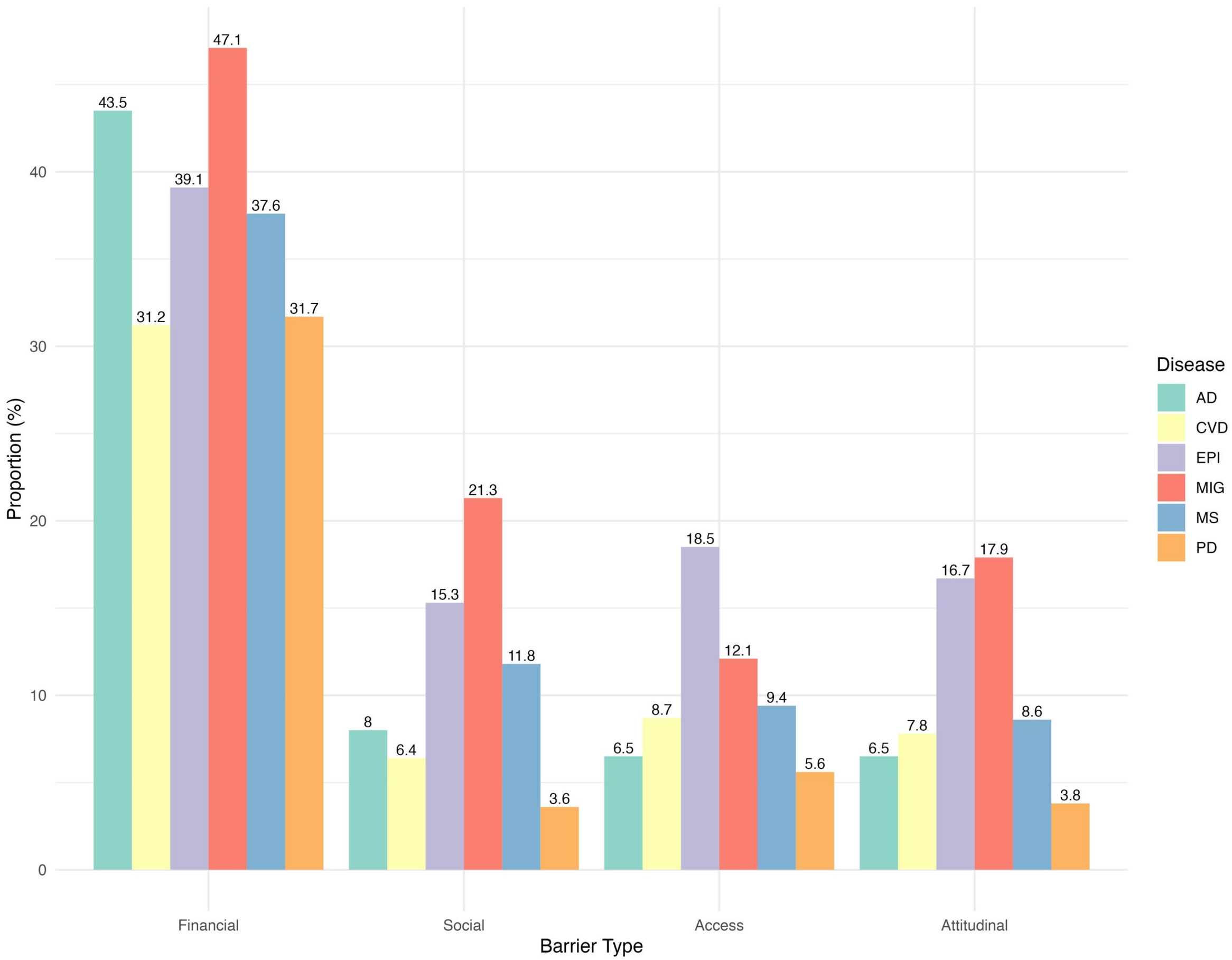


Figure 1. Comparison of Barriers Across Neurological Diseases

Table 2. Medical consultation patterns for patients with neurological disorders for whole cohort.

	AD (%)	CVD (%)	EPI (%)	MIG (%)	MS (%)	PD (%)	Total (%)	p value
Financial Barrier ¹	10 (43.5%)	112 (31.2%)	236 (39.1%)	3143 (47.1%)	184 (37.6%)	73 (31.7%)	3758 (44.9%)	< 0.001
- Asked for a lower cost of medication	7 (30.4%)	71 (19.8%)	120 (19.9%)	1737 (26.1%)	102 (20.8%)	45 (19.6%)	2082 (24.9%)	< 0.001
- Brought from another country	1 (4.3%)	10 (2.8%)	21 (3.5%)	223 (3.3%)	14 (2.9%)	8 (3.5%)	277 (3.3%)	0.977
- Delay filling a prescription	5 (21.7%)	26 (7.2%)	84 (13.9%)	1253 (18.8%)	68 (13.9%)	25 (10.9%)	1461 (17.5%)	< 0.001
- Skipped medication	4 (17.4%)	24 (6.7%)	56 (9.3%)	752 (11.3%)	44 (9.0%)	9 (3.9%)	889 (10.6%)	< 0.001
- Took less medication	4 (17.4%)	26 (7.2%)	69 (11.4%)	863 (12.9%)	44 (9.0%)	17 (7.4%)	1023 (12.2%)	< 0.001
- Used alternative	7 (30.4%)	12 (3.3%)	40 (6.6%)	853 (12.8%)	44 (9.0%)	10 (4.3%)	966 (11.5%)	< 0.001
- Not afford co-pay	3 (13.0%)	24 (6.7%)	57 (9.5%)	871 (13.1%)	46 (9.4%)	7 (3.0%)	1008 (12.0%)	< 0.001
- Deductible was too high	5 (21.7%)	15 (4.2%)	66 (10.9%)	963 (14.4%)	58 (11.8%)	9 (3.9%)	1116 (13.3%)	< 0.001
- Pay out of pocket	5 (21.7%)	47 (13.1%)	100 (16.6%)	1502 (22.5%)	94 (19.2%)	23 (10.0%)	1771 (21.2%)	< 0.001
Social Barrier ²	2 (8.0%)	26 (6.4%)	98 (15.3%)	1493 (21.3%)	61 (11.8%)	9 (3.6%)	1689 (19.1%)	< 0.001
- Not get elderly care	1 (4.0%)	7 (1.7%)	16 (2.5%)	187 (2.7%)	11 (2.1%)	3 (1.2%)	225 (2.5%)	0.561
- Not get childcare	1 (4.0%)	1 (0.2%)	20 (3.1%)	361 (5.1%)	16 (3.1%)	0 (0.0%)	399 (4.5%)	< 0.001
- Not get time off	2 (8.0%)	19 (4.7%)	73 (11.4%)	1145 (16.3%)	41 (7.9%)	6 (2.4%)	1286 (14.5%)	< 0.001
Access Barrier ³	2 (6.5%)	39 (8.7%)	126 (18.5%)	894 (12.1%)	52 (9.4%)	16 (5.6%)	1129 (12.0%)	< 0.001
- Not have transportation	2 (6.5%)	31 (6.9%)	115 (16.9%)	700 (9.5%)	43 (7.7%)	12 (4.2%)	903 (9.6%)	< 0.001
- Distance too far	1 (3.2%)	16 (3.6%)	37 (5.4%)	338 (4.6%)	14 (2.5%)	5 (1.7%)	411 (4.4%)	0.027
Attitudinal Barrier ³								
- Nervous about seeing doctor	2 (6.5%)	35 (7.8%)	114 (16.7%)	1319 (17.9%)	48 (8.6%)	11 (3.8%)	1529 (16.3%)	< 0.001
When talked dr								0.322
- Less than 6 month	29 (100.0%)	403 (94.6%)	569 (94.4%)	6121 (93.3%)	481 (93.9%)	261 (95.3%)	7864 (93.5%)	
- 6 months to 1 year	0 (0.0%)	23 (5.4%)	34 (5.6%)	443 (6.7%)	31 (6.1%)	13 (4.7%)	544 (6.5%)	
Have a place to go when sick or get advice								< 0.001
- Yes	24 (82.8%)	358 (84.0%)	496 (82.3%)	5424 (82.6%)	390 (76.2%)	204 (74.5%)	6896 (82.0%)	
- More than one	5 (17.2%)	68 (16.0%)	107 (17.7%)	1140 (17.4%)	122 (23.8%)	70 (25.5%)	1512 (18.0%)	
General doctor visits over the last year, N								0.281
- 1	3 (10.3%)	48 (11.3%)	92 (15.3%)	947 (14.4%)	81 (15.8%)	31 (11.3%)	1202 (14.3%)	
- 2 - 3	10 (34.5%)	156 (36.6%)	206 (34.2%)	2386 (36.3%)	196 (38.3%)	103 (37.6%)	3057 (36.4%)	
- 4 - 5	8 (27.6%)	96 (22.5%)	104 (17.2%)	1266 (19.3%)	101 (19.7%)	59 (21.5%)	1634 (19.4%)	
- 6+	8 (27.6%)	126 (29.6%)	201 (33.3%)	1965 (29.6%)	134 (26.2%)	81 (29.6%)	2515 (29.9%)	
Where did you get medical care, last year								0.352
- Doctor's office	29 (100.0%)	392 (92.0%)	548 (90.9%)	6088 (92.7%)	470 (91.8%)	258 (94.2%)	7785 (92.6%)	
- Emergency/Urgent Care	0 (0.0%)	29 (6.8%)	40 (6.6%)	376 (5.7%)	33 (6.4%)	10 (3.6%)	488 (5.8%)	
- Others	0 (0.0%)	5 (1.2%)	15 (2.5%)	100 (1.5%)	9 (1.8%)	6 (2.2%)	135 (1.6%)	

Abbreviations: AD: Alzheimer's Disease, CVD: Cerebrovascular disease, EPI: Epilepsy, MIG: Migraine, MS: Multiple Sclerosis, PD: Parkinson Disease
NOTE: There have been some missing and skipped questions in each group of questions; ¹Total of 8372 participants, ²Total of 8858 participants, ³Total of 9378 participants, ⁴Total of 8408 participants

Table 3. Medical consultation patterns for patients with neurological disorders for participants with age of 60 and older

	AD (%)	CVD (%)	EPI (%)	MIG (%)	MS (%)	PD (%)	Total (%)	p value
Financial Barrier ¹	10 (45.5%)	84 (27.8%)	89 (34.8%)	928 (39.4%)	80 (36.2%)	68 (31.3%)	1259 (37.3%)	< 0.001
- Asked for a lower cost of medication	7 (31.8%)	53 (17.5%)	54 (21.1%)	580 (24.6%)	42 (19.0%)	41 (18.9%)	777 (23.0%)	0.014
- Brought from another country	1 (4.5%)	10 (3.3%)	15 (5.9%)	90 (3.8%)	8 (3.6%)	7 (3.2%)	131 (3.9%)	0.657
- Delay filling a prescription	5 (22.7%)	15 (5.0%)	25 (9.8%)	301 (12.8%)	23 (10.4%)	21 (9.7%)	390 (11.6%)	< 0.001
- Skipped medication	4 (18.2%)	14 (4.6%)	22 (8.6%)	189 (8.0%)	16 (7.2%)	7 (3.2%)	252 (7.5%)	0.013
- Took less medication	4 (18.2%)	15 (5.0%)	22 (8.6%)	219 (9.3%)	14 (6.3%)	15 (6.9%)	289 (8.6%)	0.044
- Used alternative	7 (31.8%)	7 (2.3%)	9 (3.5%)	197 (8.4%)	16 (7.2%)	8 (3.7%)	244 (7.2%)	< 0.001
- Not afford co-pay	3 (13.6%)	15 (5.0%)	16 (6.2%)	164 (7.0%)	19 (8.6%)	5 (2.3%)	222 (6.6%)	0.041
- Deductible was too high	5 (22.7%)	9 (3.0%)	20 (7.8%)	199 (8.5%)	20 (9.0%)	6 (2.8%)	259 (7.7%)	< 0.001
- Pay out of pocket	5 (22.7%)	30 (9.9%)	27 (10.5%)	375 (15.9%)	44 (19.9%)	21 (9.7%)	502 (14.9%)	< 0.001
Social Barrier ²	2 (8.3%)	10 (2.9%)	14 (5.0%)	198 (7.8%)	14 (5.9%)	8 (3.4%)	246 (6.7%)	0.002
- Not get elderly care	1 (4.2%)	3 (0.9%)	6 (2.1%)	66 (2.6%)	6 (2.5%)	3 (1.3%)	85 (2.3%)	0.343
- Not get childcare	1 (4.2%)	0 (0.0%)	1 (0.4%)	8 (0.3%)	0 (0.0%)	0 (0.0%)	10 (0.3%)	0.008
- Not get time off	2 (8.3%)	7 (2.1%)	7 (2.5%)	135 (5.3%)	9 (3.8%)	5 (2.1%)	165 (4.5%)	0.008
Access Barrier ³	2 (6.7%)	27 (7.1%)	44 (14.5%)	207 (7.5%)	20 (7.6%)	15 (5.6%)	315 (7.9%)	< 0.001
- Not have transportation	2 (6.7%)	21 (5.5%)	42 (13.8%)	154 (5.6%)	17 (6.4%)	11 (4.1%)	247 (6.2%)	< 0.001
- Distance too far	1 (3.3%)	11 (2.9%)	12 (3.9%)	90 (3.3%)	5 (1.9%)	5 (1.9%)	124 (3.1%)	0.591
Attitudinal Barrier ³								
- Nervous about seeing doctor	2 (6.7%)	25 (6.5%)	37 (12.2%)	262 (9.5%)	13 (4.9%)	9 (3.3%)	348 (8.7%)	< 0.001
When talked dr								0.183
- Less than 6 months	0 (0.0%)	18 (4.9%)	12 (4.1%)	169 (6.5%)	11 (4.3%)	12 (4.6%)	222 (5.8%)	
- 6 months to 1 year	28 (100.0%)	350 (95.1%)	280 (95.9%)	2447 (93.5%)	244 (95.7%)	247 (95.4%)	3596 (94.2%)	
Have a place to go when sick or get advice								< 0.001
- Yes	23 (82.1%)	308 (83.7%)	243 (83.2%)	2212 (84.6%)	205 (80.4%)	191 (73.7%)	3182 (83.3%)	
- More than one	5 (17.9%)	60 (16.3%)	49 (16.8%)	404 (15.4%)	50 (19.6%)	68 (26.3%)	636 (16.7%)	
General doctor visits over the last year, N								0.286
- 1	3 (10.7%)	42 (11.4%)	46 (15.8%)	418 (16.0%)	36 (14.1%)	30 (11.6%)	575 (15.1%)	
- 2 - 3	10 (35.7%)	137 (37.2%)	101 (34.6%)	1024 (39.1%)	100 (39.2%)	100 (38.6%)	1472 (38.6%)	
- 4 - 5	7 (25.0%)	82 (22.3%)	53 (18.2%)	502 (19.2%)	45 (17.6%)	57 (22.0%)	746 (19.5%)	
- 6+	8 (28.6%)	107 (29.1%)	92 (31.5%)	672 (25.7%)	74 (29.0%)	72 (27.8%)	1025 (26.8%)	
Where did you get medical care, last year								0.491
- Doctor's office	28 (100.0%)	345 (93.8%)	276 (94.5%)	2484 (95.0%)	239 (93.7%)	244 (94.2%)	3616 (94.7%)	
- Emergency/Urgent Care	0 (0.0%)	20 (5.4%)	9 (3.1%)	94 (3.6%)	12 (4.7%)	9 (3.5%)	144 (3.8%)	
- Others	0 (0.0%)	3 (0.8%)	7 (2.4%)	38 (1.5%)	4 (1.6%)	6 (2.3%)	58 (1.5%)	

Abbreviations: AD: Alzheimer's Disease, CVD: Cerebrovascular disease, EPI: Epilepsy, MIG: Migraine, MS: Multiple Sclerosis, PD: Parkinson Disease
NOTE: There have been some missing and skipped questions in each group of questions; ¹Total of 8372 participants, ²Total of 8858 participants, ³Total of 9378 participants, ⁴Total of 8408 participants