


Expenditures and Healthcare Utilization of Patients Receiving Care at a Specialized Primary Care Clinic Designed with and for Autistic Adults



Gabriel Alain, DPT¹, Daniel Gilmore, BS, RDN, LD¹, Morgan Krantz¹, Christopher Hanks, MD^{2,3}, Daniel L. Coury, MD⁴, Susan Moffatt-Bruce, MD, PhD, MBA⁵, Jennifer H. Garvin, PhD, MBA, RHIA, CPHQ, CCS, CTR FAHIMA, FAHA¹, and Brittany N. Hand, PhD, OTR/L¹ 

¹School of Health and Rehabilitation Sciences, The Ohio State University, Columbus, USA; ²Center for Autism Services and Transition, Columbus, USA; ³Department of Internal Medicine, The Ohio State University Wexner Medical Center, Columbus, USA; ⁴Nationwide Children's Hospital, Columbus, USA; ⁵Royal College of Physicians and Surgeons in Canada, Ottawa, Canada.

BACKGROUND: We previously found that autistic adults who received care through a primary care embedded specialized clinic, called the Center for Autism Services and Transition (CAST), had higher satisfaction, continuity of care, and preventive care use than national samples of autistic adults.

OBJECTIVE: Examine the impact of CAST on healthcare utilization and expenditures.

DESIGN: Retrospective study of medical billing data.

SAMPLE: CAST patients ($N=490$) were propensity score matched to Medicare-enrolled autistic adults ($N=980$) and privately insured autistic adults ($N=980$) using demographic characteristics. The median age of subjects was 21 years, 79% were male, and the median duration of observation was 2.2 years.

MAIN MEASURES: We quantified expenditures and utilization for primary care; emergency department (ED) visits; inpatient hospitalizations; mental health admissions; and outpatient visits.

KEY RESULTS: CAST patients had the highest primary care utilization and expenditures. However, CAST patients had significantly lower expenditures than Medicare-enrolled autistic adults for mental health admissions (\$1074 vs \$1903), outpatient visits (\$1671 vs \$2979), and total expenditures (\$5893 vs \$6987), as well as 57% fewer inpatient hospitalizations. Compared to privately insured autistic adults, CAST patients had significantly lower expenditures for mental health admissions (\$1074 vs \$1362), inpatient hospitalizations (\$3851 vs \$4513), and outpatient visits (\$1671 vs \$6070), as well as 16% fewer inpatient hospitalizations, 24% fewer ED visits, and 50% fewer outpatient visits. On average, CAST patients had more ED visits, mental health admissions, and outpatient visits than Medicare-enrolled autistic adults and more mental health admissions than privately insured autistic adults.

CONCLUSIONS: Although CAST patients had greater primary care utilization and expenditures, our findings suggest embedding specialized clinics within broader primary

care settings could be an alternative to current standards of care and may reduce expenditures and healthcare utilization in other areas, particularly relative to standard care for privately insured autistic adults.

KEY WORDS: Autism; Primary care; Preventive care.

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INTRODUCTION

Autistic adults have more physical and mental health conditions than the general population.^{1,2} For example, autistic adults are 2.2 times more likely to have diabetes or hypertension and 3.7 times more likely to have anxiety.¹ If not addressed or under-addressed, these conditions can have serious consequences including costly emergency department visits,^{3,4} hospitalization,⁵ and premature death.⁶

Currently, autistic adults experience multiple barriers to obtaining primary care. For example, many have difficulties with verbal communication,⁷ which can make tasks like phone calls to schedule appointments challenging.⁸ Additionally, sensory sensitivities⁹ and overstimulation are barriers to social interaction at primary care visits.¹⁰ Autistic adults may receive care from a provider who has not been trained to care for autistic adults,⁷ which has particular implications for patient-provider communication. Indeed, autistic adults report providers do not always communicate in a way they can understand,⁷ and they may not be given enough time to process information at healthcare visits.⁸ These barriers, among others, like difficulty navigating the complex healthcare system,¹¹ highlight the need for informed models of care delivery that minimize barriers to healthcare access for autistic adults.

The complex healthcare needs of autistic adults necessitate a patient-centered, holistic approach to providing care. As a result, there is a well-recognized demand to identify systems of healthcare delivery that better meet the needs of the growing

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population of autistic adults.¹² One promising approach is to embed providers with specialized training in caring for autistic adults, or specialty clinics for autistic adults, within primary care facilities. Among other clinical populations, embedding specialized care within primary care has been linked with improved patient and provider satisfaction¹³ and health outcomes, such as fewer emergency department visits.¹⁴ Among autistic adults, receiving care through a primary-care embedded specialized clinic is linked with increased preventive services¹⁵ utilization. To date, however, no studies to our knowledge have examined the effects of primary-care embedded specialty clinics on other types of healthcare utilization or healthcare expenditures among autistic adults. In this study, we sought to determine how receiving care through a primary-care embedded specialized clinic for autistic adults was associated with expenditures and healthcare utilization across a broad range of service types.

METHODS

Study Design and Setting

We conducted a cross-sectional retrospective study to compare expenditures and healthcare utilization among patients at a specialized primary care clinic designed for autistic adults to national samples of autistic adults. The specialized primary care clinic we examined is the Center for Autism Services and Transition (CAST), which was designed in partnership with autistic adults and caregivers of autistic adults. In prior work, we found that autistic adults who received their care through this clinic (1) were significantly more satisfied with care¹⁶; (2) had better continuity of care¹⁷; and (3) were more likely to receive preventive care services¹⁵ than national samples of autistic adults. CAST has been described in detail elsewhere^{10,15} but we also provide a brief description in Supplemental Material 1.

Data Sources

We obtained data from our institutional Information Warehouse (IW), IBM MarketScan, and Medicare Standard Analytic Files (SAF). Our institutional IW provided records from CAST patient inpatient or outpatient visits that occurred between November 1, 2014, and October 31, 2019, at any location or with any provider within our system. We used de-identified, individual-level, outpatient, and inpatient health records from national samples of Medicare-enrolled and privately insured autistic adults. Medicare claims for services occurring during January 1, 2013–December 31, 2017, were obtained from Medicare SAF. Claims for services provided to privately insured autistic adults during January 1, 2012–December 31, 2016, were obtained from MarketScan Commercial Claims and Encounters Databases. Additional information on Data Sources is provided in Supplemental Material 1.

Sample Identification

Individuals included in this analysis (1) had at least one¹⁸ medical encounter with an autism diagnosis, as defined by International Classification of Diseases, 9th edition (ICD-9) or ICD-10 codes for autistic disorder (299.0x, F84.0), atypical autism (F84.1), Asperger's syndrome (299.8x, F84.5), or pervasive developmental disorder – unspecified (299.9x, F84.9); and (2) were aged 18–60 years. Additionally, only CAST patients who had received care through CAST for at least 6 months were included. We did not include individuals from the MarketScan and Medicare databases who live in the same state as CAST to reduce the possibility any CAST patient records were also included in these data sources.

Propensity Score Matching. After sample identification for each data source, we used propensity score matching (1:2:2) to find subsets of publicly and privately insured autistic adults who were well-balanced with CAST patients on the distribution of demographic characteristics. We used the following seven covariates for propensity score matching: age in years at first observed visit, sex, rural residence, intellectual disability, duration of observation, Charlson Comorbidity Index¹⁹, and Elixhauser Index.²⁰ Supplemental Material 1 provides additional information about propensity score matching, including how variables in the model were defined.

Variable Definitions

Demographic variables were extracted from the first recorded date of service. The primary independent variable was type of primary care received (i.e., CAST primary care vs standard primary care provided to national samples of publicly or privately insured autistic adults). The dependent variables for this study were healthcare expenditures and healthcare utilization.

Expenditures. We quantified expenditures (including insurance payments, co-pays, and co-insurance) for the following service types: (1) primary care; (2) all-cause emergency department (ED) visits; (3) all-cause inpatient hospitalizations; (4) ED visits and inpatient hospitalizations, collectively termed “admissions,” for mental health conditions; and (5) outpatient visits. We also calculated total healthcare costs by summing expenditures for all-cause ED visits, all-cause inpatient hospitalizations, and outpatient visits. Primary care was defined as outpatient visits with providers classified as general medicine, internal medicine, pediatric, geriatric, family medicine, or preventive care providers. Mental health admissions were identified based on the presence of a primary diagnosis code classified as a “mental illness” by the Healthcare Cost and Utilization Project Beta Multilevel Clinical Classification Software for ICD-10.²¹ We calculated the 5-year total expenditure per member for each service type, then determined and reported the average across members.

Utilization. We quantified utilization as the number of (1) primary care visits; (2) all-cause ED visits; (3) all-cause

inpatient hospitalizations; (4) mental health admissions; and (5) outpatient visits. Utilization was calculated as an average per year over 5 years. We calculated the 5-year total number of visits per member for each service type, then determined and reported the average across members.

Statistical Analysis

Demographic characteristics of the sample were summarized descriptively. To maintain confidentiality and compliance with our data use agreements, only categories where frequency counts were ≥ 10 for all samples are shown in the tables. To estimate variability of primary care costs, expenditures, and utilization estimates, bootstrapping on 10% samples was performed. To assess the impact of the CAST model of care compared with standard primary care, two-sample *t*-tests were performed on the estimates derived from the bootstrapping analysis. Last, we calculated mean differences from the estimates derived from the bootstrapping analysis to compare CAST patients to each of the two matched comparison samples. As a post hoc sensitivity analysis to determine the effect of CAST payor mix on our findings, we (1) compared the subset of CAST patients who were insured by Medicare to their Medicare-enrolled propensity score-matched peers and (2) compared the subset of CAST patients who were privately insured to their privately insured propensity score-matched peers.

Ethical Approval

Our Institutional Review Board (IRB) reviewed this study and determined it to be IRB exempt due to the use of limited datasets (Protocol Number: 2019E0805).

RESULTS

The final matched sample consisted of 490 CAST patients, 980 Medicare-enrolled autistic adults, and 980 privately insured autistic adults. Demographic information about each sample is shown in Table 1. Most autistic adults included in this analysis were male, did not have an intellectual disability, and lived in non-rural areas. The samples were similar with regard to median age, Charlson Comorbidity Indices, and weeks observed. All CAST patients were residents in the East North Central region of the USA. The Southern US was the most common region of residence for those with Medicare (28.3%) or private insurance (37.4%).

Table 2 provides means and 95% confidence intervals from bootstrapped estimates on our outcome variables. On average, CAST patients had significantly ($p < 0.005$) higher expenditures for primary care during the study period (mean = \$1011, 95% confidence interval [CI], 948 to 1068) than national samples of publicly (mean = \$484, 95% CI, 368 to 594) or privately (mean = \$740, 95% CI, 664 to 808) insured autistic adults.

Table 1 Sample Demographic Characteristics

Variable	CAST <i>N</i> = 490	Medicare <i>N</i> = 980	Privately insured <i>N</i> = 980
Male, <i>N</i> (%)	388 (79.18%)	791 (80.71%)	790 (77.55%)
Intellectual disability, <i>N</i> (%)	83 (16.94%)	185 (18.88%)	165 (16.84%)
Race/ethnicity, <i>N</i> (%)			
White non-Hispanic	384 (78.37%)	691 (70.51%)	—*
Black non-Hispanic	60 (12.24%)	155 (15.82%)	—*
Hispanic	12 (2.45%)	48 (4.90%)	—*
Other or unknown	34 (6.94%)	86 (8.78%)	—*
US region, <i>N</i> (%)			
Northeast			
New England	—	92 (9.41%)	38 (3.90%)
Middle Atlantic	—	171 (17.48%)	211 (21.66%)
Midwest			
East North Central	490 (100%)	130 (13.29%)	100 (10.27%)
West North Central	—	109 (11.15%)	48 (4.93%)
South	—		
South Atlantic	—	162 (16.56%)	203 (20.84%)
East South Central	—	38 (3.89%)	43 (4.41%)
West South Central	—	77 (7.87%)	118 (12.11%)
West	—		
Mountain	—	54 (5.52%)	86 (8.83%)
Pacific	—	145 (14.83%)	127 (13.04%)
Rural, <i>N</i> (%)	28 (5.71%)	68 (6.94%)	46 (4.69%)
Age in years, median (IQR)	21 (5)	21 (5)	21 (5)
Charlson Comorbidity Index, median (IQR) ^b	0 (0)	0 (0)	0 (0)
Weeks observed, median (IQR)	118.12 (134.86)	107.86 (135.0)	113.14 (171.57)

IQR, interquartile range; CAST, Center for Autism Services and Transition.

* Race/ethnicity data is not provided in MarketScan data for the privately insured sample.

Table 2 Mean Costs, Expenditures, and Utilization per Sample

	Mean (95% CI)		
	CAST (N = 490)	Medicare-enrolled (N = 980)	Privately insured (N = 980)
Expenditures (in USD)			
Primary care	1011 (948, 1068)	484 (368, 594)*	740 (664, 808)*
All-cause ED visits	371 (253, 483)	35 (25, 44)*	632 (484, 801)*
All-cause inpatient hospitalizations	3851 (1304, 6127)	3973 (3117, 4734)	4513 (2489, 6438)*
Mental health admissions	1074 (628, 1511)	1903 (1411, 2390)*	1362 (863, 1858)*
Outpatient visits	1671 (1520, 1830)	2979 (2686, 3274)*	6070 (4877, 7176)*
Total costs [†]	5893 (3309, 8268)	6987 (6068, 7894)*	11215 (8220, 14047)*
Utilization (# of visits)			
Primary care	7.83 (7.81, 7.85)	2.28 (2.27, 2.29)*	5.72 (5.70, 5.75)*
All-cause ED visits	0.50 (0.32, 0.69)	0.16 (0.12, 0.20)*	0.66 (0.54, 0.80)*
All-cause inpatient hospitalizations	0.16 (0.11, 0.21)	0.37 (0.31, 0.43)*	0.19 (0.14, 0.23)*
Mental health admissions	0.31 (0.20, 0.41)	0.24 (0.17, 0.29)*	0.21 (0.16, 0.27)*
Outpatient visits	12.24 (11.2, 13.22)	11.16 (10.55, 11.74)*	24.46 (22.1, 26.88)*

CI, confidence interval; CAST, Center for Autism Services and Transition; USD, United States dollars; ED, emergency department.

* $p < 0.005$ when compared to the respective CAST metric.

[†]Total costs, the sum of outpatient, inpatient, and ED expenditures.

Expenditures

CAST patients had significantly higher expenditures for primary care (\$1011) than national samples of autistic adults with public (\$484) or private (\$740) insurance (Table 2). CAST patients had significantly lower ($p < 0.005$) mean expenditures across all other services we examined, with two exceptions; relative to Medicare-enrolled autistic adults, CAST patients had higher ED visit expenditures and similar expenditures for inpatient hospitalizations. However, CAST patients had significantly lower expenditures than Medicare-enrolled autistic adults for mental health admissions (\$1074 vs \$1903), all-cause inpatient hospitalizations (\$3851 vs \$3973), and outpatient visits (\$1671 vs \$2979). CAST patients had significantly lower expenditures than privately insured autistic adults for mental health admissions (\$1074 vs \$1362), inpatient hospitalizations (\$3581 vs \$4513), all-cause ED visits (\$371 vs \$632), and outpatient visits (\$1671 vs \$6070). When total expenditures were compared, CAST patients had significantly lower total expenditures (\$5893) compared to Medicare-enrolled (\$6987) and privately insured (\$11,215) autistic adults.

Utilization

Relative to Medicare-enrolled autistic adults, CAST patients had significantly fewer ($p < 0.005$) all-cause inpatient hospitalizations, but significantly more ($p < 0.005$) primary care visits, all-cause ED visits, mental health admissions, and outpatient visits (Table 2). Relative to Medicare-enrolled autistic adults, CAST patients had 57% fewer inpatient hospitalizations but 213% more all-cause ED visits, 29% more mental health admissions, and 10% more outpatient visits.

Relative to privately insured autistic adults, CAST patients had significantly fewer ($p < 0.005$) all-cause ED visits, all-

cause inpatient hospitalizations, and outpatient visits but significantly more ($p < 0.005$) primary care visits and mental health admissions. Relative to privately insured autistic adults, CAST patients had 24% fewer all-cause ED visits, 16% fewer all-cause inpatient hospitalizations, and 50% fewer outpatient visits but 48% more mental health admissions.

Sensitivity Analysis

Results of the post hoc sensitivity analyses were largely consistent with our primary analyses (Table 3). Among Medicare beneficiaries, CAST patients had significantly lower healthcare expenditures than the matched national sample for all-cause inpatient hospitalizations, outpatient visits, and total expenditures. However, CAST patients had greater expenditures for all-cause ED visits and significantly more utilization across all outcome areas examined. Among privately insured autistic adults, CAST patients had significantly more primary care visits but significantly lower expenditures and less utilization than the matched national sample across all other outcome areas examined.

DISCUSSION

The unique healthcare needs of autistic people necessitate the development of patient-centered approaches to primary care.¹² This study contributes to the literature by characterizing expenditures and healthcare utilization among patients receiving care in a specialized clinic designed with and for autistic adults, embedded in a PCMH. Although our findings are inherently tied to the specific clinic from which our sample of autistic adults was obtained (i.e., CAST), this study has broader implications that highlight differences observed in expenditures and healthcare utilization when autistic adults

Table 3 Post Hoc Sensitivity Analysis of Expenditures and Utilization by Insurance Type

	Medicare beneficiaries		Privately insured beneficiaries	
	Mean (95% CI)		Mean (95% CI)	
	CAST	Matched national sample	CAST	Matched national sample
	(N = 54)	(N = 108)	(N = 310)	(N = 620)
Expenditures (in USD)				
Primary care	1273 (1026, 1536)	1202 (316, 2267)	1078 (1007, 1147)	728 (650, 807)*
All-cause ED visits	834 (251, 1437)	114 (41, 192)*	271 (169, 366)	664 (470, 858)*
All-cause inpatient hospitalizations	5287 (1090, 9949)	5858 (2636, 9083)*	4151 (774, 7369)	5188 (2174, 7889)*
Mental health admissions	3635 (713, 7140)	3518 (979, 6406)	810 (413, 1216)	1403 (822, 1952)*
Outpatient visits	2409 (1649, 3214)	4395 (2712, 6297)*	1726 (1531, 1907)	6460 (4781, 8114)*
Total costs [†]	8531 (8304, 8757)	10368 (10174, 10562)*	6149 (5959, 6338)	12312 (12103, 12521)*
Utilization (# of visits)				
Primary care	11.58 (11.46, 11.70)	2.89 (2.84, 2.93)*	6.95 (6.93, 6.98)	5.62 (5.60, 5.65)*
All-cause ED visits	1.07 (0.30, 1.95)	0.46 (0.18, 0.78)*	0.21 (0.13, 0.28)	0.68 (0.50, 0.84)*
All-cause inpatient hospitalizations	0.55 (0.16, 0.95)	0.47 (0.24, 0.70)*	0.11 (0.06, 0.16)	0.21 (0.14, 0.27)*
Mental health admissions	0.70 (0.23, 1.19)	0.52 (0.18, 0.92)*	0.16 (0.09, 0.21)	0.22 (0.15, 0.28)*
Outpatient visits	21.21 (15.48, 27.50)	15.31 (12.12, 18.68)*	10.22 (9.22, 11.20)	23.47 (20.23, 26.42)*

CI, confidence interval; CAST, Center for Autism Services and Transition; USD, United States dollars; ED, emergency department.

*p < 0.005 when compared to the respective CAST metric.

[†]Total costs, the sum of outpatient, inpatient, and ED expenditures.

receive care through specialized clinics embedded in primary care.

Autistic adults often have significantly higher healthcare expenditures than other populations, such as adults with attention deficit hyperactivity disorder (ADHD), intellectual disability, and the general population.^{5,22,23} While CAST primary care was more costly than primary care provided to national samples of autistic adults, this model of care delivery yielded cost savings across nearly all visit types we examined. These findings suggest specialized clinics for autistic adults embedded in broader primary care facilities may contribute to mitigating healthcare expenditures and utilization. Yet, CAST patients had higher expenditures than Medicare-enrolled autistic adults for ED visits. This may be due to the finding that CAST patients tended to have more ED visits than Medicare-enrolled autistic adults combined with historical trends of decreasing ED costs over time for Medicare beneficiaries²⁴ and the fact that private insurance reimbursements are significantly higher than Medicare reimbursements for the same services.²⁵ Notably, across all groups, the average number of ED visits (as well as inpatient hospitalizations and mental health admissions) was very low, and in most cases was less than 1 visit per person; as such, this finding should be interpreted cautiously.

In addition to higher healthcare expenditures, autistic adults are more likely to use most healthcare service types than adults with ADHD or the general population.^{5,22} Our study found CAST patients had significantly lower utilization of nearly all visit types examined than a national sample of privately insured autistic adults. One possible explanation for this finding is CAST patients have higher utilization of preventive care,¹⁵ which may reduce subsequent utilization of costlier services such as ED visits and inpatient hospitalizations. This finding adds to the growing body of literature demonstrating the

effectiveness of specialized care for autistic adults embedded in broader healthcare settings.²⁶

Relative to Medicare-enrolled autistic adults, CAST patients had fewer all-cause inpatient hospitalizations but not ED visits, mental health admissions, or outpatient visits. Although CAST patients had, on average, more mental health admissions and outpatient visits than Medicare-enrolled autistic adults, average expenditures for these services were significantly lower among CAST patients. A more nuanced exploration into why CAST patients had more visits but lower expenditures than Medicare-enrolled autistic adults for these services was beyond the scope of the present study. However, we posit CAST patients may have had shorter lengths of stay for mental health admissions which contribute to lower expenditures.²⁷ Additionally, the outcome of “outpatient visits” included outpatient visits of any type (i.e., medical specialist visits, community-based mental health care such as counseling or therapy, preventive care, primary care, etc.). As such, we hypothesize the greater number of visits but lower expenditures observed among CAST patients for outpatient visits may have reflected better continuity of care,¹⁷ where patients have more regular and frequent contact with their providers for the ongoing management of health conditions. Further work would need to be conducted, however, to test these hypotheses and explore reasons for increased visits but lower expenditures for some services among CAST patients.

Methodological Considerations

There are several limitations to this work. First, using medical billing data to conduct research has inherent limitations. In general, socioeconomic variables are not captured in medical billing data making it difficult to ascertain important social determinants of health that may influence results. In our study, race and ethnicity were captured for the CAST and Medicare

samples. However, our privately insured sample did not include race or ethnicity, which prohibited us from controlling for these determinants in our analysis. Propensity score matching was limited by observed demographic and clinical characteristics. Additionally, because medical visits made by CAST patients outside of our institutions healthcare system are not shared with our data information warehouse, we cannot say with certainty the medical records of CAST patients are complete. We also were restricted to analyzing costs and expenditures covered by insurance payments, co-pays, and co-insurance. We recognize there are other important costs associated with delivering care, such as provider salaries, staff salaries, and overhead, that were not included in our estimates of primary care cost and healthcare expenditures.

Secondly, we were unable to determine the extent to which our findings were attributable to features unique to CAST (e.g., experienced providers, visit accommodations) or to characteristics that are inherent to all PCMHs (e.g., patient-centeredness, care coordination). Additionally, although the likelihood of individuals included in the national samples ever receiving treatment through CAST is low given the lack of geographical proximity, we cannot know with certainty whether patients in the national samples ever received care through other PCMHs. Estimating utilization rates of PCMHs among autistic adults in the USA is difficult since to our knowledge, there are no published studies that have examined this. However, literature suggests the utilization of PCMHs is relatively uncommon among autistic pediatric populations (19%).²⁸

Finally, there are other important considerations when evaluating a model of healthcare delivery. In this study, we did not evaluate quality of care. Additionally, medical records capture only services received and would not capture an individual's unmet healthcare needs. Due to the cross-sectional nature of this study, we were unable to examine the temporal relationships of different types of healthcare utilization. As such, we were unable to determine whether high up-front primary care costs for CAST led to future reductions in healthcare utilization or costs. We also acknowledge cost savings may accrue over the long term while payments for services are ongoing. Therefore, full effects and benefits may not be immediately obvious, especially as autistic adults age into middle and older adulthood.

CONCLUSION

This study evaluated how receiving healthcare through a specialized clinic designed with and for autistic adults was associated with healthcare expenditures and utilization. Our findings suggest this model of care delivery could be an alternative to current standards of care and may reduce expenditures and healthcare utilization particularly relative to primary care provided to privately insured autistic adults. Our findings add to the growing body of literature demonstrating the benefits and

effectiveness of specialized care for autistic adults embedded in broader healthcare settings.

Corresponding Author: Brittany N. Hand, PhD, OTR/L; School of Health and Rehabilitation Sciences, The Ohio State University, Columbus, USA (e-mail: hand.58@osu.edu).

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Declarations:

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