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ORIGINAL PAPER

Language Barriers Impact Access to Services for Children with Autism Spectrum Disorders

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Abstract Racial and ethnic disparities in accessing health care have been described in children with autism spectrum disorder (ASD). In a retrospective chart review of 152 children with ASD, children of parents whose primary language was English were significantly more likely to have both social skills and communication goals within their individualized education plan (IEP) compared to children of parents whose primary language was not English. Additionally, children of primary English speakers received significantly more hours of direct services from their state disability program. After controlling for demographic covariates, findings suggest that language barriers may negatively affect parents' abilities to access health care services for their child with ASD. Acculturation factors must therefore be considered when analyzing disparities in autism.

Keywords Autism spectrum disorder · Health care disparities · Individualized education plan · Language barriers · Access to services

Introduction

Intensive therapeutic and behavioral services have been demonstrated to result in better outcomes for children with autism spectrum disorder (ASD), a neurodevelopmental disorder characterized by a continuum of social and behavioral impairments that affects an estimated 1 in 68 in the United States (Casenhiser et al. 2015; Christensen et al. 2016; Reed et al. 2007). Maximally effective intervention is dependent upon several factors including, but not limited to: early identification of developmental concerns, timely ASD diagnosis, access to state disability services and implementation of necessary special education services and supports through establishment and maintenance of an individualized education program (IEP) (Adams and Tapia 2013; Gupta et al. 2007; Lord and Luyster 2006; Ruble and McGrew 2013; Zwaigenbaum et al. 2015).

A formal diagnosis of a developmental disability (including ASD) is an eligibility requirement for children to access developmental disability services in many publically-funded, state disability programs across the United States according to a report prepared by L&M Policy Research, LLC (2014) for the Centers for Medicare & Medicaid Services. These services play an integral role in improving outcomes for children diagnosed with ASD. In a 2013 report, 90% of National Core Indicators Child Family Survey respondents in California agreed that supports funded by regional centers (the community-based agencies contracting with the State Department of Disabilities) made a positive difference in their family's life (Human Services Research Institute for the

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California Department of Developmental Services 2013). The Affordable Care Act currently mandates health insurers to provide coverage for behavioral intervention for children diagnosed with ASD, which is anticipated to lead to expanded access to services beyond the publically-funded system (Beronio et al. 2014).

Additionally, United States federal law dictates that every child with a disability that impacts their education must be provided with services and supports as outlined in an IEP per the Individuals with Disabilities Education (2004) Act (IDEA) Part B of 2004. IEPs are legally binding documents that obligate schools to carry out explicitly listed goals via special education services, accommodations and routine progress measurement (Disability Rights California 2011). It is therefore imperative that children diagnosed with ASD who require special education services are granted an IEP that lists specific functional goals to guide services and supports. According to the recommendations for educating children with autism outlined by the National Research Council (NRC) (2001), services for children with autism should address social skills to improve involvement in daily activities and verbal and non-verbal communication skills, among others. Thus, it is appropriate that an IEP for a child with ASD would include social skills and communication goals.

Despite state and federal support for services, racial and ethnic disparities have been documented in the identification and treatment of ASD in the United States. The National Institute of Medicine describes health service disparities as differences in treatment or access to care that cannot be attributed to the difference in health status between groups (Alegria et al. 2010). Data from the Autism and Development Disabilities Monitoring (ADDM) (Centers for Disease control and Prevention 2016) Network show that across the United States, white, non-Hispanic children are 1.5 times more likely than their Hispanic peers to be identified with autism. Additionally, lower socioeconomic status, non-white ethnicity, and having a foreign-born or non-English speaking parent have all been associated with later age at diagnosis of ASD (Liptak et al. 2008; Mandell et al. 2009; Manning et al. 2011). Furthermore, even when ASD has been identified, national studies suggest that there may be ethnic disparities in access to services (Alegria et al. 2010; Liptak et al. 2008) and development of an IEP (Harstad et al. 2013).

Acculturation level, or an individual's level of adoption of traits from their surrounding culture, has been shown to play a major role in health service disparities (Becerra et al. 2015; Gulley et al. 2014). Specifically, language barriers such as those faced by parents who speak Spanish as their primary language in the U.S., may cause challenges in communicating subtle signs and symptoms of their child's developmental delay to healthcare providers (Becerra et al. 2015; Villani and Mortensen 2014). A parent's ethnicity, country of origin, length of U.S. residency and primary language may therefore all contribute to differences in outcomes including whether a child is enrolled in programs through an early intervention or state disability program, how many hours of intervention a child receives and whether specific ASD-related goals are listed in their IEP.

The purpose of this study was to examine the influence of current ethnic and acculturation differences, with an emphasis on parental primary language, on child involvement in ASD-specific services within the developmental disabilities programs and school systems of a culturally diverse state. We hypothesized that both participant ethnicity and parental acculturation, operationalized as English primary language, would significantly affect two major outcomes in the following ways: (1) Hispanic children with ASD and children with ASD whose parents' primary language was not English were less likely to be enrolled in state disability programs and received fewer hours of direct ASD-related services per week when compared to non-Hispanic children and children of primary English speaking parents, respectively; and (2) Hispanic children with ASD and children with ASD whose parents' primary language was not English were less likely to have social skills goals and communication skills goals listed in their IEP when compared to non-Hispanic children and children of primary English speaking parents, respectively.

Methods

Study Design and Participants

Data for this study were collected through a retrospective chart review. Participants were children receiving services in a specialty mental health program at a large urban children's hospital in California from January 1, 2009 to December 31, 2011. Inclusion criteria included a Diagnostic and Statistical Manual (DSM) diagnosis of an ASD confirmed by the mental health therapist; child age 3–21; and presence of an IEP document in the mental health chart. Given the study timeline, DSM-IV-TR (American Psychiatric Association 2000) criteria were used; children with DSM diagnoses of autistic disorder, pervasive developmental disorder (PDD) and Asperger's disorder were included, collectively referred to in this study as ASD. Diagnosis was confirmed by a therapist to qualify under DSM-IV-TR criteria, but if questions regarding the diagnosis were raised by a parent or therapist, additional confirmatory assessments were utilized. The autism diagnostic observation schedule (ADOS) assessment was used to confirm the diagnosis of ASD when necessary. If confirmatory assessments indicated that the child did not truly meet the diagnostic criteria for autistic disorder, PDD-NOS or Asperger's disorder (per DSM-IV-TR criteria), the chart was excluded from the study. All children were covered by Medi-Cal (Medicaid) health insurance.

A total of 479 patients with a listed diagnosis of ASD were seen during this period. Based on a priori power analysis, the study team aimed to include 152 patients. 268 randomly selected charts were ultimately required to yield 152 patients who met all study inclusion criteria. Of those 268, 43 patients were excluded because despite an initial diagnostic impression of ASD documented in the chart, following the mental health assessment the clinician concluded that the child did not meet criteria for ASD. Seventy-three additional patients were excluded for a variety of other reasons, including subjects younger than 3 years of age (n = 12), as these individuals do not qualify for special education services; charts lacking sufficient identifying information about the ethnicity and language of the subject's parent (n = 16); and charts that did not include an IEP (n = 45). A total of 152 charts were included for analysis (Fig. 1).

Data Collection

A standardized data collection protocol developed by the research team was used to extract information from the electronic charts, physical charts and IEP documents. IEP documents were obtained from schools and filed in the charts by the clinicians. Diagnosis of autism was determined by the mental health therapist completing the intake. Standard protocol in the mental health clinic was for the therapist to interview parents/caregivers, observe and interview the child, review records from external agencies, and consult with referring providers and other providers treating the child to determine the clinical diagnoses. In cases where the diagnosis of ASD was not clear, children were further evaluated in the mental health clinic by interdisciplinary teams or individual psychologists.

Measures

The main predictor of interest was the language primarily spoken by the patients' parents. Parental primary language was documented in the chart based on the telephone screening and intake interview. For analytic purposes, parental primary language was coded 1 for English and 0 for any language other than English. Languages spoken other than English included the following, with number of participants whose parents reported that language as their primary language in parentheses: Spanish (80), Tagalog (4), Korean (4), Cantonese (3), Arabic (2), Armenian (2), Bangladeshi (2), Indonesian (1), Taiwanese (1) and Vietnamese (1). Additional covariates included age in years at first parental concern; patient gender (male = 1, female = 0); patient ethnicity (Hispanic = 1, non-Hispanic = 0); and location where the

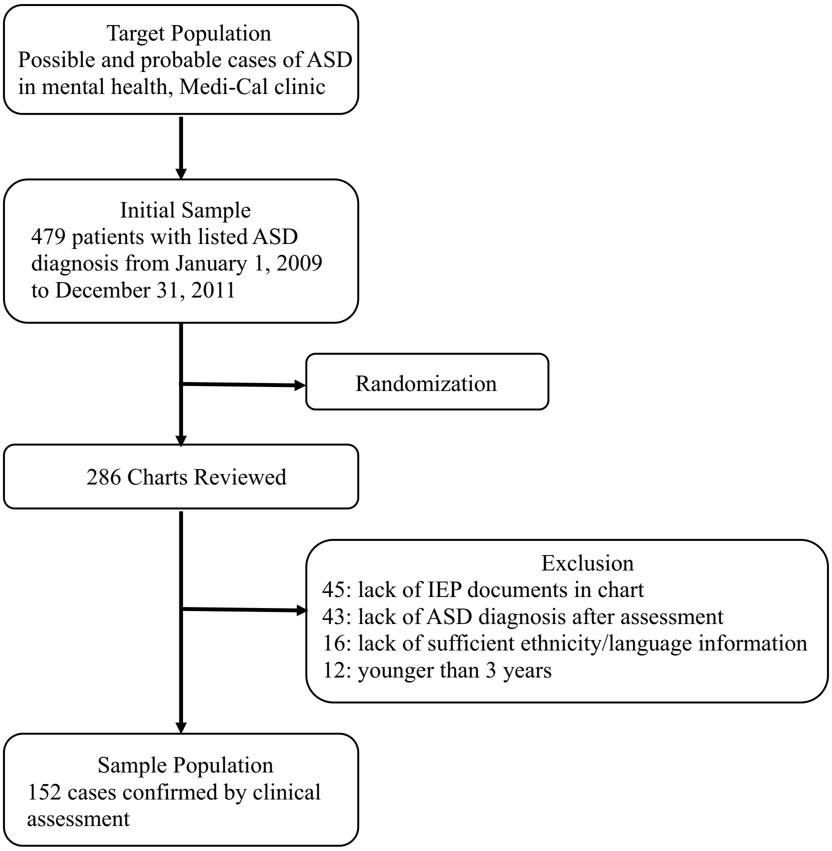

Fig. 1 Sample selection

patient was evaluated and ultimately diagnosed with ASD {the mental health program where the study was conducted, the Regional Center [California Developmental Disability program (CA DDS)], or another location}. Location was modeled as a pair of dummy codes representing home institution and regional center, with other location as the reference category.

Outcomes included whether or not the patient was assessed and found eligible for the CA DDS system (1 = yes, 0 = no); number of hours spent in direct services per week from the CA DDS; and whether social skills and communication skills goals were included in the IEP (1 = yes, 0 = no for each type of goal). Common examples of social skills goals include: "[child] will raise hand and wait to be called on before talking aloud in group settings 4/5 opportunities to do so" and "[child] will refrain from interrupting others by exhibiting appropriate social interaction skills 4/5 opportunities to do so." Examples of communication skills goals include: "[child] will initiate communicative interactions with others 4/5 opportunities to do so" and "[child] will initiate varied appropriate topics with others 4/5 opportunities to do so." Social and communication goals were classified in this study by either (1) plain language designation within the IEP document (e.g. "Communication" or "Language" goal classification denotes a communication goal) or (2) reasonable judgment based on analysis of goal content (e.g. a social goal often included reciprocal communication with others).

Services provided by the CA DDS included in this analysis were limited to those provided to directly decrease the primary symptoms of ASD. Examples of these services included applied behavior analysis (ABA), discrete trial training (DTT), behavioral therapy, developmental individual-difference relationship-based (DIR)/floortime, social skills, adaptive skills training, or any other service in which a therapist works directly with the child or family (excluding services historically covered by health insurance or school system and not by CA DDS, like physical and occupational therapy). Respite hours were not included in this analysis. Because the mental health clinic assists parents in advocating for services, only services in place at the time of intake was included in this analysis.

Analysis

Descriptive statistics were used to summarize sample characteristics. To examine the associations between ethnicity, primary language, and outcomes, a series of multiple regression analyses were conducted. Logistic regression was used to model the relationship between predictors of interest and the binary CA DDS access, social skills IEP goals, and communication IEP goals outcomes, and linear regression was used to examine effects on number of hours of direct services per week received from the CA DDS, controlling for the other demographic covariates.

Results

Descriptive statistics for sample demographics are presented in Table 1. On average, according to interview records, parents first experienced concerns about their child's development around 20 months of age but did not receive an ASD diagnosis until the child was more than 4 years old (53.6 months of age). The majority of children in the study were male (84%), Hispanic (69%), and had been diagnosed with autistic disorder (76%). Among parents, more than half spoke Spanish as their primary language (53%). Less than half of the sampled children (47%) had a social skills goal in their IEP; however, a majority did have a communication skills goal (81%). Nearly two-thirds (63%) of patients in our sample were eligible for Regional Center services, and eligible children received an average of just under 3 h of services per week.

In unadjusted analyses, Hispanic ethnicity alone did not significantly affect any measured outcome. Analyses did not find significant differences in CA DDS access (OR = 1.05, *ns*), hours of services received from the CA DDS ($\beta = -0.15$, *ns*), social skills IEP (OR = 0.60, *ns*) or communication skills IEP (OR = 1.21, *ns*) due to patients' Hispanic ethnicity. However, the parent's primary language being English was significantly associated with higher likelihood of their child's IEP containing social skills goals (OR = 3.67, $p = 0.001$) and communication skills goals (OR = 5.88, $p = 0.02$) and with accessing a greater number of hours of services from the CA DDS ($\beta = 0.22$, $p = 0.04$), though not with whether the family was able to access the CA DDS at all (OR = 0.69, *ns*). After controlling for demographic factors including child's age at assessment, gender, ethnicity, and assessment location, parent language continued to be significantly associated with social skills IEP (OR = 4.81, $p = 0.001$), communication skills IEP (OR = 11.00, $p = 0.007$), and number of hours received ($\beta = 0.24$, $p = 0.03$), but not CA DDS access alone (OR = 0.81, *ns*). However, being assessed at the CA DDS was associated with increased likelihood of receiving any services from the CA DDS (OR = 5.91, $p = 0.001$), and children assessed at an older age received a greater number of hours of services from the CA DDS ($\beta = 0.29$, $p = 0.01$). Complete linear and logistic regression results are presented in Table 2.

Discussion

This study aimed to explore two main outcomes for children with ASD based on ethnicity and acculturation levels

Table 1 Sample demographics and outcomes

Variable	Categories	N (%)
Diagnosis	Autism	116 (76%)
	PDD/ASD	32 (21%)
	Asperger's	4 (3%)
Child's gender	Male	127 (84%)
	Female	25 (16%)
Race	Hispanic	98 (64%)
	Asian	17 (11%)
	White	13 (8.5%)
	Black	13 (8.5%)
	Multiracial	7 (5%)
	Other	4 (3%)
Ethnicity	Hispanic	105 (69%)
	Non-Hispanic	47 (31%)
Parent's primary language	English	52 (34%)
	Spanish	80 (53%)
	Other	20 (13%)
Parent's secondary language	None	89 (59%)
	English	50 (33%)
	Spanish	10 (7%)
	Other	3 (2%)
Eligible for CA DDS services		95 (63%)
Social skills goals in IEP		71 (47%)
Communications skills goals in IEP		123 (81%)
Variable	**Range**	**Mean (SD)**
Age in months at time of parental concern	1–84 months	20.36 (11.16)
Age in months at time of ASD diagnosis	17–180 months	53.62 (35.66)
Hours of direct services per week	0–40 h	2.90 (6.88)

Table 2 Unadjusted and adjusted regression analyses predicting ASD services outcomes

	IEP-social skills		IEP-communication		CA DDS Access		CA DDS # hours	
	OR	p-Value	OR	p-Value	OR	p-Value	β	p-Value
Parent primary language (unadjusted)	3.67	0.001	5.88	0.02	0.69	0.30	0.22	0.04
Parent primary language (adjusted)	4.81	0.001	11.00	0.007	0.81	0.66	0.24	0.03
Age at assessment (years)	1.07	0.22	0.92	0.24	1.06	0.35	0.29	0.01
Male gender	1.04	0.93	1.22	0.78	0.78	0.68	0.04	0.69
Hispanic ethnicity	0.99	0.99	2.76	0.11	0.91	0.86	−0.06	0.61
Location: CA DDS	1.07	0.91	1.78	0.46	5.91	0.001	−0.05	0.70
Location: home institution	0.35	0.10	0.23	0.07	0.13	0.004	−0.12	0.33

represented in part by parental primary language: (1) access to and quantity of services received from state disability programs; and (2) presence of ASD-related goals within IEPs. Although we did not find ethnicity to play a significant role in either outcome, parents' primary language was significantly associated with both quantity of state disability services received and presence of ASD-related goals within IEPs.

Study results show that children whose parents spoke English as a primary language received significantly more hours of services provided by CA DDS Regional Centers than children whose parents primarily spoke a language other than English. These results are supported by previous studies showing a link between English–Spanish language barriers and reduced access to ASD-specific health care services (Liptak et al. 2008; Mandell et al. 2009) and are particularly meaningful as 53% of parents in our sample spoke Spanish as a primary language and only 34% spoke English as a primary language. It is of note that while primary language is major component and indicator of acculturation (Schumann 1986) acculturation is multi-dimensional by nature and not all components of acculturation were accounted for by this study.

Additionally, significant differences in IEP goal content were found by this study. Analyses showed that children of parents whose primary language was English were significantly more likely to have both social skills goals and communication skills goals listed in their IEP. The maintenance and continued evaluation of IEPs is dependent in large part on parent involvement [e.g. according to Disability Rights California, neither federal nor state law limits the number of IEPs a parent can request per year; parents may request initial special education service assessments (California Education Code 2001) and parents are encouraged to contribute to IEP meetings by reporting on their child's academic, developmental and functional needs, the strengths of their child and concerns regarding education enhancement opportunities (California Education Code 2010)]. The discrepancy in the quality of IEPs found by this study may represent differences in the variable profile of ASD across primary language, but may also reflect the heightened challenge faced by parents whose primary language is not English to advocate for specific, appropriate IEP content. It is possible that the language barrier between parents whose primary language is not English and CA public school administrators and teachers plays a role in rendering the content of these IEPs less specific to the needs of a child with ASD, considering previous publications citing challenges associated with language barriers in IEP meetings (Cheatham 2010; Lian and Fontánez-Phelan 2001; Salas 2004). Based on an extensive literature review, we feel that our findings regarding IEP content related explicitly to parental primary language are novel extensions of prior work documenting health disparities related to ethnicity in access to ASD services (Liptak et al. 2008; Mandell et al. 2009). These findings on specific IEP goal discrepancies not only satisfy one arm of our hypothesis but also lay a framework for studies examining IEP quality and ASD in the future.

Inclusion criteria for this study included children with a diagnosis of Autistic disorder, PDD-NOS or Asperger's disorder per DSM-IV-TR criteria, collectively referred to as ASD. If questions regarding the validity of a diagnosis with ASD remained after confirmatory ADOS assessments, the participant was excluded from the study. This exclusion of borderline cases would bias our results toward the null hypothesis. Thus, we feel that our results regarding parental primary language predicting low service outcomes are robust.

The sample (N = 152) analyzed in this study is ethnically diverse, reflecting the heterogenic milieu of California, a state hosting 22 of the 57 United States metropolitan areas where at least one-fourth of the population age 5 years and older speaks a language other than English at home (Ryan 2013). As such, these results may be more broadly generalized to other metropolitan areas across the United States with similar degrees of cultural and linguistic diversity, minimizing bias and improving this study's external validity. Internal validity was also preserved by employment of a systematic, unbiased approach to data acquisition from medical records.

This study population also reflects patients of exclusively low socioeconomic backgrounds. Based on prior results elucidating a barrier effect imposed by socioeconomic status on receipt of intervention services for ASD, our study sample may be enriched to emphasize the relationship between parental primary language and ASD service quality and receipt (Carr and Lord 2016). This circumstance presents both strengths and weaknesses for our study. Our study is strengthened by our limiting of analyses to participants of low socioeconomic status because it marks an important contribution to the scientific body of work regarding ASD. Conversely, our study is weakened because results are limited in their generalizability to populations with broader income levels. Due to the retrospective nature of this study, we were unable to ascertain data regarding income differences within this exclusively low-income population.

Given the retrospective study design, some reviewed charts were missing data and had to be excluded from analyses. Specific acculturation demographics, including parental length of US residency, were not consistently available in the medical records and thus could not be examined in this study. Additionally, only children with an IEP in their chart were included in this study, so results cannot be applied to children without access to an IEP.

Furthermore, ASD is by definition a spectrum disorder, which makes it difficult to standardize an appropriate number of hours of intervention services that should be provided to each child. While our findings did show a significant difference in number of hours spent receiving CA DDS services based on parental primary language, it is difficult to determine how many hours is suitable for any given individual. Because no adaptive or cognitive functioning measures were available for systematic analysis in this study, we were unable to correlate each child's individual needs with quantity of services received.

Under the Individuals with Disabilities Education Act (IDEA), there are 13 diagnostic classifications under which a child qualifies for special education services. While we did not record IDEA classification category among our subjects, this variable may have limited our study by moderating IEP content outcomes. However, due to the individualized nature of IEP documents, we suspect that IDEA classification should not have played a deterministic role in affecting IEP content.

The retrospective nature of this study limited our ability to determine interpreter service usage at school IEP meetings, a right conferred to all parents upon request. Therefore, variability in access to interpretation services, intuiting need for an interpreter and quality of interpretation services may have affected our results with regards to IEP content outcomes.

Children assessed in the mental health clinic are referred for treatment of primary mental health, not developmental disorders. This may bias the population of this study, because the nature of these primary behaviors are unknown. For instance, it is possible that the majority of our cases exhibited similar behaviors, such as disruptive or aggressive behaviors. This would not bias any findings in regards to language disparities, but could make our results generalize more specifically to a high risk behavioral population instead of across the greater ASD population.

Lastly, acculturation is a multi-dimensional measurement and not all facets thereof could be identified or analyzed by this study. It is possible that acculturation differences other than parents' primary language play a confounding role in the results shown here.

Implications for Further Research

While this study does not show that ethnic disparities in service access between Hispanic and non-Hispanic children exist, it does note several important differences between groups of children with ASD with regards to parental primary language. Our results show that, on balance, children of parents whose first language is not English utilize less ASD-related intervention services and are less likely to have ASD-specific goals listed in their IEPs. According to the National Institute of Medicine, one of the six aims for improving healthcare is equity (Institute of Medicine 2001). It is a matter of public health to acknowledge and understand the origin of differences in service access in order to adequately address this fundamental problem. Children who do not receive timely and appropriate intervention are less likely to improve and more likely to create an economic burden for society by way of medical costs, productivity losses and special education services (Buescher et al. 2014). Moreover, in 2007, medical expenditures alone for children and adolescents with ASD were on average 4.1–6.2 times greater than for those without ASD in the US (Shimabukuro et al. 2008). Considering community-wide goals of equity and cost reduction, more research must be conducted to understand the origin of acculturation differences and how they affect the global treatment of children with ASD in order to develop methods that ameliorate their aforementioned effects.

Furthermore, concrete steps can be taken to resolve the disparities highlighted by this study. These include (but are not limited to): increased efforts to reduce subjectivity in employing interpretation services at school IEP meetings wherever possible, widespread, multi-lingual education campaigns featuring the effectiveness of therapeutic interventions for ASD and multi-lingual online/text resources for parents navigating ASD services and IEP processes. Future research efforts aimed at elucidating interpreter efficacy, the impacts of socio-economic status on ASD service receipt and the efficacy of parental advocacy and awareness campaigns would all contribute to more fully understanding and ultimately addressing the disparities in therapeutic services among children with ASD found by this study.

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

Informed Consent For this type of study formal consent is not required. All study procedures were approved by the Institutional Review Board at the authors' home institution.

Research Involving Human and Animal Participants All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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