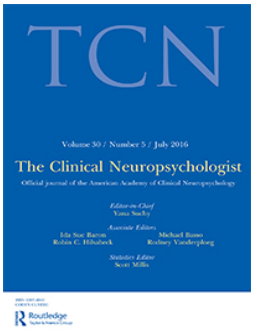

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Do parents implement pediatric neuropsychological report recommendations?

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ABSTRACT

Objective: We explored parent-reported implementation rates of medical, home/community, and school recommendations following a pediatric neuropsychological evaluation, as well as demographic group differences in, and potential barriers to, recommendation implementation.

Method: Participants were 55 parents of children and adolescents who completed an outpatient neuropsychological evaluation in a university-based hospital neuropsychology clinic within 4 to 6 months prior to study participation. Participants were contacted by phone to complete a short interview regarding implementation of report recommendations.

Results: Slightly over half (52%) of all recommendations were implemented, with higher implementation rates of school (62%) and home/community recommendations (53%) than medical recommendations (40%). Results indicated significantly lower recommendation implementation for households with low income (particularly for medical recommendations). Reported reasons for not implementing recommendations included lack of time, lack of resources (geographical and financial), ambivalence about the need to implement the recommendation, not remembering the recommendation, confusion about how to implement the recommendation, and resistance from schools and teachers.

Conclusions: The results for this study provide information for pediatric neuropsychologists regarding rates of recommendation implementation, with differences identified based on type of recommendation and demographic factors. Further empirical investigation is indicated in order to determine practical, concrete steps to improve recommendation implementation.

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Neuropsychology; recommendations; pediatric; outcomes; implementation

There is abundant research suggesting that neuropsychological assessment is useful for the clinical care of children with medical and neurodevelopmental conditions (e.g., Ellenberg et al., 2009; Farmer & Brazeal, 1998; Pritchard, Koriakin, Jacobson, & Mahone, 2014). As evidence, parents, teachers, and referring providers report a high level of

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satisfaction overall with neuropsychological evaluations (Bodin et al., 2007; Kirkwood, Peterson, Baker, & Connery, 2017). During the evaluation process, many, if not most, pediatric neuropsychologists spend a great deal of time and care in providing families with recommendations for intervention and treatment. Thus, while metrics like satisfaction are very important in understanding the impact of a neuropsychological evaluation, understanding rates of recommendation implementation is also important in improving pediatric neuropsychology as a field. There is some evidence that parents are more likely to seek evidence-based treatments following a neuropsychological evaluation; for example, certain evidence-based treatments for attention-deficit/hyperactivity disorder (ADHD) in children, such as parent behavior management training, are more often initiated by families who have undergone a neuropsychological evaluation than those who have not (Pritchard et al., 2014). Moreover, recent longitudinal process-based research provides evidence that, compared to before the initial neuropsychological evaluation, parents gain knowledge about their child's condition and understanding about how to help their child after receiving verbal and written feedback (Austin et al., 2019). However, further work in understanding implementation and impact of neuropsychologists' recommendations is needed.

To our knowledge, only two published manuscripts, focused on children with pediatric cancer (Cheung et al., 2014; Quillen, Crawford, Plummer, Bradley, & Glidden, 2011), have explored whether and to what extent parents implement specific recommendations contained within pediatric neuropsychological reports. In these studies, parents implemented between 41% to 48% of recommendations at home and school and found most implemented recommendations helpful and easy to complete. Both studies identified child reluctance, lack of parent initiative or know-how, logistical issues (e.g., long wait time for appointments with medical providers), and school reluctance to implement recommendations as key barriers to recommendation implementation. While these studies provided preliminary data regarding the implementation of neuropsychological recommendations, sample sizes were small ($n \leq 20$).

No study to our knowledge (including the two aforementioned studies) has examined the role of patient-centered factors (e.g., demographics) in successful implementation of pediatric neuropsychologists' recommendations. However, researchers in other medical fields have sought to understand such factors for several years, identifying factors positively associated with recommendation implementation, such as high income, high education, majority race/ethnicity, and ample access to healthcare (DiMatteo, 2004; Gerber, Cho, Arozullah, & Lee, 2010; Jin, Sklar, Oh, & Li, 2008; Knapp et al., 2006; Roberts, Wheeler, & Reeder-Hayes, 2015; Scheel, Hanson, & Razzhavaikina, 2004; U.S. Department of Health and Human Services (USDHHS), 2001). Many of these studies acknowledge that disentangling the influence of one contributing factor from another (e.g., race/ethnicity, education, income, etc.) is difficult because of their lack of independence from one another. Nevertheless, knowing recommendation implementation rates differ based on such factors is useful information for clinicians to consider and is a topic that has gathered increased attention over the past several years, with governmental and other entities creating programs and initiatives in this area [e.g., Merit-based Incentive Payment System (MIPS), Mental and Behavioral Health Registry (MBHR)]. Given findings from other medical fields, there is a need to explore what patient factors relate to successful implementation of recommendations within the field of neuropsychology.

The current study extends the abovementioned literature by (1) examining pediatric neuropsychology recommendation implementation in a relatively larger and more diagnostically heterogeneous sample than previous studies with similar aims and (2) investigating factors that may contribute to low implementation rates. The current study was completed in a hospital-based university neuropsychology clinic, within a part of the country that serves individuals from culturally, linguistically, and economically diverse backgrounds. We intended to explore the types of recommendations most frequently implemented (per parent report) and whether implemented recommendations were deemed helpful by parents. We expected overall recommendation implementation would be similar to that of previous studies (41% to 48%) (Cheung et al., 2014; Quillen et al., 2011). Given the exploratory nature of the study, specific hypotheses regarding differences in recommendation implementation among different sociocultural groups were not made.

Methods

Sample

The research study took place in a university hospital clinic in the southwestern region of the United States. The study received approval from the university hospital's IRB, and participants completed the study only after informed consent. Participation was voluntary, and there was no monetary compensation for participating. Parents were eligible for inclusion in the study if (1) their child was between the ages of 5 and 17, (2) they spoke either English or Spanish fluently, (3) the child was not in the custody of child protective services at the time of the evaluation, (4) the neuropsychological report documented that a clinical interview was conducted with the parent(s) during the evaluation, and (5) a feedback session was conducted with the parent(s) following completion of the neuropsychological evaluation. To determine interest in the study, research assistants called all parents who met the above inclusion criteria by phone within four to six months after the date the child's report was completed. If a child had more than one parent/guardian present at the feedback session, only one of the child's parents/guardians completed the study—whoever picked up the phone and agreed to participate. If parents did not pick up the phone on the first attempt, research assistants called one additional time on a different day at a different time of day. The research assistants did not leave voicemail messages because parents were deemed unlikely to call back about a study they had not previously heard about and that provided no monetary compensation. Of the 171 parents who were called by phone to determine interest, 56 (33%) completed the phone interview, 74 (43%) did not pick up the phone when called to determine interest, 13 (8%) answered the initial phone call but declined participation, and 28 (16%) agreed to participate at the initial phone call but did not complete the interview. Those in the last group either a) did not pick up the phone after two attempts to complete the scheduled interview or b) picked up but decided they were no longer interested. After gathering the data, one

Table 1. Background characteristics of participants, children, and families (n = 55).

Participant characteristics	
Participant age at time of evaluation, in years: mean (*SD*, range)	40.9 (8.6, 29-67)
Participant female: *n* (%)	52 (94.5)
Participant race/ethnicity	
Hispanic/Latino: *n* (%)	28 (51.9)
Non-Hispanic White: *n* (%)	19 (35.2)
Non-Hispanic Native American: *n* (%)	4 (7.4)
Non-Hispanic Asian: *n* (%)	1 (1.9)
Non-Hispanic African-American/Black: *n* (%)	1 (1.9)
Non-Hispanic multi-racial: *n* (%)	1 (1.9)
Participant language	
English only: *n* (%)	35 (64.8)
Spanish only: *n* (%)	14 (25.9)
Bilingual Spanish/English: *n* (%)	3 (5.6)
Bilingual not Spanish/English: *n* (%)	2 (3.7)
Participant education level in years: range	3-20
≤12: *n* (%)	22 (40.7)
12+: *n* (%)	32 (59.3)
Child characteristics	
Child age at time of evaluation, in years: mean (*SD*, range)	10.3 (3.3, 5-17)
Child female: *n* (%)	19 (34.5)
Child grade: range	PreK-12
Elementary: *n* (%)	33 (60.0)
Middle: *n* (%)	11 (20.0)
High: *n* (%)	11 (20.0)
Child language	
English only: *n* (%)	36 (65.5)
Spanish only: *n* (%)	2 (3.6)
Bilingual Spanish/English: *n* (%)	14 (25.5)
Bilingual not Spanish/English: *n* (%)	3 (5.5)
Child diagnoses, not mutually exclusive,	
Number of diagnoses: Mean, (*SD*, range)	3.3 (1.6, 0-7) 30 (54.5)
ADHD: *n* (%)	
Intellectual disability: *n* (%)	7 (12.7)
Autism spectrum disorder: *n* (%)	4 (7.3)
Major/mild neurocognitive disorder: *n* (%)	3 (5.5)
Specific learning disorder: *n* (%)	25 (45.5)
Other neurodevelopmental disorders: *n* (%)	21 (38.2)
Language disorder: *n* (%)	12 (21.8)
Other specified neurodevelopmental disorder: *n* (%)	5 (9.1)
Developmental coordination disorder: *n* (%)	5 (9.1)
Speech sound disorder: *n* (%)	2 (3.6)
Psychiatric: *n* (%)	29 (52.7)
Anxiety: *n* (%)	18 (32.7)
Depression: *n* (%)	9 (16.4)
PTSD: *n* (%)	2 (3.6)
Schizophrenia: *n* (%)	1 (1.8)
Oppositional defiant disorder: *n* (%)	7 (12.7)
Conduct disorder: *n* (%)	1 (1.8)
Children with identified medical condition commonly associated with cognitive difficulties (e.g., epilepsy, traumatic brain injury, perinatal stroke, cerebral palsy, hydrocephalus)	14 (25.5)
Family characteristics	
Family income	
$<12,000-41,000: *n* (%)	31 (60.8)
> $41,000: *n* (%)	20 (39.2)

ADHD = Attention-deficit/hyperactivity disorder
PTSD = Posttraumatic stress disorder
Note: Four participants did not report family income. One of these four participants also did not report participant race/ethnicity, participant language preference, or participant education.

parent who participated but whose child received no recommendations was excluded. Therefore, 55 (not 56) participants were considered in the analyses.

At the university hospital clinic where the study took place, patients are referred for evaluation by other medical providers (e.g., primary care providers, neurologists, other mental health professionals). All referrals are screened to ensure medical necessity for neuropsychological testing. The catchment area for the university hospital clinic includes both urban and rural areas. Standard payment methods for evaluations are accepted (e.g., Medicaid, private health insurances, self-pay). When asked to provide comments about their experience participating in the neuropsychological evaluation, participants did not report any insurance- or payment-related difficulties. For parents who preferred Spanish, feedback sessions were completed in Spanish or with the use of a Spanish interpreter. For these parents, a letter summarizing results and recommendations in Spanish was mailed to the family, in addition to the full report written in English. The median length of time between testing and feedback was 15 days. The median length of time between the feedback session and day the report was mailed to the family was 11 days.

Descriptive statistics of the study sample are shown in Table 1. For analyses, participants (i.e., parents or guardians) from all ethnic/racial minority backgrounds were grouped together (rather than in different ethnic/racial groups) because, in total, there were only 7 participants from ethnic/racial minority backgrounds who did not self-identify as Hispanic/Latinx (Native American, Asian, Black, multi-racial/ethnic). Participants who identified as being of ethnic/racial minority background comprised 64.8% of the participants. Demographic information was gathered for the participant, the participant's child, and the family from the child's report and/or the clinic's history questionnaire completed by a parent/guardian prior to their child's evaluation. Notably, some demographic data obtained was limited by the information provided on the history questionnaire. For instance, on the history questionnaire, participants marked one of nine different household income categories, the highest of which was "over $41,000." This figure was included as the maximum category on the questionnaire because, in years past, it was the U.S. federal poverty line for a family of ten. Because of this, delineation among household incomes over $41,000 was not possible. Other demographic variables had similar limitations, such as parental years of education, which some parents did not specify in detail on the form (e.g., wrote "some college").

Data from nonparticipants (those who either did not pick up the phone, declined, or did not complete the study) were also gathered in order to determine if those who participated in the study were a representative sample of the parents of pediatric patients seen in the clinic. Since the vast majority of study participants were mothers, non-participant data were based on the mother's demographic information unless there was no such information indicated on the clinic's history questionnaire. There were no differences between study participants and nonparticipants with regard to household income, parent education, parent ethnicity, sex of the child, or number of recommendations given (all $p > .05$). There were no differences between participants and nonparticipants with regard to proportions of children receiving diagnoses of ADHD, intellectual disability, autism spectrum disorder, learning disability, other

Table 2. By recommendation category, percent of recommendations that were implemented, deemed helpful, and deemed not difficult to implement, as well as barriers to implementation.

	% of Recs implemented	% Helpful*	% Not difficult to implement	Reported barriers to implementation from most to least cited
Medical				
1. Referals to non-established medical treatment providers	22/63 = 35%	20/22 = 91%	17/22 = 77%	• Lack of parent time • Long wait time for services • Resources not available in area/cost of travel • Disinterest in medication • Confusion about how to implement recommendation • Cost of treatment
2. Suggestions for considering adjusting medical treatment with established providers	11/19 = 58%	8/11 = 73%	9/11 = 82%	
Home/Community				
1. Home strategies (e.g., cognitive, behavioral, emotional, or medical strategies)	33/38 = 87%	30/32 = 94%	20/31 = 65%	• Family/parent time constraints • Problems accessing websites or books (poor internet/expensive books/confusion in accessing) • Child unwilling to participate • Parent did not remember recommendation • Lack of resources in geographical area
2. Self-study resources (e.g., books, websites)	17/38 = 45%	17/17 = 100%	13/16 = 81%	
3. Advocacy organizations	4/25 = 16%	4/4 = 100%	4/4 = 100%	
4. Supports with non-licensed professionals (i.e., tutors, coaches, religious leaders, tribal elders)	1/7 = 14%	1/1 = 100%	1/1 = 100%	
5. Plans for adult transition	6/8 = 75%	5/6 = 83%	3/6 = 50%	
Educational				
1. Initiation of special education services	8/13 = 62%	7/8 = 88%	8/8 = 100%	• School resistant to implementing recommendations • Lack of school resources • Lack of teacher compliance in implementing
2. Changes to current education program (e.g., addition of therapies, counseling, social skills group)	19/38 = 50%	19/19 = 100%	16/19 = 84%	
3. Instructional or behavioral supports in the classroom	34/48 = 71%	34/34 = 100%	28/33 = 85%	
Total	155/297 = 52%	145/154 = 94%	119/151 = 79%	

*Recommendations reported to be "sort of helpful" or "very helpful" were grouped together as "helpful."

neurodevelopmental disorders, or a disruptive behavior disorder (all p >.05). There was a greater proportion of participants whose children were given psychiatric diagnoses (52.7%) than nonparticipants whose children were given psychiatric diagnoses (31.0%) ($t(169) = 2.77$, $p = .006$, $d = .45$). There was also a greater proportion of

Spanish-speaking participants (32.1%) than Spanish-speaking nonparticipants (9.3%) ($t(159) = 3.78$, $p < .001$, $d = .58$).

Procedure

For those parents who answered the phone and agreed to participate, a phone interview was scheduled for a later date within the following two weeks. This was done to allow time for one of two licensed pediatric neuropsychologists to review the child's evaluation and create an individualized script for the phone interview. Recommendations were coded into three broad categories: medical, home/community, and school and then further coded into subcategories. Guidelines were developed to maintain consistency in coding and script development, with collaboration occurring between the two pediatric neuropsychologists, as needed (see Appendix). Participants who were bilingual (Spanish/English) or primarily Spanish-speaking were contacted by a bilingual (Spanish/English) research assistant. A certified translator assisted in translating scripts from English to Spanish. To verify the accuracy of translations, a translation-back-translation process was used for a portion of Spanish-speaking participants. To complete this process, a bilingual psychometrician/qualified interpreter assisted in translating the script into Spanish, a bilingual pediatric neuropsychologist translated it back into English, and the study co-investigators reviewed the scripts to verify that the original English script and the back-translated script were consistent. In completing this process, no significant discrepancies were identified.

After verbal consent was obtained, research assistants asked participants whether each recommendation was implemented (e.g., "Per the report recommendations, did you obtain psychotherapy services to address difficulties with anxiety and depression?"). If the recommendation was implemented, participants were asked if the recommendation was helpful ("Did you find this recommendation not helpful, sort of helpful, or very helpful?"). If the recommendation was not implemented, participants were asked why they did not implement the recommendation and given the opportunity for an open-ended response. Next, participants were asked whether the report was understandable, whether a copy of the report was provided to the child's school, and whether the report was helpful in attaining services. Participants were then provided the opportunity to share additional comments. Diagnoses and medical conditions, as well as additional child/participant/family demographic information, were gathered from the neuropsychological report and/or child history questionnaire by one of two pediatric neuropsychologists. Demographic information gathered in this study included: participant information (sex, age, race/ethnicity, language preference, level of education), family information (household income), and child information (sex, age, grade, race/ethnicity, language preference).

Data analysis

The main analyses sought to determine the proportion of recommendations implemented overall and for each recommendation type (medical, home/community, and school). These proportions were calculated by dividing the number of recommendations implemented by the number of recommendations given. For many of the exploratory analyses examining differences in recommendation implementation among participants, the independent variable was one of a number of demographic variables (e.g., household income, race/ethnicity, etc.), and the dependent variable was the proportion of recommendations implemented by the participant. These exploratory analyses were conducted using independent samples t-tests because of the categorical nature of the available demographic information (see study limitations). A chi-square test of independence was used to evaluate independence of demographic variables. Because of the limits of the demographic data gathered, a single "cultural" factor (e.g., Hollingshead, 1975; Nakao & Treas, 1992) was not constructed. A multiple-way ANOVA was used to determine whether the proportion of recommendations implemented by each participant was dependent on the main effects and/or interactions of multiple categorical demographic variables.

Results

Recommendation adherence and report effectiveness

After recommendations had been grouped according to script development guidelines, there were 297 recommendations in total among the 55 participants' reports (recommendations per report: $M = 5.40$, $SD = 2.21$, range = 1 to 11). Of the 297 recommendations, 82 (28%) pertained to medical intervention, 116 (39%) were intended for the home/community setting, and 99 (33%) were directed toward educational intervention or instruction (see Table 2). In total, 52% of recommendations were implemented. By category, 40% of medical recommendations, 53% of home/community recommendations, and 62% of school recommendations were implemented. Out of the 55 participants in the study, 31% of participants implemented one third of recommendations or fewer (with 9% implementing zero recommendations).

Among medical recommendations, only 35% of referrals to medical treatment providers were implemented. When implemented, however, the majority of these referrals to medical providers, such as referrals for neurology appointments, were deemed very helpful (82%) or sort of helpful (9%). Recommendations for consideration of adjusting medical treatment with established providers were implemented 58% of the time, with these recommendations typically deemed very helpful (64%) or sort of helpful (9%).

Within home/community recommendations, few participants implemented recommendations to contact advocacy organizations (16%) or non-licensed professionals (e.g., tutor; 14%). On the other hand, when given concrete strategies to implement at home, such as guidelines for sleep hygiene or to a set up a behavioral plan, the large majority of recommendations were implemented (87%). The majority of these concrete strategies were deemed very helpful (59%) or sort of helpful (34%).

Half (50%) of all recommendations for changes to current school-based programming, such as initiation of speech-language therapy, social skills groups, or counseling, were implemented. Recommendations for initiating special education services, such as creation of an Individualized Education Program (IEP), were implemented 62% of the time. When implemented, all of these recommendations were deemed either very helpful (74%) or sort of helpful (26%). Instructional or behavioral classroom accommodations were frequently implemented (71%). When implemented, all recommendations for classroom accommodations were deemed helpful (82% very helpful, 18% sort of helpful).

With regard to the report as a whole, 98% found the report understandable, 93% provided a copy to the school, and 73% found it helpful for attaining services.

Participant-reported barriers

Participant-reported barriers to recommendation implementation are shown in Table 2. Commonly cited barriers included lack of time, lack of resources (geographical and financial), ambivalence about the need to implement the recommendation, not remembering the recommendation, confusion about how to implement the recommendation, and resistance from schools and teachers. Lack of time (e.g., "we intend to, but she is one of [several] kids in our family," "have not had a chance to contact them, but I will") was the most commonly cited barrier to completing medical and home/community recommendations. Participants also commonly cited lack of available resources in the geographical area, lack of financial resources, problems accessing care due to long waitlists, and ambivalence regarding the need for the suggested intervention/medication. A few participants reported not recalling that certain home/community recommendations (e.g., self-study resources, referrals to advocacy organizations) were ever given, which could be either because they did not remember the recommendation from the feedback session and/or did not read the report with enough detail. Participants occasionally reported confusion about how to make medical appointments and/or confusion about how to access self-study resources (e.g., books). The most commonly reported barrier to completing school recommendations was resistance from the schools (e.g., "did not qualify because school did not consider patient to have delays in speech," "did not have cooperation from the teacher and the school," "the school did not accept your evaluation … said they have to do their own evaluation").

Differences in recommendation adherence by participant/patient factors

Participants in families with income greater than \$41,000 implemented a greater proportion of recommendations relative to families with income less than or equal to \$41,000 ($t(49) = 2.47$, $p = .017$, $d = 0.73$). When broken down by recommendation type (medical, community/home-based, or school), higher income families implemented a greater proportion of medical recommendations ($t(35) = 2.62$, $p = .013$, $d = .88$) but not community/home-based ($t(47) = 1.46$, $p = .152$, $d = .44$) or school recommendations ($t(44) = 1.04$, $p = .303$, $d = .32$). There was a trend suggesting greater recommendation implementation in participants who identified as non-Hispanic White versus participants of ethnic/racial minority backgrounds, though this was not significant ($t(50) = 1.98$, $p = .053$, $d = .59$). There was also a trend for participants with greater than a 12th grade education to show greater recommendation implementation than participants with a 12th grade education or less, though this was not significant ($t(52) = 1.76$, $p = .084$, $d = .48$). There were no significant differences in implementation based on preferred language (Spanish and English) ($t(53) = 0.71$, $p = .479$, $d = .21$).

Proportion of recommendations implemented was not correlated with number of diagnoses given ($r = .22$, $p = .114$) or number of recommendations given ($r = .14$, $p = 0.294$). There was no difference in recommendation implementation rate based on sex of the child ($t(53) = 0.92$, $p = .360$, $d = .25$), and child age was not significantly correlated with recommendation implementation rate ($r = .08$, $p = .558$). Participants whose children were given an ADHD diagnosis implemented a greater proportion of recommendations than participants whose children did not receive an ADHD diagnosis ($t(53) = 2.88$, $p = .006$, $d = .78$). There were no other differences in recommendation implementation based on diagnosis (all $p > .05$). There was no significant difference in demographics or number of report recommendations given between those with or without an ADHD diagnosis (all $p > .05$).

As has been shown in the literature (Reeves, Rodrigue, & Kneebone, 2016), none of the most salient demographic variables (family income, education, race/ethnicity) was independent of one another (family income and education, $\chi2$ (1, $N = 51$) $= 8.094$, $p = .004$; family income and race/ethnicity, $\chi2$ (1, $N = 49$) $= 7.871$, $p = .005$; education and race/ethnicity, $\chi2$ (1, $N = 52$) $= 6.432$, $p = .011$). For example, those with high family income tended to have higher education (85% versus 59% in the overall sample) and identify as non-Hispanic White (60% versus 35% in the overall sample). When all three demographic variables were included in a multiple-way ANOVA with implementation percentage as the dependent variable, the overall ANOVA was not significant, there was no main effect of any variable on recommendation implementation, and there were no significant interaction terms (all $p > .05$). Thus, differences in recommendation implementation noted between demographic groups (e.g., difference in implementation between high- and low-income families) may have been driven by a number of interrelated factors (rather than family income alone).

Discussion

We measured parent-reported implementation of neuropsychological report recommendations and sought to understand barriers to implementation. To our knowledge, this study was the largest empirical investigation exploring implementation of recommendations in a pediatric neuropsychological sample. The sample was culturally, linguistically, and economically diverse and included children with a wide range of medical, psychiatric, and neurodevelopmental diagnoses. Though the sample composition was unique to the location of the study, the sample characteristics support its generalizability to pediatric neuropsychological practice. Participants reported implementing 52% of recommendations overall, similar to the 41 to 48% that has been reported in other studies (Cheung et al., 2014, Quillen et al., 2011). By category, participants implemented 40% of medical, 53% of home/community, and 62% of school recommendations.

Of the many types of recommendations given, implementation rates for referrals to medical providers (35%), contacting advocacy organizations (16%), and beginning work with non-licensed professionals (14%) were among the lowest. In contrast, concrete strategies for participants to implement at home (87%) and recommendations for school accommodations (71%) were among the highest. Of note, though more than half of the recommendations were implemented in total, approximately 33% of the sample implemented fewer than one third of the recommendations in the report. Commonly cited barriers included lack of time, lack of resources (geographical and financial), ambivalence about the need to implement the recommendation, not remembering the recommendation, confusion about how to implement the recommendation, and resistance from schools and teachers. Though not explicitly stated by participants, it is also possible that some of the least-followed recommendations (referrals to medical providers, advocacy organizations, non-licensed professionals) were difficult to implement because making appointments and seeking help from professionals can be anxiety-provoking and overwhelming (Arieli & Tamir, 2018). In accordance with previous research (Bodin et al., 2007; Farmer & Brazeal, 1998; Kirkwood et al., 2017; Mahoney et al., 2017; Postal et al., 2018; Pritchard et al., 2014), our study identified that almost all participants found the neuropsychological report understandable and gave a copy to the school, while about three fourths of participants found the report helpful in attaining services.

This is the first study, to our knowledge, that has explored differences in neuropsychological recommendation implementation based on participant/patient factors (e.g., demographics). Most neuropsychologists, including those whose patients were included in this study, value cultural responsiveness and strive to be conscientious toward the uniqueness of their patients and their families. Still, despite clinicians' best intentions for their patients, results of this study show that those with low household income tended to implement a significantly smaller proportion of report recommendations than those with higher household income. Additionally, there was a trend suggesting that participants with twelve years of education or less and who identified as a member of an ethnic/racial minority group were less likely to implement recommendations. This trend is consistent with barriers identified by individuals from ethnic/racial minority backgrounds when accessing care (Nelson, 2002; U.S. Department of Health and Human Services (USDHHS), 2001). There was no difference in implementation between participants who only or primarily spoke Spanish and those who spoke English. This finding may be related to the fact that many of these participants were evaluated by Spanish-speaking clinicians or that all Spanish-speaking participants received a brief summary of results and recommendations in Spanish along with the English report. Additionally, Spanish resources and/or services are common in the part of the country in which the study was conducted, potentially increasing access to services.

The difference in recommendation implementation between high- and low-income families was most prominent for medical recommendations, extending previous findings of lower treatment implementation in those of low socioeconomic status in medical settings (Knapp et al., 2006) to neuropsychology. The reason for this distinction could be related to the costs of medical treatment and/or the costs of travel to medical appointments, both barriers identified by participants. Other potentially associated factors not measured in this study, such as personal beliefs, may also have interfered (e.g., some participants reported a dislike or distrust of medication). There was no significant difference between any of the demographic groups examined in rates of implementation of home/community or school-specific recommendations. Given that more than 90% of participants provided a copy of the report to the school, whether or not school recommendations were implemented may have been more dependent on school and personnel characteristics than parental characteristics.

As previous literature has shown, variables such as family income, years of education, and race/ethnicity are interrelated (Reeves et al., 2016), and our exploratory findings suggest that no one demographic variable was uniquely predictive of recommendation implementation when all were considered together. Therefore, while results did suggest significant demographic group differences in recommendation implementation (between high and low income participants), these findings were exploratory and should be considered preliminary. Future investigation using more detailed and comprehensive demographic data would likely help to improve delineation of the effects of all of these sociocultural factors on recommendation implementation.

Additionally, participants whose children received an ADHD diagnosis implemented a significantly greater proportion of recommendations than participants whose children were not diagnosed with ADHD. Given that treatments for ADHD have been well-researched, providers may be clearer and more direct in explaining treatment options for ADHD than when making other recommendations. In addition, parents in high distress due to the behavior problems often associated with ADHD may be more likely to implement recommendations with urgency.

Limitations

There are limitations to be considered in this study. First, while the pediatric neuropsychological report has many intended audiences (i.e., the referring provider, parent, and school system), participants were self-selected, and the study relied exclusively on parent report. Thus, the study is prone to problems with response rate and bias in survey-based research (see Baruch & Holtom, 2008; Davern, 2013). Additionally, the method of interviewing participants by phone may have induced more socially desirable response patterns than if participants had completed anonymous paper-and-pencil questionnaires (Podsakoff, MacKenzie, Lee, & Podsakoff, 2003), as some participants may have felt that admitting to not implementing recommendations reflects poorly on them (Bender, Milgrom, Rand, & Ackerson, 1998). Because the sample was self-selected, participants who were willing to participate in the study may have been those who were more likely to implement recommendations, potentially resulting in overestimates. However, overall implementation rates were similar to previous studies (e.g., Cheung et al., 2014), in which participants were also self-selected.

Second, sample characteristics could have influenced results. Thirty percent of parents initially contacted by phone completed the study, a response rate consistent with prior phone-based research in community samples (Sinclair, O'Toole, Malawaraarachchi, & Leder, 2012). The 30% of parents who completed the study did not differ from the 70% who did not complete our study in many ways, though the sample of participants did include a higher proportion of 1) Spanish-speaking parents and 2) parents of children with psychiatric disorders than in non-participants. These sample characteristics could potentially have driven either increases or decreases in overall rates of recommendation implementation, though we found that neither of these factors significantly contributed to overall recommendation implementation.

Third, recommendations were grouped according to a set of pre-determined guidelines (see Appendix). For example, a recommendation that included a list of five classroom accommodations was considered one recommendation to reduce inflation of results (i.e., one recommendation completed, rather than five separate recommendations completed) and also because participants may have limited knowledge of accommodations implemented at school. However, this could also have led to misleading numbers in cases in which, for instance, only one or two of the five accommodations were implemented (and this still counted as a completed recommendation). Using a coding/categorization method has been done in other similar studies (Cheung et al., 2014; Quillen et al., 2011) and would have been difficult to avoid; nevertheless, the method could have influenced reported implementation rates. Notably, with regard to examination of differences by participant/parent characteristics, recommendation grouping was consistent among all participants and should not have influenced any certain demographic group more than another.

Fourth, there is the possibility that provider-related factors influenced results. Providers all have different ways to communicate recommendations with patients, both during feedback sessions and in their reports. There also may be differences among providers in the number of recommendations given, types of recommendations given, and practicality of recommendations. For this study, many of the Spanish-speaking participants completed their child's evaluation with a particular Spanish-speaking pediatric neuropsychologist. Thus, there is a possibility that this neuropsychologist's particular style and/or methods influenced the results differentially (whether in a positive or negative way).

Fifth, there were limitations in the available data. For example, as indicated in the Methods section, participants reported household income categorically rather than continuously, which limited options for analysis. Additionally, though the data included more participants than in previous studies, the sample size was modest nevertheless. Thus, delineating clear differences between demographic groups was difficult. Though participants were culturally, linguistically, and economically diverse, all participants were gathered from a single clinic. Therefore, the generalizability of results is reduced. Performing similar studies in other geographic regions would help to account for differences among participants and providers in different regions.

Future directions

Future research is needed to assess whether the present findings are replicable and to expand our understanding of barriers that may affect recommendation implementation. Investigating potentially relevant factors, such as geographical area (e.g., rural versus urban) and provider factors (e.g., provider involvement in school meetings, provider feedback style, length of feedback sessions) may also be useful. Building on this research, consideration of how to make more practical recommendations and how to improve implementation will be a fruitful area of future study. Future research may examine specific strategies for improving recommendation implementation, particularly in at-risk populations (i.e., parents with higher levels of barriers). Such strategies may include following up with patients after report completion, communicating treatment recommendations with referral sources or teachers so that they can facilitate recommendation implementation (with appropriate authorizations from parents to do so), and closely considering the unique barriers a family may face when developing recommendations.

Disclosure statement

The authors report no conflict of interest.

This manuscript has not been published elsewhere and has not been submitted simultaneously for publication in another source.

Data availability statement

The data that support the findings of this study are available from the corresponding author, JE, upon reasonable request.

References

Arieli, D., & Tamir, B. (2018). Patients' stories of encounters with doctors: Expectations and anxieties. *Patient Experience Journal*, *5*(1), 27–34. doi:10.35680/2372-0247.1253

Austin, C. A., Gerstle, M., Baum, K. T., Bradley, A., LeJeune, B., Peugh, J., & Beebe, D. W. (2019). Evolution of parental knowledge and efficacy across the pediatric neuropsychological evaluation process. *The Clinical Neuropsychologist*, *33*(4), 743–759. doi:10.1080/13854046.2018.1497206

Baruch, Y., & Holtom, B. C. (2008). Survey response rate levels and trends in organizational research. *Human Relations*, *61*(8), 1139–1160. doi:10.1177/0018726708094863

Bender, B., Milgrom, H., Rand, C., & Ackerson, L. (1998). Psychological factors associated with medication nonadherence in asthmatic children. *Journal of Asthma*, *35*(4), 347–353. doi:10.3109/02770909809075667

Bodin, D., Beetar, J. T., Yeates, K. O., Boyer, K., Colvin, A. N., & Mangeot, S. (2007). A survey of parent satisfaction with pediatric neuropsychological evaluations. *The Clinical Neuropsychologist*, *21*(6), 884–898. doi:10.1080/13854040600888784

Cheung, L. L., Wakefield, C. E., Ellis, S. J., Mandalis, A., Frow, E., & Cohn, R. J. (2014). Neuropsychology reports for childhood brain tumor survivors: Implementation of recommendations at home and school. *Pediatric Blood & Cancer*, *61*(6), 1080–1087. doi:10.1002/pbc.24940

Davern, M. (2013). Nonresponse rates are a problematic indicator of nonresponse bias in survey research. *Health Services Research*, *48*(3), 905–912. doi:10.1111/1475-6773.12070

DiMatteo, M. R. (2004). Social support and patient adherence to medical treatment: A meta-analysis. *Health Psychology*, *23*(2), 207–218. [Mismatch] doi:10.1097/01.mlr.0000114908.90348.f9

Ellenberg, L., Liu, Q., Gioia, G., Yasui, Y., Packer, R. J., Mertens, A., … Zeltzer, L. K. (2009). Neurocognitive status in long-term survivors of childhood CNS malignancies: A report from the Childhood Cancer Survivor Study. *Neuropsychology*, *23*(6), 705–717. doi:10.1037/a0016674

Farmer, J. E., & Brazeal, T. J. (1998). Parent perceptions about the process and outcomes of child neuropsychological assessment. *Applied Neuropsychology*, *5*(4), 194–201. doi:10.1207/s15324826an0504_4

Gerber, B. S., Cho, Y. I., Arozullah, A. M., & Lee, S. Y. D. (2010). Racial differences in medication adherence: A cross-sectional study of Medicare enrollees. *The American Journal of Geriatric Pharmacotherapy*, *8*(2), 136–145. doi:10.1016/j.amjopharm.2010.03.002

Hollingshead, A. B. (1975). *Four factor index of social status*. New Haven, CT: University Press.

Jin, J., Sklar, G. E., Oh, V. M. S., & Li, S. C. (2008). Factors affecting therapeutic compliance: A review from the patient's perspective. *Therapeutics and Clinical Risk Management*, *4*(1), 269. doi:10.2147/TCRM.S1458

Kirkwood, M. W., Peterson, R. L., Baker, D. A., & Connery, A. K. (2017). Parent satisfaction with neuropsychological consultation after pediatric mild traumatic brain injury. *Child Neuropsychology*, *23*(3), 273–283. doi:10.1080/09297049.2015.1130219

Knapp, M., Funk, M., Curran, C., Prince, M., Grigg, M., & McDaid, D. (2006). Economic barriers to better mental health practice and policy. *Health Policy and Planning*, *21*(3), 157–170. doi:10.1093/heapol/czl003

Mahoney, J. J., Bajo, S. D., De Marco, A. P., Arredondo, B. C., Hilsabeck, R. C., & Broshek, D. K. (2017). Referring providers' preferences and satisfaction with neuropsychological services. *Archives of Clinical Neuropsychology*, *32*(4), 427–436.

Nakao, K., & Treas, J. (1992). *The 1989 socioeconomic index of occupations: Construction from the 1989 occupational prestige scores*. Chicago, IL: National Opinion Research Center.

Nelson, A. (2002). Unequal treatment: Confronting racial and ethnic disparities in health care. *Journal of the National Medical Association*, *94*(8), 666–668.

Podsakoff, P. M., MacKenzie, S. B., Lee, J. Y., & Podsakoff, N. P. (2003). Common method biases in behavioral research: A critical review of the literature and recommended remedies. *Journal of Applied Psychology*, *88*(5), 879–903. doi:10.1037/0021-9010.88.5.879

Postal, K., Chow, C., Jung, S., Erickson-Moreo, K., Geier, F., & Lanca, M. (2018). The stakeholders' project in neuropsychological report writing: A survey of neuropsychologists' and referral sources' views of neuropsychological reports. *The Clinical Neuropsychologist*, *32*(3), 326–344. doi:10.1080/13854046.2017.1373859

Pritchard, A. E., Koriakin, T., Jacobson, L. A., & Mahone, E. M. (2014). Incremental validity of neuropsychological assessment in the identification and treatment of youth with ADHD. *The Clinical Neuropsychologist*, *28*(1), 26–48. doi:10.1080/13854046.2013.863978

Quillen, J., Crawford, E., Plummer, B., Bradley, H., & Glidden, R. (2011). Parental follow-through of neuropsychological recommendations for childhood-cancer survivors. *Journal of Pediatric Oncology Nursing*, *28*(5), 306–310. doi:10.1177/1043454211418668

Reeves, R., Rodrigue, E., & Kneebone, E. (2016). *Five evils: Multidimensional poverty and race in America*. Washington, D.C., Economic Studies at Brookings Report.

Roberts, M. C., Wheeler, S. B., & Reeder-Hayes, K. (2015). Racial/ethnic and socioeconomic disparities in endocrine therapy adherence in breast cancer: A systematic review. *American Journal of Public Health*, *105*(S3), e4–e15. doi:10.2105/AJPH.2014.302490

Scheel, M. J., Hanson, W. E., & Razzhavaikina, T. I. (2004). The process of recommending homework in psychotherapy: A review of therapist delivery methods, client acceptability, and factors that affect compliance. *Psychotherapy: Theory, Research, Practice, Training*, *41*(1), 38–55. doi:10.1037/0033-3204.41.1.38

Sinclair, M., O'Toole, J., Malawaraarachchi, M., & Leder, K. (2012). Comparison of response rates and cost-effectiveness for a community-based survey: Postal, internet and telephone modes with generic or personalised recruitment approaches. *BMC Medical Research Methodology*, *12*(1), 132. doi:10.1186/1471-2288-12-132

U.S. Department of Health and Human Services (USDHHS). (2001). *Mental health: Culture race, and ethnicity—A supplement to mental health: A report of the surgeon general*. Rockville, MD: Author.

Appendix

Method for Coding Phone Scripts: Reports were reviewed by one of two pediatric neuropsychologists, who then created a phone script adhering to coding guidelines below. Guidelines were created due to the complexity/length of recommendations provided in the neuropsychological report and to improve consistency among neuropsychologists. Recommendations that were clearly a suggestion to continue services or accommodations that were in place at the time of the evaluation were not included in scripts. For example, if the recommendation was to *continue* in psychotherapy, this was not included in the study, because the patient was already receiving that service. The neuropsychologists used information from the background sections to further increase the likelihood that only new recommendations were included. Recommendations were grouped together or coded individually based on two factors. First, categories were created based on the types of recommendations most typically included in our reports. Second, parental knowledge of whether recommendations were implemented was also considered; for example, given that parents were unlikely to know every school accommodation that was being implemented, we asked whether any school accommodations were being implemented. Following a fidelity check, 1% of recommendations were dropped entirely as they did not fit into a pre-determined category, and 1% of recommendations were reduced from two questions to one question to comply with guidelines below.

Recommendations that were grouped together were deemed to be successfully implemented if at least one of the recommendations was followed.

- Example: Self-study resources (2b) - Did you review any of the websites listed in the report, such as A, B, or C (yes/no).

In contrast, some recommendations were coded individually.

- Examples: Medical referrals (1a): Did you meet with a psychiatrist for medication management (yes/no)? Did you meet with a neurologist due to your medical condition (yes/no)?

Three broad categories created were as follows: 1) medical, 2) community/home-based, and 3) educational.

	Was each recommendation coded individually?	# of recommendations written into phone scripts
Major Category #1: Medical		
1a) referrals to non-established licensed medical treatment providers (e.g., psychotherapists, neurologists, etc.)	Yes	Unlimited
1b) suggestions for considering adjusting medical treatment with established providers (e.g., medication review with current psychiatrist)	Yes	Unlimited
Major Category #2: Community/Home-Based		
2a) cognitive or behavioral supports (e.g., specific strategies to improve functioning)	No	1 recommendation maximum for each of the following subcategories: a) cognitive/academic, b) behavioral, c) emotional, and d) medical concerns
2b) self-study resources (e.g., books, websites)	No	1 recommendation maximum
2c) advocacy organizations (e.g., state parent educational advocacy groups, autism advocacy organization, etc.)	No	1 recommendation maximum for each separate concern. For example, separate concerns could include educational advocacy and autism advocacy.
2d) engagement in supports with non-licensed professionals (e.g., non-licensed tutors, coaches, religious leaders, tribal elders)	No	1 recommendation maximum
2e) plans for adult transition (e.g., Division of Vocational Rehabilitation, applying for a long-term waiver)	No	1 recommendation maximum
Major Category #3: Educational		
3a) initiation of special education services (e.g., creating an Individualized Education Program)	No	1 recommendation maximum
3b) distinct changes to current educational program (e.g., addition of therapies, social skills groups, increased time in self-contained settings)	Yes	Unlimited
3c) instructional or behavioral accommodations (e.g., specific strategies to improve functioning)	No	1 recommendation maximum