

A Teleneuropsychology Consultation Service Model for Children with Neurodevelopmental and Acquired Disorders Residing in Rural State Regions

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Abstract

Objective: Accessing neuropsychological services, which are often centralized in urban regions, poses unique challenges to children and families in rural regions. In 2017, urban neuropsychologists and a pediatrician practicing in a rural region of New Mexico started to develop a teleneuropsychology (TeleNP) consultation service model to efficiently triage and determine a clinical course of action. This pilot project, aimed at expanding clinical access to specialized pediatric services in rural areas, evolved over the course of 2 years prior to the coronavirus disease 2019 pandemic.

Method: Providers earned the trust of the local community, gained understanding of pertinent sociocultural factors, and acquired knowledge of the clinical and educational concerns for the children residing in the rural community. The application of a culturally informed approach that highlights the importance of community participation and collaboration steered the decision to implement a TeleNP consultation model. By widening access to neuropsychology, this service helped to determine whether neuropsychological testing procedures were medically indicated.

Results: We summarize the distinct processes that needed to occur at each location to support the implementation of telemedicine. We propose a clinical service decision tree with specific criteria to help guide providers on how to triage cases in order to increase access to specialized healthcare.

Conclusion: The success of implementing a TeleNP consultation service hinges upon ongoing care coordination between providers, clerical staff, patients, and families with clear goals and expectations, maintenance of legal and ethical standards, and development of specific administrative and clinical processes supporting the use of TeleNP.

Keywords: Teleneuropsychology; Cultural Neuropsychology; Pediatrics; Telemedicine

Introduction

Healthcare disparities and issues of access are magnified in rural regions. The current paper describes the process and implementation of a teleneuropsychology (TeleNP) consultation service for children and families in a rural region of New Mexico. In collaboration with a rurally located pediatrician, pediatric neuropsychologists located in an urban medical clinic piloted a TeleNP consultation service model between October 2018 and December 2019 with the goal of providing expanded neuropsychological access to families with transportation barriers. New Mexico is the fifth largest U.S. state by land area and the sixth least densely populated. This combination of features means that a large proportion of residents live in underserved, and in many cases, poverty-stricken regions with little access to specialized tertiary care services, such as a neuropsychological assessment. Residents often must travel upward of 5–6 hr to obtain specialized services that are unavailable in their counties

of residence. These distances can be a direct barrier for families due to lodging, travel, and food expenses. The limited number of trained neuropsychologists who practice in rural areas is another significant barrier. At a national level, approximately only 8% of clinical neuropsychologists provide clinical services in rural areas and 11% serve a combination of both urban and rural areas (Sweet, Benson, Nelson, & Moberg, 2016). In October 2018, 8 of 10 pediatric neuropsychologists had practices in the largest urban community in New Mexico, and only 1 was bilingual (Spanish/English). Unfortunately, this poor access to services compounded with the lack of availability of providers perpetuates health disparities in rural states.

One year prior to implementation, the rural pediatrician and the urban neuropsychologists began discussing how a TeleNP consultation service could provide enhanced neuropsychological access to rural children with transportation barriers. Of note, the rurally located pediatrician had an established telemedicine service with the nephrology team at the same urban medical center and was interested in expanding telemedicine to include other specialized services. The pediatrician informed the neuropsychologists that many of their patients had significant barriers to traveling extended distances for medical services. Several children they intended to refer for neuropsychological evaluation were demonstrating significant behavioral dysregulation and developmental delays; thus, traveling the distance of 130 miles by car to the urban location would not be feasible for the families. Further, it was directly discussed that clinicians involved in the provision of neuropsychological services, whether provided in person or via telemedicine, would need to understand specific cultural and linguistic factors among their patients, such as the high prevalence of low health literacy and limited English proficiency (monolingual Spanish speakers). Also reviewed were the rural pediatrician's concerns that their patients were not receiving adequate educational services due to limited local resources and that their confidence in the school systems' ability to provide valid diagnostic evaluations was low. Based on months of conversations, the rural community requested the development of a telemedicine approach in neuropsychology to increase healthcare access and address their concerns regarding education and traveling barriers.

After a year of implementing this TeleNP consultation service, health concerns during the coronavirus disease 2019 (COVID-19) pandemic have led to use of personal protection equipment and social distancing measures during neuropsychological testing procedures in face-to-face settings. This practice, although important for mitigating the spread of infectious disease, may not be feasible for obtaining valid neuropsychological results in certain pediatric populations, such as children with significant behavioral dysregulation and developmental delays, or certain types of assessment, such as social communication abilities in the context of autism evaluations. Additionally, children and families with medical conditions that pose increased risk of negative health outcomes with COVID-19 may be reluctant and anxious about attending medical appointments in person, despite providers' use of safe practice guidelines. The feasibility of this TeleNP pilot project was necessarily dependent on the implementation of an innovated clinical service that was patient and community centered to address the specific needs of children living in rural New Mexico.

As discussed within current recommendations for TeleNP practice during the COVID-19 pandemic by the InterOrganizational Practice Committee (Bilder et al., 2020) and neuropsychologists previously (Bilder, 2011), neuropsychologists have a broad range of knowledge and competency that can be utilized for clinical services that do not necessarily include standardized, neuropsychological testing procedures. Parents of children with specific medical conditions have rated face-to-face consultation neuropsychology models as acceptable with high levels of satisfaction (Kirkwood, Peterson, Baker, & Connery, 2017). A review of telemedicine health research a decade ago found that the use of telemedicine for psychiatric diagnosis and treatment was promising with regards to patient satisfaction and concordance with face-to-face appointments (Richardson, Frueh, Grubaugh, Egede, & Elhai, 2009). Evidence-based practice telemedicine health guidelines from the American Telemedicine Association indicated evidence that video conference formats are accepted, useful, and valid in diagnostic situations (Grady et al., 2011). This may be enhanced by use of medical and school record review, prior standardized testing and/or behavior ratings, and contemporaneous behavior ratings in clinical settings. Similarly, as the use of telemedicine grows in the field of neuropsychology, researchers have found that, on average, many older adults (with and without cognitive impairment) find use of a videoconference format acceptable for completing neuropsychological testing procedures and do not express preference for in-person testing over the videoconference format (Parikh et al., 2013). Neuropsychological research with adult individuals has also indicated that beyond use of telemedicine for psychiatric consults, evidence is growing that many neuropsychological tests results obtained via videoconference are as reliable and valid as test results obtained in-person (Cullum, Hynan, Grosch, Parikh, & Weiner, 2014; Brearly et al., 2017). The importance of establishing rapport and a therapeutic alliance, being aware of nonverbal communication, and potential limitations of clinical assessments is heightened as neuropsychologists learn to conduct clinical services in this new video format. Telemedicine health guidelines have also indicated that successful implementation of telemedicine services is related to the clarity of recommendations and coordination of care with local providers and families (American Psychological Association, 2013).

Research aimed at understanding barriers to the implementation of telemedicine language assessments for children living in rural Australia suggested that both the children and families viewed the use of telemedicine positively and testing results using the videoconference format were similar to face-to-face sessions (Sutherland, Hodge, Trembath, Drevensek, & Roberts, 2016).

<u>Pediatrician/Rural Clinic</u>	<u>Neuropsychologist/Urban Clinic</u>
Referral	Scheduling in urban location
Legal documents (consent, medical release)	Review of medical and school information provided by rural clinic
Scheduling in rural location	Neurobehavioral status exam with patient and parent via video-conference call
Medical and school records	Clinical decision-making regarding need for neuropsychological testing
Review of neuropsychological report with patient	Neuropsychological report with recommendations based on results that may or may not include standardized testing
Business administration and information and technology (IT) support	Feedback session with patient and parent via videoconference to review recommendations
	Business administration and IT support
	Billing of neuropsychological procedures

Fig. 1. Rural and urban clinic coordination.

The researchers found that use of commercial grade technology and increased communication between providers and families was essential to this telemedicine service. Therefore, to implement a TeleNP consultation service in New Mexico, multiple preimplementation meetings were held between the rural pediatrician and the urban neuropsychologists to discuss patient and community needs, computer equipment, privacy and consent, and scheduling and clinic processes. In 2018, challenges related to obtaining insurance payments for TeleNP included significant restrictions to neuropsychological evaluation procedures (e.g., insurance payments only for the neurobehavioral status exam, Current Procedural Terminology (CPT) code 96116). Patient-specific characteristics, such as familiarity and comfort with using computers, were also considered for each child referred to the TeleNP consultation service. Of utmost importance to the rural pediatrician was improving the educational experience afforded to their patients. Many of their patients with behavioral disorders were functioning poorly at school, and it was not clear to the neuropsychologists based on available background information whether all of these patients met insurance-based requirements for establishing medical necessity for neuropsychological testing procedures. Jointly, the clinicians considered the possibility that a consultative-type neuropsychological service that included use of extensive record review, behavioral ratings, neurobehavioral status exam, and written report with clear school-based recommendations could be utilized in the future to improve educational outcomes for these children. The following sections outline the process for developing and piloting a videoconference TeleNP consultation service model and the lessons learned through this process so other neuropsychologists can consider implementing this model of practice.

Methods

Providers at the rural and urban medical clinics determined distinct processes to occur at each location to support the implementation of unique factors related to telemedicine (Fig. 1). For example, although patients were being evaluated by a neuropsychologist located at an urban clinic, the family needed to arrive at the rural clinic and “check-in” with their pediatrician for the neuropsychology appointment. Together, providers determined where telemedicine equipment would be located to ensure compliance with Health Insurance Portability and Accountability Act regulations, what technology to utilize, how to simulate in-person clinician behavior during a videoconference, how services would be billed, which clinic would be responsible for types of patient communication, and who would obtain current behavioral ratings, as well as signatures on legal documents, such as consent to use of telemedicine and release of school records. As part of piloting the TeleNP consultation service, the processes in each location were reviewed repeatedly by the team in order to streamline the feasibility.

Neuropsychologists working to improve access to specialized care for rural patients have a clear ethical responsibility to consider principals of justice. All patients need to receive equitable treatment and access for the benefit and care of the patient and their family. Iterations of the clinical process led to the development of a decision tree that addressed ethical concerns raised by the neuropsychologists at the urban clinic (Fig. 2). Issues of access, medical necessity of testing procedures, and health literacy were carefully considered. First, we discussed that prioritized scheduling of neuropsychological testing procedures for telemedicine patients may lead to unfair access relative to patients waiting for in-person testing at the urban clinic. Consequently,

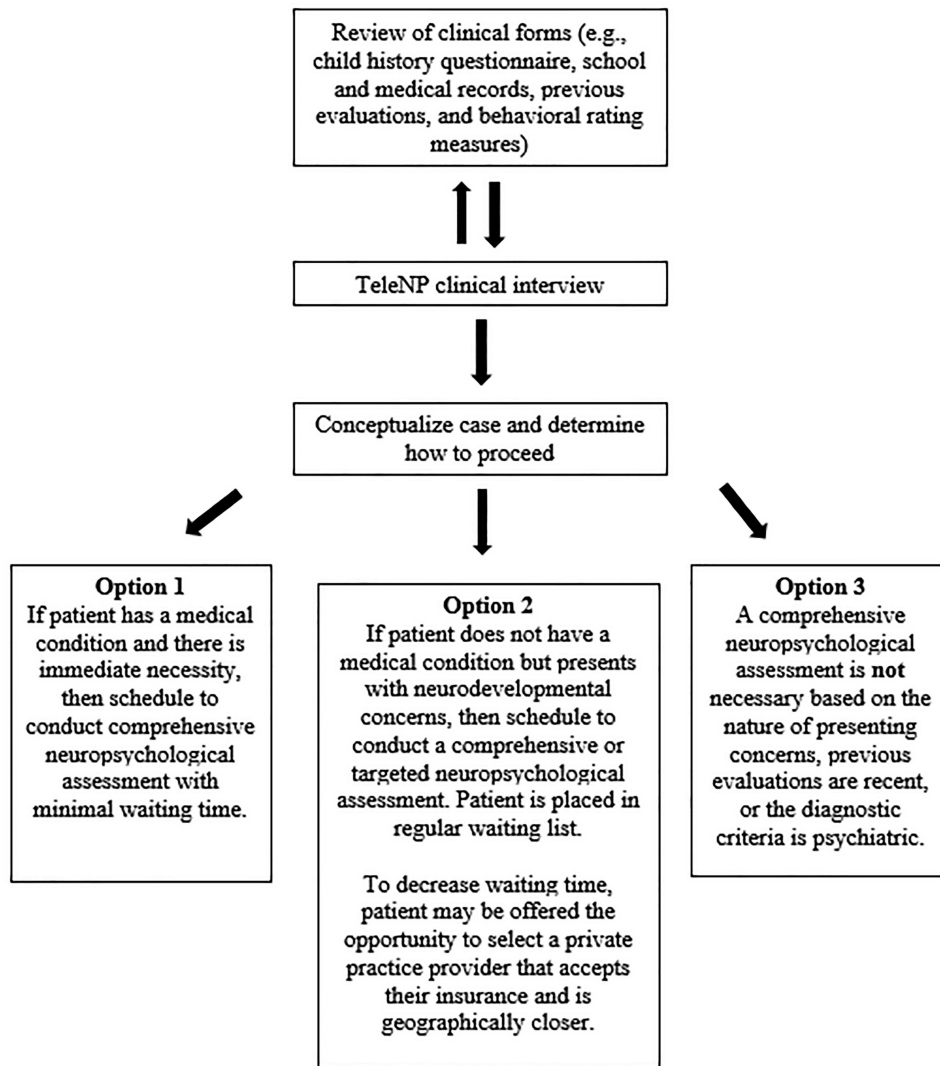


Fig. 2. Clinical service decision tree to determine if neuropsychological testing is needed.

we created Options 1 and 2 for scheduling patients with necessity due to medical and neurodevelopmental conditions that affected functioning. Second, we recognized that many of the referrals from the rural practice were for patients with significant behavioral concerns, who may or may not need standardized testing. Completing unnecessary testing procedures may do more harm than good for patients and their families, especially those with additional burdens of extensive travel and limited financial resources. Therefore, we decided for all referred patients to complete a telemedicine consultation/clinical interview upon referral to determine if neuropsychological testing was necessary and added Option 3 of the decision tree (Fig. 2). For patients and families with low health literacy or limited English proficiency, we appreciated that patients and families from culturally and linguistically diverse backgrounds may be limited in their understanding of how neuropsychological testing may be beneficial for their child. Our patient communication aimed to be clear, concise, and with no technical jargon. Documents were available in English and Spanish, and recommendations and neuropsychological impressions were provided in Spanish when indicated. Thus, the TeleNP service model was developed to be centered in the delivery of culturally informed services.

Results

Twelve pediatric patients were referred for TeleNP consultation between December 2018 and September 2019. The mean age was 10 years with a range of 5–17. Eleven of the 12 patients were new referrals and 1 patient was referred for a reevaluation.

The majority ($n = 9$) were referred due to behavioral problems and others were patients with medical conditions and/or developmental delays.

Five of the 12 patients participated in the TeleNP consultation service (42% of referrals), including 1 bilingual (Spanish/English) patient. The remaining 7 patients did not complete the TeleNP consultation due to problems scheduling the initial appointment at the rural clinic (e.g., clinic staff reported being unable to contact the patient or the patient was scheduled but did not show up). One of the five patients seen completed an in-person clinical interview and in-person testing procedures at the urban medical clinic prior to the development of the clinical decision tree to address ethical concerns of inequitable access; thus, a videoconference was only utilized for the feedback session with this patient. For the TeleNP consultation and feedback sessions, the parent was asked to sit in the room with the child, who was seated in front of the computer but allowed to move as needed. By observation, all of the children demonstrated some degree of distractibility during the videoconferences. Of the four patients who were seen for TeleNP clinical interview, two presented with evidence for potential cognitive deficits and were determined to need follow-up neuropsychological testing services. Both patients completed testing procedures at the urban medical clinic, prior to the team identifying a trusted community neuropsychologist. To accommodate extended travel time, patients were granted a later appointment arrival time than usual (i.e., 10 a.m. instead of 9 a.m.). Two patients were not recommended for neuropsychological testing due to report or record of advanced cognitive and/or academic learning abilities obtained during the consultation. Similar to in-person evaluations, clinical reports were provided to the patients and the rural pediatrician for all individuals seen as part of the TeleNP consultation service. Reports included review of relevant background information, clinical observations, procedures, results (with or without testing data), case conceptualization, diagnosis, and specific recommendations to alleviate symptoms and optimize daily functioning.

Clinical service decision tree

Our culturally informed approach in the provision of clinical neuropsychological services highlights the importance of community participation and collaboration. Therefore, the clinical service decision tree evolved over the course of this pilot project to augment our ability to increase access given patient- and community-centered goals while maintaining professional ethics. In a broad sense, the neuropsychologists designed the clinical service decision tree to determine follow-up steps after conducting a TeleNP clinical interview (Fig. 2). Embedded within this process of medical decision-making is the fundamental concept that neuropsychologists are able to determine levels of medical acuity for neuropsychological testing procedures. Due to the extensive wait time of 6–8 months for an in-person pediatric neuropsychological evaluation at the urban medical clinic prior to piloting the telemedicine service, the neuropsychologists developed a priority scheduling system for children needing neuropsychological testing primarily for medical care (e.g., epilepsy treatment planning) as compared with children needing neuropsychological testing primarily for educational services (e.g., updating special education services). Over time in reviewing the clinical processes, the neuropsychologists determined that their ability to conceptualize each case and select an option was optimal when the clinical interview was complete and all relevant background information was received, including a clear referral question and medical history, school records, previous evaluations, and current behavioral ratings. Figure 2 illustrates the three possible decision tree options. When in doubt, the neuropsychologists consulted with each other to deliver equitable healthcare access. To optimize care coordination, the selected option was also reviewed with the pediatrician and in all cases; they were in agreement with the neuropsychologists' recommended follow-up steps.

The urban team selected Option 1 if the patient had a medical condition (e.g., epilepsy, tuberous sclerosis, or spina bifida) and a comprehensive neuropsychological assessment was deemed medically necessary for treatment and interventions. The urban medical setting reserved two in-person assessment days per month for these patients to ensure timely access to clinical services, such that all evaluation procedures would be complete within 2 months of referral. Urban providers chose Option 2 if the patient did not have a medical condition but had a significant history of neurodevelopmental concerns (e.g., learning, language, or attentional disorder) and a comprehensive assessment was necessary to document the need for special education services and other interventions. For Option 2, the patient was triaged to the regular waiting list (6–8 months) for in-person assessment at the urban neuropsychological clinic. Iterations of the clinical processes also led the neuropsychologists to review whether a neuropsychologist in private practice, located geographically closer to the family, could be an option for completing neuropsychological testing procedures. Given ethical concerns that not all neuropsychologists are similarly trained in the use of a culturally informed approach to clinical care, the neuropsychologists and pediatrician together identified neuropsychologists in private practice that demonstrated competence by history of education and practice in using this approach. Coordination with the pediatrician regarding the plan for in-person neuropsychological assessment also necessarily considered insurance and billing requirements given available insurance payers with the community neuropsychologist and that the interview and testing procedures could potentially be completed several months apart. Finally, the neuropsychologists recommended Option 3 if the patient did not require a comprehensive neuropsychological assessment at that moment due to the nature of the presenting

concerns, availability of recent, prior evaluations, or the diagnosis was mainly psychiatric (e.g., depressive disorder). All patients and families participated in a videoconference feedback session to review results (with or without standardized testing) and recommended follow-up steps. The clinical case was closed when a neuropsychological report or clinical summary was sent to both the pediatrician and caregiver of the patient; given the cultural and linguistic factors, all reports were written in the patient's preferred language (i.e., Spanish or English) with reduced technical jargon as well as clear, follow-up recommendations that had been previously discussed in the feedback session.

Ongoing communication with the rural pediatric provider and family was crucial throughout the overall process. However, we also recognized that communication and guidance with staff on clinical processes was essential for successful implementation. The rural and urban clinics, for instance, hired and designated bilingual (Spanish/English) administrative staff members at each location to specifically manage the TeleNP process and scheduling of patients upon determining that the additional burden of clerical work associated with telemedicine was not being adequately completed by the current administrative staff. The individual hired in the rural location was also expected to communicate with schools to collect special education services paperwork. The efficiency obtaining school records increased over the course of this pilot project as trust and communication improved between the clinical team and school staff.

Discussion

As clinicians, pediatric neuropsychologists are trained to apply scientific knowledge of brain–behavior associations in the context of developmental, social, and cultural factors to provide diagnostic impressions of and treatment recommendations for children with acquired and neurodevelopmental disorders. Traditionally, the provision of clinical neuropsychological services has occurred in direct, person-to-person contact. With technological advances, clinicians are now afforded an opportunity to provide neuropsychological services using telemedicine. Harder and colleagues shared the first pediatric study that indicated that home-based neuropsychological services may be valid, feasible, and acceptable for specific clinical populations with limitations due to medical conditions (Harder et al., 2020). The importance of recognizing the breadth of clinical services neuropsychologists can offer patients has increased during the COVID-19 pandemic given the physical distancing constraints for in-person clinical neuropsychological evaluations (Bilder et al., 2020). There is a nascent body of literature regarding the extent and manner for providing TeleNP consultation services. The implementation of TeleNP consultation service to address the needs of children residing in rural communities offers an opportunity to reduce the burden of travel for these families. Expanding clinical neuropsychological services to provide videoconferenced consultation can afford greater access to specialized care. However, continued research on patient outcomes is needed to investigate the manner and by what methods clinical neuropsychological services may lead to changes in symptoms and improved functioning for children with neurodevelopmental or acquired disorders.

As part of piloting, this TeleNP consultation service, the neuropsychologists planned for regular reviews of the clinical processes that included site visits and meetings with the pediatrician and staff at the rural medical clinic, meetings with neuropsychologists and clerical staff at the urban clinic, and verbal feedback from patients and families. Being open to learning new procedures and willing to change processes that are inadequate were deemed to be essential components for everyone involved in the implementation of this TeleNP consultation service. In this endeavor, the neuropsychologists learned that development of a clinical decision tree was essential to providing enhanced clinical access to rurally located children given the raised ethical concerns for inequitable treatment, as well as nonessential travel and financial burden. To make informed clinical decisions regarding testing needs, the neuropsychologists carefully considered available medical and school records, current behavioral ratings, and information gleaned from family report and observation during the consultation with the parent and child. Factors that complicated the neuropsychologists' ability to provide a valid, professional opinion from the consult service alone included low health literacy and behavioral problems during the videoconference. For example, it was suspected that observed communication difficulties with the caregiver during the videoconference may have been related to both low health literacy and increased distractibility due to the child's behavior. When available records included recent cognitive and behavioral test results gleaned from standardized measures, the neuropsychologists' ability to provide a valid, professional opinion was bolstered. This is not unlike traditional neuropsychological practice completed during in-person procedures. Using a TeleNP consult service to complete neurobehavioral status exams and make testing determinations has the potential to improve the efficiency for neuropsychological service, as well as provide access to children who may not need comprehensive testing but may benefit from professional diagnostic opinion with recommendations regarding medical and educational needs. Additional barriers that negatively affected this TeleNP consultation service included communication problems between clerical staff and patients (e.g., establishing a clear process for scheduling and billing services). The success of implementing a TeleNP consultation service necessarily includes ongoing care coordination between providers, clerical staff, patients, and families with clear goals and expectations, maintenance of legal and ethical standards, and development of specific administrative and clinical processes supporting the use of telemedicine.

This pilot project has limitations that are relevant for others who may implement this type of consultation model. As described throughout the paper, the main limitations we encountered were centered on access to equitable service and factors relevant to delivery care in a rural state with marked lack of resources and financial supports. The TeleNP consultation service model was limited by: available school resources to complete psychoeducational assessments for children, available financial resources and administrative support for telemedicine implementation at a specific clinical location, unavailability of digital testing and sociocultural factors contributing to inadequate home internet access for families, and long wait times for clinical neuropsychological service at the urban medical clinic due to limited number of clinical neuropsychologists to provide statewide services. However, the clinical decision tree and TeleNP consultation service model consider these limitations and aim to improve healthcare access within the cultural context and resources of New Mexico.

The reasons for some patients' difficulties with scheduling the initial consult appointment are generally unknown as we did not obtain details regarding this from the clerical staff at the rural clinic. Thereby, we are not aware of the reason why some families did not participate in the TeleNP consultation service. Some research has suggested that individuals from underrepresented groups do not perceive telemedicine as preferable to seeing a doctor in person and recognize distrust and discomfort about being around a camera (George, Hamilton, & Baker, 2012). The percent of patients that "show" versus "do not show" for in-person medical care at the rural clinic is unknown and, therefore, is not tracked and it is unknown whether use of a videoconference format negatively affected the family's willingness to participate. To address this limitation, significant efforts to improve scheduling included designating and training clerical staff on the TeleNP process, revising oral and written communications to third-grade reading level, and ongoing collaboration with the pediatrician regarding each patient's needs and concerns and how TeleNP could be beneficial. The cost-effectiveness of TeleNP is unknown due to billing errors by clerical staff that were discovered, but not resolved, by the neuropsychologists during this pilot project. The neuropsychologists worked with the finance department at the urban medical center to clarify billing requirements and optimize reimbursements prior to and during the implementation of this new service.

Strengths of this endeavor include considerations and modifications over time to address sociocultural factors specific to this rural community. Intentional and programmatic changes included hiring and/or designating bilingual (Spanish/English) clinicians and staff to support this service. Writing clinical reports in the patient's preferred language with a significant reduction in the use of technical jargon are intentional efforts that in turn reduce the negative effect of low health literacy. Further, the rural clinic had an established telemedicine program with the urban medical center to serve as a foundation to the development of this clinical expansion. Therefore, computer equipment, videoconference platform (Zoom.us), and telemedicine consent documents were available prior to initiating this TeleNP consultation service. The neuropsychologists also completed educational activities to learn how to effectively use videoconference for clinical interviews, such as how to simulate in-person behavior, reduce distractions, and maintain privacy.

The current COVID-19 pandemic mobilized neuropsychologists to explore different service delivery options to continue providing care to pediatric patients and families in the midst of in-person testing restrictions. Practice guidelines for TeleNP are evolving rapidly during the pandemic with growing evidence that patients view the use of telemedicine positively and that valid diagnostic impressions, as well as testing results are obtainable within some clinical populations (Bilder et al., 2020; Harder et al., 2020; Parikh et al., 2013; Sutherland et al., 2016). Thus, more neuropsychologists are inspired to think "outside the testing room" and determine when testing is immediately and medically necessary to provide services. The marriage of technology and neuropsychology increases the versatility of what can be offered to children and families in rural communities. Piloted and developed prior to COVID-19, this TeleNP consultation service model can now be implemented to facilitate triaging and increase equitable access to healthcare.

Conflict of Interest

None declared.

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