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Optimizing Neurocritical Care Follow-Up Through the Integration of Neuropsychology

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Abstract

BACKGROUND: Pediatric critical care survivors often suffer persisting multisystem health problems and are left with treatment needs that go unmet due to limits in current care models. We proposed that integration of neuropsychology into neurocritical care follow-up provides incremental benefit to the identification and treatment of persisting complications and reduction in co-morbidities.

BASIC PROCEDURES: The aims of this study were three-fold. First, we described pilot programs at two pediatric hospitals as models for implementing systematic follow-up care with interdisciplinary clinic teams consisting of critical care, neurology, and neuropsychology. Second, we described working models specific to neuropsychological service delivery in these programs. Third, we presented preliminary data from the first six months of one of the pilot programs in order to examine incremental benefit of neuropsychology in improving patient care and parent satisfaction.

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MAIN FINDINGS: A total of 16 patients (age range three to 17 years) were seen by neuropsychology within the first six months of the program. Results showed that integration of neuropsychology into follow-up care resulted in recommendations being made for services or concerns not already addressed in 81% of cases. Parents reported high satisfaction, endorsing the highest possible rating on 96% of all items. Parents reported that neuropsychological consultation improved their understanding and communication with their child, and helped them know what to expect from their child during postacute recovery.

CONCLUSIONS: The results of this pilot study suggest that integration of neuropsychology into neurocritical care follow-up programs contributes to parent satisfaction and may provide incremental benefit to patient care.

Keywords

Neuropsychology; Neurology; Neurocritical care; Outcome; PICS; Pediatric; Parent satisfaction

Introduction

Each year, thousands of children are admitted to a Pediatric Intensive Care Unit (PICU) for critical neurological illness and injury. Over the last 20 years, advances in neurocritical care have reduced mortality rates of children,[1] creating a pressing need for providers to consider the long-term outcomes and morbidities of these patients.[2] Indeed, survivors of critical care often suffer long-term impairments in physical, psychological, cognitive, emotional, and social domains, collectively termed the postintensive care syndrome (PICS). After discharge, these children are often left with substantial treatment needs that go unrecognized and unmet due to limits in our present care models. We propose that integration of clinical neuropsychology into interdisciplinary critical care follow-up will aid in improving patient care in pediatric survivors of neurocritical injury by identification and treatment of PICS and further reduction in comorbidities.

In this brief report, we present two service models for the integration of neuropsychology into interdisciplinary critical care follow-up programs with the goal of highlighting important overlapping components and offering a comparison of alternative approaches for implementation. Details of these models are based on current care delivery at two urban children's hospitals. We present preliminary data on the incremental benefit of neuropsychological screening within the neurocritical care follow-up program at one program.

Current standard

Neuropsychological assessment provides rich information identifying a child's individualized neurobehavioral strengths and weaknesses across multiple domains, and is critical in reaching treatment goals by guiding the development of specific evidence-based strategies to improve adaptive functioning in the presence of cognitive impairment. Neuropsychologists have specialized knowledge of brain-behavior relationships that can be of great service in providing information regarding postacute cognitive and behavioral changes, identifying patients at greatest risk of PICS, and guiding recommendations for

optimizing transition from postacute injury back to the community and school. Despite the high morbidities associated with many neurocritical injuries, comparatively few children receive inpatient rehabilitation or outpatient follow-up services.[3–7] Even fewer children with neurocritical injuries receive a neuropsychological evaluation following PICU admission.[3]

Typically, neuropsychology uses a consultation model whereby a patient is referred only after significant problems and changes have become apparent.[8] However, delaying evaluation until after a problem has gone unad-dressed or even worsened may increase the child's risk for additional psychosocial stressors and comorbidities (e.g., self-esteem, anxiety, and being misunderstood by caregivers and teachers). Indeed, there is some evidence that earlier identification may mitigate development of such complications.[9,10] Comprehensive neuropsychological evaluation, which can involve three to five hours of testing,[11] is impractical during the postacute phases of neurocritical injury due to factors such as patient fatigue and rapid neurocognitive gains early in the course of recovery, making test results relevant for a relatively brief period of time. These factors call for an alternative, abbreviated consultation model of neuropsychological service delivery. Abbreviated models for neuropsychological evaluation are uncommon,[8] although targeted models have begun to emerge in recent literature.[12] Providing systematic and focused neuropsychological consultation early in recovery can allow for early identification and treatment of specific concerns, thereby usurping the development of comorbidities related to neurocritical injury and optimizing outcome.

Sample models of integrated service delivery

We offer two pilot programs as models and starting points for implementation of systematic neurocritical care follow-up within a pediatric hospital setting. The pilot studies were conducted at Doernbecher Children's Hospital (DCH) and St. Louis Children's Hospital (SLCH); both of which are metropolitan academic-medical centers with active PICU departments treating a variety of medical and surgical conditions. DCH is a 145-bed tertiary children's hospital within Oregon Health & Science University located in Portland, Oregon (city population = 632,309; metropolitan area = 2.4 million[13]) with approximately 1300 PICU admissions annually. SLCH is a 250-bed tertiary children's hospital within Washington University School of Medicine (WUSM) located in St. Louis, Missouri (city population = 308,626; metropolitan area = 2.85 million[14]). SLCH has approximately 2000 PICU admissions per year. Table 1 presents a comparison of clinic structures.

Target populations for integrated neurocritical follow-up programs are children admitted to the PICU with an expectation of survival to hospital discharge, with a minimum length of PICU stay of one to two days. Critical care physicians perform a Functional Status Score assessment within 48 hours of admission (DCH), and again at hospital-discharge (DHC/SLCH). PICU staff screens census daily for eligible patients for enrollment into the program. Families are given a clinic pamphlet and receive in-person education about PICS and the child's diagnosis by PICU and/or Neurology staff. Social worker provides mental health support as needed during the PICU stay. Patients are seen inpatient by neuropsychology to document premorbid status and to provide recommendations for care prior to initial follow-up clinic. At the time of hospital discharge, the PICU team schedules

with the family an initial follow-up appointment with neurology and neuropsychology in the critical care outpatient clinic.

For initial follow-up appointment, patients and families return between four and six weeks postdischarge for both DCH and SLCH programs. Neuropsychology evaluates children between the ages of 2.5 and 18 years. Children younger than 2.5 years are referred to pediatric psychology for developmental assessment. Briefly, similarities between programs include team composition, patient populations, age ranges, and time of initial follow-up clinic from hospital discharge. The primary difference between programs is in the role of neuropsychology at initial follow-up visit. At DCH, the neuropsychologist sees all patients and provides consultation to the family through chart review and briefing from neurology. Patients who are determined by the neuropsychologist to be at risk for neurocognitive changes are scheduled for an outpatient neuropsychological evaluation occurring alongside a follow-up neurology appointment approximately four to six months post-PICU discharge.

In contrast, the program at SLCH includes brief neurocognitive testing conducted at four weeks postdischarge. Neuropsychology does not see all patients. Rather, neuropsychology and neurology meet in advance to determine which patients are at risk for neurocognitive impairment and schedule accordingly. The neuropsychological screening is not intended to obtain a robust neurocognitive profile, but to identify general cognitive compromise. Tests are selected based on sensitivity to brain injury and patient-specific factors (e.g., aphasia, hemiparesis). The caregiver completes the *Behavior Assessment Scale for Children, Third Edition* (BASC-3)[15] while the child is completing neurocognitive testing. BASC-3′s are accessed via an online link, administered on a tablet, and are immediately scored and printed for interpretation by neuropsychologist. The neuropsychologist scores the screening battery and meets with the family to take a brief history and provide feedback regarding neurocognitive testing and BASC-3 results. Children who have two or more scores falling 1.5 standard deviations below the mean are classified as having cognitive impairment[16] and scheduled for a comprehensive outpatient neuropsychological evaluation at an appropriate time interval. At conclusion of the initial follow-up appointment, parents are asked to complete an anonymous, validated parent satisfaction survey known as the Parent Experience of Assessment Scale[17] regarding their experience with the neuro-psychological consultation.

Follow-up neuropsychological evaluations are scheduled before the family leaves the clinic and usually far enough out such that there is no back-log or wait-time. The neuropsychologist tracks follow through of recommendations and provides ongoing support as needed to ensure smooth transition back to school and the community. At the comprehensive neuropsychological evaluation (four to six months after the initial one-month follow-up visit), the neuropsychologist monitors the patient’s recovery and adjusts recommendations accordingly.

Main Findings

The SLCH program captured 4.8% of the entire PICU population, with a 100% follow-through rate for patients who qualified. Five patients were less than 2.5 years of age, so were

not evaluated by neuropsychology, leaving 16 patients (age range three to 17 years) who were seen by both neurology and neuropsychology at the initial one-month follow-up visit. Preliminary outcome data illustrate incremental benefit for inclusion of neuropsychology in improving patient outcomes by identifying areas of concern and need for services in 81% of the patients. Nine patients (56%) were referred for follow-up comprehensive neuropsychological evaluation, eight of these nine kept their appointment. Additional details regarding outcome data are provided in Table 2.

Parents produced high satisfaction ratings on the Parent Experience of Assessment Scale, endorsing the highest possible rating on 96% of all items. Parents reported that the neuropsychological service added value to their child's care by improving parent-child communication, improving parents understanding of their child, and helping parents know what to expect from their child in the upcoming months.

In summary, these novel programs demonstrate methods by which neuropsychology can be integrated early in a child's postacute recovery to improve outcome after neurocritical injury. Inclusion of neuropsychological expertise, whether through consultation or implementation of brief neurocognitive screening, serves multiple purposes: (1) identify children at greatest risk for neurocognitive deficits; (2) facilitate determination of need for more comprehensive assessment; (3) identify areas of neurocognitive strength and weakness; (4) connect patients and families with necessary social-emotional support services; (5) guide school reintegration with appropriate recommendations; and (6) prepare parents to care for their children through early stages of recovery. These preliminary data also suggest that consultation with neuropsychology early in the postintensive care course may improve patient care by identifying areas of weakness and making treatment recommendations before such problems gain momentum in the child's life.

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Table 1.

Comparison of Clinic Structure Between DCH and SLCH

	OHSU DCH	**WUSM SLCH**
Referral system	Patients identified and referrals placed by PICU staff	
Qualifying diagnoses	Traumatic brain injury (TBI), spinal cord injury, stroke, neuro-infectious and inflammatory diseases (e.g., meningitis, encephalitis, Guillain-Barré), hypoxic-ischemic injury after cardiac arrest, and status epilepticus. Other cases have been referred on a case-by-case basis, including patients with sepsis, prolonged mechanical ventilation, hemolytic uremic syndrome, cardiothoracic surgery, and patients on ECMO	
Time to initial follow-up visit	4–6 weeks follow-up Initial follow-up clinic	
Clinic frequency	Clinic functions ½ day per week, 4 days per month (4 patients/day)	Clinic functions ½ day per week, 2 days per months (8 patients/day)
Clinic staff	Neurology	
	PICU physician	
	Neuropsychology	
Screening measures	Primary care PTSD screening tool for the DSM-5 (PC-PTSD-5)[18] Pediatric Quality of Life Inventory (PedsQL)[19] Brief Infant Sleep Questionnaire (BISQ)[20] (less than 3 years of age)Sleep Disturbances Scale for Children (SDSC)[21] (3 years and older)PROMIS[22]	
	- Parent proxy numeric rating scale v.1.0—pain intensity	
	- Parent proxy pain behavior—short form	
	- Parent proxy anxiety	
	- Parent proxy depressive symptoms	
	- Parent proxy fatigue	
Neurology	30 min appointment	
Interdisciplinary care	Briefing between neurology and neuropsychology	
Neuropsychology	30 min appointment	90 min appointment
	Provides consultation to all patients at initial follow-up appointment	30-min neurocognitive screen 15 min scoring 45 min interview and feedback
	Comprehensive neuropsychological testing evaluation 4–6 months post PICU discharge as indicated	Referral and follow-up for comprehensive neuropsychological testing evaluation 3–6 months after the initial appointment as indicated
Parent satisfaction	N/A	Parent Experience of Assessment Scale (PEAS)

Abbreviations:

DCH = Doernbecher Children’s Hospital

OHSU = Oregon Health & Science University

PICU = Pediatric Intensive Care Unit

SLCH = St. Louis Children’s Hospital

WUSM = Washington University School of Medicine.

Table 2.

SLCH NCFP Data From August 4, 2017 to January 19, 2018

	Raw	Percent
Total number of patients seen by neuropsychology in NCFP	16	100%
Previously seen by neuropsychology on the neuro-rehab program	4	25%
Had returned to school at the time of clinic	5	31%
Parent or patient reported cognitive concerns	5	31%
[*]Neurocognitive impairment	6	38%
Processing speed	5	31%
Attention and executive functioning	6	38%
Memory	5	31%
Semantic fluency / confrontation naming	2	13%
Visual spatial	3	19%
Fine motor	7	44%
[†]Intact neurocognitive results, by neuropsychologist's impressions	4	25%
[‡]Abnormal BASC-3 results	2	13%
Recommendations made by neuropsychology	13	81%
Special education supports and/or IEP	7	-
Development of appropriate return to school plan	6	-
Return to activity/sports in conjunction with the neurologist	4	-
Compensatory strategies for neurocognitive impairments	4	-
Recommendation for speech-language therapy	3	-
Recommendation for occupational therapy	3	-
Behavioral interventions	2	-
Development of a behavioral plan to cope with or adjust to fatigue	2	-
Safety precautions	2	-
PEAS (% of items ranked at highest possible rating)	16	96%
DIAGNOSES	Raw	Percent
TBI moderate/severe (including closed and penetrating injuries [GSW])	7	44%
Stroke/AVM	3	19%
TBI mild	1	6%

	Raw	Percent
Meningioencephalitis	1	6%
Hypoxia/CO^2 poisoning	1	6%
Delirium	1	6%
Respiratory failure with hypoxia	1	6%
Hemolytic-uremic syndrome	1	6%

Abbreviation:

TBI = traumatic brain injury.

*"Neurocognitive impairment" is based on a predefined, empirically-based criteria of two or more test scores that fall > 1.5 standard deviations below the mean.

†"Intact neurocognitive results" is not simply the inverse of number for "Neurocognitive Impairment." Intact Neurocognitive results is based on the *clinical opinion* of the neuropsychologist, and is not related to the criteria for "Neurocognitive impairment." For instance, some patients produced test scores that did not meet the 1.5 SD criteria, but did have several below average scores that were considered weaknesses consistent with the expected neuroanatomical localization of their injuries (e.g., visual spatial deficits in a right hemisphere stroke, or language deficits in a left hemisphere TBI with SDH). In these cases, their neurocognitive screening results did not meet the criteria for "Neurocognitive impairment," but were not considered "intact." Recommendations were made accordingly.

≠Defined as having any score > 1.5 SD above the mean for clinical scales, or below for adaptive scales.