Mapping of Pediatric Chronic Illness Sequelae to Inform Evaluation Planning

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Pediatric chronic illnesses are characterized as conditions that last one year or more, require continuous medical intervention, and have implications for the overall functioning, including neuropsychoeducational functioning, of a child (Centers for Disease Control, 2021; Torpy et al., 2010). Reviews of the literature indicate that students with chronic illnesses are at risk for compromised cognitive and physical functioning, resulting in a wide range of academic, emotional, behavioral, and daily living difficulties (Dempsy, 2020). Of additional concern to school psychologists, 58% of these students routinely miss school and approximately 10% of students miss more than a quarter of the academic year (Thies, 1999). Decreased school engagement not only negatively impacts learning, but also the ability of students to develop adequate peer and teacher–student relationships.

Due to the psychoeducational challenges that face students with pediatric conditions, eligibility for special education services under the category of other health impairment (OHI) must be considered (Wodrich & Spencer, 2007). As defined in the codification of the Individuals with Disabilities Education Act (2004), OHI means:

> ...having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, and Tourette syndrome; and adversely affects a child's educational performance. (*Federal Register*, 2006, p. 46757)

Establishing if a student with a chronic illness qualifies for special education services requires the learner to be evaluated in *all areas of suspected disability* (IDEA, 2004). School psychologists must therefore be prepared to develop comprehensive evaluation plans that consider specific referral questions posed by parents and educators and explore the known neuropsychoeducational sequelae of particular pediatric conditions. Further underscoring the need for comprehensive evaluation planning, evaluations conducted by school psychologists are known to be highly valued by parents and teachers of students with chronic illnesses because the assessment process identifies unique strengths and weaknesses of the individual during the medical management of the condition (Lurie & Kaufman, 2001).

In their recent discussion of the school-based evaluation of children with chronic illnesses, Hayutin et al. (2020) advocate that school psychologists should create an outline of factors to consider when developing an evaluation plan for individual children. The purpose of this study was to support school psychologist evaluation planning by identifying pediatric conditions commonly encountered in the educational setting and then adopting a school neuropsychological assessment approach (Miller & Maricle, 2019) to investigate the neuropsychoeducational domains for which "limited" performance at home, at school, and in the community may be expected. In turn, these might become targets of assessment within a comprehensive evaluation plan. The explicit research question for this study was the following: For pediatric chronic health conditions commonly encountered by school psychologists, what are the neuropsychoeducational domains for which performance differences are present and in turn be considered suspected areas of disability?

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METHODS

The first step of this investigation was to identify pediatric chronic illnesses that school psychologists encounter in their practice. Our aim was to explore the neuropsychoeducational manifestations of a spectrum of disease types so that the scale of OHI-related evaluation plans would become evident. Barraclough and Macheck (2010) examined the roles of school psychologists in serving children with chronic illnesses and, as part of that inquiry, identified 21 distinct conditions that school psychologists encounter. Obvious to us was that not all of the conditions listed would typically be associated with OHI eligibility. As a result, we eliminated conditions that would be served under special education categories other than OHI, such as traumatic brain injury, deafness, visual impairment, orthopedic impairment, and intellectual disability. Then, conditions were removed that are not conventionally associated with cognitive processing deficits or direct learning implications (e.g., eczema). As can be seen in Table 1, 11 pediatric conditions remained that a school psychologist should associate with evaluation for OHI special service eligibility. With the conditions of the study selected, we then turned our attention to what neuropsychoeducational domains we would inventory.

We adopted a school neuropsychological assessment framework (Miller & Maricle, 2019) that encourages school psychologists to consider a broad-spectrum evaluation plan not to simply determine special service eligibility, but to more fully appreciate chronic illness manifestations and inform the selection of evidence-based interventions at school. After reviewing the model and consulting other resources that describe typical components of neuropsychological evaluations, we established that we would explore contemporary empirical literature to learn if there are performance differences that might be expected for students across the 11 pediatric conditions in the following domains: processing speed, verbal reasoning and language skills, nonverbal reasoning and visual–spatial skills, memory and learning, attention and executive functioning, motor skills, academic achievement, and social–emotional functioning. The next step in our process was to obtain and examine the relevant literature.

Four school psychology doctoral students examined contemporary empirical literature across the last 20 years (2001–2020). Procedures for the specific searches described below were conducted by two school psychology doctoral students resulting in two independent literature searches and coding of articles. The researchers conducted literature searches by cross referencing APA PsychInfo, ERIC, and Medline databases. Then, each pediatric condition was individually entered into the search engine and crossed 17 distinct times with the following terms: *neuropsychological, processing speed, verbal reasoning, language, nonverbal reasoning, visual– spatial skills, memory, learning, attention, executive functioning, motor, academic achievement, reading, writing, math, behavior,* and *social–emotional.* Articles, including meta-analyses, that contained empirical information regarding the neuropsychoeducational functioning of school-age individuals were obtained. If the article pointed to reduced neuropsychoeducational functioning on our domains of interest, the study was coded as "yes, evidence of reduced functioning on this domain." Once three empirical articles were identified for a pediatric condition that demonstrated reduced functioning on the particular domain, no further articles were reviewed. The rationale for this decision was that there was sufficient evidence to suggest that the functional domain should be considered an area of possible disability and become an evaluation target for school psychologists.

At the culmination of this data collection procedure, the data were aggregated for visual display. By decision rule, we considered the existence of at least three supporting articles to be "clear evidence" that the functional domain may be impacted for students with the pediatric condition. One or two supporting empirical articles was considered as offering "some evidence" of possible functional difference. Finally, an assessment domain with no supporting empirical articles was assigned the designation, "no known current evidence" of performance differences.

RESULTS

Table 1 displays the empirical evidence within our search parameters that links neuropsychoeducational performance differences to each chronic illness. Across the 11 conditions and 8 functional domains studied, 82% of the cells are associated with a "clear" literature base that indicates a child with that chronic illness may have decreased functioning in that performance area. Only one cell within the matrix represents a lack of published empirical articles that directly linked a condition to a performance difference (i.e., cystic fibrosis and academic achievement). With respect to the chronic illnesses investigated, asthma and cystic fibrosis (two pulmonary conditions) are associated with the fewest number of neuropsychoeducational performance differences. On the other hand, seven of the 11 chronic illnesses are associated with clear evidence of performance differences across all functional domains.

Table 1. Neuropsychoeducational Sequelae of Pediatric Chronic Illnesses

● ● ● = Clear evidence of a performance difference (3+ empirical articles)
● ● = some evidence (1–2 empirical articles)
● = no known current evidence (0 identified empirical articles)

CHRONIC ILLNESS	NEUROPSYCHOEDUATIONAL DOMAINS							
	Processing speed	Verbal reasoning/ language skills	Nonverbal reasoning/ spatial skills	Memory & learning	Attention & executive functioning	Motor	Academic achieve-ment	Social–emotional/ behavioral
Asthma	● ●	● ●	● ● ●	● ●	● ●	● ●	● ● ●	● ● ●
Epilepsy/seizure disorder	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●
Cerebral Palsy	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●
Diabetes	● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●
Cancer	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●
Cystic Fibrosis	● ●	● ●	● ●	● ● ●	● ● ●	● ●	●	● ● ●
Sickle Cell Disease	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●
Spina Bifida	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●
Brain Tumor	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●
Muscular Dystrophy	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●
HIV/AIDS	● ● ●	● ● ●	● ●	● ● ●	● ● ●	● ● ●	● ● ●	● ● ●

With respect to the neuropsychoeducational domains of study, each domain is represented with great frequency across the chronic illnesses. Social–emotional/behavioral differences received "clear evidence" designation across all 11 conditions (100%). Alternatively, the processing speed category received a "clear evidence" designation for the fewest chronic illnesses (8), although the other three conditions were associated with a "some evidence" designation.

SUMMARY AND DISCUSSION

The purpose of this study was to support school psychologists' evaluation planning by identifying commonly encountered pediatric conditions and investigating the neuropsychoeducational domains for which "limited" performance might be expected. These performance areas might then become targets of assessment within a comprehensive evaluation plan when evaluating for OHI special service eligibility. Results of this investigation affirm that pediatric chronic illnesses commonly encountered by school psychologists are associated with a broad array of neuropsychoeducational sequelae. In fact, every disorder of study may be associated limited functioning in each of the neuropsychoeducational domains of interest in this investigation. There was only one crossing that we did not uncover an empirical study pointing to a possible performance difference using our literature search parameters: cystic fibrosis and academic achievement. This finding is probably the result of the fact that that contemporary researchers have not undertaken this intersection in a recent empirical study. Particularly with clear contemporary evidence that cystic fibrosis is related to memory/learning and attention/executive functioning differences (see Table 1), one would expect some degree of difference in academic achievement compared to typically developing students without a chronic illness.

School psychologists, and other school team members, likely will not be surprised that neurologic disorders such as epilepsy, spina bifida, and brain tumor are associated with a variety of negative neuropsychoeducational outcomes. We make this statement because it is the experience of the senior author (AS) that members of multidisciplinary evaluation teams intuitively link disorders of the central nervous system to school functioning (i.e., impaired brain functioning must culminate in limitations in cognitive processes). In fact, these disorders were associated with performance differences in each of the eight neuropsychoeducational domains of this study.

Important for school psychologists and evaluation teams to recognize, however, is that nonneurologic pediatric conditions like asthma, diabetes, and sickle cell disease are also associated with negative outcomes across domains of functioning. Empirical evidence exists that each of these disorders may be associated with limited functioning in each of the eight performance domains.

Worth highlighting is that limited social–emotional/behavioral functioning was noted in at least three recent empirical studies for every chronic illness of study. Reasons for decreased social–emotional functioning will vary by disorder, but may be a behavioral manifestation of the biological condition, tolerance of medical intervention protocols, ongoing individual adjustment to this disorder, or even factors like levels of family dysfunction in the face of the chronic illness (see Dempsey, 2020; Roberts & Steele, 2017 for excellent reviews of individual pediatric conditions, including assessment and intervention considerations). Given the direct link between social–emotional functioning and school performance, this is an area that should be considered for evaluation for every student with a chronic illness, even when overt behavior problems are not present.

Multidisciplinary evaluation teams, including school psychologists, are mandated to evaluate students in all areas of suspected disability when determining eligibility for special services under the category of OHI. This brief report demonstrates that in order to meet this obligation, school psychologists must be prepared to administer assessments related to processing speed, verbal reasoning/language skills, nonverbal reasoning/visual spatial skills, memory and learning, attention and executive functioning, motor skills, academic achievement, and social–emotional/behavioral functioning. If a school psychologist does not feel prepared to evaluate students in each of the functional domains included in this investigation, we argue that is the school psychologist's ethical responsibility to engage in training and supervised practice in order to develop those skills.

No study is without limitations. Results of this inquiry are restricted by the utilized search terms, search engines, and publication years. The fact that there may be "some" or "no known" evidence in table 1may be an artifact of the above, human error (although two researchers conducted each individual search), or the simple lack of research in the particular area. Regarding the latter point, we discovered that written expression and school attendance do not commonly appear to be targets of study. Lack of evidence is therefore possibly related to lack of investigations rather than empirical studies that were conducted but found no differences.

In closing, we encourage readers of this article to consider the pediatric conditions we investigated and engage in professional self-reflection. Do you currently have sufficient knowledge of the neuropsychoeducational implications of each of the disorders? If you do not, where can you find easily consumed information? In addition to Dempsey (2020) and Roberts and Steele (2017) referenced above, the Healthy Children webpage of the American Academy of Pediatrics can be a very valuable resource (https://www.healthychildren.org/English/health-issues/conditions/Pages/default.aspx). Finally, and perhaps most importantly, are you prepared to administer common assessment tools related to the eight domains of neuropsychoeducational functioning of this study? If not, additional professional development, frequently provided through NASP conventions and online learning (NASP, n.d.; https://www.nasponline.org/professional-development), may be required to meet your ethical obligation to evaluate all students, and especially those with chronic illnesses, in all areas of suspected disability. ■

References

American Academy of Pediatrics. (n.d.). *Conditions.* https://www.healthychildren.org/English/health-issues/conditions/Pages/default.aspx

Barraclough, C., & Machek, G. (2010). School psychologists' role concerning children with chronic illnesses in schools. *Journal of Applied School Psychology, 26*(2), 132–148.

Centers for Disease Control. (2021, January 12). *About chronic diseases.* https://www.cdc.gov/chronicdisease/about/index.htm

Dempsey, A. G. (2020). *Pediatric health conditions in schools: A clinician's guide for working with children, families, and educators.* Oxford University Press.

Hayutin, L., Walsh, C. E., & Bennett, E. (2020). Assessment of needs and intervention effectiveness. In A. G. Dempsey (Ed.) *Pediatric health conditions in schools: A clinician's guide for working with children, families, and educators.* (pp. 121–139). Oxford University Press.

Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004)

Lurie, M., & Kaufman, N. (2001). An initial reintegration treatment of children with acute lymphoblastic leukemia (ALL). *Research in the Schools, 8*(1), 29–43.

Miller, D. C., & Maricle, D. E. (2019). *Essentials of school neuropsychological assessment, third edition.* Wiley.

National Association of School Psychologists. (n.d.). *Professional development.* Author. https://www.nasponline.org/professional-development

Roberts, M. C., & Steele, R. G. (Eds.). (2017). *Handbook of pediatric psychology, 5th ed.* The Guilford Press.

Thies, K. M. (1999). Identifying the educational implications of chronic illness in school children. *Journal of School Health, 69*(10), 392–397.

Torpy, J. M., Campbell. A., & Glass, R. M. (2010). Chronic diseases of children. *The Journal of the American Medical Association, 303*(7), 682.

Wodrich, D. L., & Spencer, M. L. (2007). The other health impairment category and health-based classroom accommodations. *Journal of Applied School Psychology, 24*(1), 109–125.