Learning Trajectories of Children With Special Health Care Needs Across the Severity Spectrum

Sharon Goldfeld, PhD, FRACP; Meredith O'Connor, DEdPsych; Jon Quach, PhD; Joanne Tarasuik, PhD; Amanda Kvalsvig, MSc (Epidemiology), MRCP

From the Royal Children's Hospital (Dr Goldfeld, Dr O'Connor, Dr Quach, Dr Tarasuik, and Dr Kvalsvig), Murdoch Childrens Research Institute (Dr Goldfeld, Dr O'Connor, Dr Quach, and Ms Kvalsvig), University of Melbourne (Dr Goldfeld, Dr O'Connor), and Swinburne University of Technology (Dr Tarasuik), Melbourne, Victoria, Australia

The authors declare that they have no conflict of interest.

Address correspondence to Sharon Goldfeld, PhD, FRACP, Murdoch Childrens Research Institute, Royal Children's Hospital, Parkville Victoria 3052, Australia (e-mail: Sharon.goldfeld@rch.org.au).

Received for publication January 23, 2014; accepted September 4, 2014.

ABSTRACT

OBJECTIVE: A significant proportion of school-aged children experience special health care needs (SCHN) and seek care from pediatricians with a wide range of condition types and severity levels. This study examines the learning pathways of children with established (already diagnosed at school entry) and emerging (teacher identified) SHCN from school entry through the elementary school years.

METHODS: The Longitudinal Study of Australian Children (LSAC) is a nationally representative clustered cross-sequential sample of 2 cohorts of Australian children which commenced in May 2004. Data were analyzed from the LSAC kindergarten cohort (n = 4,983), as well as a subsample of 720 children for whom teachers also completed the Australian Early Development Index checklist, a measure of early childhood development at school entry that includes SHCN.

RESULTS: Latent class analysis was utilized to establish 3 academic trajectories from 4–5 to 10–11 years: high (24.3%), average (49.8%), and low (23.6%). Descriptive statistics revealed a trend for both children with established and emerging SHCN to fall into weaker performing learning pathways. Multinomial logistic regression focusing on those children with emerging SHCN confirmed this pattern of results, even after adjustment for covariates (relative risk 3.06, 95% confidence interval 1.03–9.10). Children who additionally had low socioeconomic standing were particularly at risk.

CONCLUSIONS: Even children with less complex SCHN are at risk for academic failure. Early identification, together with integrated health and educational support, may promote stronger pathways of educational attainment for these children. Achieving these better outcomes will require the involvement of both educational and health practitioners.

KEYWORDS: academic achievement; chronic health condition; disability; school functioning; special health care needs

ACADEMIC PEDIATRICS 2015;15:177–184

WHAT'S NEW

Even children with less complex special health care needs are at risk for poorer learning pathways over the early years of schooling. These differences appear early and may even widen by the end of elementary school.

PEDIATRICIANS AND FAMILY physicians working with children are increasingly confronted with the so-called millennial morbidities: chronic and sometimes intractable problems associated with complex biopsychosocial and environmental dimensions.[1] This includes primarily organic chronic conditions such as obesity, as well as mental health and developmental difficulties such as attention-deficit/hyperactivity disorder (ADHD), behavior problems, autism spectrum disorders, and learning issues.[1,2] Children can also differ widely in the severity of their condition and complexity of their needs.[3]

Often referred to as children with special health care needs (SHCN), these children "have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and… also require health and related services of a type or amount beyond that required by children generally."[4] Prevalence estimates from the United States range between 13% and 19% for 0- to17-year-olds.[5] Australian data similarly suggest that around a fifth of children in their first year of schooling experience SCHN.[6]

This definition of SHCN is purposefully inclusive of children considered to be at increased risk for being diagnosed with a chronic condition (which we refer to as experiencing emerging SHCN), in recognition of the important potential benefits of early intervention.[7] Australian estimates suggest that while 4% of children have established SHCN formally recognized within the educational system, many more—around 18%—experience emerging SHCN.[6] Despite their number, these children tend to be underrepresented in research and policy discussions, and they continue to be at high risk of missing out on services.[8]

IMPACT OF SHCN ON LEARNING AND SCHOOL ACHIEVEMENT

Children with SHCN tend to begin school with weaker early academic skills than their peers,[6] and disparate academic outcomes continue to be evident in the later elementary years.[9] In the long term, these children have lower rates of high school completion, postsecondary education, and decreased earnings and labor market participation.[10] Many different factors are likely to contribute to these poorer outcomes, such as school absenteeism, decreased participation at school, and restricted involvement in social activities with peers.[11]

However, research to date has tended to focus on children at the severe end of the disability spectrum, with the academic pathways of children with emerging SHCN (those with undiagnosed or “gray area” difficulties) neglected in both empirical investigations and policy discussion.[12] In many countries, including Australia, funding systems are still aligned to limited diagnostic categories, and children with emerging SHCN can miss out on access to support if their difficulties do not fit neatly into often rigid criteria for eligibility based on severe impairment.[8,11] Yet the potential benefits of early intervention[13] constitutes a strong argument for also understanding and addressing the support needs of these children.

Compounding the risk for underachievement and disengagement at school is the impact of socioeconomic disadvantage. Children with SHCN are overrepresented in more disadvantaged settings in countries such as the United Kingdom,[14] the United States,[15] Canada,[16] and Australia,[6] and disadvantage in turn is associated with poorer academic pathways throughout the school years.[17,18] These effects are further amplified in the context of SHCN,[19] making the potential for double jeopardy a real risk.

CURRENT STUDY

The impact of SHCN on early (and therefore more mutable) pathways of learning and school functioning has been underexplored,[20] particularly in relation to children with emerging SHCN.[11] In this study, we capitalized on the unique opportunity provided by the Longitudinal Study of Australian Children (LSAC),[21] combined with teacher report from the Australian Early Development Index (AEDI), a population measure of early childhood development,[22] to examine the learning and academic pathways of children with SHCN across the elementary school period. We hypothesized that children with both established and emerging SHCN would be overrepresented in trajectories characterized by weaker academic skill development. Socioeconomic disadvantage was expected to account for some but not all of this relationship.

METHODS

DATA SOURCES

Growing Up in Australia: the Longitudinal Study of Australian Children (LSAC) is a nationally representative clustered cross-sequential sample of 2 cohorts of Australian children—the birth cohort (B cohort) of 5,107 infants and the kindergarten cohort (K cohort) of 4,983 4-year-olds—which commenced in May 2004.[21] A cluster design and stratification of postal codes were used to ensure a geographically representative sample of the Australian population for each age cohort, with the exception of children living in remote areas.[23] The families of 18,800 children received letters of invitation to take part in the LSAC, and the final overall response rate for both cohorts was 54%.[24] To date, 4 main waves of data have been collected, approximately every 2 years. Approval for this methodology was gained from the Australian Institute of Family Studies human ethics review board.

Families were visited by an interviewer at the main waves of data collection who conducted a parent interview, completed direct-child assessments and observational measures, and left behind a self-completed questionnaire to return via postal mail. Teacher report was collected during each of the main waves via a mail-out survey. Information was also gained using data linkage to a number of administrative datasets, including the National Assessment Program—Literacy and Numeracy assessments (NAPLAN), which is an Australia-wide assessment conducted in schools with all children in school years 3, 5, 7 and 9.[25]

Here we focus on a subsample of 720 children from the K cohort (4- and 5-year-olds) who also had data on SHCN collected through the Australian Early Development Index (AEDI).[22] The AEDI is an Australian adaptation of the Canadian Early Development Instrument (EDI); it is a relative population measure of young children’s development completed by teachers.[22] This subsample consisted of all the children in LSAC who resided in the states of Queensland, Victoria, or Western Australia. With the parents’ consent obtained, the child’s teacher was sent a battery of questionnaires that included the AEDI checklist. Preliminary analyses found this subset to be representative of the full LSAC K cohort.

MEASURES

SPECIAL HEALTH CARE NEEDS

Three questions from the AEDI checklist were used to determine SHCN status. For all children, teachers were asked: 1) whether the child required “special assistance due to chronic medical, physical, or intellectually disabling conditions (eg, autism, cerebral palsy, Down syndrome),” with instructions to base their answer on an established medical diagnosis; 2) whether any of 9 physical and psychosocial impairments in their view impacted the student’s ability to do school work in a regular classroom (Table 1); and 3) whether they thought that the child needed further assessment and/or was currently being assessed.

All children who were reported by teachers to have previously diagnosed SHCN according to item (1) were categorized as having established SHCN. Children were categorized as experiencing emerging SHCN if teachers responded yes to either or both questions (2) and (3), indicating that the child needed further assessment and/or had area/s of impairment affecting their learning. Finally, all other children were categorized as belonging to the standard population.[6] This assessment of SHCN status has been shown to correlate with other developmental indicators as expected.[6]