48

TRANSFORMING TRANSITIONS: DEVELOPING CUL-TURAL COMPETENCE IN SUPPORTING CAREGIVERS OF CHILDREN AND YOUTH GROWING UP WITH AUTISM SPECTRUM DISORDER

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BACKGROUND: Transition to adulthood is a stressful time for caregivers of children and youth with Autism Spectrum Disorder (ASD). Anecdotally, we know that cultural perspectives can directly influence decisions made around ASD diagnosis, treatment, and transition to adulthood. However, there is a paucity of research into these cultural perspectives and how they may affect illness trajectories.

OBJECTIVES:

1.Through open-ended responses, identify cultural values that play a role in decision making around health care and life course planning during transition to adulthood in ASD.

2.Identify criteria for success in adulthood from parents of children and youth with ASD in a culturally diverse population.

3.Identify systemic barriers that prevent families from accessing culturally sensitive care

4.Educate health care workers on any unique cultural perspective that may impact transition planning.

DESIGN/METHODS: In-depth interviews (IDIs) were conducted with caregivers (i.e., parents/guardians) of children and youth with autism. Interviews were recorded, transcribed, and coded using deductive and inductive coding methods by two independent coders, with inter-rater reliability confirmed by Cohen's kappa coefficient.

RESULTS: A total of 12 IDIs were conducted. The main themes that were discussed included caregivers' understanding of adulthood for their child with ASD, barriers to accessing services, the importance of culture and religion/spirituality to their child's future, recommendations to improve current services and programming and the impact of the COVID-19 pandemic on decision-making. Caregivers expressed their desire for their child to be independent as they transition to adulthood. They also described how cultural or religious/spiritual practices are integrated into their child's life and the importance of maintaining their cultural identity. Caregivers emphasized the lack of culturally tailored resources as their child transitions to adulthood to maintain that sense of community.

CONCLUSION: Caregivers' cultural perspectives are an integral part of their identity and an important aspect of their environment that should be taken into consideration as children and youth with ASD transition to adulthood.

49

IMPLEMENTATION OF A SENSORY TOOLKIT IN THE EMERGENCY DEPARTMENT FOR CHILDREN WITH AU-TISM SPECTRUM DISORDER

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BACKGROUND: Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by deficits in social communication and restricted, repetitive patterns of behaviour, interests, or activities. Children with ASD frequently visit the emergency department (ED), and present more for primary care-related issues and other non-emergent reasons than children without ASD. Visiting the ED can be challenging and stressful for children with ASD, their caregivers, and the healthcare professionals caring for them. Sensory Toolkits are a collection of sensory items that can help to distract and calm children, including during times of stress. We hypothesized that a Sensory Toolkit will improve the experience of children with ASD and their families in our ED. **OBJECTIVES:** The primary objective of this study was to evaluate the effect of a Sensory Toolkit on the experience of children with ASD and their families visiting a tertiary-care hospital ED.

DESIGN/METHODS: After ethical approval was obtained, a pre-implementation survey was conducted on parents of children with ASD about prior experiences in the ED and their interest in a Sensory Toolkit. A Sensory Toolkit specific to children with ASD was developed through literature review and in consultation with families of children with ASD. The Sensory Toolkit, which included a light wand, squeeze ball, push-pop bubble toy, and other items, was launched in a tertiary-care hospital ED in June 2021 with 50 Toolkits. A post-implementation survey was conducted to explore parents' experiences of their child using the Sensory Toolkit in the ED and to obtain feedback to help improve the Toolkit.

RESULTS: In the pre-implementation survey, 80% (32/40) of parents felt that a Sensory Toolkit would improve the experience of children with ASD in the ED. Post-implementation, 100% (12/12; response rate \sim 25% from 50 Toolkits) of parents felt that the Sensory Toolkit was helpful for their child. Parents reported that the Sensory Toolkit was "AMAZING" and "A really great idea, thank you!". Feedback provided regarding improvements that could be made to the Sensory Toolkit was highly patient-specific and often contradictory. One parent suggested more items to chew on while another parent suggested elimination of the chewable items and one parent loved the light up toy while another suggested to remove it.

CONCLUSION: The Sensory Toolkit contributes positively to the experience of children with ASD and their families in a tertiary-care hospital ED. This study will help inform improvement of the Sensory Toolkit in the ED, including consideration of more specialized Sensory Toolkits to meet individual patient needs. Given the success in the ED, the Sensory Toolkit could be expanded into other areas of the tertiary-care hospital and beyond.

50

RISK FACTORS FOR SEVERE COVID-19 IN HOSPITALIZED CHILDREN IN CANADA: A NATIONAL PROSPECTIVE STUDY FROM MARCH 2020–MAY 2021

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BACKGROUND: Children living with chronic comorbid conditions are at increased risk for severe COVID-19 disease, though there is limited evidence regarding the risks associated with specific conditions and which children may benefit from targeted COVID-19 therapies. Age-specific baseline indicators of COVID-19 severity are also needed to evaluate the effectiveness of SARS-CoV-2 vaccination strategies in the paediatric population.

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OBJECTIVES: In this study, we aimed to 1) identify factors associated with severe COVID-19 in children, and 2) describe rates of hospitalization, intensive care unit (ICU) admission, and severe COVID-19 within specific pediatric age groups.

DESIGN/METHODS: We conducted a national prospective study on hospitalized children with microbiologically confirmed SARS-CoV-2 infection via the Canadian Paediatric Surveillance Program from March 2020-May 2021. Cases were reported voluntarily by a network of >2800 paediatricians and paediatric subspecialists. SARS-CoV-2 hospitalizations were classified as COVID-19-related, incidental infection, or infection control/social admissions. Severe disease was defined as intensive care, ventilatory or hemodynamic requirements, select organ system complications, or death. Outcomes were described among children aged <6 months, 6-23 months, 2-4 years, 5-11 years, and 12-17 years. Risk factors for severe disease were identified using multivariable Poisson regression, adjusting for child age and sex, coinfections, and timing of hospitalization.

RESULTS: We identified 541 children hospitalized with SARS-CoV-2 infection, including 329 (60.8%) with COVID-19-related disease. Median age at admission was 2.8 years (IQR 0.3-13.5) and 42.9% (n=232) had at least one comorbidity. Among COVID-19-related hospitalizations, severe disease occurred in 29.5% of children (n=97/329), including a higher proportion of children aged 2-4 years (48.7%) and 12-17 years (41.3%) (Table 1). Comorbidities associated with severe disease are described in Figure 1, and included technology dependence (adjusted risk ratio [aRR] 1.96, 95% confidence interval [CI] 1.31-2.95), neurologic conditions (e.g. epilepsy and chromosomal/genetic conditions) (aRR 1.87, 95% CI 1.34-2.61), and pulmonary conditions (e.g. bronchopulmonary dysplasia and uncontrolled asthma) (aRR 1.66, 95% CI 1.13-2.42).

CONCLUSION: While severe outcomes were detected at all ages and among patients with and without comorbidities, neurologic and pulmonary conditions as well as technology dependence were associated with increased risk of severe COVID-19. Children aged 2–4 years more commonly experienced severe COVID-19 in this study, which was conducted at a time when no children were eligible for SARS-COV-2 vaccines. Notably, this high-risk group remains without access to approved vaccines. These findings may help guide vaccination programs and prioritize targeted COVID-19 therapies for children.

Table 1 Severity and tre	atment outcomes of children hornit	alized with COVID-19 in Cana	da by age group
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Channelstein	All Cases -	Child age				
Characteristics		<6 months	6-23 months	2-4 years	5-11 years	12-17 years
COVID-19-related hospitalizations, N	329	123	46	39	29	92
COVID-19 severity, n (%)						
Mild/moderate illness	232 (70.5)	106 (86.2)	33 (71.7)	20 (51.3)	19 (65.5)	54 (58.7)
Severe illness	97 (29.5)	17 (13.8)	13 (28.3)	19 (48.7)	10 (34.5)	38 (41.3)
Admitted to ICU, n (%)	60 (18.2)	12 (9.8)	7 (15.2)	13 (33.3)	7 (24.1)	21 (22.8)
Length of ICU stay, median (IQR)	4 (2-7)	3 (3-10)	4 (3-6)	2 (2-4)	2 (1-9)	6 (3-8)
Respiratory/hemodynamic support required, n (%) ¹	108 (32.8)	20 (16.3)	15 (32.6)	17 (43.6)	9 (31.0)	47 (51.1)
Low-flow oxygen	58 (17.6)	13 (10.6)	8 (17.4)	6 (15.4)	6 (20.7)	25 (27.2)
High-flow nasal cannula	33 (10.0)	5 (4.1)	<5 (<10.9)	5 (12.8)	<5 (<17.2)	15 (16.3)
Non-invasive ventilation (e.g. CPAP or BiPAP)	14 (4.3)	<5 (<4.1)	<5 (<10.9)	<5 (<12.8)	<5 (<17.2)	5 (5.4)
Conventional mechanical ventilation	25 (7.6)	<5 (<4.1)	<5 (<10.9)	10 (25.6)	0 (0.0)	8 (8.7)
Vasopressors	8 (2.4)	0 (0.0)	<5 (<10.9)	<5 (<12.8)	0 (0.0)	<5 (<5.4)
Child died, n (%)	5 (1.5)	DNS	DNS	DNS	DNS	DNS

³Multiple supports could be reported and therefore specific supports do not sum to any supports

Characteristic		aRR (95% CI)
Sex		
Male (ref = female)	⊢ ●_+	0.76 [0.54, 1.07]
Any co-infection		
Yes (ref = No)	⊢ ●1	1.41 [0.93, 2.16]
Timing of hospitalization		
Second wave (ref = first wave)	⊢	1.41 [0.73, 2.71]
Third wave (ref = first wave)	• • • • • • • • • • • • • • • • • • •	1.87 [0.97, 3.58]
Chronic conditions		
Non-complex (ref = None)	⊢ ●(1.12 [0.72, 1.74]
Complex (ref = None)	⊢ ●1	1.38 [0.91, 2.11]
Specific chronic conditions		
Bronchopulmonary dysplasia	⊢	2.38 [1.36, 4.17]
Recurrent aspiration pneumonia	• • • • • • • • • • • • • • • • • • •	2.23 [0.97, 5.09]
Asthma, without controller medication	⊢ ●i	2.11 [1.41, 3.14]
Epilepsy	⊢	2.10 [1.45, 3.02]
Genetic/chromosomal disorders	⊢ ●i	2.06 [1.34, 3.15]
Technology dependence (any)	⊢ ●1	1.96 [1.31, 2.95]
BMI Z-score ≥3	⊢ −−−1	1.89 [1.09, 3.28]
Neurologic/neurodevelopmental (any)	⊢● →	1.87 [1.34, 2.61]
Parenteral nutrition		1.72 [1.03, 2.89]
Chronic encephalopathy		1.70 [1.07, 2.70]
Pulmonary (any)	⊢ ●1	1.66 [1.13, 2.42]
Congenital heart disease	⊢− −1	1.52 [0.78, 2.96]
Obesity (any)	⊢ _●1	1.35 [0.87, 2.08]
Cerebral palsy	⊢	1.34 [0.61, 2.97]
BMI Z-score 2-<3	⊢	1.25 [0.66, 2.39]
Autism spectrum disorder	⊢	1.12 [0.44, 2.84]
Diabetes	⊢	1.03 [0.54, 1.99]
Metabolic disease	⊢	0.95 [0.38, 2.41]
Leukemia	⊢	0.82 [0.30, 2.20]
Chronic renal disease	⊢ i	0.78 [0.26, 2.31]
Gastrointestinal/liver disease	⊢	0.78 [0.30, 1.99]
Malignancy (any)	⊢	0.66 [0.23, 1.93]
Immunocompromising medications	⊢	0.53 [0.20, 1.42]
Immunosuppression (any)	⊢	0.43 [0.16, 1.17]
Asthma, with controller medication	⊢	0.33 [0.05, 2.22]
Hematologic disease (any)	⊢	0.33 [0.09, 1.16]
Sickle cell disease	• • • • • • • • • • • • • • • • • • •	0.20 [0.03, 1.41]
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Figure 1. Risk ratios for severe COVID-19 by sex, co-infections, timing of hospitalization, and chronic conditions.

Risk ratios were calculated using Poisson regression with robust standard errors. The primary model included continuous age (analyzed as a restricted cubic spline with four evenly space knots), sex, coinfections, timing of hospitalization, and chronic condition category (i.e. none/unknown, noncomplex, complex). Separate models were then run for each specific chronic condition, by substituting the overall chronic condition category with only the condition of interest.