The incidence and cohort prevalence of autism spectrum disorders on the Avalon Peninsula, Newfoundland and Labrador, Canada

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Outline

• Present a recent study which examined the incidence and one-year cohort prevalence of children with ASD on the Avalon;

• Discuss the implications of the findings.
Starting point - 2010

• There were numerous studies and reports about increases in the prevalence of Autism Spectrum Disorders (ASDs) world wide.

• No national Canadian level data on prevalence and incidence.

• A few Canadian Studies:
  
  
  
Starting Point - 2010

• Within the Department of Child Development at the Janeway hospital, there was interest in looking at autism rates in NL.

• All of our pediatric residents need to conduct a research project as part of their residency program.

• Dr. Lorine Pelly, one of our pediatric residents, took on this topic as her research project.
Defining the Project

- The project was designed to use information available for patients seen at some point within the Department of Child Development.

- This Department is the only development pediatric program in NL.
Defining the Project

- Although the department does assess and follow children from all parts of the province, the pediatricians we consulted said that they would be only confident that almost all children diagnosed on the Avalon would be seen by the department.

- We classified people as being from the Avalon Peninsula if they were living in a community in Census Division No. 1 at time of diagnosis.
Census Division No. 1
Defining the Project

- It was 2011 by the time that the chart review was finally planned out and we had necessary ethics and institutional approvals in place to allow us to proceed with the study.

- To look at the rate incidence, we included patients diagnosed in one of the last 5 years for which we had full year of data, i.e., 2006 – 2010.

- Under the age <15 years at time of diagnosis.
Inclusion Criteria

- People diagnosed with ASD;
- Diagnosed between January 1, 2006 and December 31, 2010;
- Listed as living in a community in Census Division No. 1 at time of diagnosis;
- Assessed in the Department of Child Development at the Janeway;
- Under the age <15 years at time of diagnosis.

- People diagnosed with another genetic syndrome that may have symptoms of ASD were excluded, even if they were also given a diagnosis for ASD.
Identifying Included Patients

• The Department maintained a list of new patients from 2005 to 2011.

• We verified this list with each developmental pediatrician in the Department in order to ensure no cases meeting the inclusion criteria were missed.
Chart Review

- Basic demographic information (age, gender)
- Type of ASD diagnosed
- Testing employed to diagnose the condition
- Co-morbidities
- Some information of referrals

- No personal identifying information was included.
Number of Cases

• We found 290 people who met our inclusion criteria.

• 18 cases were children who also had a genetic syndrome that may have symptoms of ASD, so were excluded.

• We did our analysis on 272 cases.
## Cases

<table>
<thead>
<tr>
<th></th>
<th>Total Number (n=272) Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>234 (86.0%)</td>
</tr>
<tr>
<td>Female</td>
<td>38 (14.0%)</td>
</tr>
<tr>
<td><strong>Specific Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>ASD</td>
<td>74 (27.2%)</td>
</tr>
<tr>
<td>AD</td>
<td>130 (47.8%)</td>
</tr>
<tr>
<td>Asperger</td>
<td>56 (20.6%)</td>
</tr>
<tr>
<td>PDD-NOS</td>
<td>12 (4.4%)</td>
</tr>
<tr>
<td><strong>Autism Diagnostic Observational Schedule</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>269 (98.9%)</td>
</tr>
<tr>
<td>No</td>
<td>3 (1.1%)</td>
</tr>
<tr>
<td><strong>Autism Diagnostic Observational Schedule Module</strong></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>112/269 (41.6%)</td>
</tr>
<tr>
<td>II</td>
<td>75/269 (27.9%)</td>
</tr>
<tr>
<td>III</td>
<td>82/269 (30.5%)</td>
</tr>
<tr>
<td>IV</td>
<td>0 (0.0%)</td>
</tr>
</tbody>
</table>
Cases

• Diagnosed through multiple observations by a multidisciplinary team, consultation with a developmental pediatrician, and a detailed patient history.

• Most were continued to be followed by the Department.
## Age of Diagnosis

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - &lt;1</td>
<td>0 (0.0%)</td>
</tr>
<tr>
<td>1 - &lt;2</td>
<td>10 (3.7%)</td>
</tr>
<tr>
<td>2 - &lt;3</td>
<td>77 (28.3%)</td>
</tr>
<tr>
<td>3 - &lt;4</td>
<td>57 (21.0%)</td>
</tr>
<tr>
<td>4 - &lt;5</td>
<td>33 (12.1%)</td>
</tr>
<tr>
<td>5 - &lt;7</td>
<td>43 (15.8%)</td>
</tr>
<tr>
<td>7 - &lt;11</td>
<td>44 (16.2%)</td>
</tr>
<tr>
<td>11 - &lt;15</td>
<td>8 (2.9%)</td>
</tr>
</tbody>
</table>
### Service Referrals

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Genetics Referral</strong></td>
<td>193 (71.0%)</td>
<td>1 (0.4%)</td>
<td>78 (28.6%)</td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Neuroimaging</strong></td>
<td>79 (29.0%)</td>
<td>185 (68.0%)</td>
<td>8 (3.0%)</td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Unknown</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Provinical Autism Program Referral</strong></td>
<td>195 (71.7%)</td>
<td>75 (27.6%)</td>
<td>2 (0.7%)</td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
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<tr>
<td>No</td>
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<td></td>
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<tr>
<td>Unknown</td>
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</tbody>
</table>
Incidence

• Incidence is the number of new cases in an at-risk population in a given period.

• Numerator: The number of new cases diagnosed in each year we looked at (2006 – 2010).

• Denominator: We averaged the census population for the age 0-14 in 2006 (38,915) with that population in 2011 (40,080), resulting in a population of 39,498.
Incidence

• In 2006, there were 40 new cases of ASD diagnosed at the Janeway.

  • \[ \frac{40}{39,498} = 0.001013 \]

  • \[ 0.001013 \times 10,000 = 10.1271 \]

  • The incidence rate in 2006 at the Janeway for children living on the Avalon was 10.1 cases diagnosed for every 10,000 people in the population at risk.
# Incidence 2006 - 2010

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Cases</th>
<th>Incidence per 10,000 population (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006</td>
<td>40</td>
<td>10.1 (7.2 to 13.7)</td>
</tr>
<tr>
<td>2007</td>
<td>50</td>
<td>12.7 (9.4 to 16.7)</td>
</tr>
<tr>
<td>2008</td>
<td>54</td>
<td>13.7 (10.3 to 17.8)</td>
</tr>
<tr>
<td>2009</td>
<td>62</td>
<td>15.7 (12.0 to 20.1)</td>
</tr>
<tr>
<td>2010</td>
<td>66</td>
<td>16.7 (12.9 to 21.3)</td>
</tr>
<tr>
<td>Total</td>
<td>272</td>
<td></td>
</tr>
</tbody>
</table>
Incidence 2006 - 2010

• The number of cases diagnosed at the Janeway increased each year over the period that we studied.

• Why?
  • Increased rate of ASD in the population?
  • Increased numbers of people being referred to the Janeway?
  • Increased capabilities of the Janeway to diagnose cases, e.g., more staff?

• Although we do not have the data, informally I have been told that the rate of increase has at the very least leveled off.
Prevalence

• Prevalence measures the level of a condition in a defined population.

• Numerator: The number of cases diagnosed in children born in 2006.

• Denominator: We averaged the 2011 census population for children aged 4 (2670) and aged 5 (2665), resulting in a population of 2668.
Prevalence

• By the end of our study period (2010), there were 33 children born in 2006 who had been diagnosed with ASD.

• We were asked to update our data by CMAJ, and we identified, 25 new cases diagnosed in this population between the end of 2010 and 2013.

• 123.4 cases/10 000 or 1 in 81 (95% CI: 1 in 56 to 1 in 113).

• 215.77 cases / 10000 or 1 in 46.
Prevalence

- We reported the highest prevalence ever reported for a population reported in Canada.

- Fombonne reviewed 43 prevalence studies of ASD published since 1966 and found the average prevalence of ASD at 60-70/10,000.

- Our cohort prevalence is over three times higher than the average prevalence reported in a systematic review by Elsabbagh et al. (62/10 000).
Prevalance

• The latest CDC autism numbers in the United States uses a survey of a cohort of children age 8 and reported a cohort prevalence of ranging from 57 to 219.14/10000 in 2010.

• Our cohort prevalence was 215.77/10 000, which is at the high end of the range of the ADMM survey.
Prevalence

• Of particular interest is work presented by the Ouellette-Kunzt et al., which calculates prevalence rates for the entire province of Newfoundland in 2013.

• They report prevalence rates for this cohort at 4-5 years of age as 61.8/10,000 and 94.2/10,000 at 6-7 years.
Prevalence

• Ouellette- Kunzt et al. use cases ascertained from “agencies that provide services to children with autism.”

• Our study found that only 72.4% of diagnosed cases were reported as being referred to the provincial program for autism services.

• Dodds et al. reported approximately the similar level of correspondence (69.1%) between data obtained directly from clinical departments and data captured from wider administrative sources for ASD.
Advantages of this work

- It provides some numbers around the incidence rate of ASD in NL.

- Clinically diagnosed and followed cases.

- The data was collected with a lot of care, and checked with charts.

- This is a solid core of patients, but likely a conservative estimate of ASD, even on the Avalon.
Who is not captured?

- It only provides part of the picture for NL.
  - Other parts of the province.
  - Children older than in our range.
  - Children with ASD, but not diagnosed.
  - Children not diagnosed by a pediatrician.
Who is diagnosis?

• NL Autism Society’s Needs Assessment surveys found that while developmental pedestrians diagnosed most cases, others identified family doctors, speech pathologists, child psychiatrists and psychologists as providing their child’s diagnosis.

• The diagnostic picture even on the Avalon may be more complicated than we initially presumed.
Implications

• Although we found that NL had a steady increase in incidence over the period studied, and a high prevalence, it would be useful to get more data to confirm these conclusions.

• For the incidence data, not long a time for evaluating, so the trend may not hold.

• Given the small population studied, small increases in numbers can have a big impact on the rates. For example, 25 new cases moved our rate to 1 in 81 to 1 in 46.
Implications

• The Public Health Agency of Canada National Autism Surveillance System.

• ASD is complicated from a service provision point of view, which means that it is also difficult from a tracking point of view.

• The issues we raised about the differences between clinic level data and other administrative data sources need to be accounted for in the new surveillance system.
Implications

• Currently, it is not feasible for an information management perspective to do a national surveillance study by drawing on data from the clinical setting, even if we confine it to pediatric hospitals.

• This type of data should not be as hard as it was for us to compile.
Implications

• For policy makers, our study provides added evidence of the scope of NL families affected by ASD.

• It shows that ASD burdens our region as much, if not more, that other places globally.

• While more work is needed around ASD incidence and prevalence, more work should focus on service aspects of treating the diverse group of people affected by ASD.
PEDIATRIC RESIDENTS had the opportunity to showcase their research projects March 15 at the annual Pediatric Residents Research Day. There were 10 presentations, covering a wide range of topics including diabetes, trampoline injuries, endocrinology, allergies, transgender health issues, epinephrine use, skin infections, autism spectrum disorders and asthma.

Dr. Colleen Nugent was awarded the prize for the best second-year research proposal. She is conducting a retrospective review of Janeway Hospital outcomes of mild and moderate diabetic ketoacidosis admissions, comparing intermittent rapid acting subcutaneous insulin to low dose continuous intravenous insulin. The project is being completed with Drs. Ara Healey, Roger Chafe and Lorine Pelly.
Thank You

- Janeway Foundation
- Eastern Health and the Department of Child Development
- Newfoundland and Labrador Centre for Health Information (NLCHI)