Injury in young people with intellectual disability: descriptive epidemiology

J Sherrard, B J Tonge, J Ozanne-Smith

Abstract

Objectives—To assess the public health importance of injury in a representative sample of young people with intellectual disability relative to the general population.

Setting—This study forms part of the Australian Child and Adolescent Development (ACAD) program examining emotional and behavioural problems in a cohort of young people with intellectual disability (IQ<70). The program has collected extensive biopsychosocial data from carers of subjects at two time intervals, 1990 (n=579) and 1996 (n=465).

Method—Carer report of medically attended injury to subjects was collected for the first time during 1996 (age 5–29 years) and supplemented with medical record injury data from hospitals and general practitioners for 147 of the ACAD sample and 110 supplementary subjects. These data were compared with general population injury data to assess relative epidemiological differences.

Results—Annual injury mortality and morbidity rates were 150/100 000 and 55.6/100 000 persons, with age standardised mortality and morbidity ratios of 8 and 2 respectively. Males and females had similar injury rates. The rate for injury hospitalisations was twice that of the general population. Falls were more common and transport injury and intentional injury less common causes of injury morbidity compared with general population. The patterns of cause, circumstances, and severity of injury in young people with intellectual disability have more similarities with younger children than with their same age group in the general population.

Conclusion—This study should alert clinicians and others to the increased risk for injury and possible further handicap in this population. It is essential that injury prevention programs be implemented and evaluated for their effectiveness in reducing the substantial additional burden of suffering, care and cost resulting from injury to young people with intellectual disability.

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Keywords: epidemiology, intellectual disability; mental retardation

Injury is the major preventable public health problem for the general population to age 44 years.1 2 General population injury epidemiology and prevention strategies are well documented, but there is no clear picture quantifying the potential public health impact of injury and relevant prevention for populations with intellectual disability.2 3 Increased injury risk in this population is likely because of limitations in both understanding hazards and coping with environmental challenges.3–6 10

This study forms part of the Australian Child and Adolescent Development (ACAD) program examining the emotional and behavioural problems of young people with intellectual disability.5 9 The program sample enrolled in 1989–90 (IQ<70, aged 4–18 years) is representative of young people with intellectual disability known to agencies and schools.11 12 Subjects live in six large geographic regions across the states of Victoria and New South Wales which contain 60% of the Australian population (approximately 18 million).13 The program has collected an extensive range of biopsychosocial data from carers (parents/professional carers) of subjects at two time intervals, time 1 (1990, n=579) and time 2 (1996, n=465).

Study objectives were to (1) describe the epidemiology of medically attended injury in the ACAD sample using carer data complemented with medical record data and (2) compare findings with the general population to assess relative public health importance.

Method

SUBJECTS

The sample for carer survey was ACAD program subjects at time 2. As it was impractical to collect complementary medical record injury data from the 100 hospitals and 250 general practitioners serving all ACAD subjects in the six program regions, data collection was restricted to the largest region (group 1 subjects, n=147) (fig 1).

However, this practical approach limited power for medical record analyses, so a supplementary group of subjects with intellectual disability (group 2 subjects, n=110) was recruited from the same region using the same procedures as the ACAD program.11

DATA COLLECTION

Carer report

The ACAD program questionnaire sent to carers at time 2 included, for the first time, questions typical of general population injury surveys: number of times the young person with intellectual disability was injured in the previous year, level of medical attention received, and cause of injury.14–17 Carers of

Correspondence and reprint requests to: Dr J Sherrard, Monash University Accident Research Centre, PO Box 70A, Monash University, Victoria 3800, Australia

ejenny.sherrard@general.monash.edu.au

www.injuryprevention.com
The six geographical regions of the ACAD program.

Figure 1 Source of matched data from carer questionnaires and medical records in one of the six geographical regions of the ACAD program.

Group 1 ACAD subjects carer data (n = 147)
Group 2 supplementary subjects carer data (n = 110)
Subjects with some local hospital and general practice medical records available (n = 242)
Complete medical records (n = 107)
Complete medical records (n = 78)
Carer data matched with medical records (n = 185)

Time 1: 1990
ACAD sample (n = 579)

Time 2: 1996
ACAD sample (n = 465)

Time 3: 2000
ACAD sample (n = 185)

Complete medical records (n = 107)
Carer data matched with medical records (n = 185)

The nature and circumstances of injury in the study group and the general population were compared using medical records. Injury severity was compared using the maximum abbreviated injury score (MAIS), the highest single AIS score in an injured patient.

Results
Carer report
Demographics
Carer response rate for ACAD subjects at time 2 was 80.0% (465/579). Group 1 is representative of program subjects (table 1) but group 2 is approximately four years younger. The recruitment rate for group 2 was 71.9% (110/153).
Table 1  Characteristics of all subjects in the Australian Child and Adolescent Development (ACAD) program at time 2 compared with group 1 ACAD program subjects and group 2 supplementary subjects

<table>
<thead>
<tr>
<th>Variable</th>
<th>A: ACAD program</th>
<th>B: group 1</th>
<th>C: group 2</th>
<th>p=0.000.</th>
<th>Injury incidence was similar across levels of intellectual disability: mild 27.7/100, moderate 23.0/100, severe/profound 33.1/100 subjects.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males %</td>
<td>57.8 (269)</td>
<td>58.5 (86)</td>
<td>63.6 (70)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean age (CI)*</td>
<td>16.13</td>
<td>15.91</td>
<td>12.17</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age group % (n)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0—4</td>
<td>0</td>
<td>0</td>
<td>4.5 (6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5—9</td>
<td>5.4 (25)</td>
<td>5.4 (8)</td>
<td>42.5 (50)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10—14</td>
<td>37.3 (173)</td>
<td>40.1 (59)</td>
<td>15.5 (17)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15—19</td>
<td>31.3 (145)</td>
<td>29.3 (43)</td>
<td>15.5 (17)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20—24</td>
<td>23.5 (108)</td>
<td>21.8 (32)</td>
<td>12.7 (14)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25—29</td>
<td>2.8 (13)</td>
<td>3.4 (5)</td>
<td>6.4 (7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intellectual disability level %</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Profound</td>
<td>4.1 (18)</td>
<td>4.2 (6)</td>
<td>4.3 (4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td>23.9 (106)</td>
<td>25.2 (36)</td>
<td>18.1 (17)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>41.2 (183)</td>
<td>38.5 (55)</td>
<td>37.2 (35)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>30.9 (137)</td>
<td>32.2 (50)</td>
<td>40.8 (38)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>(21)</td>
<td>(5)</td>
<td>(16)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*A–C=3.96 (CI 2.69 to 5.31), B–C=3.74 (CI 2.27 to 5.19).

Table 2  Carer report of medically attended injury in the previous year for Australian Child and Adolescent Development (ACAD) program subjects and group 2 subjects

<table>
<thead>
<tr>
<th>Variable</th>
<th>ACAD subjects (n=465)</th>
<th>Group 2 (n=110)</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incidence of injury events/year</td>
<td>27.5</td>
<td>40.9</td>
<td>13.4 (CI 3.4 to 23.4)</td>
</tr>
<tr>
<td>Subjects injured % (n)</td>
<td>55.6</td>
<td>62.5</td>
<td></td>
</tr>
<tr>
<td>Subsidiary %</td>
<td>16.8 (77)</td>
<td>28.2 (31)</td>
<td>11.6 (CI 2.5 to 20.7)</td>
</tr>
<tr>
<td>Times injured %</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Once</td>
<td>63.6 (49)</td>
<td>64.5 (20)</td>
<td></td>
</tr>
<tr>
<td>Two or more</td>
<td>36.4 (28)</td>
<td>35.5 (11)</td>
<td></td>
</tr>
<tr>
<td>Total injuries</td>
<td>128</td>
<td>45</td>
<td></td>
</tr>
<tr>
<td>Frequency of visits for medical attention % (n)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General practice</td>
<td>49.1 (237)</td>
<td>32.5 (14)</td>
<td></td>
</tr>
<tr>
<td>Emergency department</td>
<td>37.9 (44)</td>
<td>62.8 (27)</td>
<td></td>
</tr>
<tr>
<td>Admission</td>
<td>10.3 (12)</td>
<td>4.7 (2)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>2.7 (3)</td>
<td>0.0 (0)</td>
<td></td>
</tr>
<tr>
<td>Total visits % (n)*</td>
<td>100.0 (116)</td>
<td>100.0 (43)</td>
<td></td>
</tr>
<tr>
<td>Admitted from emergency department %†</td>
<td>21.4</td>
<td>6.9</td>
<td>14.5 (CI 3.4 to 25.6)</td>
</tr>
</tbody>
</table>

*Type of visit (general practice, emergency department, admission) is recorded by carers for up to three separate injury events only. Therefore, totals do not necessarily correspond to the total for “Times injured” which allowed scoring of up to “five or more” separate injury events on the questionnaire.

†The denominator for calculating proportion of subjects admitted to hospital from emergency department includes the numbers admitted since it is assumed that they would first present to general practice.

There were no differences in age, IQ, or sex distributions between responders and non-responders in the ACAD program.

Injury

Group 2 had a higher carer reported injury incidence than program subjects (table 2) but there was no difference after adjustment for recall bias. Program subjects were more likely to be hospitalised than group 2.

Falls caused most injuries to ACAD subjects (60.2%) followed by burns (7.3%), transport (5.3%), and intentional injury (15.0%). Injury presentation for subjects at home (24.9%) was similar to those in professional care (27.1%)

Carer reported injury incidence for males and females was similar (30.1/100 and 24.0/100 subjects), but females (61.5%) presented to general practice more than males (41.7%); difference 19.8 (CI 1.5 to 38.1).

Injury rates for program subjects aged 5—14 and 15—29 years were similar (29.3/100 and 26.5/100 subjects) and mostly caused by falls (59% and 61% respectively). Other injury occurred at low frequency. The pattern of injury in the younger group persisted into the older age group. Younger children (5—9 years) presented to general practice more than emergency departments (χ² for trend 12.46,
The study group pattern for cause of injury presentation to emergency for ages 5–14 and 15–29 years were similar. In contrast, the general population sustained twice the rate for falls in the younger group (47%), than the older group (21%) and a 10-fold increase in intentional injury for the older group. The study group pattern for cause of injury presentation to general practice was similar to the general population with falls causing more injury in younger subjects (40%) than older subjects (20%).

Comparative injury profiles

Table 4 compares the study group and the general population across all levels of medical care combined (admission, emergency department, general practice).

The incidence of injury in the study group is clearly higher than the general population particularly after adjustment for carer recall bias (table 4). Age standardised morbidity ratio (indirect method) across all levels of medical care is 2.0. Unlike the general population, the ratio of injured males to females is 1.

Medical record data confirms carer report of a substantially increased hospitalisation rate for ACAD subjects (table 4). Across all levels of medical care, medical record data show a higher risk for falls, and a lower risk for transport injury and intentional injury for study subjects than the general population.

The difference for falls between carer report and subject medical records may be partly explained by carers misclassifying an injury event involving a bicycle as a fall, rather than a transport injury, on the questionnaire. The difference in carer report and medical records for intentional injury may also be a carer misclassification error due to their misinterpretation of intent, or may be a hospital coding error based on insufficient information in medical records resulting in underestimating intentional injury.

The ratio of injury deaths, admissions, emergency department presentations, and general practice presentations for the study population are similar for carer report (1: 18: 65: 84) and medical records (1: 13: 65: 122) but differ from the general population (1: 44: 312: 354).

Injury severity

Hospitals provided a total of 38 study group admissions matched to 114 general population injury admission controls. Overall, the study group sustained less traumatic injury and substantially more foreign body aspirations than the general population: 63.2% v 89.5% (difference 26.3: CI 10.0 to 42.6) and 26.3% v 0.9%: (difference 25.4: CI 11.3 to 39.5) respectively.

Table 4 Injury profiles by carer report and medical record audits for young people with intellectual disability and the general population for all levels of medically attended injury

<table>
<thead>
<tr>
<th>Injury characteristic</th>
<th>Carer reported injury (CI) (n=465)</th>
<th>Regional group medical records (CI) (n=257)</th>
<th>Victorian population medical records* (n=1650851)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incidence of injury events/100 persons/year by carer recall</td>
<td>27.5 (23.4 to 31.6)</td>
<td>59.6 (Range 41.3–86.0)</td>
<td>Range 14.5–28.5</td>
</tr>
<tr>
<td>Proportion (%) of injuries admitted to hospital from emergency department</td>
<td>21.4 (10.7 to 32.1)</td>
<td>20.3 (14.6 to 27.0)</td>
<td>10.4</td>
</tr>
<tr>
<td>Proportion (%) of injury events caused by falls</td>
<td>60.2 (51.2 to 69.2)</td>
<td>33.2 (29.7 to 36.7)</td>
<td>25.2</td>
</tr>
<tr>
<td>Proportion (%) of injury events caused by transport</td>
<td>5.3 (1.2 to 9.4)</td>
<td>9.2 (7.4 to 11.0)</td>
<td>13.9</td>
</tr>
<tr>
<td>Proportion (%) of injury events caused by intentional injury</td>
<td>15.0 (8.4 to 21.6)</td>
<td>4.7 (3.4 to 6.0)</td>
<td>9.8</td>
</tr>
<tr>
<td>Male: female ratio for injury events</td>
<td>1.3 to 1 (0.8 to 1.9)</td>
<td>1.2 to 1 (0.8 to 1.8)</td>
<td>2 to 1</td>
</tr>
</tbody>
</table>

*General population injury incidence extrapolated from Victorian data for VIMD, VEMD, and ELVIS combined.
The AIS does not code non-traumatic injury (foreign body aspirations, poisoning, immersion), so we employed the criteria of Walsh and Jarvis28 to code foreign body aspirations. Although coding reliability for poisoning and immersion injuries was limited due to insufficient medical record data on both cases and controls, we assumed they were severe for analyses.28

MAIS scores were grouped into "severe" (MAIS ≥ 3), "moderate" (MAIS = 2), and "mild" (MAIS = 1). Assuming most injuries were single, MAIS groupings for severity are largely equivalent to Walsh and Jarvis who employed the injury severity scale (ISS) for "severe" (ISS ≥ 9), "moderate" (ISS ≥ 4), and "mild" (ISS 1–3). This assumption is reasonable, since most injuries were not caused by road trauma where multiple injury is more likely. Figure 2 compares injury severity for all study group and general population hospitalisations. The odds ratio for all severe injury admissions in the study group was 2.5 (CI 0.9 to 6.8) assuming that poisoning and immersion injuries were severe. More reliably, the odds ratio for the study group for severe traumatic injury only (excluding foreign body aspirations, poisoning, immersion) was 6.6 (CI 1.4 to 31.8).

Discussion
We describe the first Australian and possibly the first international, population based comparative study specifically designed to investigate public health implications of injury in young people with intellectual disability. This group has an eight times excess injury mortality and double the injury morbidity of their counterparts in the general Australian population and populations elsewhere.30 The excess mortality is highly associated with asphyxia and drowning. Because mortality data are based on a small sample, any intervention in this area would benefit from a more detailed investigation of asphyxia deaths.

The increased morbidity risk is associated with a higher risk for aspiration and falls hospitalisations. Admissions occur at double the rate and with more severe injury than the general population. It is noteworthy that the childhood pattern of injury for emergency and general practice presentations in the study group (age 5–14) persists into young adult life in sharp contrast with the general population. It is possible that this childhood pattern at later ages results in higher injury severity because of their greater size and mass. The difference in injury pyramid ratios reflects more severe injury (deaths and hospitalisations) for the study group compared with the general population.

Although our sample size appears small compared with general population injury studies, it is related to the prevalence of intellectual disability and substantial difficulties in case ascertainment and recruitment. Indeed, our sample is among the largest of any published study specifically designed to examine injury in intellectual disability and is representative of a general population of more than 179 000 Australian children.11 12 31 The difference in age of the study group and group 2 (additional regional sample) may have influenced the medical record findings for patterns of injury. However, we consider the influence to be minor as carer report indicated similar patterns of injury for both the 5–14 and 15–29 age groups.

It is recognised that IQ measurement alone is insufficient to characterise intellectual disability and measures of adaptive behaviour, although subjective, are vital for disability services assessment.13 However, as IQ is less influenced by environmental setting and social expectations, it is the preferred method for epidemiological research and comparative studies.33–35 Avoidance of exposure to injury hazards entails a superior cognitive function to that of recognition alone.16 17 Given that young people with intellectual disability have a more limited capacity for these functions, their higher injury risk is not unexpected.
Implications for prevention
Our research findings progress the understanding of the relationship between injury and intellectual disability in young people and provide a basis for developing prevention approaches appropriate for young children with a poor understanding of consequences. Allowance would need to be made for their greater size and weight which can influence exposure to hazards and possible injury severity. With safeguards in place, the environment could then be used to advantage for maximizing development and physical fitness of the young person with intellectual disability with as little restraint as possible.

There is a need to increase the awareness of health professionals to the potential for injury and possible further handicap in this disabled population. Importantly, parents require substantial information, advice, and guidance for injury prevention in young people with intellectual disability because of the deinstitutionalization of this population which has transferred the enormous responsibility for daily routine care and possible injury care onto parents.

It is both timely and feasible to implement and evaluate injury prevention programs aimed at improving the quality of life of these young people and their families. Such programs should provide more information, education, guidance, and on-going support for parents, schools, and disability services concerning specific hazards in home environments and relevant safety approaches. Home visits could include surveillance for change in the presence of hazards and safety items. General practitioner counseling of parents could enhance falls injury reduction particularly if doctors are supplied with relevant information.

These various approaches to injury prevention in young people with intellectual disability, particularly if coordinated, require investigation and evaluation for effectiveness. If shown to be successful, not only would these families benefit, but potential service and cost savings for hospitals, disability services, and general practitioners would be likely.

We gratefully acknowledge the support given by consenting families and carers of our study group, Monash University Ethics Committee for Human Research granted approval for our research. Two expert Research Associates at the Monash University Accident Research Centre coded the medical record data. The National Health and Medical Research Council is funding the Australian Child and Adolescent Development program and provided a doctoral scholarship for the first author, who was also awarded a Monash University Postgraduate Research Award.