Title: Injury among adolescents with intellectual disability: a prospective cohort study

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ABSTRACT

Introduction: Injury is the leading cause of mortality and morbidity in adolescents worldwide, and injury rates have been shown to be higher among youth with intellectual disability. Despite this, injury among adolescents with intellectual disability remains poorly investigated. This study aimed to identify characteristics associated with injury among adolescents with intellectual disability living in the community.

Methods: A cohort of adolescents with intellectual disability living in southern Queensland, Australia was investigated prospectively between January 2006 and June 2010. Personal characteristics were collected via postal questionnaire. Injury information, including mechanism and location of injury, was extracted from general practitioner records. The association between demographic, social and clinical characteristics of participants and episodes of injury was investigated using negative binomial regression.

Results: A total of 289 injuries were recorded from 432 participants over 1627.3 years of study-time. The overall annual injury incidence was 17.5 (95%CI 14.7, 20.9) per 100 person years. Presence of ADHD and less severe disability was associated with increased risk of injury. Down syndrome and reduced verbal communication capacity were associated with decreased risk of injury. Falls accounted for the highest single mechanism of injury (19.0%) with the majority (73.2%) of injuries involving either upper or lower limbs.

Conclusions: ADHD is a co-morbidity that increases risk of injury among adolescents with intellectual disability. A critical component of injury prevention is avoidance of the great variety of environmental risk factors for injury relevant to this population.

KEYWORDS

Intellectual disability; adolescent; injury; risk factors

Introduction

More than half a million Australians (2.9%) have intellectual disability [1]. Adults with intellectual disability have significantly poorer health status than their non-disabled peers [2,3], with mortality rates up to three times higher [4], more than twice the number of health problems [5], and a greater number of unrecognised diseases [6]. Fewer studies have investigated mortality and morbidity among children and adolescents with intellectual disability but these studies suggest similar trends of increased burden of disease [7,8]. Over the last two decades injury prevention among youth with disabling conditions, such as intellectual disability, has received increased attention with studies reporting that young people affected by disability have a higher risk of injury than their unaffected peers [9-16].

Injury is one of the leading causes of disease burden among children and adolescents worldwide, with The World Health Organisation listing unintentional injury as the leading cause of death in all age groups from 1 to 44 years [17]. In Australia, injury is the leading cause of death in those aged 12–24 years, accounting for more deaths than all other causes of death combined [18]. While some studies have demonstrated substantially increased injury-related mortality and morbidity among youth with intellectual impairment [9,12,19-21], results have been inconsistent with non-comparable samples. Any increased injury risk in adolescents with intellectual disability may be due to disabling conditions that are often co-morbid with intellectual disability, such as attention deficit hyperactivity disorder (ADHD) [22], epilepsy [23,24], autism [25,26], psychopathology [27-29], and perceptual and communication impairments, such as hearing and visual limitations [14,30,31], as these conditions have also been found to be associated with increased injury rates. Despite the significant burden of injury demonstrated among the general population of adolescents, and the preventable nature of injury-related mortality and morbidity there is a lack of high-quality

research into the epidemiology of injury among adolescents with intellectual disability. The aim of this study is to characterise the rate of injury in a sample of adolescents with intellectual disability living in the community, and identify characteristics associated with higher injury rates.

Methods

Study population

A cohort of adolescents with intellectual disability who lived in the community in southern Queensland, Australia was followed prospectively between January 2006 and June 2010. Data were collected as part of a larger randomised control trial, the Ask Study, which investigated the effectiveness of a Health Intervention Package, which consisted of classroom teaching focused on health communication, use of a hand-held personal health diary, and a health check [32]. The intervention was designed to assist in the transition of adolescents from the paediatric to adult healthcare systems. Children and young people were eligible for participation in the Ask Study if they had an Education Queensland verified intellectual disability, which requires evidence of impairment from a guidance officer or psychologist. Participants were eligible for participation in this sub-study while they were aged between 13-19 years. Participants attended either a Special Education Unit (SEU) or Special Education School (SES). An SEU is located on the campus of a mainstream primary or secondary school. An SES is a segregated special school for children and adolescents who have significant intellectual disabilities and/or multiple disabilities, and usually require specialist teaching and therapy services that support an individualised education program. Individual consent was received from the participants' parent/carer, and their General

Practitioner (GP). Participants from both the intervention and control arms of the Ask trial were eligible for inclusion in the current study. Ethics approval was granted by The University of Queensland Behavioural and Social Sciences Ethical Review Committee (Clearance No: 2004000081) and the Queensland Government Department of Education and the Arts (File No: 550/27/424).

Data collection

Information regarding the adolescent and their family was collected using postal questionnaires completed by the adolescent's parent or carer in May 2007. Contact details of the participants' usual GP were supplied, and consent to access the adolescent's medical records was sought. In July 2009 parents confirmed that the GP nominated remained the adolescent's usual GP and, if this was not the case, nominated an alternative GP. Consent was then sought from this second GP and records were collected from both practices. Copies of all medical records, including correspondence and results of investigations, were obtained from January 2006 to date of contact. For security reasons, data were collected from practices by project staff. Most practice records were computerised and practice managers or doctors produced a print-out of all data. Other practices provided photocopies of printed records. Injury data collected before the child turned 13 years, and after 20 years, was not included in the analyses.

Measures

Injury

All symptoms and conditions diagnosed by the participants' GP or specialist, including injury details, were extracted by a single experienced paediatric nurse from medical records. Identified injuries were then reviewed independently by two GPs (one of whom was D.W.) in order to ensure that recorded data related to independent injury episodes, that episodes were appropriately categorised, and to identify the mechanisms and locations of injuries. Where there was disagreement, a third expert (R.W.) adjudicated. Injury episodes were categorized according to their cause or mechanism as falls, assault/altercation, sports/play related, cut/laceration, bike/board related, burns, seizure/syncope related, motor vehicle related, self-injury, and other/miscellaneous. Self-injury was defined as self-inflicted injury sufficient to cause tissue damage, but without suicide intent [33]. Injury locations were categorised as upper limb, lower limb, head/neck, back, torso (including chest and abdomen), and pelvis.

Demographic and social characteristics

Demographic characteristics recorded in the parent/carer questionnaire included age and sex. Social characteristics included years of schooling of the primary carer, and the participant's family structure (dual-parent/single-parent/other). Social position was measured at the postcode level using the Australian Bureau of Statistics Socio-Economic Index for Areas, a measure of Relative Disadvantage [34]. The general health of the adolescent was assessed on a five-point scale (poor/fair/good/very good/excellent). Mobility was classified as independent/walks with aid/uses wheelchair/immobile. Communication level was categorised as verbal/some verbal/non-verbal. Psychopathology was measured using the Developmental Behaviour Checklist-Short Form (DBC-P24), an overall measure of behavioural and emotional disturbance [35]. Participants were categorised as having 'no behavioural problems' if their Mean Behaviour Problem Score was less than 0.48 [35]. Participants with

behavioural problems were further classified as having ‘minor’ or ‘major’ problems using a cut-off of 0.83, the median score for those with behavioural problems. Cause of disability (Down syndrome/other syndrome/cause unknown) was identified, as were the presence of epilepsy, and hearing and vision problems. Medical records were used to identify participants with diagnosed autism and ADHD.

Statistical analysis

Data were summarised as frequency (percentage) for categorical variables. Annual injury incidence rates per 100 person years and 95% confidence intervals (95% CI) were calculated. The association between demographic, social and clinical characteristics and injury episodes was investigated using negative binomial regression with time-in-study as a model offset. First univariable analyses were conducted and then multivariable analyses where the models were adjusted for age, sex, school type, cause of disability, general health and carer education. Age was included as a time-varying variable and other variables were time-fixed. Variables included in multivariable models were selected based on a literature review. Results are reported as incidence rate ratios with 95% CIs. Analyses were conducted using Stata statistical software v12.0 (StataCorp, College Station, TX, USA).

Results

There were 592 carers of children and young people with intellectual disability who completed questionnaires, with the vast majority (93.1%) being parents. To assess the representativeness of the study sample, age, sex and social position were compared between Ask participants and all students attending special schools or special education programmes

in south-east Queensland. Although the data did not allow a direct statistical comparison, the Ask study group appeared very similar in terms of age and social position, but the proportion of males was lower (61% overall vs 55% in Ask study). GP medical records were available for 432 (73.0%) participants, and included injury data for 1627.3 person-years (median duration= 4.0 years). There were 232 (53.7%) male participants, 235 (54.4%) were from a special education school, and 66 (15.3%) had Down syndrome. Demographic, social and clinical characteristics of participants for whom medical records were available were similar to those for whom medical records were not available, apart from cause of disability, where participants with Down syndrome were more likely to have records (Supplementary Table 1).

Overall, 152 (31.3%) participants recorded at least one injury episode during the study period, with 289 injury episodes in total. The overall incidence of injury for all adolescents with intellectual disability was 17.5 per 100 person-years (95% CI:14.7, 20.9). During the study period there were no fatalities due to injury. Demographic, social and clinical characteristics of participants and their association with incidence of injury per 100 person years are displayed in Table 1. Participant characteristics univariably associated with increased risk of injury included the presence of ADHD, and psychopathology, lower levels of carer education, and less severe disability (represented by attendance at a special education unit). After adjustment for the potentially confounding variables age, sex, cause of disability school type, general health and carer education, participants with ADHD were more likely to be injured (IRR=1.7, 95% CI:1.1, 2.7) than those without ADHD. Participants attending a special education unit had an increased rate of injury compared with participants attending special education schools (IRR=1.8, 95% CI 1.2, 2.6). The presence of Down syndrome reduced the rate of injury compared with other known syndromes (IRR=0.5, 95% CI 0.3, 1.0), and being non-verbal also reduced the rate of injury (IRR=0.4, 95% CI 0.2, 0.8). Vision

and hearing impairments, as well as family structure, autism, epilepsy, mobility and sex were not associated with statistically significant risk of injury.

The single mechanism of injury contributing to the greatest proportion of injury episodes was falls (19.0%), followed by assault/altercation (9.7%), sports related injuries (8.3%), and lacerations (8.3%) (Table 2). There was a total of five incidents of self-injury recorded from four participants. Unfortunately, a high proportion of injury episodes recorded in GP notes did not include sufficient detail to identify a mechanism of injury (26.6%); these injuries were from a diverse range of heterogeneous mechanisms unable to be grouped into a single classification. Injuries classified as miscellaneous or with mechanism not recorded are listed in Supplementary Table 2. Injuries most frequently occurred to upper (34.6%) and lower (38.4%) limbs, followed by head injuries (18.3%).

Discussion

In this prospective cohort of Australian adolescents with intellectual disability the presence of ADHD, attendance at a special education unit, and lower levels of carer education were associated with an increased likelihood of injury, while Down syndrome and non-verbal communication were associated with reduced rate of injury. The injury patterns observed in this study revealed upper and lower limbs were most commonly involved in the majority of injury episodes, with the majority of injuries related to falls, assaults/altercations and sports related activities. Compared with their non-disabled peers, injury rates in this sample of adolescents with intellectual disability were approximately doubled. This finding is consistent with previous research in children and young people [12] and adults [36] where similar rates were reported, indicating that people with intellectual disability are at increased risk of injury throughout their life-course.

Characteristics associated with risk of Injury

These findings support previous literature which has consistently demonstrated ADHD [22] as increasing risk of injury. ADHD may lead to injury as a result of poorer risk perception and increased level of high-risk behaviour among these individuals [14]. As reported previously in young people aged 4-18 by Sherrard [20], the injury risk in people with intellectual disability also increased with the level of psychopathology.

A relationship between the level of carer education and injury was found, similar to findings in a study on children with disabilities more generally that found that carers of children with disability were less likely to have a bachelor's degree or higher level of education [14]. This suggests sociological factors may be of importance in risk of injury among children and young people with intellectual disability but this has not been adequately investigated in literature [20].

Participants with lower levels of verbal communication were also found to have reduced risk of injury which differs from the findings of Sherrard and colleagues who found an increased injury risk among non-verbal intellectually impaired youth [20]. Further analyses revealed that, after stratification for school type (a proxy for severity of disability), this association remained both univariably and after adjusting for the potentially confounding variables age, sex, cause of disability, general health and carer education. These figures suggest that, within the Ask sample, this is a true association between communication and injury rate, and this relationship warrants further investigation in future research.

Mechanism and Location of Injury

Falls has been previously identified as contributing to a large proportion of injury related morbidity among youth with intellectual disability [9,12]. The proportion of falls related injury among youth with intellectual disability found in the present study is similar to previous proportions found using medical records [12]. Assault/altercation was found to be a common cause of injuries and participants attending an SEU were found to have significantly more injuries than those attending an SES. SEUs, which are located within normal schools, tend to have students with less severe levels of intellectual disability and mix with non-impaired peers in a less supervised environment, and as a result may be more likely to be subject to physical abuse and bullying. There were substantially more injury episodes recorded in GP records as being specifically related to assault of participants than there were injuries recorded as being related to altercations where the participant may be responsible for initiating or contributing to violence. This may be a reflection of an attitude towards intellectually disabled students, with those with intellectual disability being more vulnerable to bullying and struggling to gain social acceptance. A meta-analysis of 16 studies involving children less than 19 years with disabilities found them to be more likely to be victims of violence than their peers [37] and a Californian study in “adapted” schools where children with special needs are mainstreamed with able-bodied children, found children with disabilities in all grades from kindergarten to 12 had more than double the rates of school injury than children without a disability [38]. Almost one third of those injuries were due to fights, roughhousing and assaults although children with cognitive disabilities had comparatively lower rates of injuries than children with physical disabilities.

The findings from this study also agree with those of a US study which noted a significant proportion of disabled youth were injured while engaged in sports activities [13]. Down syndrome was associated with lower injury incidence compared with other known syndromes. The mechanism behind this finding is unclear as previous studies investigating

injury among children and young people with disabilities have not specifically reported risk of injury among individuals with Down syndrome, although Finlayson [36] reported similar results in adults. The reduced risk among participants with Down syndrome found in the present study may be due to physiological and anatomical concerns specific to this population which may mean young people with Down syndrome may not be encouraged to participate in sporting activities [39] limiting their potential for injury in this area. The lower incidence of injury may also be due to the behavioural or temperamental characteristics of these participants as lower levels of aggression and behavioural difficulties have been reported among those with Down syndrome [40]. However, further research is required to verify these findings.

The difficulty in finding a common mechanism of injury for a significant proportion of injuries highlights the complex diversity in causes of injury in this population. This varied and diverse group of mechanisms ranged from animal bites to gardening related injuries and presents a challenge to injury prevention efforts as many mechanisms of injury occur as a result of a complex interplay between a wide range of unpredictable circumstances and factors making targeted prevention strategies difficult.

Strengths and Limitations

The present study describes anatomical pattern of injury, which to the authors' knowledge has not previously been described in a group of adolescents with intellectual disability. Injuries were extracted from medical records by a trained health professional rather than retrospective carer report of injury episodes as in some previous studies, reducing the likelihood of recall and misclassification bias. Participants are similar in age and social position to the population of Queensland school children from which they are drawn, although there are slightly more females in our sample. Although not all participants

contributed the same amount of study-time to the sample, drop-out during the study was not related to either participant or carer characteristics, and consequently this drop-out is unlikely to threaten the internal validity of the study [41].

The reported incidence rate for injuries may be under-estimated as it is possible a proportion of participants may have received medical care by a GP who was not their regular GP. Furthermore, milder injuries managed at home and severe injuries where emergency services were used may not be reported in GP records. While data are derived from GP records, in some cases medical practitioners did not record relevant information regarding mechanism or location of injury episodes, limiting the information available for analysis. There may also be a degree of inaccuracy as these were collected by carer report in regard to participant's co-morbidities, such as perceptual disturbances, but this is likely to be small. Although data in this study were analysed longitudinally, it was originally collected as part of a randomised trial [42]. Main trial results found that in the twelve-month follow-up period participants allocated to the intervention had fewer injuries than those allocated to usual care, although the intervention was not designed to reduce injury rates, and this was an unexpected and unexplained finding of the trial, it is possible that receipt of the health education intervention may have led to lower injury rates than expected.

Results from this study are likely to be generalizable to the population of students attending special education schools and special education units, which include students from mild to severe levels of disability.

Conclusions

This study provides important insight into risk factors for injury among a group of intellectually disabled adolescents, a vulnerable, but poorly investigated group. Clinically

these finding should alert clinicians and carers to the higher risk of injury in adolescents with these conditions. It is important to highlight that a critical component of injury prevention in adolescents affected by these disorders is not only avoidance of environmental risk factors but also proper management of these conditions ensuring optimisation of treatment therapies. Schools and educational institutions where youth with intellectual disability attend may benefit from recognising these individuals are at an increased risk of physical assault. Several injury-focussed retrospective studies now exist regarding children and young people with intellectual disability but as yet there is no current well designed prospective study aimed at investigating this issue. Future research efforts could include prospective analyses aimed at finding mechanisms of injury and should begin to focus on implementing injury prevention strategies and assessing the effectiveness of targeted injury prevention interventions in order to reduce the burden of preventable disease among this population.

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Conflict of Interest

There is no potential conflict of interest on the part of any of the authors to declare.

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Table 1

Frequencies of Patient Characteristics and Incidence Rate Ratios for 432 adolescents with intellectual disability living in the community is southern Queensland, Australia. Effect estimates are presented as incident rate ratios (IRRs) and 95% confidence intervals (95% CI)

Variable/Characteristic	Frequency	Incidence per 100 person-years	Unadjusted	Adjusted ^a
	n(%)	Mean (95% CI)	IRR (95% CI)	IRR (95% CI)
Age ^b				
13-14	309 (71.5%)	20.9 (15.7, 27.7)	1.0	1.0
15-16	416 (96.3%)	17.7 (13.9, 22.5)	0.8 (0.6, 1.2)	0.7 (0.5, 1.0)
17-19	326 (75.5%)	15.7 (11.8, 20.9)	0.8 (0.5, 1.1)	0.7 (0.5, 1.0)
Sex				
Male	232 (53.7%)	17.7 (13.9, 22.5)	1.0	1.0
Female	200 (46.3%)	17.4 (13.4, 22.5)	1.0 (0.7, 1.4)	0.8 (0.6, 1.2)
General Health				
Excellent	115 (26.6%)	12.2 (8.4, 17.6)	1.0	1.0
Very Good	145 (33.6%)	15.8 (11.7, 21.5)	1.3 (0.8, 2.1)	1.4 (0.8, 2.3)
Good	129 (29.9%)	23.2 (17.2, 31.4)	1.9 (1.2, 3.1)	1.8 (1.1, 2.9)
Fair	37 (8.6%)	18.7 (10.5, 33.4)	1.5 (0.8, 3.1)	1.8 (0.9, 3.7)
Poor	6 (1.4%)	32.2 (8.9, 116.8)	2.6 (0.7, 10.1)	4.2 (1.1, 16.1)
Social position				
Highest	104 (24.1%)	12.4 (8.4, 18.4)	1.0	1.0
Higher	142 (32.9%)	18.5 (13.7, 25.0)	1.5 (0.9, 2.5)	0.9 (0.5, 1.5)
Lower	113 (26.2%)	21.8 (15.8, 30.2)	1.8 (1.1, 2.9)	1.1 (0.6, 1.8)
Lowest	73 (16.9%)	15.9 (10.3, 24.5)	1.3 (0.7, 2.3)	0.8 (0.5, 1.5)
Carer Education				
Year 12	145 (34.1%)	11.6 (8.3, 16.1)	1.0	1.0
Year 10	219 (51.5%)	18.9 (14.8, 24.0)	1.6 (1.1, 2.5)	1.3 (0.8, 1.9)
Not year 10	61 (14.4%)	26.1 (17.0, 39.9)	2.3 (1.3, 3.9)	1.4 (0.8, 2.5)
Family structure				
Two parents	291 (68.6%)	16.7 (13.5, 20.8)	1.0	1.0
Single parent	117 (27.6%)	18.4 (13.1, 25.7)	1.1 (0.7, 1.6)	0.9 (0.6, 1.4)
Other	16 (3.8%)	23.6 (9.8, 57.2)	1.4 (0.6, 3.5)	1.6 (0.7, 3.8)
School Type				
Special ed. school	235 (54.4%)	12.5 (9.7, 16.2)	1.0	1.0
Special ed. unit	197 (45.6%)	23.2 (18.3, 29.4)	1.9 (1.3, 2.6)	1.8 (1.2, 2.6)
Mobility				
Independent	370 (85.7)	18.6 (15.4, 22.4)	1.0	1.0
Aids	32 (7.4)	13.7 (6.9, 27.4)	0.7 (0.4, 1.5)	1.0 (0.5, 2.0)
Wheelchair	25 (5.8)	7.3 (2.7, 19.3)	0.4 (0.1, 1.1)	0.5 (0.2, 1.3)
Immobile	5 (1.2%)	10.1 (1.6, 63.7)	0.5 (0.1, 3.5)	0.5 (0.1, 3.5)
Communication Difficulty				
Verbal	324 (75.2%)	20.1 (16.6, 24.4)	1.0	1.0
Some verbal	59 (13.7%)	10.5 (6.1, 18.2)	0.5 (0.3, 0.9)	0.7 (0.4, 1.2)
Non-verbal	48 (11.1%)	8.4 (4.5, 15.9)	0.4 (0.2, 0.8)	0.4 (0.2, 0.8)
Cause of Disability				
Known Syndrome exc.	235 (54.4%)	17.9 (14.2, 22.5)	1.0	1.0
Down				
Down Syndrome	66 (15.3%)	6.4 (3.5, 11.7)	0.4 (0.2, 0.7)	0.5 (0.3, 1.0)
Cause not known	131 (30.3%)	22.3 (16.6, 29.9)	1.2 (0.9, 1.8)	1.2 (0.8, 1.8)

Psychopathology/DBC				
Score				
No problems	131 (30.7%)	11.8 (8.4, 16.7)	1.0	1.0
Minor problems	149 (34.9%)	19.9 (14.4, 27.6)	1.7 (1.0, 2.7)	1.5 (0.9, 2.4)
Major Problems	147 (34.4%)	20.6 (15.9, 26.7)	1.7 (1.1, 2.7)	1.5 (0.9, 2.3)
Epilepsy				
No	347 (80.7%)	16.6 (13.6, 20.2)	1.0	1.0
Yes	83 (19.3%)	22.0 (14.9, 32.2)	1.3 (0.9, 2.0)	1.5 (0.9, 2.4)
Vision Problem				
No	284 (66.1%)	16.9 (13.5, 21.0)	1.0	1.0
Yes	146 (33.9%)	18.9 (14.0, 25.4)	1.1 (0.8, 1.6)	1.0 (0.7, 1.5)
Hearing Problem				
No	370 (85.9%)	17.3 (14.3, 21.0)	1.0	1.0
Yes	61 (14.1%)	18.8 (11.9, 29.9)	1.1 (0.7, 1.8)	1.1 (0.7, 1.9)
Autism				
No	356 (82.4%)	16.8 (13.9, 20.5)	1.0	1.0
Yes	76 (17.6%)	20.9 (13.8, 31.4)	1.2 (0.8, 2.0)	1.2 (0.8, 2.0)
ADHD				
No	371 (85.9%)	15.0 (12.4, 18.2)	1.0	1.0
Yes	61 (14.1%)	32.7 (21.8, 49.1)	2.2 (1.4, 3.4)	1.7 (1.1, 2.7)

a Adjusted analyses adjust for age, gender, school type, cause of disability, general health and carer education.

B Age is analysed as a time-varying variable. Consequently participants can contribute study-time to more than one age category.

Table 2**Mechanism and location of injury in adolescents with intellectual disability**

	Frequency (%)
Cause/mechanism of injury	
Falls	55 (19.0%)
Assault/altercation ^a	28 (9.7%)
Sports/play related ^b	24 (8.3%)
Cut/laceration	24 (8.3%)
Bike/board related	13 (4.5%)
Burns	9 (3.1%)
Seizure/syncope related	8 (2.8%)
Motor vehicle related	8 (2.8%)
Self-injury	5 (1.7%)
Other/miscellaneous ^c	38 (13.1%)
Mechanism not recorded	77 (26.6%)
Injury location*	
Upper limb	100 (34.6%)
Lower limb	111 (38.4%)
Head/neck	53 (18.3%)
Back	16 (5.5%)
Torso (chest/abdomen)	10 (3.4%)
Pelvis	4 (1.4%)

a includes being assaulted or involved in fight

b includes ball sports, and play equipment such as trampoline, swings.

c examples include animal related(bite/scratch), being hit by objects

**Injury episodes which involved more than one body location were counted towards both locations*

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