A Prospective Study of Hospital Encounters by People with Intellectual and Developmental Disability and a Comparison Group

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Hospital Encounters for People with Intellectual and Developmental Disability

- Higher rates in terms of emergency department presentations (ED) and re-presentations (Balogh et al., 2010; Dunn et al., 2017; Glover et al., 2019; Reppermund et al., 2017)

- Longer hospital stays (Glover et al., 2017)

- Reasons include conditions that can be prevented or managed in primary care (Balogh et al., 2010; Dunn et al., 2017; McDermott et al., 2018; Skorpen et al., 2016)

- Concerns about poor quality care, failure to conduct diagnostic assessments, diagnostic over-shadowing, failure to implement reasonable adjustments (Iacono et al., 2014; Tuffrey-Wijne et al., 2014)
  
  - Listen to family or paid carers
  
  - Adapt communication
  
  - Allowing more time
Aims

• Prospectively document hospital encounters of people with IDD
  – Contrastive data for people with a previous Traumatic Brain Injury (TBI)
• Explore potential indicators of care quality
• Obtain data for Australia
Participants

- 60 Primary Participants
  - Adults with Cognitive Disability who had a hospital encounter (mostly Emergency Department) during Nov 2014 – Oct 2017 (35 months)
  - 50 IDD; 35 male; aged 18-74 (mean = 42.9, SD = 14.5)
  - 10 TBI; 9 male; 25-84 years (mean = 50, SD = 18.3)
  - 85% at least 1 chronic health condition (mostly epilepsy for IDD, mental health for TBI)

- Living situation
  - 27 (45%) with family
  - 24 (40%) in supported accommodation
  - 8 (13%) Independently or semi-independently
  - 1 (2%) missing data
Frequency of Encounters

- 186 across participants within 35 months
  - Range = 1-16 (median = 2)
- 114 encounters (62%) within first 3 months of being in the study
  - Range 1-9 for IDD; 1-3 TBI
179 Hospital Encounters via Emergency Department
Comparisons with National Hospital Performance Data

Getting there:
IDD: 59% ambulance; 36% private car
TBI: 76% ambulance; 17% private car
National Data: 24% ambulance

Emergency Department (ED)
62% > 4 hours
General Patient Data (2013)
H1: 38-46%
H2: 24%
H3: 44%

AIHW, 2013-14
Initial Triage Codes

1. Resuscitation: immediate (within seconds) $n = 4$ (2%)
2. Emergency: within 10 minutes $n = 21$ (12%)
3. Urgent: within 30 minutes $n = 92$ (51%)
4. Semi-urgent: within 60 minutes $n = 58$ (32%)
5. Non-urgent: within 120 minutes $n = 2$ (1%)

Not recorded $n = 2$ (1%)

83% vs 79%
AIHW, 2014
After ED to

Ward | Home | Short Stay Unit | Another Hospital

66 (46%) | 51 (34%) | 31 (19%) | 2 (2%)
After ED to …

- 11 (38%) Ward
- 8 (28%) Self Discharge
- 5 (17%) Home
- 4 (14%) Short Stay Unit
- 4 (100%) Home

TBI

Another Hospital

After ED to …

- 1 (3%) Ward
- 8 (28%) Self Discharge
- 5 (17%) Home
- 4 (14%) Short Stay Unit
- 4 (100%) Home

TBI
After ED to...

IDD

- Ward: 66 (46%)
- Short Stay Unit: 31 (19%)
- Home: 51 (34%)
- Another Hospital: 2 (2%)

TBI

- Ward: 11 (38%)
- Short Stay Unit: 4 (14%)
- Home: 51 (34%)
- Another Hospital: 8 (28%)
- Self Discharge: 1 (3%)
Diagnostic Tests

% of Encounters
At least 1 type in ED
88% encounters of people with IDD
76% encounters for people with TBI
### Australian Refined Diagnostic-Related Groups

<table>
<thead>
<tr>
<th>Number</th>
<th>Disease Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>Diseases &amp; Disorders Nervous System</td>
</tr>
<tr>
<td>04</td>
<td>Diseases &amp; Disorders respiratory system</td>
</tr>
<tr>
<td>05</td>
<td>Diseases &amp; Disorders circulatory system</td>
</tr>
<tr>
<td>06</td>
<td>Diseases &amp; Disorders digestive system</td>
</tr>
<tr>
<td>08</td>
<td>Diseases &amp; Disorders musculoskeletal system &amp;...</td>
</tr>
<tr>
<td>09</td>
<td>Diseases &amp; Disorders skin &amp; subcutaneous tissue</td>
</tr>
<tr>
<td>10</td>
<td>Endocrine, nutritional, &amp; metabolic diseases &amp;...</td>
</tr>
<tr>
<td>11</td>
<td>Diseases &amp; Disorders of kidney &amp; urinary tract</td>
</tr>
<tr>
<td>12</td>
<td>Diseases and Disorders of the male reproductive...</td>
</tr>
<tr>
<td>16</td>
<td>Diseases &amp; Disorders of the blood &amp; blood...</td>
</tr>
<tr>
<td>17</td>
<td>Neoplastic disorders</td>
</tr>
<tr>
<td>18</td>
<td>Infectious &amp; parasitic diseases</td>
</tr>
<tr>
<td>19</td>
<td>Mental diseases &amp; disorders</td>
</tr>
<tr>
<td>21</td>
<td>Injuries, poisoning &amp; toxic effects of drugs</td>
</tr>
</tbody>
</table>

The chart shows the distribution of Intellectual Disability and TBI across various disease categories.
Time in Wards
0.2-35 days
Mean = 5.4 (SD=7)
Median = 3.1

Time in Wards
0.2-11 days
Mean = 3.7 (SD=3.6)
Median = 3.4

n=73  n=10
Exceeding the benchmark of 72 hours since discharge

- $n= 24$ IDD (16%)
- $n=2$ TBI (7%)

Time between presentations

$<1 – 364$ days ($M=50; SD = 68; \text{Median} = 21$)
Frequent ED Presentations

- 5 or more presentations in 1 year (benchmark, Fuda & Immekus, 2006)
  - 8 (16%) people with IDD
  - 1 (10%) people with TBI
Trends

• Indicators of high hospital usage?
  – 179 encounters across 60 participants
  – Only 16% of IDD and 10% of TBI met benchmark for frequent ED presentations in 1 year
  – Few re-presentations within 72 hours

• Both IDD and TBI more likely to get to ED by ambulance compared to national data

• Most receive urgent or semi-urgent triage codes ~ national data
Trends

- Most receive at least one, but often multiple diagnostic assessments
- Diagnoses reflect findings from other studies for people with IDD (Skorpen et al., 2014)
  - Often for chronic health problems with high occurrence in this group—e.g., epilepsy, gastrointestinal problems
  - Reflect findings from Ambulatory Care Sensitive Conditions research
- Lengthy stays?
  - Except for some extreme examples in IDD group, stays in wards were relatively short (medians ~ 3 days)
  - Use of ED and SSU to complete diagnostics and observations, resulting in ~ half encounters going home rather than a ward
Discussion

- Did not find evidence of high usage or long stays in general (exceptions)
  - Further data needed for TBI group (more likely to have mental health problems)
- General indications were for good care (some exceptions)
  - Outcome of patient-centred focus in training of medical and nursing staff?
  - No evidence of diagnostic overshadowing
- Reasonable adjustments
  - Short stay units may provide the means by which hospitals can provide the additional time needed by people with cognitive disability
  - Other indicators explored in companion qualitative study
- Direct comparisons with other studies and with national data (other than benchmarks) difficult
- TBI and IDD comparisons are indicative only
References


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