Healthcare Use, Ill-health and Mortality in Adults with Intellectual Disabilities and Mealt ime Support Needs

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INTRODUCTION

Background

- People with intellectual disabilities (ID) experience significant health inequalities when compared to the general population. 1
- An estimated 15% of all adults with ID have eating, drinking and/or swallowing (EDS) difficulties that necessitate mealtime support to ensure safe and adequate nutrition. 2 This support consists of a diverse range of interventions, from modifying food texture and mealt ime environment to full enteral feeding. 3
- Approximately 8% of adults with ID have diagnosed dysphagia (swallowing problems): a medical condition associated with an increased risk of choking, aspiration, undernutrition and illnesses such as aspiration pneumonia. 4
- We set out to explore health outcomes in a sample of adults with ID and EDS problems including, but not limited to, dysphagia, as they have not yet been comprehensively examined.

Aims

1. To establish the incidence of eating and drinking-related health service use, health problems, and all-cause mortality in a sample of adults with ID and mealt ime support needs, over a one-year period.
2. To describe the factors that predict negative health outcomes in this population: emergency hospital visits and respiratory infections.

METHODS

Recruitment

- All adults (aged 18 or older) known to specialist ID services in Cambridgeshire or Northeast Essex, England, who required support with eating and/or drinking were invited to participate (N = 726).

Data Collection

- Structured interviews with the carer or paid support worker of all those who consented to participate were carried out (N=142; 20% of all eligible individuals).
- Information was collected on: socio-demographic characteristics; disability-related characteristics; need for mealt ime support; and health care use over the previous year (Year 1).

One year later, 95% (N=133) of those participants were followed-up, and their carer or support worker was asked additional questions regarding vital status and health care use over the previous year (Year 2). Of these, 94% (N=127) were alive. Cause of death was confirmed using death certificates.

Statistical Analysis

- We used the Pearson chi-squared and Fisher’s exact test to examine associations between categorical variables, and the independent samples t-test and Mann-Whitney U test for continuous variables. All analyses were carried out in SPSS and R.

- We developed preliminary logistic predictive models for emergency hospitalisations and respiratory infections using (backward) stepwise variable selection, based on Akaike’s Information Criterion (AIC).

PARTICIPANT CHARACTERISTICS

Of the 127 participants who were alive and participated in both rounds of data collection, at baseline:
- Their mean age was 46.6 years old (range: 18-90).
- 1 in 6 lived in their own/family home.
- 1/3 required full support at mealtimes and 1/2 had an increasing need for mealt ime support
- Over 1/3 had diagnosed dysphagia and 46% had carer-reported swallowing problems.
- 33% had epilepsy and 80% had a physical disability.
- Less than 10% had dementia

The age distribution of our participants reflects that of the adult population known to ID services in England, with peaks in the 20s and in middle age.

RESULTS

Incidence of Healthcare Use, Ill-health & Mortality

Healthcare Utilisation in Each Year of Study (N=127)

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of participants with any healthcare contact (%)</th>
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</thead>
<tbody>
<tr>
<td>Year 1</td>
<td>119 (94%)</td>
</tr>
<tr>
<td>Year 2</td>
<td>103 (85%)</td>
</tr>
</tbody>
</table>

EDS-related GP visits

- 58 (46%) of the 127 participants had at least one EDS-related GP visit.
- 38 (31%) of the 127 participants had at least one EDS-related hospitalisation.
- 6 (5%) of the 127 participants had at least one EDS-related emergency hospitalisation.

C-statistic

- The C-statistic of the final model was 0.833 (0.58 – 0.97)
- The model was able to discriminate well between people with and without EDS problems

Best model: Age (continuous)

- Lives alone
- Lives in own/family home
- Has increased mealt ime support need
- Has swallowing problems
- Has dementia
- Has epilepsy

Emergency hospitalisations related to EDS

- The rate of emergency hospitalisations related to EDS problems was 6.9/100 person-years.

Illnesses related to eating and drinking are a common cause of health service use:

- 20% of all annual GP and emergency hospital visits were attributable to EDS problems.

Respiratory infections are a major health problem in this population:

- One-quarter of all participants reported an ERS on at least one occasion.
- Nearly half (47%) of all emergency hospitalisations were for respiratory infections.
- These hospitalisations were long (mean: 25 days; range: 1-12 days).

High annual mortality:

- Eight people died in the second year. This was 5.6% (95% Wilson CI: 2.9 to 10.7%) of our baseline sample.
- Almost three times as many people died than would be expected in a group of adults of the same age with ID and no EDS problems (standardised mortality ratio = 267).
- Six of the eight deaths occurred in participants under 65 years old (median age at death: 53.5 years).
- Respiratory infections were the primary cause of death in all eight cases (100%).

Preliminary Predictive Models of Respiratory Infections & Emergency Hospitalisations related to Eating, Drinking & Swallowing (EDS) Problems:

- Our participants had regular contact with both primary and secondary health services for their EDS problems. While respiratory infections are a known risk for all people with intellectual disabilities (causing an estimated 35% of deaths,a), our findings suggest that the level of risk is increased for adults with ID and mealt ime support needs.

DISCUSSION

Health service implications of a likely future increase in EDS problems: Recent life expectancy gains amongst all people with ID mean that the number of adults requiring mealt ime support for EDS problems (older men and women & young adults with severe/profound ID) is likely to increase over time. Health and social services will need to adjust to increasing service demands.

Need for increased awareness & regular assessment: Eating and drinking skills among high risk groups (e.g. adults with dementia) should be assessed regularly. GPs and caregivers should be vigilant for signs of dysphagia and problems with eating and drinking skills.

Future research: Studies involving larger populations and/or longer time periods are needed to examine predictors of negative health outcomes (particularly mortality) in more detail. Additional studies with a larger number of participants will be necessary to validate our preliminary predictive models.

IMPLICATIONS FOR RESEARCH & PRACTICE

REFERENCES


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