Scottish Learning Disabilities Observatory

Respiratory-associated deaths in people with intellectual disabilities

Dr Maria Truesdale, Professor Craig Melville, Fiona Barlow, Dr Kirsty Dunn, Angela Henderson, Laura Hughes-McCormack, Dr Arlene McGarty, Dr Ewelina Rydzewska, Dr Gillian Smith, Dr Joesph Symonds, Dr Bhautesh Jani & Dr Deborah Kinnear

The Scottish Government

ScotLDO

University of Glasgow

Overview

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Background

- People with intellectual disabilities are known to experience poorer health (Hatton et al., 2015; Robertson et al., 2015) and multimorbidity (Kinnear et al. 2018), and die up to 20 years earlier (O'Leary et al. 2018), from avoidable causes, compared to those in the general population

- Respiratory disorders are the leading cause of death among people with intellectual disabilities (Tyrer et al.2007; Heslop et al., 2014; Glover et al., 2017)

- Standardised Mortality Ratios* (SMRs) differ widely across studies

**Standardised Mortality Ratio is the quantity expressed either as a ratio or percentage quantifying the increase or decrease in mortality of a study cohort*

Aim & Method

To investigate and quantify the risk of, and factors, associated with, respiratory-associated deaths in people with intellectual disabilities

- Conducted a systematic review and meta-analysis
- Identified studies using Embase, ISI Web of Science, CINAHL and PsycINFO from 1st January 1985-27th April 2020
- Covidence software was employed for title and abstract screening
- Mortality data was extracted and pooled using STATA (version 14)

Methods

Inclusion criteria

Systematic review:

- People who had and intellectual disability and a comparison group of people in the general population, with respiratory disorders included as a separate cause of death
- Studies including multiple disabilities, at least 70% of participants had to have intellectual disabilities

Meta-analysis:

- Studies had to report SMRs with 95% confidence intervals for respiratory associated deaths based on external comparison group or to have presented data allowing such outcomes to be derived

Exclusion criteria:

- Studies focused on specific aetiologies of intellectual disabilities such as Down syndrome
- Full paper was not in English
- Studies focused on post-operative and post-treatment deaths
- Small sample sizes

Study quality: Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields.

Findings

Identified 2,063 studies, 17 were included in the narrative synthesis and 10 studies (11 cohorts) in the meta-analysis

Data from 90,302 people with intellectual disabilities and 13,808 deaths from all causes in people with intellectual disabilities were extracted

Findings: Evidence synthesis

Respiratory-associated mortality

- Respiratory disorders were the dominant cause of death in 5 (29%) papers
- 3 (18%) papers reported this as the second most common cause of death
- Comparative results for deaths due to respiratory disorders were reported in 10/17 (59%) of studies
- Higher reported deaths for people with ID than the general population, however 1 study reported similar rates and another reported that respiratory disorders were the most commonly cited cause of death for both groups

Individual respiratory disorders and mortality

- Pneumonia was the most common cause of respiratory death 10/17 (59%)
- Pneumonitis featured as an underlying cause for between 8-21% of respiratory deaths
- COPD was found to be a common cause of death in two studies focusing on older adults

Findings: Evidence synthesis

Factors associated with respiratory-associated deaths

- 4/17 (23.5%) of papers reported on factors associated with the risk of respiratory-associated deaths
- Two studies reported SMRs separately for males and females while two reported proportions of respiratory associated deaths between males and females
- None directly compared males vs females or reported tests of significance
- One study reported higher SMRs among females, another reported separate SMRs for different age-bands
- Level of ID was only reported as associated with respiratory associated deaths in one study with 35 yr follow up using relative risk but failed to report confidence or p-values.
- Relative risk of respiratory related deaths was 2.6 times higher for people with mild ID and 5.8 times higher for people with profound and multiple intellectual disabilities

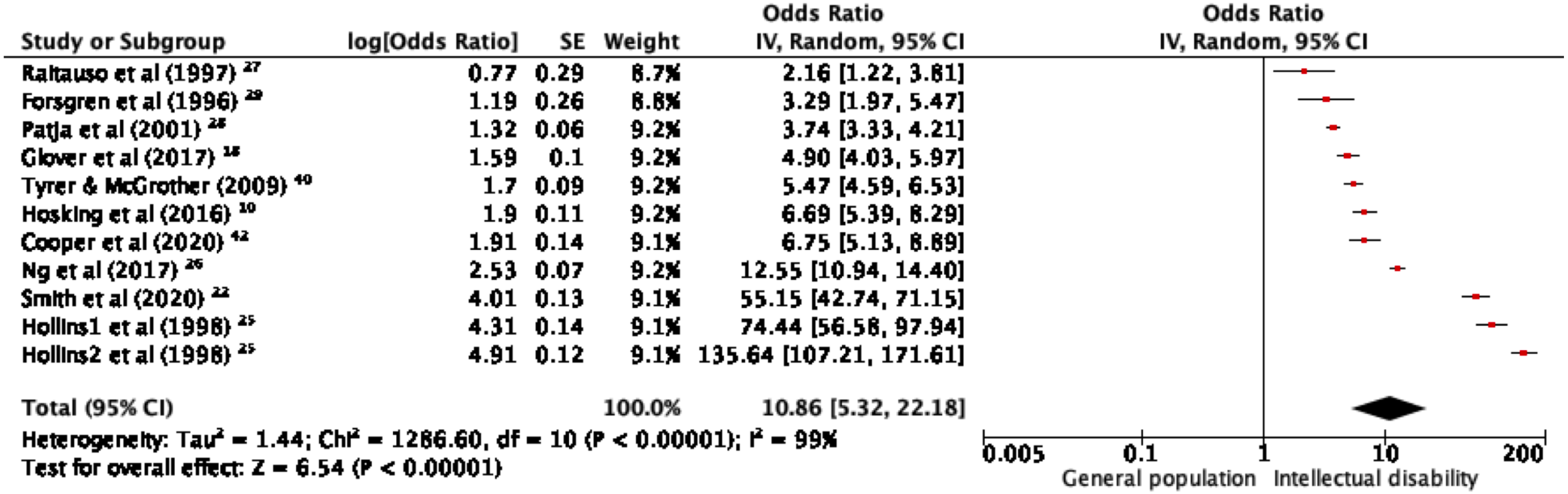
Respiratory mortality among children and young people

- Common cause of death across all five studies
- Four included comparisons with the general population for respiratory causes of death, while one included the national population without ID
- All analyses were limited by the small numbers of deaths
- One study (Patja et al., 2001) reported higher SMRs for males aged 2-19yrs but not females.
- Another study (Smith et al. (2020) reported 8% deaths had respiratory disease as the underlying cause but the SMRs were not reported.

Findings:
Meta-analysis outcomes

People with intellectual disabilities are almost **11 times** (SMR 10.86) more likely to die from respiratory illness compared with the general population

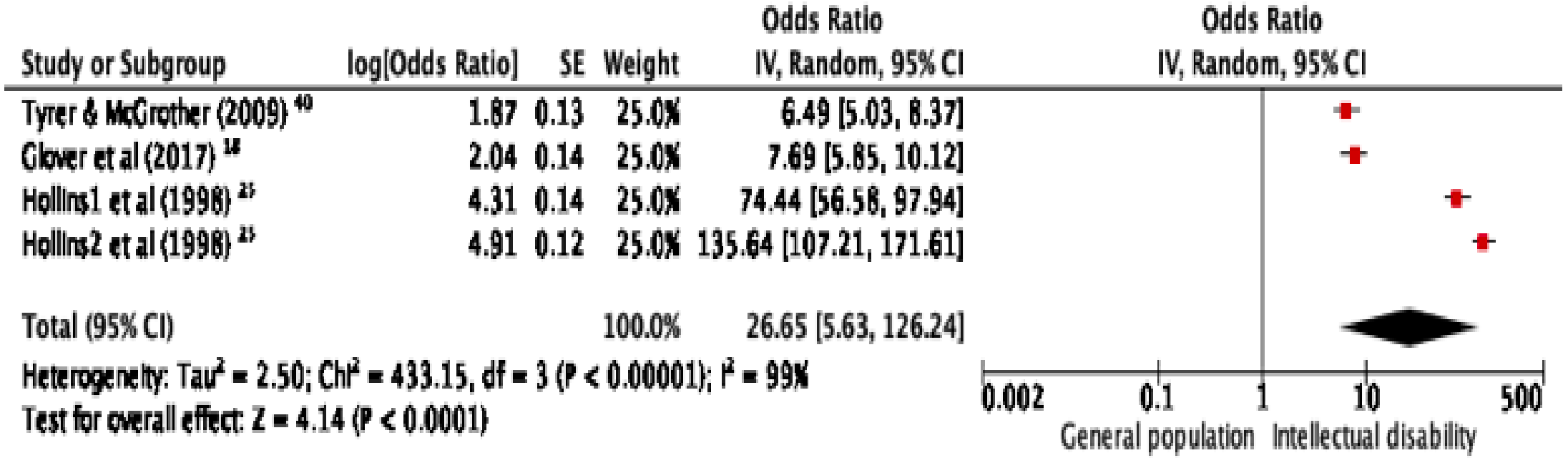
Figure 1: Forest plot for respiratory related mortality



Findings:
Meta-analysis outcomes

The risk of death from pneumonia is almost **27 times** (SMR 26.65) higher for people with intellectual disabilities

Figure 2: Forest plot for pneumonia related mortality



Findings:
Meta-analysis outcomes

- Insufficient data and results provided by studies to investigate predictors or factors associated with respiratory-related deaths
- Meta-regression or stratification was not possible

Recommendations

- Routine monitoring and reporting of respiratory deaths
- Implementation of preventative action
- Increased uptake of flu vaccinations and other targeted infection control measures
- Community and hospital based sepsis management programmes should have a lower threshold for investigating and treating pneumonia and other respiratory infections

Current health initiatives, strategies and action plans

Scottish Government Health Checks for people with ID

Scottish Government Respiratory Care Action Plan 2021-2026

International Dysphagia Diet Standardisation Initiative (IDDSI) framework launched by NHS HIS in April 2019

British Thoracic Society guidelines on managing acquired pneumonia

LeDeR guidance on aspiration pneumonia

Respiratory Health for People with Profound and Multiple Learning Disabilities
PAMIS

Learning Disabilities is a priority for action in the NHS HIS Excellence in Care Strategy (Lead by Isla McGlade)

Postural Care Strategy for Scotland
'Your Posture Matters'

NHS Education Scotland DVD and Learner's handbook, "Making Dysphagia Advice easier to Swallow"

Scottish Patient Safety Programme guidance on paediatric sepsis identifies children with complex neurodisabilities at higher risk of sepsis

NHS GGC clinical nurse specialist in respiratory and learning disability in post

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